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Analysis of Privacy Policies and Practices of Direct-to-Consumer Genetic Testing Companies: Private Sector Databanks and Privacy Protection Norms

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Executive Summary

This report discusses privacy issues in the context of direct-to-consumer (DTC) sale of genetic testing services. A growing number of companies, mainly U.S.-based, sell genetic tests directly to consumers. To provide this service, the companies collect biological samples and personal information from clients, raising questions about the use, disclosure, retention, and security of these materials.

We analysed the privacy policies of 32 DTC genetic testing companies against the fair information principles developed by the Canadian Standards Association in the *Model Code for the Protection of Personal Information* and incorporated into the federal *Personal Information Protection and Electronic Documents Act*. These ten principles are: accountability; identifying purposes; consent; limiting collection; limiting use, disclosure and retention; accuracy; safeguards; openness; individual access; and challenging compliance.

There is wide variation in the extent to which DTC genetic testing companies address protection of personal information and biological samples. Of the 32 company websites we studied, 20 provide a privacy policy on their websites. Some focus on internet use (e.g. how the website tracks visitors) and some briefly address handling of samples and/or results. Seven of the 20 companies have more comprehensive policies that explain how the company collects and uses information via its website and how samples and results are handled.

This report concludes with a list of privacy-related questions we recommend consumers should consider before buying genetic tests over the internet. Consumers who seek answers to the questions – through careful review of company privacy policies and direct contact with companies – will be able to make a more informed choice about sending their personal information and genetic samples to a company.

The Health Law Institute, University of Alberta, acknowledges generous funding support from the Office of the Privacy Commissioner of Canada (OPCC). The OPCC identified genetic privacy and biobanking as a priority area for its 2009-2010 Contributions Program. Nola M. Ries, Research Associate with the Health Law Institute, was lead author of this report. Monique Dull, a law student at the University of Victoria, provided valuable assistance in researching company privacy policies.

Introduction

The Rise of Direct-to-Consumer Genetic Testing Services

A 2009 editorial in the respected journal, *Nature*, observed that “the availability of affordable, direct-to-consumer genetic tests has mushroomed ... Dozens of companies now offer inexpensive home kits that allow people to spit into tubes, send the samples for DNA analysis and receive a report that allegedly details their ancestry or their possible susceptibility to a long list of disorders that have been linked — often tenuously — to particular genes.”¹ Indeed, direct-to-consumer (DTC) genetic testing companies are attracting much curious interest and critical scrutiny from the media, professional and governmental organizations, academic researchers, and members of the public. *Time* magazine declared the retail DNA test offered by the company, 23andMe, the best invention of the year for 2008.² 23andMe launched their services in Canada during that same year,³ and many other companies offer fast and convenient genetic testing kits through online commerce or toll-free telephone numbers. A *New York Times* article, titled “The Wide, Wild World of Genetic Testing,” points out: “With a few mouse clicks, consumers can order tests that promise to tell them if they are at risk for particular diseases, to trace their ancestry back to the time of Genghis Khan, to help choose which antidepressant would be best for them, to identify the sex of their fetus as few as five weeks into pregnancy and to give advice on diet or exercise.”⁴ Numerous blogs recount individuals’ experiences with buying personal genome analyses and Canadian media sources have run stories profiling individuals who have purchased DTC genetic tests.⁵ The cost of personal genetic testing currently ranges between approximately \$195 (US) to over \$1000 (US). In addition to providing test results to individual customers, some companies offer social networking services by which individuals can connect with others who share similarities in genetic ancestry, disease risks or other traits.

Numerous concerns have been raised about DTC marketing and sale of genetic tests.⁶ First, many critics argue that DTC sale of numerous health-related tests is premature as there is not yet

¹ Editorial, “Putting DNA to the test” (2009) 461 *Nature* 697 at 697.

² A. Hamilton, “Invention of the Year: The Retail DNA Test” *Time*, online: http://www.time.com/time/specials/packages/article/0,28804,1852747_1854493_1854113,00.html.

³ CBCNews.ca, “Personal DNA testing comes to Canada” (23 January 2008) online: <http://www.cbc.ca/health/story/2008/01/23/dna-sale.html?ref=rss>.

⁴ A. Pollack, “The Wide, Wild World of Genetic Testing” *The New York Times* (12 September 2006) G4.

⁵ See, for example, H. Mick, “Personal genetic tests: genius or bogus? Promises of ferreting out cancer and heart disease should be taken with a grain of salt, critics say” *Globe and Mail* (26 April 2007) L10. In December 2007, CBC television’s *Marketplace* ran a story on home DNA testing kits. Global National’s *The Bigger Picture* aired a story on personal genome testing on November 8, 2009.

⁶ There is a vast literature on critiques of DTC genetic testing. See, for e.g., T. Caulfield, N.M. Ries, P. Ray, C. Shuman and B. Wilson, “Direct-to-Consumer Genetic Tests: Good, Bad or Benign?” (2009) *Clinical Genetics*, DOI: 10.1111/j.1399-0004.2009.01291.x; C.J.W. Janssens *et al.*, “A Critical Appraisal of the Scientific Basis of Commercial Genomic Profiles Used to Assess Health Risks and Personalized Health Interventions” (2008) 82 *American Journal of Human Genetics* 593; S. Hogarth, G. Javitt & D. Melzer, “The Current Landscape for Direct-

sufficient scientific evidence to demonstrate clinical validity and reliability. Second, an individual can typically order DTC genetic tests without involvement of a health care professional and DTC companies may not provide adequate (or any) pre- and post-test counseling to help clients weigh the advantages and drawbacks of genetic testing and understand the results if they decide to undergo testing. Third, learning genetic information may have adverse psychological and behavioural consequences if individuals develop anxiety about genetic predisposition to disease, seek potentially inappropriate health care interventions, or develop fatalistic attitudes. In this regard, genetic tests may promote a misleading “genetic reductionist” or “deterministic” view, implying that one’s genetic make-up is the strongest predictor of one’s disease susceptibilities or other conditions. This view may downplay or ignore important environmental and/or lifestyle factors. It has been suggested that “the combination of consumer ignorance, scant government regulation, aggressive marketing practices, and the often overzealous media attention to genetic testing is a recipe for harm to individual consumers and public health.”⁷

On the other hand, knowledge about genetic predispositions may empower individuals and motivate them to make lifestyle changes or seek early medical intervention to reduce known disease risks. Learning that one is not affected by a familial genetic condition may provide relief from worry. Seeking testing outside the health care system also provides an option for individuals who do not want genetic test results recorded in a medical record. In the absence of evidence of harms to consumers, it can be argued that there is no reason to limit individuals from purchasing genetic tests for health purposes or even as a novel form of recreation.⁸

Canadians and DTC Genetic Testing

To date, there have been only a few studies examining Canadians’ knowledge of and attitudes toward DTC genetic tests. Public opinion research commissioned by the Public Health Agency of Canada in 2007/08 explored Canadians’ knowledge of and attitudes toward DTC nutritional genetic testing services, where genetic testing is used to identify genes that affect nutrient metabolism and susceptibility to diet-related diseases.⁹ This research involved 12 focus groups in five cities across Canada (Vancouver, Edmonton, Toronto, Montreal and Halifax). Many participants expressed interest in the potential health benefits of genetic testing for themselves

to-Consumer Genetic Testing: Legal, Ethical and Policy Issues” (2008) 9 *Annual Review of Genomics and Human Genetics* 161.

⁷ Y. Liu & Y.E. Pearson, “Direct-to-Consumer Marketing of Predictive Medical Genetic Tests: Assessment of Current Practices and Policy Recommendations” (2008) 27:2 *Journal of Public Policy and Marketing* 131 at 131.

⁸ For commentary on the notion of recreational genomics, see e.g. J.P. Evans, “Recreational Genomics: What’s in it for You?” (2008) 10:10 *Genetics in Medicine* 709.

⁹ Phoenix Strategic Perspectives Inc., *Exploring How Canadians Understand Nutrigenomics: Results of Focus Groups with Members of the General Public and Health Care Professionals* (Prepared for the Public Health Agency of Canada), copy on file with Health Law Institute.

and their family members, particularly to help inform healthier lifestyle choices to prevent or control disease. Participants were exposed to a mock website for a company offering DTC genetic testing and the majority of them quickly expressed privacy concerns with providing a DNA sample and personal details to a company, especially one operating outside Canada. Participants expressed concerns about security of samples and information, non-consensual uses of information and third-party access (e.g. insurance companies) that could result in harms to individuals.

A 2008 survey of approximately 1,200 residents of Alberta asked about willingness to pay for different types of genetic tests, as well as general attitudes toward genetic testing.¹⁰ Few respondents stated that they would pay more than \$500 for a genetic test, though 62% felt that the public health care insurance system should cover the cost of genetic tests for manageable health conditions. Approximately 60% of respondents indicated that privacy and discrimination fears would influence their decision to undergo genetic testing. Thirty-two percent of respondents stated they were aware that genetic tests could be purchased directly from companies over the internet. This proportion is likely to increase with continuing media coverage of genetic testing companies. Indeed, research from other jurisdictions demonstrates growing public knowledge about genetic testing. A comparison of US data from the years 1990 to 2004 shows an increase from 12.8% to 18.1% of respondents who say they know “a great deal” about genetic tests, with a corresponding drop from 25.8% to 14.1% of those who say they know “nothing at all.”¹¹

Internet use and online commerce is increasingly popular among Canadians; this factor, too, may push greater interest in DTC genetic testing services. According to Statistics Canada’s surveys of Canadians’ internet use,¹² 68% of Canadians use the internet on a daily basis. Close to 60% of Canadians with internet access visit websites offering health and medical information and the internet is the second most common source of health information, ranking only behind health care practitioners. Over 40% of internet users purchase goods and services online.

Privacy Concerns and DTC Genetic Tests

The process of buying genetic testing services in an internet marketplace raises significant privacy concerns, as consumers, who increasingly seek health information and services via the internet, may turn over biological samples and personal information to companies without a clear

¹⁰ N.M. Ries, R. Hyde-Lay & T. Caulfield, “Willingness to Pay for Genetic Testing: A Study of Attitudes in a Canadian Population” (2009) *Public Health Genomics*, published online October 2009 DOI:10.1159/000253120.

¹¹ E. Singer *et al.*, “Trends in U.S. Attitudes toward Genetic Testing, 1990-2004” (2008) 72 *Public Opinion Quarterly* 446.

¹² Statistics Canada, Canadian Internet Use Survey, 2007 data available at: <http://www.statcan.gc.ca/daily-quotidien/080612/dq080612b-eng.htm> and 2005 data available at: <http://www.statcan.ca/Daily/English/060815/d060815b.htm>.

understanding of the privacy implications, or of the companies' policies and practices for handling biological samples and personal information. Individuals who wish to undergo testing must provide personal information to the company, including basic contact and demographic information. The company may also collect details about the person's medical and family history. The client must also submit a biological sample to the company, usually a saliva or cheek swab sample. The company may carry out genetic testing on the sample in-house, or send the sample to a third-party laboratory contracted to carry out testing. Results are then returned to the client. As discussed in more detail below, this commercial transaction raises numerous privacy issues regarding the collection, use, disclosure and retention of the client's personal details and biological samples.

Some commentators have raised privacy concerns with DTC genetic testing. A December 2008 editorial on DTC testing in a leading oncology journal, *Lancet Oncology*, states: "The privacy of patients is also of paramount importance—how can we safeguard their genetic information against exploitation by individuals and corporations? ... While the choice to undergo genetic testing is obviously down to the individual, they must be fully informed of the inherent risks, and their rights and privacy protected and respected."¹³ Similarly, a commentary on genetic testing, biobanking and privacy in the *New England Journal of Medicine* notes:

Using the Internet for the marketing and purchasing of genetic tests sidesteps the doctor–patient relationship and eliminates meaningful, face-to-face genetic counseling. It also magnifies an older but unresolved danger: whenever identifiable DNA samples are collected and stored, there is a high risk that violations of genetic privacy will follow. As the evolution of DNA banking for research demonstrates, DNA donors shouldn't assume that the privacy protections they take for granted in medical care and clinical research apply. People give up more than they realize when they hand over their DNA.¹⁴

A 2009 article on DTC genetic testing companies suggests that companies have different target clientele based on individuals' attitudes toward privacy of genetic test information:

... Among the early adopters of personal genomics services ... [some display] what has been called 'informational exhibitionism: the willingness to share access to one's personal genomics information on weblogs and internet forums. 23andMe and deCODEme seem to target mostly those groups: healthy, well-off individuals curious to learn more about 'who they are.' Navigenics, on the other hand, seems to cater to a more cautious clientele ...¹⁵

¹³ Editorial, "Direct-to-consumer genetic tests: unethical and flawed" (2008) 9:12 *Lancet Oncology* 1113.

¹⁴ P.A. Roche and G.J. Annas, "DNA Testing, Biobanking and Genetic Privacy" (2006) 355:6 *New England Journal of Medicine* 545 at 545.

¹⁵ D. Gurwitz & Y. Bregman-Eschet "Personal Genomics Services: Whose Genomes?" (2009) 17:7 *European Journal of Human Genetics* 883 at 884.

This same article comments on privacy issues that may arise when companies go out of business or are taken over by another commercial enterprise: “Privacy interests might also be compromised in the event that a personal genetics company decides to sell its database, containing genotypic and phenotypic information of its customers (potentially along with identifying information such as customers’ birthdates or zip codes), to a third party. In such cases, personal information might be transferred to a company and/or a country with less strict privacy protection mechanisms.”¹⁶

Regulatory and consumer protection bodies in some jurisdictions have issued public communication statements that send a ‘buyer beware’ message about DTC genetic tests. For example, the US Federal Trade Commission gives the following advice to consumers who are considering DTC genetic tests: “Protect your privacy. At-home test companies may post patient test results online. If the website is not secure, your information may be seen by others. Before you do business with any company online, check the privacy policy to see how they may use your personal information, and whether they share customer information with marketers.”¹⁷

Some health professional associations express concerns about privacy aspects of DTC genetic testing. The American Society of Human Genetics (ASHG), for example, has cautioned:

Some DTC companies use privacy as a marketing tool, touting the benefits of obtaining genetic testing outside the health care system and thereby avoiding the risks of having genetic information contained in a medical record. However, these companies do not necessarily disclose their privacy policies or explain that a patient’s subsequent disclosure of the test results to a physician may lead to the information becoming part of his or her medical record. Further, DTC companies are not necessarily subject to the health privacy regulations issued pursuant to the Health Insurance Portability and Accountability Act (HIPAA), leaving consumers vulnerable to having their information used or disclosed in a manner that would be impermissible in the health care system.¹⁸

Professional associations, governmental agencies and scholarly commentators have suggested recommendations or ‘best practices’ that DTC genetic testing companies should follow to protect privacy. The ASHG recommended in a 2007 position statement that “[c]ompanies offering DTC testing should maintain the privacy of all genetic information and disclose their privacy policies, including whether they comply with HIPAA.”¹⁹ The US National Society of Genetic Counselors also recommends that DTC genetic testing companies must ensure appropriate safeguards to

¹⁶ See note above at 885.

¹⁷ See, for example, United States, Federal Trade Commission, *At-home Genetic Tests: A Healthy Dose of Skepticism may be the Best Prescription* (2006), online: Federal Trade Commission <http://www.ftc.gov/bcp/edu/pubs/consumer/health/hea02.shtm>.

¹⁸ American Society of Human Genetics, “ASHG Statement on Direct-to-Consumer Genetic Testing in the United States” (2007) 81:3 *American Journal of Human Genetics* 635 at 635.

¹⁹ See note above.

protect client privacy.²⁰ The American College of Medical Genetics' statement on DTC genetic testing states:

Privacy concerns must be addressed. Prior to testing, the consumer should be informed regarding who will have access to test results, what security is in place to protect these results, what will happen to the DNA sample once testing is complete and how to access a complaint procedure to report breaches of privacy. Also, the issues of possible employment and insurance discrimination and the potential impact on other family members should be discussed prior to obtaining genetic testing.²¹

The 2008 OECD Guidelines for Quality Assurance in Molecular Genetic Testing state that “[p]ersonal genetic information should be subject to privacy protection and security in accordance with applicable law.”²² In autumn 2009, the UK Human Genetics Commission (HGC) held a consultation on guiding principles for DTC genetic testing services; results from the consultation are pending as of March 2010. In regard to data protection, the HGC set out the following principles:²³

- Genetic information is sensitive personal data and requires the highest level of security and confidentiality. Records containing personal data and genetic information that can be linked to an identifiable person should be subject to privacy protection and security in accordance with professional guidance and applicable laws on data protection and confidentiality.
- The test provider and laboratories should not release biological samples or records containing personal data and genetic information that can be linked to an identifiable person to any third party without the prior consent of the person to whom they relate.
- Companies who wish to record consumers' details on to a database that will be held by the test provider, or a laboratory or professional associated with the testing procedure, should obtain prior consent from the consumers. Consent should also be obtained prospectively for consumers to be contacted in the future by these organisations or individuals.
- If a test provider ceases trading, they should dispose of personal and genetic data securely or provide for transfer of responsibilities in accordance with the terms of consent given by the consumer.

²⁰ National Society of Genetic Counselors, *Position Statement on Direct to Consumer Genetic Testing* (2007) online: <http://www.nsgc.org/about/position.cfm#DTC>.

²¹ American College of Medical Genetics, *ACMG Statement on Direct-to-Consumer Genetic Testing* (2008) online: http://www.acmg.net/AM/Template.cfm?Section=Policy_Statements&Template=/CM/ContentDisplay.cfm&ContentID=2975.

²² Organisation for Economic Cooperation and Development, *Guidelines for Quality Assurance in Molecular Genetic Testing* (2007) online: <http://www.oecd.org/dataoecd/43/6/38839788.pdf>.

²³ Human Genetics Commission, *A Common Framework of principles for direct-to-consumer genetic testing service* (2009) at 12-13, online: <http://www.hgc.gov.uk/UploadDocs/Contents/Documents/Principles%20consultation%20final.pdf>.

In regard to handling of biological samples, the HGC proposed the following principles:

- The use, storage, transfer and disposal of biological samples provided for genetic testing should be carried out in accordance with applicable legal, ethical and professional standards. The nature, purpose and maximum duration of the storage should be specified.
- Biological samples should be used, stored, transferred and disposed of in conditions that ensure their preservation and security.
- If a test provider ceases trading, they should dispose of consumers' biological samples securely or provide for transfer of responsibilities in accordance with the terms of consent given by the consumer.

The HGC also generally recommends that DTC genetic testing companies should provide the following information to customers:

- information about measures taken by the test provider and laboratories to ensure the confidentiality of personal records and security of biological samples;
- information about the maximum period of storage of the biological sample and personal records, and procedures for storage, transfer and disposal of biological samples and personal records;
- information about whether biological samples may be used for any secondary purposes, such as additional research purposes, and about or whether personal genetic information may be passed on to third parties and, if so, under what conditions; and
- information about procedures for handling and resolving consumer complaints.²⁴

The Nature of Genetic Information

The commentary and recommendations summarized above reveal a particular concern about protection and handling of genetic information. At a November 2009 workshop on privacy and genetic research, the Privacy Commissioner of Canada noted several key features of genetic information: “Genetic information is sensitive, it’s intimate; it’s predictive; it’s powerful and it’s shared.”²⁵ The Commissioner also pointed out that “[g]enetic information is the ultimate

²⁴ See note above at 19.

²⁵ Privacy Commissioner of Canada, *Genetic Information: Consent, Privacy and Research Biobanks*, Remarks at the

identifier.”²⁶ Indeed, genetic information has characteristics that set it apart from other types of personal information. The International Declaration on Human Genetic Data²⁷ posits that genetic information has “special status” based on the following features of human genetic data:

- i. they can be predictive of genetic predispositions concerning individuals;
- ii. they may have a significant impact on the family, including offspring, extending over generations, and in some instances on the whole group to which the person concerned belongs;
- iii. they may contain information the significance of which is not necessarily known at the time of the collection of the biological samples;
- iv. they may have cultural significance for persons or groups.

Some academic commentators question the extent to which genetic information is different from other types of personal information and thus deserving of special legal protection.²⁸ This report does not advocate a specific position on this question; rather, our aim is to examine the policies of DTC genetic testing companies against ten principles relevant to protection of all types of personal information. At present, Canadian privacy and human rights laws do not regulate genetic information in a way distinct from other types of personal characteristics or information.²⁹

Genome Canada/Office of the Privacy Commissioner Workshop (November 27, 2009) online: http://www.priv.gc.ca/speech/2009/sp-d_20091127_e.cfm.

²⁶ See note above.

²⁷ United Nations Educational, Scientific and Cultural Organization, *International Declaration on Human Genetic Data* (2003), Article 4 - Special Status, online: http://portal.unesco.org/en/ev.php-URL_ID=17720&URL_DO=DO_TOPIC&URL_SECTION=201.html.

²⁸ See e.g., S. Holm, “There is Nothing Special about Genetic Information” in *Genetic Information: Acquisition, Access and Control*, A.K. Thompson & R.F. Chadwick, eds. (Kluwer Academic: New York, 1999); M. Richards, “How Distinctive is Genetic Information?” (2001) 32:4 *Studies in History and Philosophy of Science* 663; G.J. Annas, “The Limits of State Laws to Protect Genetic Information” (2001) 345:5 *New England Journal of Medicine* 385.

²⁹ In February 2010, a Member of Parliament proposed a private member’s bill to amend the federal *Human Rights Act* to protect people from discrimination based on results of genetic testing. An advocacy group, the Coalition for Genetic Fairness, supports the initiative. See L. Kusch, “Private member’s bill would outlaw genetic discrimination” *Winnipeg Sun*, 26 February 2010.

Research Methods

This research examined the websites of 32 genetic testing companies, primarily based in North America, that advertise and sell health-related genetic tests directly to consumers via the internet. These companies advertise and sell a range of health-related genetic tests, including tests for susceptibility to various diseases/conditions, including cancers (breast, ovarian, prostate, colorectal), Alzheimer's disease, osteoporosis, blood clotting disorders, glaucoma and macular degeneration, diabetes, obesity, inflammatory bowel disease, celiac disease, multiple sclerosis, cardiovascular disease, rheumatoid arthritis, and fertility/pregnancy complications. Tests are also sold that identify genetic factors that influence metabolism of foods, pharmaceuticals, alcohol, caffeine and nicotine. These tests can identify individuals who may have adverse reactions to prescription drugs, greater susceptibility to diet-related diseases and propensity to substance addictions. Several companies offer prenatal genetic tests.

Genetic Testing Companies Examined in this Study³⁰

23andMe (California, USA)	Holistic Heal (Maine, USA)
BioMarker Pharmaceuticals (California, USA)	Inherent Health (Massachusetts, USA)
Consumer Genetics (California, USA)	Inneova (Vancouver, Canada)
Counsyl (California, USA)	Kimball Genetics (Colorado, USA)
CyGene Direct (Florida, USA)	Knome Inc. (Massachusetts, USA)
DeCODE Genetics (Iceland)	Matrix Genomics (New Mexico, USA)
DNA-CardioCheck (Illinois, USA)	MediChecks (United Kingdom)
DNADirect (California, USA)	MyGeneProfile (Connecticut, USA & UK)
DNA Plus (California, USA)	MyGenome (Massachusetts, USA)
DNA Traits (Texas, USA)	Navigenics (California, USA)
easyDNA (Toronto, Canada)	New Hope Medical (Nevada, USA)
G-nostics (United Kingdom)	Nimble Genomics (location not specified)
Genelex (Washington, USA)	Pathway Genomics (California, USA)
GeneLink Biosciences Inc. (Florida, USA)	Prenatal Genetics Center (Toronto, Canada)
Graceful Earth (Hawaii, USA)	Scienta Health (Toronto, Canada)
HealthCheckUSA (Texas, USA)	The Genetic Testing Laboratories (New Mexico, USA)

³⁰ The Genetics and Public Policy Center (GPPC), based at Johns Hopkins University in the US, maintains an up-to-date list of companies that advertise and sell genetic tests directly to consumers. The 29 companies we studied are current to the March 9, 2010 list published by the GPPC: <http://www.dnapolicy.org/resources/AlphabetizedDTCGeneticTestingCompanies.pdf>.

We commenced our research by examining company websites to obtain privacy policies publicly available online. For uniform analysis of the privacy policies, we developed a coding frame to examine the policies in relation to the ten fair information principles.³¹

The Ten Fair Information Principles

<p>Accountability An organization is responsible for personal information under its control and shall designate an individual or individuals who are accountable for the organization's compliance with the following principles.</p>	<p>Accuracy Personal information shall be as accurate, complete and up-to-date as is necessary for the purpose for which it is used.</p>
<p>Identifying Purposes The purposes for which personal information is collected shall be identified by the organization at or before the time the information is collected.</p>	<p>Safeguards Personal information shall be protected by security safeguards appropriate to the sensitivity of the information.</p>
<p>Consent The knowledge and consent of the individual are required for the collection, use or disclosure of personal information, except where inappropriate.</p>	<p>Openness An organization shall make specific information about its policies and practices relating to the management of personal information readily available to individuals.</p>
<p>Limiting Collection The collection of personal information shall be limited to that which is necessary for the purposes identified by the organization. Information shall be collected by fair and lawful means.</p>	<p>Individual Access Upon request, an individual shall be informed of the existence, use, and disclosure of his or her personal information, and shall be given access to that information. An individual shall be able to challenge the accuracy and completeness of the information and have it amended as appropriate.</p>
<p>Limiting Use, Disclosure and Retention Personal information shall not be used or disclosed for purposes other than those for which it is collected, except with the consent of the individual or as required by law. Personal information shall be retained only as long as necessary for the fulfillment of the stated purposes.</p>	<p>Challenging Compliance An individual shall be able to address a challenge concerning compliance with the above principles to the designated individual or individuals accountable for the organization's compliance.</p>

³¹ These principles are established in the Canadian Standards Association Model Code for the Protection of Personal Information. These principles are incorporated into law in the federal *Personal Information Protection and Electronic Documents Act*, S.C. 2000, c. 5.

In visiting the company websites, we first took note of the accessibility of the privacy policy; that is, whether a link to a privacy policy was readily found on the company's homepage or whether a visitor to the website must search on other pages to locate a privacy policy or statements about the company's privacy practices. We also examined what aspect of consumer privacy the policy addresses. For example, does the statement only address privacy aspects of visiting the website (e.g. when a visitor goes to the website, does the website automatically log information about the user's computer system or place a 'cookie' on the visitor's computer that allows the company website to recognize repeat visitors)? Or does the policy provide details on how personal information and biological samples will be handled for the purposes of conducting the genetic analysis and providing results to the client? More specifically, we examined if companies state policies in regard to:

- handling of biological samples;
- handling of personal information, including information derived from testing biological samples and information collected from customers about lifestyle and medical history;
- length of retention of samples and personal information;
- use of samples and/or information for secondary purposes (e.g. research);
- compliance with specific privacy legislation (e.g. do companies operating in the United States refer to the *Health Insurance Portability and Accountability Act, HIPAA*, that establishes privacy rules applicable to physicians, laboratories and hospitals);
- compliance with voluntary privacy codes of conduct;
- managing banks of biological samples and personal information in the event the company ceases to exist (e.g. the company loses financial viability or is acquired by another company);
- consent and the extent to which consumers are asked to give permission for various uses of biological samples and personal information; and
- procedures by which a consumer may obtain further information or make complaints about how the company handles personal information and biological samples.

The following section of this report describes our findings on these questions. We begin with a summary of key observations, then discuss each of the ten fair information principles. We quote illustrative extracts from company privacy policies and provide full copies of the privacy policies in Appendix I.

Findings

General Observations

Based on information available on company websites, there is wide variation in the extent to which DTC genetic testing companies address privacy issues and protection of personal information and biological samples. Of the 32 company websites we studied, 20 provide a privacy policy on their websites. Of these 20, five focus solely on internet usage with descriptions of how the company collects and uses information via their website. This includes statements about collection of a customer's name, email address, and other personal details to establish an account. Such policies also describe how the company's website uses cookies and log files to track data about visits to the site. Seven companies have policies that focus mainly on internet usage, but also include brief statements about handling of biological samples and/or test results. One company's policy provides only a brief description of how test results are handled. Seven companies have more comprehensive policies that explain how the company collects and uses information via its website and how biological samples and genetic test results are handled.

Several companies do not have a privacy policy, but make general promises about privacy on their website. DNA Traits, for example, states on its 'About Us' page, that the company's "services are private, affordable, and meet or exceed HIPPA requirements and the policy statement set forth by the American College of Medical Genetics".³² Under 'Our Philosophy', the website states that "DNA Traits does not accept reimbursement from insurance companies as this might limit our ability to ensure your privacy." GeneLink Biosciences states that "to protect your privacy, any information you submit is completely confidential. GeneLink will not release this information, nor will it be used to specifically identify any individual."

For those companies that have a privacy policy, it is typically accessible from a 'Privacy Policy' link found on a menu at the bottom of the website homepage. The font size was sometimes very small and a website visitor would need to scroll down to locate the menu. On a few websites, the privacy policy link was not apparent on the homepage and was located on another page of the website, such as an 'About Us' page, or 'Terms and Conditions' link. One company (Scienta Health) has the words 'Privacy Policy' at the bottom of its homepage, but it does not provide a link.

The table below indicates which companies have privacy policies available on their websites and briefly notes the nature of the policy, for example, whether it addresses collection and use of information via the website or is more comprehensive and also addresses handling of other types of personal information, including test results, and biological samples.

³² All quotations in this section of the report are taken from the company privacy policies. These policies are reproduced in Appendix I.

Overview: DTC Genetic Testing Company Websites & Privacy Policies

Company		Privacy policy on website	Comments about the privacy policy or general website statements about privacy
1.	23andMe www.23andme.com	Yes	Provides a 'Summary' and 'Full' privacy policy. Comprehensive policy that addresses collection and use of personal information via website, genetic information, and biological samples.
2.	BioMarker Pharmaceuticals www.biomarkerinc.com	Yes	Addresses collection and use of personal information via website.
3.	Consumer Genetics www.consumergenetics.com	Yes	Addresses collection and use of personal information via website. Brief statement about biological samples.
4.	Counsyl www.counsyl.com	Yes	Brief policy that focuses on handling of test results.
5.	CyGene Direct www.cygenedirect.com	Yes	Addresses collection and use of personal information via website. Mentions genetic information and biological samples.
6.	deCODE Genetics www.decode.com	Yes	Addresses collection and use of personal information via website, genetic information, and biological samples.
7.	DNA-CadioCheck www.dnaidcheck.com	No	
8.	DNA Direct www.dnadirect.com	Yes	Addresses collection and use of personal information via website. Mentions handling of test results.
9.	DNA Plus www.dnaplus.com	Yes	Primarily addresses collection and use of personal information via website.
10.	DNA Traits www.dnatraits.com	No	Website makes general statement that services are private and meet legislative and professional standards.
11.	easyDNA www.easydna.ca	Yes	Primarily addresses collection and transmission of personal information via website.
12.	G-nostics www.g-nostics.com	No	
13.	Genelex www.healthanddna.com	Yes	Addresses collection and use of personal information provided via website. Provides additional statement that materials and test results "are held in strict confidence and stored in monitored, secure facilities under the supervision of trained personnel."
14.	GeneLink Biosciences Inc. www.genelinkbio.com	No	Only has the following privacy statement on the page where a customer can contact the company by email: "Privacy Statement: In order to protect your privacy, any information you submit is completely confidential. GeneLink will not release this information, nor will it be used to specifically identify any individual."
15.	Graceful Earth www.gracefulearth.com	No	
16.	HealthCheckUSA www.healthcheckusa.com	Yes	Mainly addresses collection and use of personal information via website. Also has a HIPAA Privacy Policy that addresses collection, use and disclosure of personal health information.

17.	Holistic Heal www.holisticheal.com	No	Website provides only a short statement that information collected on website will not be sold or disclosed.
18.	Inherent Health www.inherenthealth.com	Yes	Addresses collection and use of personal information via website, genetic information, and biological samples. Has a paragraph specific to Canadian customers.
19.	Inneova www.inneova.com	Yes	Addresses collection and use of personal information via website, genetic information, and biological samples.
20.	Kimball Genetics www.kimballgenetics.com	No	
21.	Knome, Inc. www.knome.com	No	Website under revision as of March 2010.
22.	Matrix Genomics www.matrixgenomics.com	Yes	Brief policy mentions personal information and biological samples.
23.	MediChecks www.medichecks.com	Yes	Addresses collection and use of personal information via website.
24.	My Gene Profile www.mygeneprofile.com	Yes	Comprehensive policy that addresses collection and use of personal information via website, genetic information, and biological samples. Note that this policy is virtually identical to Navigenics' privacy policy.
25.	MyGenome www.mygenome.com	No	The 'Why MyGenome?' page states: " WARNING: Please do not send any private medical information by email at this time. This is not currently a secure, HIPAA-compliant medium for communicating medical information."
26.	Navigenics www.navigenics.com	Yes	Comprehensive policy that addresses collection and use of personal information via website, genetic information, and biological samples.
27.	New Hope Medical www.newhopemedical.org	Yes	Addresses collection and use of personal information via website.
28.	Nimble Diagnostics www.nimblediagnosics.com	No	Statement about privacy provided on FAQ page.
29.	Pathway Genomics www.pathway.com	Yes	Provides a 'Summary' and 'Full' privacy policy. Comprehensive policy that addresses collection and use of personal information via website, genetic information, and biological samples.
30.	Prenatal Genetics Center www.prenatalgeneticscenter.com	No	
31.	Scienta Health www.scientahealth.com	No	Has the words 'Privacy Policy' at the bottom of the screen but it is not a hyperlink and does not lead anywhere.
32.	The Genetic Testing Laboratories www.gtldna.com	Yes	Addresses collection and use of personal information via website. Brief mention of test results.

Analysis of Compliance with the Ten Fair Information Principles

Accountability

“An organization is responsible for personal information under its control and shall designate an individual or individuals who are accountable for the organization's compliance with the following principles.”

Companies with the most comprehensive privacy policies were more likely to indicate a designated individual to whom questions or concerns about privacy matters should be directed. Three companies (23andMe, Navigenics, Pathway Genomics) identify that they have a Chief Privacy Officer. Another company (DNA Direct) directs customers to contact its ‘Privacy Help Desk.’ Several companies repeated a general contact email address (e.g. DNA Plus, easyDNA, Genelex) or an email address that indicates that it is dedicated to receiving correspondence about privacy matters, such as *privacy@company-name.com*.

Identifying Purposes

“The purposes for which personal information is collected shall be identified by the organization at or before the time the information is collected.”

All the privacy policies indicate at least some purposes for which personal information is collected. As noted earlier, some policies address only collection and use of customers’ information for the purposes of establishing an account and monitoring website usage. More comprehensive policies identified purposes for which biological samples and other personal information, such as medical history, is collected. Nine of the 20 companies that have privacy policies identify that they may use clients’ information for research purposes. Research is discussed in more detail below.

Cygene Direct’s privacy policy offers an example of a more comprehensive statement of purposes for which personal information is collected and used: “Cygene Direct uses information for the following general purposes: to customize the advertising and content you see, fulfill your requests for products and services, improve our services, contact you, conduct research, and provide anonymous reporting for internal use only.” Inherent Health lists the following purposes: “We may use your personally identifiable information for the following purposes: To process and fulfill your order, including to send you emails confirming your order status and shipment; To generate and send you requested test results; To communicate with you and to send you information by email, mail, or other means about our products, new services, and special offers we think you will find valuable; To notify you about important changes to our Website.” Inneova specifically addresses biological samples: “The DNA is used only for the purpose of predictive genetics testing.”

Consent

“The knowledge and consent of the individual are required for the collection, use or disclosure of personal information, except where inappropriate.”

Our analysis of privacy policies provides a partial picture of information available to consumers to make an informed choice about purchasing DTC genetic testing services. Several companies refer to consent forms, which we did not examine as part of this study,³³ but which presumably outline additional details about the nature of the service and potential benefits and harms of undergoing genetic testing. 23andMe and Inneova provide access to their consent forms on their websites.

The seven companies that have more comprehensive privacy policies clearly offer more details to inform a potential customer’s decision-making about whether to purchase testing services from that company. By providing personal information via the website, ordering a test kit, and supplying a biological sample, there is a general assumption that customers consent to the use of their information and sample for the purpose of fulfilling their genetic test request. Ten companies (23andMe, Counsyl, deCODE Genetics, Genelex, HealthCheckUSA, Inneova, My Gene Profile, Navigenics, Pathway Genomics and The Genetic Testing Laboratories) state in their policies that they will not disclose personal information without the client’s express consent, though, as discussed below, some companies have exceptions to this general rule of no disclosure without consent.

Limiting Collection

“The collection of personal information shall be limited to that which is necessary for the purposes identified by the organization. Information shall be collected by fair and lawful means.”

For the most part, the privacy policies suggest that the companies limit collection of information to that necessary to provide online access to genetic testing services. Most policies discuss information collected when a customer accesses the company’s website and places an order for a genetic test kit. Collection of a biological sample is also necessary to carry out the testing service. Several policies (e.g. 23andMe, My Gene Profile, Navigenics) indicate that clients can choose or decline to complete questionnaires that collect information about their personal medical history, family history, and lifestyle details.

Limiting Use, Disclosure and Retention

“Personal information shall not be used or disclosed for purposes other than those for which

³³ Dr. Edna Einsiedel and Rose Geransar of the Faculty of Communication and Culture, University of Calgary, have conducted analyses of consent forms from some DTC genetic testing companies, as well as some marketing aspects of company websites. See e.g. R. Geransar & E. Einsiedel, “Evaluating online direct-to-consumer marketing of genetic tests: informed choices or buyers beware?” (2008) 12:1 *Genetic Testing* 13.

it is collected, except with the consent of the individual or as required by law. Personal information shall be retained only as long as necessary for the fulfillment of the stated purposes.”

In regard to the principle of limiting use, disclosure and retention, we examined privacy policies for statements about how companies manage the following five issues: use and disclosure for research; disclosure to third parties generally; retention of data and samples and termination of an account; company dissolution, merger or acquisition; and client-initiated information disclosure.

Use and disclosure for research

Eight companies (23andMe, Cygene Direct, deCODE Genetics, Genelex, HealthCheckUSA, My Gene Profile, Navigenics, Pathway Genomics) state in their privacy policies that they will use customers’ information for research purposes. Some of these policies refer to disclosure of information to research partners, though some specify that only de-identified information will be shared. HealthCheckUSA states, for instance, that they may use information about clients “for studies and to develop reports” but states that any such “reports do not identify specific people. For example, we may want to determine how many individuals of a sex in an age range from a defined population have a cholesterol value over 240 mg/dl.”

Pathway Genomics states that it may provide de-identified genetic and other information (such as health and family history) “to research collaborators to conduct Pathway Genomics-authorized scientific research and development.” The policy states that clients “cannot opt-out from this research” and that the company “may pass on to you a research collaborator's request that you volunteer additional information or participate in a study.” The company states that it will only share clients’ names or account information with research collaborators with express individual consent.

Navigenics describes research uses in more detail, stating that the company “may analyze our members' genetic data and associated phenotype information on an aggregated basis and de-linked from any member account information” for research purposes. The website states that if individuals “elect to contribute your genetic information to science through the Navigenics service, you allow us to share Your Genetic Data and Your Phenotype Information (de-linked from Your Account Information)³⁴ with not-for-profit organizations who perform genetic or

³⁴ Navigenics’ privacy policy defines ‘Your Genetic Data’, ‘Your Phenotype Information’ and ‘Your Account Information’ as follows:

‘Your Genetic Data’ means the genotyping results that we generate for you or your physician through our services (namely, the set of "A"s, "G"s, "T"s and "C"s at particular locations in your genome) but only to the extent such results, by themselves or when linked to other personally identifiable information, are sufficient to uniquely identify you.

‘Your Phenotype Information’ means your gender, your birth date and, optionally, other personal information about you that you or our physician may voluntarily provide to us, which may include your ethnicity/ancestry, the geographic regions where you or your ancestors have lived, any diseases or other health conditions that run in your family, and personal traits such as height and weight.

medical research, and you allow such not-for-profit organizations to separately or jointly publish study results that include Your Genetic Data and Your Phenotype Information (but not Your Account Information), in peer-reviewed scientific and medical journals and otherwise, and to deposit such data and information into public data repositories or otherwise make them publicly available to the extent required by such journals. If you elect not to contribute your genetic information to science through the Navigenics service, we will not share Your Genetic Data or Your Phenotype Information with such organizations.”

23andMe, which also has much involvement in research, advises customers that the company collects “personal information from you to provide you with our service and for conducting 23andMe-authorized research.” It also states it will share personal information with “third party organizations” for research, but that customer names and account information will be removed first. The privacy policy also states that 23andMe will not disclose personal information to “any outside company” without explicit consent. The terms ‘third party organization’ and ‘outside company’ are not defined or further described in the policy.

Disclosure to third parties generally

Some companies contract with a third party laboratory that conducts the genetic sequencing test. Where privacy policies address this (e.g. 23andMe, CyGene Direct, DNA Direct, Inherent Health and Matrix Genomics), they state that the biological sample is sent to the laboratory labeled with a code and no individual identifiers are attached. 23andMe provides a very clear instruction to clients to ensure that they place only a coded sticker on the sample and do not put identifiers, such as their name, on the sample collection kit. The privacy policy states: “To protect your privacy, samples sent with any identifier other than the barcode will not be processed.”

Where policies address disclosure of results, the common approach is that information will not be provided to insurance companies, health care providers, family members or other third parties without client consent. Several companies advise that the company retains discretion to share client personal information with “partner companies” who may contact the client to market products and services. As HealthCheckUSA puts it: “In cases where we believe your health interests will be served, HealthCheckUSA may share your information ... with HealthCheckUSA Business Partners, who can alert you about new products and services in the offering.”

While a company may make a general promise that they will not disclose information without

‘Your Account Information’ means the information that you or your physician provide to us when creating or updating your Navigenics account, or purchasing our services, that can be used to uniquely identify you, such as your name, telephone number, email address, billing/shipping address or credit card number.

client consent, some may impose a broad caveat on that promise. For example, Inneova states that it will not disclose personal information without consent “except to its medical, scientific, and other service partners, subsidiaries and related business entities, legal advisors, agents, or appointees for the purpose of performing genetic testing or interpretation services, as well as any associated administrative transactions, as deemed necessary by ICL [Inneova Corporation Limited] in the normal course of business.”

Retention of data and samples and termination of an account

Companies that have privacy policies offer few details about retention of data and biological samples. At one extreme, HealthCheckUSA states that the company does not maintain copies of test results after they have been provided to the client: “All client reports are mailed directly to the client only and copies are not retained.” Yet, this statement is subsequently contradicted by their policy for compliance with the US *Health Insurance Portability and Accessibility Act*, which states: “An individual’s clinical information is forwarded directly to the individual and some form of record is either retained in secure hard copy file or with a laboratory’s archival record for 3 years.”

Inherent Health states that it will destroy the biological sample within 10 days of completing the client’s test request but that they are “required by law to archive and retain copies of the test report for 7 years”, even if the client otherwise asks the company to terminate their account. Inneova states that each sample is “discarded following a secure protocol” after testing is completed. Matrix Genomics also states that samples are destroyed after testing.

deCODE Genetics advises that “[t]he buccal swab sample and the DNA extracted from the sample will be stored by deCODE only for the time necessary to perform the Genetic Scan and will be discarded upon successful measurements. Thus, deCODE will only use buccal swab samples and samples derived from them for the specific measurements ordered by its customers.” deCODE continues on to state that the company “guarantees that Genetic Scan data is always accessible at deCODEme for a minimum of 3 months after it was generated. This does not mean that data will be deleted from deCODEme servers after that.”

Consumer Genetics states that “left over samples may be used for quality control purposes and testing”, though a customer may opt out of this use at the time of ordering. If the customer opts out, the company states that “any remaining sample will be destroyed according to state and local regulations.”

Pathway Genomics states that a customer may make a written request (by email or hard copy letter) that the company destroy “your remaining sample and DNA obtained from it, and delete your Account from our systems.” The company cautions, however, that “not all personal information can be removed from our systems. We are required by law and standards of medical practice to preserve medical records, some contact information, and disclosure records for specified time periods. Information archived on data backup media also

cannot be deleted, however is protected by encryption. Aggregate Information³⁵ and information in logs cannot be deleted.” It is worth noting that another section of this company’s website makes two claims that directly contradict one another: “...when we are finished analyzing your DNA we destroy your sample in a manner that maintains your privacy. As a matter of fact, we place it in our proprietary DNA Lockbox™ for safekeeping.” It is difficult to understand how the company destroys the sample while also placing it in a ‘DNA Lockbox’ for safekeeping.

DeCODE Genetics states it will destroy the client’s information 60 days after receiving a request (the time delay exists to ensure the destruction request was not accidental or malicious). The company explains that “your data will be deleted from all the operational systems at deCODEme and eliminated from all future backup restores of the operational systems. However, the data may not be eliminated from all historical archival tapes of the operational systems.”

Navigenics promises to delete genetic data and personal information within 90 days of receiving a request. As with deCODE, Navigenics states that they “will not be obligated to delete your Genetic Data or Your Phenotype Information from historical archives of our systems.” Navigenics’ privacy policy specifically addresses continuing research use of genetic data and personal information. The policy implies a default position that such data will continue to be used for research after the client terminates their account, unless the client specifically opts out of future research use. The policy states: “Upon account termination, you will be given an opportunity to withdraw your consent for us to use Your Genetic Data and Your Phenotype Information (de-linked from Your Account Information) for our internal research purposes If you previously have elected to contribute your genetic information to science through the Navigenics service, you will also have the opportunity upon account termination to withdraw your consent for not-for-profit organizations to begin new studies using Your Genetic Data and Phenotype Information after the 90-day period. However, Your Genetic Data and Your Phenotype Information will not be removed from any ongoing or completed studies or publications in which Your Genetic Data or Your Phenotype Information was utilized.”

Company dissolution, merger or acquisition

The 2009 financial downturn demonstrates the financial tenuousness of small biotechnology firms, including some DTC genetic testing companies. Acu-Gen Biolabs, which sold a genetic test that alleged to determine fetal sex, filed for bankruptcy protection in December 2009. The bankruptcy application was due, in part, to a class action lawsuit by 100 women who allege the test was inaccurate in predicting the sex of their baby.³⁶ As of February 2010, DNA Direct was acquired by another company, MedCo.³⁷ The possibility that a company

³⁵ Pathway Genomics’ privacy policy defines ‘Aggregate Information’ as “summarized information unlinked to name or Account Information.”

³⁶ See J.M. Donnelly, “Acu-Gen Biolab files for Ch. 11 bankruptcy” (17 December 2009) <http://www.masshightech.com/stories/2009/12/14/daily59-Acu-Gen-Biolab-files-for-Ch-11-bankruptcy.html>.

³⁷ Press release, “Medco Acquires Leading Genetics Healthcare Company, DNA Direct” (2 February 2010)

may go bankrupt, merge with or be acquired by another company, or otherwise cease doing business means that privacy policies should address how client information and biological samples are handled in these circumstances.

Eight companies (23andMe, deCODE, DNA Direct, HealthCheck USA, Inherent Health, My Gene Profile, Navigenics and Pathway Genomics) specifically notify customers in their privacy policies about the prospect of sale or dissolution of the company and/or its assets. For example, DNA Direct states: “We may sell or transfer assets or portions of our business as we continue to improve our product and service offerings. In the event of such transactions, in order to provide continuity of service, user information (whether Non-Personal Information, Personally, Personally Identifiable Information and/or Personal Health Information) may be transferred.” HealthCheck USA states in its *HIPAA* privacy policy that personal health information about customers “may be disclosed as part of a potential merger or acquisition involving our business in order to make an informed decision regarding any such prospective transaction. Should a merger or acquisition take place, our database of names and addresses may be part of the process.”

Pathway Genomics states that it will require any acquiring company to uphold the terms of the company’s privacy policy: “If Pathway Genomics enters into a business transaction, such as a merger, acquisition by another company, or selling some or all of its assets, your personal information will, in most instances, be part of the assets transferred. We will require the acquiring company to comply with the material provisions of the Full Privacy Statement.”

Client-initiated information disclosure

Several companies provide ‘social networking’ opportunities for clients to share test results online with third parties, including friends, family members and other persons who may share similar characteristics. deCODE Genetics describes its social networking features as follows: “Users are free to enter further information about themselves into their user profile (my settings) or settings, such as gender, date of birth, or even their full names if the so choose. In every case, they can specify who is able to share their user attributes: make the attribute visible to all deCODEme users, visible only to their friends, or fully private and visible only to themselves.” The privacy policy elaborates that: “Friends are created by sending invitations to existing users or by sending an email to potential future users. In both cases, the individuals have to accept the invitation in their invitation inbox or by following a link in the email they receive. Friendships are reciprocal, i.e. if user A is the friend of user B then user B is also the friend of user A. Finally, existing friendships can be terminated simply by removing users from the friend lists.”

23andMe offers a similar social networking function: “Our service gives you access to your Genetic Information, as well as the opportunity to share and compare your Genetic and

online: www.dnadirect.com/pdf/media/medcoAcquisition_020110.pdf.

Phenotypic Information with that of other people who have also agreed to share such information. ... 23andMe gives you the ability to connect with other individuals who have 23andMe accounts through our sharing features. Whether you use these features is entirely your choice.” Pathway Genomics also permits clients to allow third parties to access information online: “The Pathway Genomics website allows you to share your personal information with other individuals, including family members, friends, physicians and other health care providers. It is your decision whether to allow these individuals to have access to your personal information.”

These companies caution clients about allowing online access to their information, or to sharing it in other ways. Pathway Genomics “recommends that you carefully consider whether to grant these individuals access to your personal information, which individuals you will allow access, and what information you will make available to these individuals.” 23andMe points out in its privacy policy that “you may choose to disclose, through other means not associated with 23andMe, your personal information to friends and/or family members, groups of individuals, third-party service providers, doctors or other professionals, and/or other individuals. We recommend that you make such choices carefully.”

Several of the companies remind customers to safeguard their results once returned to them. deCODE Genetics, for example, states that “[u]sers are free to download the genotypes from the Genetic Scan, however, we urge them to ensure the security of the data once it is on their computer, e.g. by encrypting the data file.” Some companies add that they cannot be held liable for privacy breaches that may result from the client’s own handling of their information. 23andMe points out: “Personal information, once released or shared, can be difficult to contain. 23andMe will have no responsibility or liability for any consequences that may result because you have released or shared personal information with a third party.”

Accuracy

“Personal information shall be as accurate, complete and up-to-date as is necessary for the purpose for which it is used.”

DTC genetic testing companies collect information directly from clients, so this helps to ensure the information is accurate and up-to-date. DNA Direct notes in its privacy policy: “You are responsible for ensuring the accuracy of the Personally Identifiable Information and Personal Health Information you submit to DNA Direct. Inaccurate information will affect the information you receive when using our website and tools and our ability to contact you. For example, your email address should be kept current because that is the primary manner in which we communicate with you.”

Inherent Health advises customers to notify the company to correct any inaccurate information: “If you believe that the personally identifiable information about you that we have collected is incomplete or inaccurate, we will correct the information upon verification

of the omission or error and of the identity of the person requesting the change.”

Safeguards

“Personal information shall be protected by security safeguards appropriate to the sensitivity of the information.”

Safeguards include physical, technical and administrative measures to protection information and biological samples from unauthorized access, use, disclosure, alteration or destruction. Almost all the company privacy policies make statements about security safeguards, though the degree of detail varies substantially. As an example of a more comprehensive statement, 23andMe describes its security safeguards in each of the three categories:

Technical:

- We protect our network perimeters with firewalls.
- Our databases are designed to keep Genetic Information and Phenotypic Information separate from Account Information.
- We encrypt storage of certain personal information, including Account Information and Genetic Information.
- We encrypt all connections to and from our website.
- We conduct internal and external audits of perimeter and software code security.
- We monitor our employees' use of our databases and maintain records of all access to personal information.

Physical:

- Physical access to internal servers is restricted to authorized personnel.
- We restrict data center access to approved personnel via photo and passcode authentication, biometrics, and other security protocols.

Administrative:

- We prohibit personal information from being extracted from our systems and loaded onto laptops or other mobile devices, or from being sent out electronically.
- We limit access to personal information to certain employees for limited, approved purposes based on their specific responsibilities.
- We require annual privacy and security training for employees with access to personal information.

In contrast, other companies make very general statements about security measures. DNA Plus asserts: “We maintain physical, electronic, and procedural safeguards that comply with federal standards to guard your non-public personal information.” Some generic statements provide no meaningful information. One example is easyDNA’s claim: “This Web site takes every precaution to protect our users’ information. When users submit sensitive information via the Web site, their information is protected both online and off-line.” The policy provides no further explanation of what it means by protection “both online and off-line.”

Inherent Health states that employees and contractors who have access to clients' personal information "are trained appropriately and are required to sign a confidentiality agreement that aligns with [the company's] privacy policy."

Somewhat surprisingly, one company (Matrix Genomics) invites clients to submit their test kit under a false name: "You do not have to reveal any identifiable information about yourself when you contact us, even your name -- you are welcome to create an alias...."

Some companies are careful to note that they cannot guarantee security. For instance, Pathway Genomics explains that it "has adopted administrative, physical and technical security measures to protect your personal information. However no method of transmission over the Internet or method of electronic storage is 100% secure. Therefore, while we use commercially reasonable and appropriate means to protect your personal information, we cannot guarantee its absolute security."

Several companies address safeguards specific to biological samples, stating that samples are labeled with a code/tracking number to protect a client's identity (e.g. 23andMe, CyGene Direct, DNA Direct, Inherent Health, Inneova). For example, Inherent Health states: "DNA samples are assigned a unique, anonymous barcode to track the Genetic Information independent of the user information. User information is always stored separately from Genetic so that Genetic Information remains anonymous to laboratory personnel." Inneova explains that it "uses a specific tracking system to identify your sample as soon as it enters our facilities. Molecular biologists in charge of your sample do not know who the actual sample belongs to, but only see each sample as a number. This tracking number is associated with your name and contact information only within our secure database, which is not accessible by the lab or anyone outside of our company."

Openness

"An organization shall make specific information about its policies and practices relating to the management of personal information readily available to individuals."

This principle underscores the entire aim of this research project; namely, we have sought to examine the extent to which DTC genetic testing companies make specific information available about their privacy policies and practices. As noted at the outset of the Findings section, openness varies widely among companies. While more than half the companies we examined – 20 out of 32 companies – have a privacy policy, the policies vary substantially in their content.

Individual Access

"Upon request, an individual shall be informed of the existence, use, and disclosure of his or her personal information, and shall be given access to that information. An individual shall be able to challenge the accuracy and completeness of the information and have it amended

as appropriate.”

As mentioned earlier, some companies (e.g. 23andMe, deCODE) allow clients to access and share their personal information online via the company’s website. Aside from access of this nature, some companies (e.g. HealthCheckUSA, Inherent Health, Pathway Genomics) make an explicit statement in their privacy policies that a client may request access to personal information held by the company. For instance, HealthCheckUSA states: “You may request access to all your personally identifiable information that we collect online and maintain in our databases....” Pathway Genomics states: “You have the right to request an accounting of all disclosures, other than for treatment, payment, or healthcare operations.” Inherent Health’s privacy policy has a paragraph specific to Canadian customers, which advises that “Canadian citizens, except under circumstances defined by law, are entitled to access their own Personal Information collected by” the company.

Challenging Compliance

“An individual shall be able to address a challenge concerning compliance with the above principles to the designated individual or individuals accountable for the organization’s compliance.”

As described under the ‘Accountability’ principle, several companies identify an individual such as a Chief Privacy Officer to whom questions or concerns about privacy matters may be addressed. Several companies also identify a third party organisation or regulatory body that may receive privacy-related complaints. DNA Direct provides the name of a contact person within the company to whom privacy concerns should be addressed. In the event that the matter is not concluded to the client’s satisfaction, the privacy policy advises clients to contact a third party Internet privacy organisation, TRUSTe³⁸, which “will then serve as a liaison with us to resolve your concerns.”

Pathway Genomics advises customers: “You may also file a complaint with the Secretary of the U.S. Department of Health and Human Services and/or the California Department of Public Health. Pathway Genomics will not take retaliatory action against you for filing a complaint about our privacy practices.” Similarly, HealthCheck USA states in its privacy policy: “You have the right to file a complaint if you do not agree with how we have used or disclosed PHI [personal health information] about you. All complaints must be submitted in writing. Your services will not be affected by any complaints you make. We cannot retaliate against you for filing a complaint or refusing to agree to something that you believe to be unlawful.”

BioMarker Pharmaceuticals states: “In the event we are unable to resolve an issue regarding our compliance [regarding privacy], we will contact the appropriate Data Protection Authorities to expeditiously resolve the complaint.”

³⁸ For more information about TRUSTe, see www.truste.com.

Other Issues

In addition to examining the extent to which privacy policies address the ten fair information principles, we considered three additional topics. First, do companies identify specific privacy statutes or other legislation that regulates their activities? Second, and related to the fair information principles of Consent and Individual Access, do companies make statements about ownership of personal information and biological materials? Issues of ownership of genetic information and biological samples remain unsettled in Canadian law,³⁹ so we examined privacy policies to determine if companies address questions of ownership. Finally, we noted whether policies address genetic testing of children. Although the numerous issues related to children's privacy and genetic testing⁴⁰ are outside the scope of this paper, we identified policies that make some reference to carrying out testing on minors.⁴¹

Compliance with Legislation

Some companies refer generically to compliance with laws or regulations; for example, Cygene Direct states: "We have physical, electronic, and procedural safeguards that comply with federal regulations to protect personal information about you." The regulations are not specified by name, however, nor are the scope of alleged protections explained. Two companies, BioMarker Pharmaceuticals and The Genetic Testing Laboratories, state that they comply with the United States Department of Commerce Safe Harbor Standards, but do not explain what these standards involve.⁴²

Several United States-based companies (Counsyl, Inherent Health, Pathway Genomics) refer in their privacy policies to the *Genetic Information Non-Discrimination Act (GINA)*, a federal law enacted in 2008 which prohibits discrimination in health coverage and employment based on genetic information.⁴³ Company statements about the scope of *GINA* may, however, be misleading. For example, Counsyl's website states that *GINA* "categorically protects Americans against discrimination based on their genetic information."⁴⁴

³⁹ For example, a Canadian court has observed that "Case law from the 1600s to present day has held that a human body is not property, at least not in the normal sense." *R.v. Polimac* (2006) 149 C.R.R. (2d) 161. For scholarly commentary on property law, human tissue and genetic research, see e.g. A. Charo, "Body of Research – Ownership and Use of Human Tissue" (2006) 355 *New England Journal of Medicine* 1517.

⁴⁰ For discussion, see e.g. L.F. Ross & M. R. Moon, "Ethical Issues in Genetic Testing of Children" (2000) 154 *Archives of Pediatrics and Adolescent Medicine* 873; A. McConkie-Rosell & G.A. Spiridigliozzi, "Family Matters: A Conceptual Framework for Genetic Testing in Children" (2004) 13:1 *Journal of Genetic Counseling* 9; and R.E. Duncan *et al.*, "An International Survey of Predictive Genetic Testing in Children for Adult Onset Conditions" (2005) 7:6 *Genetics in Medicine* 390.

⁴¹ For more detailed analysis of DTC genetic testing company policies regarding testing of minors, see P. Borry, H. Howard, K. Sénécal & D. Avaré, "Health-Related Direct-to-Consumer Genetic Testing: A review of companies' policies with regard to genetic testing in minors" (2010) 9:1 *Familial Cancer* 1389.

⁴² These standards were developed to facilitate trade between the United States and the European Union to ensure that U.S. companies meet privacy protection requirements mandated under European laws. For additional detail, see United States National Export Initiative website: http://www.export.gov/safeharbor/eu/eg_main_018365.asp.

⁴³ For more information about *GINA*, see the fact sheet from the US Department of Health and Human Services (6 April 2009) online: <http://www.genome.gov/Pages/PolicyEthics/GeneticDiscrimination/GINAInfoDoc.pdf>.

⁴⁴ <https://www.counsyl.com/about/privacy/>.

Several U.S. companies also refer to the *Health Information Portability and Accountability Act (HIPAA)*, which applies to health care professionals to restrict disclosure of patients' personal information without their consent. Counsyl's website notes that if a customer shares their genetic test results with their physician, any information recorded in their medical record will fall under the scope of *HIPAA* protections. One company, Cygene Direct, cautions that "[o]nce your genetic information becomes part of your permanent medical record, insurance carriers and others may have access to your genetic information."

A few companies stipulate in their privacy policies that laws of a particular jurisdiction govern their commercial activities. Pathway Genomics provides the following statement to clients who reside outside the United States: "You expressly consent to the processing of your personal information in the United States in accordance with the Full Privacy Statement. United States privacy laws and regulations may be less stringent than the laws in your country." One company (easyDNA) that has offices in Canada stipulates in its privacy policy that the laws of the British Virgin Islands apply to transactions with the company, but offers no explanation for the choice of this legal jurisdiction. The company further states that it "complies with the requirements of the Data Protection Act 2001 with regard to the collection, storage, processing and disclosure of personal information and is committed to upholding the Act's core Data Protection Principles." It does not explain the requirements of this statute or its core data protection principles.

Another company (Inherent Health) has a paragraph in its privacy policy specific to Canadian customers. It advises how Canadian customers may request access to and correction of their personal information held by the company.

deCODE Genetics, on its deCODEme.com site, states that it complies with the 'Health on the Net' Code of Conduct. This code, established by the non-governmental organisation Health on the Net Foundation, lists eight principles⁴⁵, including the following principle about

⁴⁵ The principles are:

- Authoritative: "Any medical or health advice provided and hosted on this site will only be given by medically trained and qualified professionals unless a clear statement is made that a piece of advice offered is from a non-medically qualified individual or organization."
- Complementarity: "The information provided on this site is designed to support, not replace, the relationship that exists between a patient/site visitor and his/her existing physician."
- Privacy and confidentiality: "Confidentiality of data relating to individual patients and visitors to a medical/health Web site, including their identity, is respected by this Web site. The Web site owners undertake to honor or exceed the legal requirements of medical/health information privacy that apply in the country and state where the Web site and mirror sites are located."
- Attribution: "Where appropriate, information contained on this site will be supported by clear references to source data and, where possible, have specific HTML links to that data. The date when a clinical page was last modified will be clearly displayed (e.g. at the bottom of the page)."
- Justifiability: "Any claims relating to the benefits/performance of a specific treatment, commercial product or service will be supported by appropriate, balanced evidence in the manner outlined above in Principle 4."
- Transparency: "The designers of this Web site will seek to provide information in the clearest possible manner and provide contact addresses for visitors that seek further information or support. The Webmaster will display his/her E-mail address clearly throughout the Web site."
- Financial disclosure: "Support for this Web site will be clearly identified, including the identities of

privacy and confidentiality: “Confidentiality of data relating to individual patients and visitors to a medical/health Web site, including their identity, is respected by this Web site. The Web site owners undertake to honor or exceed the legal requirements of medical/health information privacy that apply in the country and state where the Web site and mirror sites are located.”

Ownership Statements

Only two companies state in their privacy policies that customers ‘own’ their DNA. deCODE Genetics states that “[t]he user owns their genetic data” and DNA Direct states that the company believes “that your genetic information is your property, and it is your right as a consumer to be able to confidentially obtain and control this information.” Knome’s website (which is under revision as of March 2010) previously stated that: “Core to the fundamental principles of the company, you retain full ownership of your personal genetic information.”

23andMe implies that the company owns the information as it advises in its privacy policy that clients will be informed of any “change in ownership” of their personal information, such as through merger or acquisition. Statements in privacy policies about handling of client information and samples in the event of a merger or acquisition also imply that the company owns these materials, since such statements typically indicate that these ‘assets’ will form part of a transfer to a new corporate owner. Two companies (Genelex and easyDNA) state that the company owns information collected via its website.

Children and DTC Genetic Tests

Eight of the company privacy policies address advertising and/or sale of genetic tests to children (23andMe, CyGene Direct, deCODE Genetics, DNA Direct, Inherent Health, MediChecks, Navigenics, and Pathway Genomics). Four of these companies (CyGene Direct, deCODE Genetics, MediChecks and Navigenics) state that they do not advertise and sell to persons under age 18. Navigenics explains this policy: “This website is not directed toward minors under 18 years of age. Given the ethical, privacy and informed consent considerations regarding genetic testing of minors for predisposition or carrier status of adult-onset genetic disorders, Navigenics does not knowingly collect or use information from minors under the age of 18.”

23andMe, DNA Direct and Inherent Health state that their websites are not intended to attract children under the age of 13. Inherent Health adds that it will not knowingly collect information about children under 13. DNA Direct and 23andMe, however, state that a parent

commercial and non-commercial organizations that have contributed funding, services or material for the site.”

- Advertising policy: “If advertising is a source of funding it will be clearly stated. A brief description of the advertising policy adopted by the Web site owners will be displayed on the site. Advertising and other promotional material will be presented to viewers in a manner and context that facilitates differentiation between it and the original material created by the institution operating the site.”

or guardian may order genetic tests for their child. 23andMe provides the following statement about children's privacy: "23andMe is committed to protecting the privacy of children, as well as adults. Neither 23andMe nor any of its services are designed or intended to attract children under the age of 13. A parent or guardian, however, may order and set up an account for our services on behalf of his or her child. The parent or guardian assumes full responsibility for ensuring that the information that he/she provides to 23andMe about his or her child is kept secure and that the information submitted is accurate."

Pathway Genomics states that it will not knowingly market tests to those under age 18 but the company will provide testing services for a minor aged 13 or older provided consent is also obtained from a parent/guardian. The company's privacy policy advises: "In accordance with the Children's Online Privacy Protection Act ("COPPA"), if a child activates an account and completes any surveys, we shall attempt to contact the child's parent or guardian, identified during the activation process, to obtain verifiable consent to maintain collected information from children under the age of 13. If we are unable to obtain parental or guardian consent, we will erase such information from our records, except for information that may be archived on encrypted data back-up media."

Conclusions

DTC Genetic Testing Companies and the Fair Information Principles

The growing availability of DTC genetic testing services has left “regulation lagging behind.”⁴⁶ Various professional associations and government bodies have proposed voluntary codes of conduct or statements of best practices for DTC companies but, “if or when prices drop further and the tests become more popular ... government regulators may feel compelled to step in on the grounds that industry self-policing no longer offers consumers adequate protection.”⁴⁷ Until that happens – if it does – consumers must be prepared to protect themselves in conducting online commerce with DTC genetic testing companies. Analysing company privacy policies and practices against the ten fair information principles is a useful way to evaluate the extent to which a company complies with prevailing norms.

We draw several concluding points from our analysis of the privacy policies of DTC genetic testing companies. First, wide variation in the comprehensiveness and ‘quality’ of privacy policies is readily apparent. We judge quality here by considering the extent to which a policy addresses most or all of the ten fair information principles. Not surprisingly, companies with more comprehensive policies are more likely to address the ten principles and, as a result, provide a potential customer with details needed to make an informed choice about whether the company’s stated practices provide the consumer with the level of privacy protection they desire.

Second, in our view, over half of the privacy policies we examined are deficient in not addressing how the company handles the biological samples submitted by customers. In collecting these samples, the companies become private sector biobankers with control over biological materials that are, as the Privacy Commissioner of Canada has stated, “the ultimate identifier.”⁴⁸ Failing to explain how the company handles these samples leaves potential customers uninformed about a key privacy issue.

Third, and more subtly, we note that some company websites make assertions about privacy protection practices that are really no more than advertising claims. For example, My Genome states on its homepage that its services allow for “personal control over private genetic information” and “confidential access to the health benefits of genomic discovery.”⁴⁹ A privacy policy, however, is not available on the website. As another example, Pathway Genomics claims that it provides unique, proprietary technology to protect genetic samples: “No other DNA testing firm offers this level of security. Others send your DNA elsewhere for testing, even to locations overseas!”⁵⁰

⁴⁶ See note 1.

⁴⁷ See note above.

⁴⁸ See note 25.

⁴⁹ <http://www.mygenome.com/pages/1/index.htm>.

⁵⁰ http://www.pathway.com/more_info/on_site_lab.

Fourth, some policies contain confusing internal inconsistencies. The privacy policy for HealthCheck USA, for example, states that client test results containing laboratory data “are mailed directly to the client only and copies are not retained.”⁵¹ This statement is contradicted, however, by the company’s HIPAA Privacy Policy, which advises that “[a]n individual’s clinical information is forwarded directly to the individual and some form of record is either retained in secure hard copy file or with a laboratory’s archival record for 3 years.” The privacy policy also promises that “[u]nder no circumstances will this information [client test results] be made available to third parties such as insurance carriers or representatives of any health provider without the prior consent of the individual.” The policy continues on to give the company broad discretion to share information with business partners: “In cases where we believe your health interests will be served, HealthCheckUSA may share your information (with the exception of account, credit card, and ordering information) with HealthCheckUSA Business Partners, who can alert you about new products and services in the offering.” Some financial information is excluded from this information-sharing policy, but it is unclear whether client test information will be shared. This type of information sharing, which gives wide discretion to the company, does not accord with the principles of consent and limiting disclosure.

To conclude this report, the next section provides a list of privacy-related questions that we recommend consumers should consider before purchasing genetic tests from a company over the internet. We also offer some questions that consumers should consider about their own privacy practices. The questions related to company policies and practices are organized around the ten fair information principles. Consumers who seek answers to these questions – through careful review of company privacy policies and direct contact with company representatives before purchasing genetic testing services – will be in a position to make a more informed choice about sending their personal information and biological samples to a commercial enterprise.

⁵¹ See the HealthCheck USA privacy policy in the Appendix.

Questions to Ask Before Doing Business with a DTC Genetic Testing Company

Accountability

- Does the company identify an individual, such as a Chief Privacy Officer, who is responsible for the company's privacy policies and practices?
 - If no, contact the company to ask if they have a staff member responsible for how the company handles personal information about clients.
 - If yes, contact this person to clarify any questions you have about the company's privacy policies and practices. If you contact the person by email or by leaving a telephone message, how long does it take to receive a reply? Does the reply answer your question(s) clearly and fully?

Identifying Purposes

- Does the company have a privacy policy and/or consent form that clearly identifies the purposes for which it collects personal information and biological samples from you?
 - If you are unsure of the purposes, contact the company to ask for more information.

Consent

- Does the company give you enough information – in its consent form, privacy policy, and other available documentation – so that you can make an informed choice about whether to buy genetic testing services from them?
 - If you need more information to make an informed decision, contact the company for more details before agreeing to buy their genetic testing service.

Limiting Collection

- Does the company limit its collection of information from you to ensure they collect only what they need to provide the service you wish to purchase?
 - If you are not sure what information the company collects from customers, ask them. If you are not sure why the company needs to collect certain pieces of information, ask them.

Limiting Use, Disclosure and Retention

- Does the company share your personal information or biological sample with third parties without your consent?
 - If yes, who are the third parties and why does the company share your personal information or sample with them?
- How does the company handle the biological sample you send to them? Here are some specific questions to ask:
 - Does the company send the sample to an external laboratory for testing? If yes, is the sample labeled with your name or with a code so the laboratory does not know your actual identity?
 - Does the company destroy the sample after testing is complete or does it retain the sample? If the sample is retained, for what purposes is it kept? How long is it kept? Where is it stored?

- If the company has a policy of retaining samples, will they destroy samples on client request?
- How does the company handle your genetic test results?
 - How are results returned to you?
 - Are results shared with any third parties without your consent?
- How may you request termination of your account and how does the company handle such requests?
 - Even if they agree to delete your file, do they maintain copies of some information for a period of time? If they keep copies, why do they do so?
- Does the company use or disclose your personal information and biological sample for research purposes?
 - If yes, does the company allow you to choose whether or not your personal information and sample are used for research?
- What happens to personal information and samples if the company goes out of business, merges with another company, or is taken over by another company?
 - In these circumstances, will the company contact you to allow you to choose whether or not your personal information and sample are transferred to a new company?

Accuracy

- How does the company ensure that your personal information is accurate, complete and up-to-date?

Safeguards

- What security safeguards does the company use to protect your personal information and biological sample from unauthorized access, use, disclosure, alteration or destruction?
 - How does the company protect personal information transmitted by email or accessed online?
 - How does the company safeguard information or samples that it shares with third parties?
 - If the company says it uses a special security feature (e.g. *patent-protected SecureDNAKeyTM*), can the company explain this in plain language?

Openness

- Does the company readily provide clear and complete information to you to explain how it handles personal information and biological samples?

Individual Access

- Does the company permit you to access your personal information and do they provide you with details about how they have used and shared your information?

- Does the company allow you to request corrections of inaccurate information?

Challenging Compliance

- Does the company provide information about its procedures for handling and resolving customer concerns or complaints?
- Does the company identify a government body or other neutral third party that you may contact to express concerns or complaints about the company's practices?

Last, but not least consider your own privacy practices

- If you buy genetic testing services from a company, who, if anyone, would you share the test results with?
 - Some DTC genetic testing companies allow you to create an online account where you can permit others – such as your health care provider, family members or friends – to access your test results. Some companies have social networking features where you can connect and share personal information with other users who may share similar genetic traits or other characteristics. In using such features, consider carefully who – if anyone – you want to have access to your personal information, including genetic test results. Keep in mind that it is difficult to control your information once other people have access to it.
- If you set up an account to buy online genetic tests (or other online products and services), how well do you protect your account information?
 - Do you keep your password private? Do you access your account from a public computer where another person may be able to access your information?
- Do you review website privacy policies before doing business with a company over the internet?
 - The questions listed above encourage you to inform yourself before buying a service like genetic testing over the internet. If a company's policies and practices are not satisfactory to you, do not do business with that company.

Appendix: Privacy Policies of Direct-to-Consumer Genetic Testing Companies

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23andMe

www.23andme.com

Summary

- 23andMe respects your privacy.
- This notice provides highlights of our full [Privacy Statement](#) and applies to 23andMe's collection and handling of your personal information.
- We are committed to providing a secure, user controlled environment to access, share, and explore your genetic information.

Personal Information

- When you sign up for our service, 23andMe collects and stores personal information about you, including Account Information (contact and payment information) and Genetic Information (the As, Ts, Cs, and Gs at particular locations in your genome).
- On a voluntary basis, we may collect Phenotypic Information (disease conditions and personal traits) if you choose to participate in 23andMe-authorized research by answering an online survey and/or questionnaire.
- We also collect non-personal information (browser types, domains, page views) on how you use our web site through log files and cookies.

Uses of Information

- 23andMe collects personal information from you to provide you with our service and for conducting 23andMe-authorized research.
- We use Account Information to enable your purchase, inform you when your Genetic Information is available to you, and authenticate your website visits and usage.
- We may use Genetic and Phenotypic Information to conduct 23andMe-authorized scientific research and development. Any Phenotypic Information you provide is done on a voluntary basis. We may provide third party organizations access to this information for scientific research, but without your name or any other Account Information.
- We give you the ability to connect with other 23andMe customers through sharing features, but it is entirely your choice to do so.
- We will not release your personal information to any outside company without your explicit consent.
- We use non-personal information to track and monitor aggregate usage of our website and for internal analysis, quality control, and improvements to our services.

Your Choices

- Participation in activities and services that involve personal information beyond initial account and Genetic Information is voluntary and permission-based.
- It is entirely within your discretion to provide information or answer survey questions.
- At your request we will delete your account and personal information linked to your account from our systems.

Additional Information

- We encourage you to read 23andMe's full [Privacy Statement](#).
- For additional information about our views on privacy, please see our [Core Values](#) and [Policy Forum](#).

How to Contact Us

Questions about this statement, our full Privacy Statement, or about 23andMe's handling of your personal information may be emailed to privacy@23andme.com, or

Privacy Administrator
23andMe, Inc.
1390 Shorebird Way
Mountain View, CA 94043

Full Privacy Statement

23andMe Respects Your Privacy

23andMe recognizes the importance of privacy and respects your choices to store and access your information in a private and secure manner.

This Privacy Statement is intended to answer questions that you may have related to how we handle your personal information. We want to explain what information we collect from you and what we do with it. We have many controls, systems, and procedures that govern how we use, handle, and store this information in a secure and private manner and we want you to know about them. We also want to clarify how this information may be shared with other parties and what controls you have regarding the handling of your information.

Our services connect you with your genetic information. 23andMe collects and stores your genetic information for you in our databases and offers you access to a web-based interface with unique tools to help you interpret and review the information. We are committed to providing you a secure, user-controlled environment to access, share, and explore your genetic information. At the same time, you share some responsibility for maintaining privacy and security, like keeping your password secure.

We encourage you to familiarize yourself with our Privacy Statement. Our [Consent Form](#) and [Terms of Service](#) explain that, by using our website and signing up for our service, you are allowing us to process your personal information according to the provisions set forth in those documents and this Privacy Statement.

Personal Information

23andMe collects several types of personal and non-personal information either directly from you and/or through our service providers and partners. These can be described as follows:

Personal Information

Personal information is information that can be used to uniquely identify you or that you may consider sensitive. We collect such information from you when you purchase our services, create a personal account, complete surveys and questionnaires, and/or when you communicate with us or request information from us directly. We collect three primary types of personal information through our service and website.

- **Account Information** - Account Information is personal information that we collect from you when you purchase our service. Examples of such information include your name, credit card information, billing and shipping addresses, and contact information such as an email address or telephone number. We also use log files and cookies to maintain our website and monitor the quality of the service we provide to you. Cookies used by the website are linked

to a customer's Account Information. (See Log Files and Cookies below for more information.)

- **Genetic Information** - Genetic Information consists of your genotype, that is, the As, Ts, Cs, and Gs at particular locations in your genome. When you purchase 23andMe's service, you send your saliva sample to us by postal mail for analysis, along with a barcode that identifies you to us but not to the processing laboratory. Our contracted laboratories extract and analyze DNA from saliva samples and securely communicate the resulting Genetic Information to us along with the barcode for each individual analyzed. DNA and saliva samples are destroyed after the laboratory completes its work, which includes processing, analysis and reporting of data.

Genetic Information is then stored securely in our databases and can be accessed by you via our website by using the claim code and creating your personal account. It is important to note that the laboratories conducting DNA extraction and analysis do not have access to your name or any of your Account Information, as described above. Our instructions for sample collection and shipment clearly indicate that you must send only your saliva sample, which is labeled with a unique barcode, with no other identifier. To protect your privacy, samples sent with any identifier other than the barcode will not be processed.

- **Phenotypic Information** - Phenotypic Information is personal information that includes disease conditions (e.g., Type 2 Diabetes), other health information (e.g., pulse rate, cholesterol levels, visual acuity) personal traits (e.g., eye color, height), ethnicity, and family history (e.g., similar information about family members). We obtain this information from you on a voluntary basis when you choose to participate in 23andMe-authorized research by answering our surveys and/or questionnaires.

Non-Personal Information

Non-Personal Information includes information that we gather as you navigate our website. We log this information when you visit and browse our website. We record details such as browser types, domains, statistics of your visit including page views, and time spent on the website. We use this information to improve our services for you and other customers. Although it is non-personal, this information is linked to your Account Information if you are logged into our website.

Uses of Information

We use personal information to provide you with the service that you have purchased and for 23andMe-authorized research. Our service gives you access to your Genetic Information, as well as the opportunity to share and compare your Genetic and Phenotypic Information with that of other people who have also agreed to share such information.

We use personal information that we collect about you to:

- Authenticate your website visits and usage (e.g., user names and passwords)
- Enable your purchase (e.g., credit card number, billing address)
- Provide you the information, services, and products that you have requested (e.g., contact, Genetic Information)
- Inform you when your Genetic Information is available to you (e.g., e-mail address)
- Inform you of services and products that may be of interest to you (e.g., contact)
- Manage and improve our website, software, and services (e.g., website usage information)
- Conduct 23andMe-authorized scientific research and development (e.g., Genetic and Phenotypic Information)

We use Non-Personal Information to track and monitor aggregate usage of our website and for internal analysis, quality control, and improvements to our service. We collect such information by

using cookies and other standard web technologies. (See Log Files and Cookies below for more information.)

Information Sharing and Disclosure

23andMe gives you the ability to connect with other individuals who have 23andMe accounts through our sharing features. Whether you use these features is entirely your choice. In addition, you may choose to disclose, through other means not associated with 23andMe, your personal information to friends and/or family members, groups of individuals, third-party service providers, doctors or other professionals, and/or other individuals. We recommend that you make such choices carefully.

Personal information, once released or shared, can be difficult to contain. 23andMe will have no responsibility or liability for any consequences that may result because you have released or shared personal information with a third party. Likewise, if you are reading this because you have access to the personal information of a 23andMe customer, we urge you to recognize your responsibility to protect the privacy of that person.

23andMe will not release your personal information to any outside company without your explicit consent. Please see the [consent form](#) to be completed prior to purchase.

23andMe may disclose personal information for other purposes as stated below:

Disclosure to Research Partners:

One of 23andMe's goals is to contribute to scientific research and the advancement of genetic knowledge. To achieve our research goals, 23andMe may enter into partnerships with commercial and/or non-profit organizations that conduct scientific and/or medical research. Such partnerships may allow an organization access to our databases of Genetic Information and other contributed Phenotypic Information, so that, for example, the organization can search, without knowing the identities of the individuals involved, for the correlation between presence of a particular genetic variation and a particular health condition or trait. We may receive compensation from these research partners. Before we embark on any research collaborations we will establish a research advisory committee to guide such collaborations and undertakings. In addition, we will require partner organizations by contract to agree to maintain confidentiality consistent with this Privacy Statement. Partner organizations will not have access to your Account Information (e.g., name, contact information, payment information).

On occasion, we may pass along a request to you from such a partner, asking for you to participate in a specific study or to volunteer further information. The partner does not know to whom we send these queries and you have no obligation to respond.

Disclosure to Commercial Partners

23andMe may enter into commercial arrangements to enable partners to provide our service to their customers and/or to provide you access to their products and services. We may collect fees for these referrals. We will require informed consent from you as a precondition to providing any personal information to these commercial partners.

Disclosure Required By Law

Please be aware that under certain circumstances personal information may be subject to disclosure pursuant to judicial or other government subpoenas, warrants, or orders. In the event that we are legally compelled to disclose your personal information to a third party, we will notify you with the

contact information you have provided to us in advance unless doing so would violate the law or a court order.

Non-Disclosure to Linked Websites

23andMe provides links to third-party websites operated by organizations not affiliated with 23andMe. These links may be found within our content or placed beside the names or logos of these third parties. 23andMe does not disclose your personal information to organizations operating third-party websites. We may receive compensation from organizations operating third-party websites, which will be noted on the page the link appears. 23andMe does not review or endorse, and is not responsible for, the privacy practices of these organizations. We encourage you to read the privacy statements of each and every website that collects personal information. This Privacy Statement applies solely to information collected by 23andMe.

Your Choices and Privacy Preferences

At 23andMe, customer choice and control are critical to our goal of providing genetic information within a trusted environment. Participation in activities and services that involve personal information beyond the initial Account and Genetic Information is voluntary and permission-based. Examples of such activities include sharing your account information with other 23andMe customers, responding to surveys, joining a 23andMe-authorized research project, and subscribing to a newsletter.

If your personal information changes, or if you no longer wish to subscribe to our services, then you may correct, update, or delete your account by making the change via your account page, by sending a request to our Customer Support at help@23andme.com.

When deleting an account, we remove from our systems all Genetic and Phenotypic Information that can be associated with your Account Information. As stated in our Consent Form, however, Genetic Information and/or Phenotypic Information you have provided for research prior to your request for deletion will not be removed from ongoing or completed studies that are using the information. Neither Account Information nor a link to your account are used in 23andMe-authorized research. In addition, we retain limited Account Information related to your order history (e.g., name, contact, and transaction data) for accounting and compliance purposes.

Children's Privacy

23andMe is committed to protecting the privacy of children, as well as adults. Neither 23andMe nor any of its services are designed or intended to attract children under the age of 13. A parent or guardian, however, may order and set up an account for our services on behalf of his or her child. The parent or guardian assumes full responsibility for ensuring that the information that he/she provides to 23andMe about his or her child is kept secure and that the information submitted is accurate.

Log Files and Cookies

Log Files

As do operators of most websites, 23andMe gathers certain information automatically and stores it in log files. This information includes Internet Protocol (IP) addresses, browser type, Internet Service Provider, referring/exit pages, operating system, date/time stamp, and clickstream data (i.e., a list of pages or URLs visited). We use this information, which is not designed to identify individual users, to analyze trends, administer the site, track users' movements around the site, and gather demographic information about our user base as a whole. We may, in some circumstances, need to review this

automatically collected data in combination with specific Account Information to identify and resolve issues for individual users.

Cookies

The 23andMe website also uses cookies. A cookie is a small text file that is stored on a user's computer when you visit our website or any other website through your computer. We use both session cookies and persistent cookies to make it easier for you to navigate our site, improve the security of your personal information, enhance the functionality of certain features, and improve performance. The cookies we employ are used to enable secure access to your account when you are logged in and are only applicable within the confines of our website.

A session cookie expires when you close your browser. A persistent cookie remains on your hard drive for an extended period of time. You can remove persistent cookies by following directions provided in your Internet browser's "help" file. However, if you set your browser to reject cookies, your ability to use our site will be significantly impaired. In particular, you will not be able to access any part of our site that requires a log in, such as your personal genome account.

Security

23andMe takes seriously the trust you place in us. To prevent unauthorized access or disclosure, to maintain data accuracy, and to ensure the appropriate use of information, 23andMe uses a range of physical, technical and administrative procedures to safeguard the information we collect.

While there is always some risk of a security compromise, we tightly control access to personal information through the following technical, physical, and administrative security measures. By contract, we require third parties with whom we share personal information to implement appropriate security measures to maintain the confidentiality of such information.

Technical:

- We protect our network perimeters with firewalls.
- Our databases are designed to keep Genetic Information and Phenotypic Information separate from Account Information.
- We encrypt storage of certain personal information, including Account Information and Genetic Information.
- We encrypt all connections to and from our website.
- We conduct internal and external audits of perimeter and software code security.
- We monitor our employees' use of our databases and maintain records of all access to personal information.

Physical:

- Physical access to internal servers is restricted to authorized personnel.
- We restrict data center access to approved personnel via photo and passcode authentication, biometrics, and other security protocols.

Administrative:

- We prohibit personal information from being extracted from our systems and loaded onto laptops or other mobile devices, or from being sent out electronically.
- We limit access to personal information to certain employees for limited, approved purposes based on their specific responsibilities.

- We require annual privacy and security training for employees with access to personal information.

Please recognize that protecting your personal information is also your responsibility. We ask you to be responsible for safeguarding your password, secret questions and answers, and other authentication information you use to access our services. You should not disclose your authentication information to any third party and should immediately notify 23andMe of any unauthorized use of your password. 23andMe cannot secure personal information that you release on your own or that you request us to release.

Despite 23andMe's efforts to protect your personal information, there is always some risk that an unauthorized third party may find a way around our security systems or that transmissions of your information over the Internet will be intercepted.

Business Transitions

In the event that 23andMe goes through a business transition such as a merger, acquisition by another company, or sale of all or a portion of its assets, your personal information and non-personal information will likely be among the assets transferred. You will be notified in advance via email and prominent notice on our website of any such change in ownership or control of your personal information. We will require an acquiring company or merger agreement to uphold the material terms of this privacy statement, including honoring requests for account deletion.

Changes to this Privacy Statement

This Privacy Statement was last updated November 11, 2007. A notice will be posted as part of this Privacy Statement and on our customer accounts' login pages for 30 days whenever this Privacy Statement is changed in a material way, highlighting both the old and new content in a way that makes the changes easy to understand. In addition, all customers will receive an email with notification of the changes.

Contact Information

If you have questions about this statement, please send an e-mail to 23andMe's privacy administrator at privacy@23andme.com. You can also contact us at this address if you have a question about 23andMe's handling of your information:

Privacy Administrator
23andMe, Inc.
1390 Shorebird Way
Mountain View, CA 94043

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Biomarker Pharmaceuticals

www.biomarkerinc.com

Privacy, Copyright Notice, and Terms of Use

BioMarker Pharmaceuticals, Inc. values the privacy of those who provide private personal information to the Company. This policy summarizes what personally identifiable information we may collect, and how we might use this information. This policy also describes other important topics

relating to information privacy. BioMarker Pharmaceuticals, Inc. has voluntarily certified that it meets the United States Department of Commerce Safe Harbor Standards for adequate privacy protection.

Information Collection

EXTERNAL INFORMATION SOURCES (Customer Inquiries)

BioMarker Pharmaceuticals, Inc. only will collect personally identifiable information (such as name, title, company name, address, telephone number, or e-mail address) that is voluntarily provided through our website or e-mail correspondence. We will collect general information (such as the type of browser used, the files requested, and the domain name and country which requests information) to improve our Web site and better meet customer needs.

Use of Information

Before we collect any personally identifiable information, we will provide an explanation for the possible use of the data. The information supplied will be used by BioMarker Pharmaceuticals, Inc. to respond to inquiries, supply requested information on BioMarker Pharmaceuticals, Inc. products and services, or track orders placed with BioMarker Pharmaceuticals, Inc. Authorized third parties may be utilized by BioMarker Pharmaceuticals, Inc. collect, track and process such information. If you have submitted personal information to BioMarker Pharmaceuticals, Inc. electronically and would like it removed or modified, please contact us at info@biomarker.com We will use reasonable efforts to comply with your request.

[Statement about employee information omitted]

Security

BioMarker Pharmaceuticals, Inc. is committed to protecting personal information from loss, misuse, disclosure, alteration, unauthorized access and destruction. BioMarker Pharmaceuticals, Inc. takes all reasonable precautions to safeguard the confidentiality of personally identifiable information.

Compliance

BioMarker Pharmaceuticals, Inc. conforms to the US Department of Commerce Safe Harbor Principles through self-assessment. We make every effort to ensure privacy and encourage you to contact us at any time if you feel we are not in compliance with the Safe Harbor Principles. In the event we are unable to resolve an issue regarding our compliance, we will contact the appropriate Data Protection Authorities to expeditiously resolve the complaint.

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OTHER IMPORTANT INFORMATION

The BioMarker Pharmaceuticals, Inc. Web site may contain links to other sites. We do not endorse or otherwise accept responsibility for the content or privacy policies of those sites. Additionally, some of our Web pages may contain "cookies," which are data that may be sent to your Web browser and stored on your computer. This allows our server to "recognize" you when you visit our Web site in the future. Most Web browsers can be configured to not accept cookies, or to notify you if a cookie is sent to you.

[Copyright notice omitted]

The practices described in this privacy policy statement are current personal data protection policies, as of September, 2002. BioMarker Pharmaceuticals, Inc. Reserves the right to modify this privacy policy at any time. We will promptly reflect any such modifications in these Web pages.

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Consumer Genetics

www.consumergenetics.com

Privacy and Disclaimer

The makers of Pink or Blue® respect every client's privacy. Our company does not share, sell, or distribute your information to third parties. Your personal information is used solely for ordering our services, and anything that is relevant to your order which may require information such as email, phone number, or address.

When you visit the website, we may automatically collect IP addresses and site usage information from you. This information helps us evaluate how our visitors and customers use and navigate our site, including the number and frequency of visitors and subscribers to each Website page, and the length of their visits. Such information does not include personally identifiable information, such as your name or address; this site traffic information is not shared with third parties.

Online transactions are handled through scripting designed for order submittal with Secure Sockets Layer (SSL) encryption. Your personal information, including your credit card number, is transmitted across the Internet in an encrypted form, and decoded once it enters our internal database. This provides a reliable and confidential ordering environment for your security. Ordering via telephone or postal mail is also available.

Unsolicited information, ideas, questions, comments, or suggestions sent to Pink or Blue® via email or otherwise will be deemed non-confidential and are not protected under our privacy rights. Such unsolicited disclosures shall become the exclusive property of Pink or Blue® and Pink or Blue® shall obtain the rights to such information or ideas for any purpose whatsoever, including but not limited to, developing, manufacturing and marketing products.

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1. Provision of Services

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1.7 The biological samples supplied to Pink or Blue® by the client may be unrecoverable due to the laboratory procedures required to extract DNA. Left over samples may be used for quality control purposes and testing. At the time of ordering, the customer has the option to request that left over sample not be used for quality control testing. In this case, any remaining sample will be destroyed according to state and local regulations.

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Counsyl

www.counsyl.com

Privacy Policy

At Counsyl, our privacy policy is clear: *no one will ever have access to your data without your express consent.* Specifically:

1. If you order from the website using your credit card, your results will only be known to you.

2. If you order from the website using your health insurance coverage, we will not send the report to the insurer until they request it. We will notify you if such a request occurs; this information would enable them to approve coverage of [preventive measures](#) in the event of a positive result. *Please note that health insurers are [prohibited by law](#) from using the results of a genetic test to raise premiums.*
3. If you order the test [through your doctor](#), he or she will see your results. With your consent, this may be added to your private medical record. This protected medical information is guarded by the rigorous [confidentiality standards](#) of the Health Insurance Portability and Accountability Act (HIPAA) and can only be seen by medical professionals who you have specifically authorized to treat you.”

GINA's Privacy Guarantees

The [Genetic Information Nondiscrimination Act](#) (GINA) categorically protects Americans against discrimination based on their genetic information. *Because of GINA, you may not be denied health insurance on the basis of your genes.*

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Cygene Direct

www.cygenedirect.com

What This Privacy Policy Covers

This policy covers how Cygene Direct treats personal information that Cygene Direct collects and receives, including information related to your past use of products and services. Personal information is information about you that is personally identifiable like your name, address, email address, or phone number, and that is not otherwise publicly available.

How Does CyGene Ensure Patient Anonymity?

CyGene is dedicated to customer privacy and protecting the confidentiality of all customer genetic information. CyGene has a patent pending method of ensuring that the customer name, address or other identifiable information can not be correlated to the DNA specimen or results report. CyGene provides you with a username (barcode number) and an 8-character password that are printed on the DNA specimen card contained in the collection kit. Your DNA card is received at our laboratory in a self-addressed prepaid envelope that we provide, with nothing else than these two numeric identifiers. No one, other than yourself and CyGene, knows the bar code number and your password, and your name can not be matched with your DNA by anyone who works at or with CyGene.

You may choose to share your genetic profiling results with your doctor or healthcare provider. At that time, your information will become part of your permanent medical record and falls under the Health Insurance Portability and Accountability Act of 1996 (HIPAA). Once your genetic information becomes part of your permanent medical record, insurance carriers and others may have access to your genetic information. The HIPPA provisions protect your personal health information and should be discussed in detail with your provider.

Information Collection and Use

- Cygene Direct collects personal information when you register and/or use or purchase products or services, when you visit Cygene Direct pages or the pages found on our other Websites directly affiliated and controlled by the Cygene Direct.

- When you register for various Products and/or Services through Cygene Direct Websites we ask for information such as your name, e-mail address, physical address, and zip code. For some products and services we may also ask for your credit card number and other billing information. Once you register with Cygene Direct and sign in to our services, you are not anonymous to us.
- Cygene Direct collects information about your transactions with us to provide shopping and various services to you.
- Cygene Direct automatically receives and records information on our server logs from your browser, including your IP address, cookie information, and the pages you request during your visit to the Cygene Direct Websites.
- Cygene Direct uses information for the following general purposes: to customize the advertising and content you see, fulfill your requests for products and services, improve our services, contact you, conduct research, and provide anonymous reporting for internal use only.
- Cygene Direct does not rent, sell, or share personal information about you with other people or nonaffiliated companies, except to provide products or services you've requested and when we have your permission.
- We will not send you unsolicited advertisements or solicitations without providing you the opportunity to decline to receive them. However, we reserve the right to send you certain communications, such as service announcements, administrative messages and Purchase Invoices, that relate to or are part of products or services you have purchased or agreed to obtain from Cygene Direct, without offering you the opportunity to opt-out of receiving the communications.

Children

- Children under the age of 18 are not permitted to register and/or purchase products or services through the Cygene Direct website.

Cookies

- Cookies are small pieces of data that are stored on a computer. Cygene Direct may set and access cookies on your computer only for the purpose of providing services through our Website, to customize the advertising and content you see, and provide anonymous reporting for internal use only. For example, Cygene Direct might set a cookie on your computer so that the next time you visit our Website the information and/or content displayed could be customized according to selections you made the last time you visited the site. You can refuse to accept cookies and can remove them from your computer.

Confidentiality and Security

- We limit access to personal information about you to employees who we believe reasonably need to come into contact with that information to provide products and/or services to you or in order to do their jobs.
- We have physical, electronic, and procedural safeguards that comply with federal regulations to protect personal information about you.

Changes to the Privacy Policy

- Cygene Direct may update this policy at anytime. We will notify you about significant changes in the way we treat personal information by sending a notice to the primary email address submitted to Cygene Direct and/or by placing a prominent notice on our site.

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deCODE Genetics

www.decode.com

Note that deCODE has three sites: decode.com, deCODEme.com and deCODE diagnostics.com. The last site is aimed at health care professionals and contains a statement of compliance with the Health Insurance Portability and Accountability Act. The privacy policies for decode.com and deCODEme.com are provided below.

deCODE Privacy Policy

deCODE takes your online privacy seriously. deCODE does not gather personally identifiable information about visitors to the deCODE Website except as described below. In some circumstances, deCODE may request relevant personal information from you, such as your name, e-mail address, company name or telephone number. Your response to these inquiries is strictly voluntary. deCODE uses this information to customize your experience on this Website and to process specific requests you may choose to make. For instance, if you do not provide deCODE with your e-mail address, deCODE will not be able to include you on its mailing lists. In general, however, you may visit this Website without divulging any personal information.

deCODE may use information about you for internal research and development. deCODE is interested in assessing the number of visitors to the different sections of this Website, what information is of most and least interest, determining technical design specifications, and identifying system performance or problem areas. For site security purposes and to ensure that this service remains available to all users, deCODE uses software programs to monitor network traffic to identify unauthorized attempts to upload or change information, or otherwise cause damage. Information in the aggregate, such as demographic information, may be made available to our customers, partners, developers and others through static or semi-static reports. All information made available to any third party will be stripped of personal information and cannot be traced back to individuals.

Some pages on this site use "cookies," small files that the site places on your hard drive for identification purposes. These files are used for site registration and customization the next time you visit this Website. You should note that cookies can not read data from your hard drive. Your web browser may allow you to be notified when you are receiving a cookie, giving you the choice to accept it or not. Not accepting cookies may render some pages only partially functional and you may be unable to access certain information on this Website. In most cases however, declining cookies should have no adverse effects on browsing this Website.

deCODE will take reasonable steps to protect your personally identifiable information as you transmit your information from your computer to this Website and to protect such information from loss, misuse, and unauthorized access, disclosure, alteration, or destruction. You should keep in mind that no Internet transmission is ever 100% secure or error-free. In particular, e-mail sent to or from this Website may not be secure, and you should therefore take special care in deciding what information you send to this Website via e-mail. Moreover, where you use passwords, ID numbers, or other special access features on this Website, it is your responsibility to safeguard them.

deCODE will not wilfully share your personally identifiable information with third parties without your express consent except (i) to contractors deCODE uses to support its business (e.g., fulfilment services, technical support, and delivery services), in which case deCODE will require such third parties to agree to treat such information in accordance with this Privacy Policy, (ii) in connection with the sale, assignment, or other transfer of the business of this Website to which the information relates, in which case deCODE will require any such buyer to agree to treat such information in

accordance with this Privacy Policy, or (iii) where required by applicable laws, court orders, or government regulations.

To keep your personally identifiable information accurate, current, and complete, please contact deCODE at webmaster@deCODE.is. deCODE will take reasonable steps to update or correct personally identifiable information in its possession that you have previously submitted via this Website.

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About Children

This Website is not intended for children under the age of 18. deCODE will not knowingly collect information from Website visitors in this age group.

deCODEme.com Privacy Policy

deCODE Genetics has been working in large scale population genetic research for over ten years and has always focused on using the highest standards in data security and privacy policies. deCODEme is no different – we believe that genetic information is both personal and private. You should have total control over access to your deCODEme account and be the one who decides who can compare or share your information.

User accounts

deCODEme allows you to select your username at will, as long as it doesn't conflict with existing usernames of other people. Email addresses are required for contacting deCODEme users; however, many users can in principle share the same email address. Thus, email cannot be used to directly identify users and users can change email addresses once the account has been created.

User profile (my settings) visibility and friends

Users are free to enter further information about themselves into their user profile (my settings) or settings, such as gender, date of birth, or even their full names if they so choose. In every case, they can specify who is able to share their user attributes: make the attribute visible to all deCODEme users, visible only to their friends, or fully private and visible only to themselves.

Friends are created by sending invitations to existing users or by sending an email to potential future users. In both cases, the individuals have to accept the invitation in their invitation inbox or by following a link in the email they receive. Friendships are reciprocal, i.e. if user A is the friend of user B then user B is also the friend of user A. Finally, existing friendships can be terminated simply by removing users from the friend lists.

Genetic data

Once a Genetic Scan has been bought and processed, users can use the various analysis features in the deCODEme website. What features are available may depend on the type of the Genetic Scan. As an example of features are genetic risk calculations and comparison of genetic variants with the corresponding variants of their friends, e.g. relationship analysis and genetic sharing. In both cases, the user has full control over it who can compare his genetic data and what details are made visible.

The user owns their genetic data and therefore we do not keep the data locked from the user in the deCODEme website. Users are free to download the genotypes from the Genetic Scan, however, we

urge them to ensure the security of the data once it is on their computer, e.g. by encrypting the data file.

Our use of your personal data

User attributes, public or private, will be used by deCODE only to gather statistical aggregate information about the users of the deCODEme website. Such analysis may include, but is not limited to; counting the number of users grouped by age, or associating genetic variants with any of the self reported user attributes. In the process of presenting any such statistical information, deCODE will ensure that users identities are not exposed.

deCODE may disclose your personal information only if we believe such action is necessary to: comply with the law or legal process served upon deCODE or to protect and defend the rights or property of deCODE in relation to your agreement with deCODEme. Except for the above, deCODE will under no circumstances provide any 3rd party, including insurance companies, health management organizations, hospitals, and government agencies, access to any of your personal data or data derived from your samples, unless you grant us an explicit authorization in your privacy settings.

The use of email addresses

Email addresses, provided by users, are only used for the purposes of contacting users in relation to the services of the deCODEme website, e.g. for friend invitations or for the deCODEme newsletters. Under no circumstances will the email addresses be provided to 3rd parties. Users can choose to opt out from deCODEme newsletters and from invitations to participate in research studies by deCODE genetics.

Since email is not guaranteed to be secure or private, users can choose to disable the “forgot password option”, i.e. the option to allow the deCODEme system to send out password renewal invitation in email.

Secure Socket Layer

Once you log into your code page (myCODE) from the deCODEme home page, all data transfer between the deCODEme web-server and your web client is encrypted using the HTTPS protocol. deCODEme uses public-key pairs, private key and a certificate, issued by Verisign. Your web browser should be configured to authenticate such certificates.

Cookies

deCODEme uses cookies to maintain secure sessions with clients. Cookies are small files that are placed on your hard disk by your browser and automatically uploaded by the web browser to the web server in the domain that issued the cookie. deCODEme cookies have time expiration and are intelligible to any other applications.

Page caching

Some deCODEme pages contain disease related information that is based on people’s gene profile. Users should keep this in mind when they access their data from an insecure client computer because some browsers may cache the content of these pages to the hard disk drive.

Sample measurements

The buccal swab sample and the DNA extracted from the sample will be stored by deCODE only for the time necessary to perform the Genetic Scan and will be discarded upon successful measurements. Thus, deCODE will only use buccal swab samples and samples derived from them for the specific measurements ordered by its customers.

Data storage and archival

deCODE uses a state-of-the-art network and storage infrastructure. Our server rooms have rigorous access restrictions and our policies and development procedures have in the past been designed to meet the requirements of SOX and FDA.

deCODE guarantees that Genetic Scan data is always accessible at deCODEme for a minimum of 3 months after it was generated. This does not mean that data will be deleted from deCODEme servers after that. However, in the unlikely case of a catastrophic failure of the disk storage systems, users with older data may be required to upload their data to deCODEme, whereas users whose data is less than 3 months old can request to have a new Genetic Scan carried out, free of charge.

Termination of your account

If you choose to terminate your account your account will be deactivated. To prevent your accounts from being accidentally or maliciously removed, the termination request is not executed until 60 days after initiation. During this time period, you can always attempt to re-login to your account and reactivate it.

If your account is not reactivated within the time frame specified above, your data will be deleted from all the operational systems at deCODEme and eliminated from all future backup restores of the operational systems. However, the data may not be eliminated from all historical archival tapes of the operational systems.

Changes to this Privacy Policy

deCODE reserves the right to update this privacy policy. In such an event, you will be notified through our newsletter and we will update the revision date of the policy.

Revision date 12th November 2007

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DNA Direct

www.dnadirect.com

DNA Direct, Inc. ("**DNA Direct**," "**we**" or "**our**") recognizes that medical privacy is essential and is dedicated to protect the privacy of its users ("**users**," "**you**" or "**your**") both on- and off-line. We understand that genetic information is very personal, even in the context of your own family members. We are also aware of your concerns regarding the potential for genetic information being misused by insurers and/or employers. DNA Direct has created a framework uniquely designed for the genetic testing service available through the DNA Direct website. Our website is supported by advanced technology that seeks to secure your interactions with DNA Direct. We believe that your genetic information is your property, and it is your right as a consumer to be able to confidentially obtain and control this information. Because the success of DNA Direct is dependent on building and maintaining goodwill with our customers, we are committed to implementing measures designed to protect your privacy. Moreover, we see it as our responsibility to help set an example and establish the standards for medical privacy on the Internet.

Although DNA Direct respects your privacy, we do collect information from you. This Privacy Policy governs your interaction with the DNA Direct website, and your registration for and use of DNA Direct's service. By using the DNA Direct website, you agree to the collection and use of information as set forth in this Policy. If you do not agree to this Policy, please do not use the DNA Direct website. This Policy is the sole authorized statement of our practices concerning the collection, use and protection of personal information through the DNA Direct website. Except as set forth within this Privacy Policy and our Terms of Service and other published guidelines, we do not release Personally Identifiable Information about our users without their permission.

1. INTRODUCTION

While you may use some of the functionality of the DNA Direct website without registration, some of the specific tools and services require registration. If you do not use the tools, features or services offered on or through the DNA Direct website, the only information we collect will be Non-Personal Information (i.e., Information that is not traceable back to you and cannot be used to identify you. Non Personal Information includes information such as the web pages that you have viewed through the use of Cookies (i.e., Small data files that are stored on the hard drive of a computer used to view websites that are accessible only by the party or site that placed the Cookie on the hard drive.). If you choose to register with our website for certain tools and/or services, we require you to submit Personally Identifiable Information (i.e., Information that can be traced back to you. Personally Identifiable Information includes information such as your name, home address, telephone number and email address). Depending on the tool or service you have selected, we also may collect Personal Health Information (i.e., The combination of Personally Identifiable Information with known health characteristics. Personal Health Information includes the combination of your Personally Identifiable Information with information that you provide to us about a certain disease or condition that you have). You are responsible for ensuring the accuracy of the Personally Identifiable Information and Personal Health Information you submit to DNA Direct. Inaccurate information will affect the information you receive when using our website and tools and our ability to contact you. For example, your email address should be kept current because that is the primary manner in which we communicate with you.

2. THE INFORMATION WE GATHER

DNA Direct gathers three types of information about users:

2.1. Non-Personal Information. When users come to the DNA Direct website, we collect and aggregate Non-Personal Information indicating, among other things, which pages of our website were visited, the order in which they were visited and which hyperlinks were "clicked." Collecting such information involves the logging of the IP addresses, operating system and browser software used by each user to the DNA Direct website. Although such information is not Personally Identifiable Information, we can determine from an IP address a user's Internet Service Provider and the geographic location of his or her point of connectivity.

We also use Cookies and other technologies to help us determine the type of content and sites to which a user to the DNA Direct site links, the length of time each user spends at any particular area of the DNA Direct site and the DNA Direct services users choose to use. Essentially, Cookies are a user's identification card for the DNA Direct computers, or servers, that placed them there. Cookies are only read by the server that placed them, and are unable to execute any code or virus. Cookies allow DNA Direct to serve you better and more efficiently, and to personalize your experience at DNA Direct's website. Cookies also may be used to facilitate a user's log-in, but are not used to retain Personally Identifiable Information

or Personal Health Information. We also do not link Non-Personal Information from Cookies to Personally Identifiable Information without your permission.

You should be able to control how and whether Cookies will be accepted by your web browser. Most browsers offer instructions on how to reset the browser to reject Cookies in the "Help" section of the toolbar. If you reject our Cookies, certain of the functions and conveniences of our website may not work properly, but you do not have to accept our Cookies in order to productively use the DNA Direct website.

This Privacy Policy covers the use of cookies by DNA Direct. Overture.com uses cookies on our site. We have no access to or control over these cookies. This Privacy Policy does not cover the use of cookies by Overture.com.

2.2. Personally Identifiable Information. We collect Personally Identifiable Information that you provide to us when you register with us to save partially-completed risk assessment questionnaires, order genetic tests made available by DNA Direct, sign-up for email messages, or leave us a return phone number and/or name through our toll free customer service number. Among other things, we use the Personally Identifiable Information that you provide to respond to your questions, provide you the specific services you select, send you email messages about website maintenance and updates, and inform you of significant changes to this Privacy Policy.

(a) Risk Assessment Questionnaires. In order to help our users in determining whether they might benefit from ordering a particular genetic test made available through the DNA Direct website, our users may answer a risk assessment questionnaire specific to the condition or disease in question that requires the users to provide Personal Health Information to DNA Direct. Upon completing a risk assessment questionnaire, DNA Direct will use the responses to the questionnaire to provide the user with a benefit index that will help the user in determining whether he or she might benefit from ordering the genetic test to which such risk assessment questionnaire relates. In some questionnaires, users may be asked to provide gender and/or their age range. DNA Direct does not collect Personally Identifiable Information (such as name, date of birth, address) as part of the risk assessment questionnaire.

(b) Saving Risk Assessment Questionnaires. As a service to the users of the DNA Direct website, users may save partially-completed risk assessment questionnaires and return to our website at a later time to complete such questionnaire. Users may also save fully-completed risk assessment questionnaires if they wish to return to our website at a later time to complete the ordering process. In order to save a risk assessment questionnaire, a user will need to provide DNA Direct with an email address and a unique password created by the user.

(c) Genetic Test Orders. When ordering a genetic test, users are required to provide DNA Direct with Personally Identifiable Information as part of the billing process in addition to the Personal Health Information they provided in completing the risk assessment questionnaire. DNA Direct uses this Personally Identifiable Information and Personal Health Information to process the order and to send the user the test kit that is needed to conduct the particular genetic test.

(d) Email Messages You Send to DNA Direct. This Privacy Policy does not protect you when you send Personally Identifiable Information, Personal Health Information, other information, feedback, suggestions, content, business ideas, concepts or inventions to DNA Direct by email. If you want to keep Personally Identifiable Information, Personal Health Information, other information, feedback, suggestions, content, business ideas, concepts or inventions private or proprietary, do not send them in an email message to DNA Direct. We try to answer every email within 48 business hours, but are not always able to do so.

2.3. Testimonials. In order to help our users determine whether or not they would find value from ordering our tests or using our services, we collect and post, with permission of our customers, testimonial statements. From time to time testimonial statements are published on our website. These statements are published with the customer's initials and their state of residence or their name, depending on their personal preference.

3. HOW WE USE (AND DO NOT USE) THE INFORMATION WE GATHER

Please take some time to familiarize yourself with the different ways DNA Direct uses the information that it gathers.

3.1. Non-Personal Information. DNA Direct uses Non-Personal Information in aggregate form to build higher quality, more useful services by performing statistical analyses of the collective characteristics and behavior of our users, and by measuring demographics and interests regarding specific areas of the DNA Direct website.

3.2. Personally Identifiable Information and Personal Health Information. This Privacy Policy serves as notice that DNA Direct collects Personally Identifiable Information and Personal Health Information in the manners described above. Except as set forth in this Privacy Policy or as specifically agreed to by you, DNA Direct will not disclose any Personally Identifiable or Personal Health Information it gathers from you on our website. DNA Direct will only release Personally Identifiable or Personal Health Information to third parties: (a) to comply with valid legal requirements such as a law, regulation, search warrant, subpoena or court order; or (b) in special cases, such as a physical threat to you or others. In the event that we are legally compelled to disclose your Personally Identifiable Information or Personal Health Information to a third party, we will attempt to notify you unless doing so would violate the law or court order. We cooperate with law enforcement agencies in identifying those who may be using our servers or services for illegal activities. We also reserve the right to report any suspected illegal activity to law enforcement individuals or entities for investigation or prosecution. Finally, we may disclose Personally Identifiable Information and Personal Health Information as described below.

(a) Disclosure to DNA Direct Operations and Maintenance Contractors. DNA Direct operations and maintenance contractors include vendors and suppliers that provide us with technology, services, and/or content related to better operation and maintenance of our website. Access by these contractors to either your Personally Identifiable Information or your Personal Health Information, but not to both, is limited to the information reasonably necessary for the contractor to perform its limited function for DNA Direct. We also contractually require that our operations and maintenance contractors not use or disclose your Personally Identifiable Information and Personal Health Information for any purpose other than providing us with products and services.

Contractors such as our ecommerce vendor have access to your Personally Identifiable Information (i.e.- billing and demographic information) but not to your Personal Health Information in the course of providing products or services to DNA Direct. These contractors may have access to your email address to send newsletters to you on our behalf, such as confirmation of a purchase. Contractors such as our server support have access to your Personal Health Information and email address only. These contractors are not authorized to send any information on behalf of DNA Direct.

(1) Agents. We use an outside shipping company to fulfill orders, and a credit card processing company to bill you for goods and services. These companies do not retain, share, store, or use Personally Identifiable Information for any other purposes.

(2) Service Providers. We use other parties such as YourPay.com and Miva Merchant to provide e-commerce services on our site. When you order a product from us we will share your Personally Identifiable Information (i.e.- billing and demographic information) but not to your Personal Health Information as is necessary for them to provide e-commerce service. These contractors have access to your email address to send communications to you on our behalf, such as confirmation of a purchase. These third parties are prohibited from using your Personally Identifiable Information for any other purpose.

(b) Disclosure to Genetic Testing Labs. DNA Direct does not disclose your Personally Identifiable Information or Personal Health Information to any genetic testing lab that performs the genetic tests that you order through the DNA Direct website. The only information that DNA Direct will provide to any genetic testing lab on your behalf is your unique Order ID Number.

4. **CHILDREN**

We are committed to protecting the privacy of children. Neither DNA Direct nor any of its services are designed or intended to attract children under the age of 13. We do not collect Personally Identifiable Information from any person we actually know is under the age of 13. A parent or guardian, however, may do any of the following things on behalf of his or her child: (a) complete a risk assessment questionnaire; (b) register to save partially-completed risk assessment questionnaires; (c) save partially-completed risk assessment questionnaires; (d) order genetic tests; and (e) register to receive promotional communications. The parent or guardian assumes full responsibility for ensuring that the information that it provides to DNA Direct about his or her child is kept secure and that the information submitted is accurate.

5. **LINKED SITES**

For your convenience there are links to websites operated by companies other than DNA Direct ("**Third Party Websites**") that we believe may be of interest to you. DNA Direct does not disclose your Personally Identifiable Information or Personal Health Information to these Third Party Websites. DNA Direct does not endorse and is not responsible for the privacy practices of these Third Party Websites. If you choose to link to one of these Third Party Websites, you should review the privacy policy posted on this other website to understand how that Third Party Website collects and uses your Personally Identifiable Information and Personal Health Information.

6. **EMAIL AND MAILING LIST POLICY**

We use your e-mail, mailing address, and phone numbers only to confirm your order or communicate with you regarding your case, questions or requests, or other products or services you may find useful. Except as specified in our Privacy Policy, we do not share our email list, mailing list, or telephone numbers with anyone for third-party marketing or promotional use.

Service-related Announcements

We will send you strictly service-related announcements on rare occasions when it is necessary to do so. For instance, if our service is temporarily suspended for maintenance, we might send you an email.

Choice/Opt-out

We provide you the opportunity to 'opt-out' of having your Personally Identifiable Information used for direct marketing purposes. For example, if you purchase a product/service but do not wish to receive any additional marketing material from us, you can 'opt-out' by emailing us at support@dnadirect.com, calling us at 1-877-646-0222, or mailing a letter to:

DNA Direct
Pier 9, Suite 105
San Francisco, CA 94111

If you no longer wish to receive our promotional communications, you may opt-out of receiving them by following the instructions included in our communications or by emailing us at support@dnadirect.com, calling us at 1-877-646-0222, or mailing a letter to the address above.

Tell-A-Friend

If you choose to use our referral service to tell a friend about our site, we will ask you for your friend's name and email address. We will automatically send your friend a one-time email inviting him or her to visit the site. DNA Direct stores this information for the sole purpose of sending this one-time email. Your friend may contact us at support@dnadirect.com to request that we remove this information from our database.

7. DNA DIRECT SECURITY PROCEDURES

The following are some of the security procedures that DNA Direct uses to protect your privacy:

- DNA Direct requires both a personal username (an email address) and a password in order for users to access their Personally Identifiable Information or Personal Health Information, including their Personalized Report that is generated upon completion of genetic testing.
- DNA Direct uses firewalls to protect information held in our servers.
- DNA Direct utilizes Secure Socket Layer (SSL) encryption in transmitting Personally Identifiable Information to our servers. In order to take advantage of encryption technology, you must have an Internet browser which supports 128-bit encryption.
- DNA Direct closely monitors the limited number of DNA Direct employees who have potential access to your Personally Identifiable Information.
- DNA Direct requires all DNA Direct employees to abide by our Privacy Policy and be subject to disciplinary action if they violate it.
- DNA Direct backs-up our systems to protect the integrity of your Personally Identifiable and Personal Health Information.
- When you purchase a genetic test through the DNA Direct website, a unique Order ID Number is automatically generated and assigned to that test and the corresponding test results and such unique Order ID Number remains the only identifying code associated with your test sample and test results.
- DNA Direct has an internal firewall to ensure, except as required for business purposes, that employees who have access to your Personally Identifiable Information (including name, address, and billing information) do not have access to your Personal Health Information (including risk assessment questionnaire and genetic test results), and vice versa, except as required for business purposes. The only link between these information servers is the unique Order ID Number.

Despite DNA Direct's efforts to protect your Personally Identifiable Information and Personal Health Information, there is always some risk that an unauthorized third party may find a way around our security systems or that transmissions of your information over the Internet will be intercepted.

DNA TALK DISCLOSURE

DNA Direct, in maintaining the blog DNA Talk <http://talk.dnadirect.com>, owns all information published by DNA Direct on DNA Talk. DNA Direct will not publish any personally identifiable information on DNA Talk. DNA Direct is not responsible for and does not own any information published in the "Comments" section of each blog entry. This privacy policy does not cover comments posted in the blog.

CHANGES TO THIS PRIVACY POLICY

Please note that DNA Direct reviews its privacy practices from time to time, and that these practices are subject to change. We ask that you bookmark and periodically review this web page to ensure continuing familiarity with the most current version of our Privacy Policy. To contact DNA Direct about privacy issues, to report a violation of our Privacy Policy, or to raise any other issue, please e-mail us at expert@dnadirect.com.

If we decide to change our privacy practices, we will post those changes to this Privacy Policy, the homepage, and other places we deem appropriate so that you are aware of what information we collect, how we use it, and under what circumstances, if any, we disclose it. We reserve the right to modify this Privacy Policy at any time, so please review it frequently. If we make material changes to this Policy, we will notify you here, or by means of a notice on our homepage.

DELETING/UPDATING YOUR PERSONALLY IDENTIFIABLE INFORMATION

If you want to delete your Personally Identifiable Information and/or Personal Health Information from our systems or update the Personally Identifiable Information that you have provided to us you can email us at customerservice@dnadirect.com. We try to answer every email within 48 business hours, but may not always be able to do so. Another way to update your Personally Identifiable Information and/or Personal Health Information is to take a new questionnaire and register as a new user. Keep in mind, however, that there will be residual information that will remain within DNA Direct databases, access logs and other records, which may or may not contain such Personally Identifiable Information and/or Personal Health Information. The residual information will not be used for commercial purposes; however, DNA Direct reserves the right, from time to time, to recontact former customers or users of DNA Direct.

If you do not receive adequate resolution of a privacy related problem, you may write to DNA Direct's Privacy Help Desk at:

DNA Direct, Inc.
Attn: Privacy Help Desk
Pier 9 - Suite 105
San Francisco, CA 94111

Or call toll free:

(877) 646-0222

BUSINESS TRANSFERS

We may sell or transfer assets or portions of our business as we continue to improve our product and service offerings. In the event of such transactions, in order to provide continuity of service, user information (whether Non-Personal Information, Personally, Personally Identifiable Information and/or Personal Health Information) may be transferred.

DNA Direct is a licensee of the TRUSTe Privacy Program. TRUSTe is an independent, non-profit organization whose mission is to build user's trust and confidence in the Internet by promoting the use of fair information practices. This Privacy Policy covers the site www.dnadirect.com. Because DNA Direct wants to demonstrate its commitment to your privacy, it has agreed to disclose its information practices and have its privacy practices reviewed for compliance by TRUSTe.

If you have questions or concerns regarding this statement, you should first contact Adam Ward at 1-877-646-0222. If you do not receive acknowledgement of your inquiry or your inquiry has not been satisfactorily address, you should contact TRUSTe at http://www.truste.org/consumers/watchdog_complaint.php. TRUSTe will then serve as a liaison with us to resolve your concerns.

DNAPlus

www.dnaplus.com

Privacy Policy

The following describes our Privacy Policy. Please take a moment to review it and feel free to contact us with any questions. Thank you for the trust you have placed in us. We look forward to working very hard to continue to earn your trust.

All your information is considered highly confidential.

What is our commitment to you?

DNA Plus and its family of affiliated companies are committed to maintaining the trust and confidence of our customers. We want you to understand how we protect your privacy when we collect and use information about you, and the measures we take to safeguard that information. Keeping customer information secure and private is a priority for us.

What types of non-public personal information about you do we receive?

In the course of providing service to you, we receive nonpublic personal information about you from the following sources:

- Information provided by you on contact forms sent through this website (e.g., name, address, etc.)
- Information provided by you on paternity testing forms and other standard forms (e.g., name, address, etc.)
- Information provided by you on when we receive payment (e.g., your credit number, checking account number, etc.)

This information is never collected for any use other than to provide our products and services to you.

How do we protect the confidentiality and security of your non-public personal information?

Keeping your information secure is one of our most important responsibilities. We restrict access to non-public personal information about you to those employees and agents who need to know that information in order to provide products or services to you. We maintain physical, electronic, and procedural safeguards that comply with federal standards to guard your non-public personal information.

Do we disclose to any non-affiliated third parties your non-public personal information?

No. We *never* sell, share or disclose your non-public personal information to non-affiliated third party marketing companies.

Do we disclose within our family of affiliated companies your non-public personal information?

No. In the course of providing services to you, we do not share within our family of affiliated companies information about our transactions.

We reserve the right to change this policy at any time and you will be notified via this website if any changes occur.

If you have any questions after reading this Privacy Policy, please contact us.

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easyDNA
www.easyDNA.ca

Introduction

Access to and use of this Web site is provided subject to the following terms and conditions, which you should read carefully. By proceeding further you shall accept them as the exclusive terms and conditions governing the access to and use of this Web site.

Governing Law and Jurisdiction

All the information appearing on the pages of this Web site is provided in accordance with and subject to the laws of the BVI. Accordingly, by browsing or accessing this Web site you have accepted the laws of the BVI as the law governing the conduct and operation of this Web site.

The Courts of the BVI shall have exclusive jurisdiction over all claims or disputes arising in relation to, out of or in connection with this Web site and its use. Should you decline to accept the laws of the BVI or the exclusive jurisdiction of the Courts of BVI as aforesaid, we must ask you to immediately discontinue further in this Web site and to disconnect from same.

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Information Collection And Use

easyDNA Limited is the sole owner of the information collected on this website. easyDNA Limited collects information from our users at several different points on our Web site. We use the information solely to track how many individuals use our site, which pages they use. This information enables us to improve our site for all customers. We do not share, sell or pass on any of this information to third parties.

We store information that we collect through cookies, log files, to create a profile of our users. A profile is stored information that we keep on individual users that details their viewing preferences. Consequently, collected information is tied to the users personally identifiable information to provide

offers and improve the content of the site for the user. This profile is used to tailor a user's visit to our Web site, and to direct pertinent marketing promotions to them. We do not share your profile with other third parties

A cookie is a piece of data stored on the user's computer tied to information about the user. Usage of a cookie is in no way linked to any personally identifiable information while on our site. We use session ID cookies. For the session ID cookie, once users close the browser, the cookie simply terminates.

Like most standard Web site servers we use log files. This includes internet protocol (IP) addresses, browser type, internet service provider (ISP), referring/exit pages, platform type, date/time stamp, and number of clicks to analyze trends, administer the site, track user's movement in the aggregate, and gather broad demographic information for aggregate use. IP addresses, etc. are not linked to personally identifiable information.

Security

This Web site takes every precaution to protect our users' information. When users submit sensitive information via the Web site, their information is protected both online and off-line.

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Transmissions To easyDNA Limited

In accessing this Web site you accept that electronic mail and other transmissions passing over the Internet may not be free from interference by outside parties and may not remain confidential. In consequence, easyDNA Limited cannot guarantee the privacy or confidentiality of any information passing over the Internet.

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Data Protection Compliance

easyDNA Limited complies with the requirements of the Data Protection Act 2001 with regard to the collection, storage, processing and disclosure of personal information and is committed to upholding the Act's core Data Protection Principles.

If users have questions or concerns regarding this statement, they should contact Customer Care by E-mail: info@easydna.net.

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Genelex

www.healthanddna.com

Note: This company has a longer privacy policy regarding Internet usage and collection of personal information via their website. A much more abbreviated policy addresses genetic information.

Privacy & Ethics

Our Mission

To provide the latest and best in genetic testing and information to private citizens and medical, legal, and other professionals.

Using Genetic Information Responsibly

The information we provide to clients can help them to better understand their circumstances and nature, enable them to make improved life decisions, and enhance the effectiveness of their interactions with medical and legal institutions, provided it is used in a responsible manner. **WE EXPECT OUR CLIENTS TO SEEK PROFESSIONAL ADVICE CONCERNING ANY MEDICAL OR LEGAL ACTIONS THAT MIGHT BE SUGGESTED BY THE INFORMATION WE OFFER.** If you have questions or need help in the responsible use of information we provide, please contact us at info@genelex.com or (800) 523-3080.

Genelex Privacy Policy

All information and materials provided to us by our clients and all test results are held in strict confidence and stored in monitored, secure facilities under the supervision of trained personnel.

Personal, identifiable information of any kind will not be released to a third party without express written instructions. We are required to provide de-identified information of a statistical nature to our accrediting agencies and reserve the right to use such anonymous information for research purposes.

Client privacy concerns are Genelex concerns. If you have any questions or comments regarding privacy issues, please direct them to info@genelex.com.

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The more extensive Privacy Policy is as follows.

At Genelex, we are committed to respecting your privacy. We recognize that when you choose to provide us with information about yourself, you trust us to act in a responsible manner. We take this trust very seriously, and that's why we have put a policy in place to protect your personal information. **This policy allows us to document our commitment to you that we will not sell or share your personally identifiable information, including your name, email address, or the information you look up in our medical references, without your permission or as required by law.**

The Genelex Privacy Policy set out below describes our policies and practices regarding the information we collect from you, how we use that information, and our commitment to you to safeguard that information.

What information does Genelex collect?

At times, we may request that you voluntarily supply us with personal information.

Generally this information is requested when you request information or when you provide information in connection with an online transaction. For example:

- When you order, we ask you for your name, email address, shipping and billing addresses, telephone number, and credit card information so that we can complete the transaction.
- When you request information from Genelex, we ask for demographic and contact information including your name, email and address so that we can provide you with more customized service and information.
- There may be other instances when we ask you for information. For example, when you participate in a survey or test or when you enter a contest or other promotional event, we may ask for additional personal information. The information collected, its purpose, and how/by whom it will be used will be explained to you at the point of collection.

We also may collect and store certain information automatically. This information will not be shared with anyone beyond the web site support staff, except when required by law enforcement investigation, and will be used only as a source of anonymous statistical information. This information may include:

- Internet Protocol (IP) address of the domain from which You access the Internet, either Your individual address or the proxy provided by Your Internet Service Provider (ISP).
- Date and time You access our site.
- Pages You view (recorded by the text and graphics files that compose that page).
- Web address of the site from which You linked directly to our site.
- Browser version and operating system of the computer You are using.

Genelex is the sole owner of the information collected on the Genelex web site. Genelex collects personally identifiable information from our users at several different points on our Web site.

We may use the summary statistics to help us make our site more useful to visitors, such as assessing what information is of most and least interest to visitors, and for other purposes such as determining the site's technical design specifications and identifying system performance or problem areas.

Will Genelex share the information it collects with others?

Please be assured that Genelex :

- Does not share or sell names, email addresses or contact information;
- Does not disclose the identity of people that contact us; and
- Does not disclose information on how contacts are using Genelex products except in aggregate or non-personally identifiable form.

Genelex may provide *aggregate or non-personally identifiable* statistics about our customers, sales, product usage or traffic patterns, and related website information, but these statistics will not include any personally identifying information.

Note: We obviously must disclose certain information to credit card processors when you make an online purchase. The service providers we use are not permitted to use your information for any secondary purposes. Genelex may also disclose personal information as allowed or required by applicable law, including making disclosures that are necessary or advisable to: (a) protect the rights, safety or property of subscribers of our website and products, the public, or Genelex , and (b) conform to legal or regulatory requirements. No other disclosures of personally identifiable information will be made without your prior consent.

How does Genelex protect your information?

Genelex safeguards the security of the data you send us with physical, electronic, and managerial procedures.

These procedures include limiting access to the information in various ways depending on the nature of the information as well as training our employees on the proper handling of contact information. While we believe we have taken appropriate measures to protect the information that we have received, we urge you to take every precaution to protect your personal data when you are on the Internet. Change your passwords often, use a combination of letters and numbers, and make sure you use a secure browser.

When you place orders or access your account information, we offer the use of a secure server. The secure server software (SSL) encrypts all information you input before it is sent to us. Furthermore, we take extra steps to protect this data from unauthorized access, disclosure, alteration, or destruction.

What access does Genelex give you to your personal information?

You may delete or update your Genelex personal information and email preferences, at any time. You have the option of correcting, updating and/or changing contact and demographic information and other information previously provided and stored in our database. If you wish to correct, update or change your information, simply email info@genelex.com with your request.

How does Genelex use "cookies" and log files?

"Cookies" are small pieces of information that are stored by your browser on your computer's hard drive. We use both session cookies and persistent cookies on our website to help us provide you with a more personalized experience. Most web browsers automatically accept cookies, but you can usually change your browser settings to prevent that if you would rather not store the information for future use. Disabling cookies in your browser, however, may prevent access to some parts of our website.

As is true of most websites, we gather and use certain information automatically and store it in log files. This information includes Internet protocol (IP) addresses, browser type, Internet service provider (ISP), referring/exit pages, operating system, date/time stamp. We use this information to analyze trends, to administer the website, to track users' movements around the website and to gather demographic information about our user base as a whole. We do not link the information we store in cookies to any personally identifiable information you submit while on our website.

How does Genelex link with other websites?

The Genelex website contains links to and from other websites. Genelex does not share your personal information with those websites and is not responsible for their privacy practices. We encourage you to learn about the privacy policies of those companies.

Does Genelex keep email addresses of recipients who receive forwarded content?

If you chose to use our service to send a colleague or friend information from a Genelex communication (e.g. email) or from Genelex Online (refer a friend, interaction report), we will ask for that person's email address. We will automatically send a one-time email with the clinical information requested by the sender. Genelex does not use the recipients email address for anything other than the intended one time use. Genelex does not store the recipients email address except in the case when the recipient requests we include them in future Genelex communications.

Is Genelex responsible for personally identifiable information on our blog or bulletin board?

If you contribute to a blog or bulletin board on the Genelex website, you should be aware that any personally identifiable information you submit there can be read, collected, or used by other users of these forums, and could be used to send you unsolicited messages. We are not responsible for the personally identifiable information you choose to submit in these forums.

Is this privacy statement subject to change?

Yes. The Genelex Privacy Policy is subject to change at any time. By using our website, you consent to the collection and use of this information by Genelex as disclosed in this statement. If we decide to

materially change our privacy practices, we will post a prominent notice of those changes on the homepage and/or send an email so that you are always kept informed of what data we collect, how we use it, and under what circumstances we disclose it. Please check this page for changes from time to time to make sure you are aware of our latest privacy practices.

Important Terms

In this policy, when we use the term "we" or "our", we mean both Genelex and third parties with whom Genelex contracts to assist in its business operations. These contractors may, however, only access your information in furtherance of their services to Genelex and may not use or disclose your information except as permitted by Genelex .

What is "personally identifiable" information?

When reviewing any privacy policy on the Internet, you should be familiar with the terms "personally identifiable" and "non-personally identifiable" information. "Personally identifiable information" is any information that can be used to identify, contact or locate you as an individual, as well as any additional data tied to such information. Common examples are your name and email address, along with purchase information associated with those fields. Non-personally identifiable information is information — either in "profile" or "aggregate" form — that, in contrast, is not intended to identify you as an individual. For instance, we may store a profile of an oncologist in New York without linking this information to a name, address, or other personally identifiable information. We may also aggregate information to produce general data, such as figures that show that half of our subscribers are over thirty-five years old.

How to send us feedback

Our goal is to respect your privacy and we encourage user feedback to help us improve our privacy policies. If you have any questions or suggestions about this privacy statement, please contact us at: info@genelex.com.

Genelex Corp.
3000 First Ave. Ste. One
Seattle, WA 98121

Privacy policy updated November 5, 2009

HealthCheck USA

www.healthcheckusa.com

HealthCheckUSA recognizes that individuals with whom we conduct business value their privacy. However, in order to conduct global business in this increasingly electronic economy, the collection of personal information is often necessary and desirable. It is HealthCheckUSA's goal to balance the benefits of e-commerce with the right of individuals to prevent the misuse of their personal information.

The collection of personal information

In general, you can visit our site without divulging any personal information. However, in order to receive laboratory tests, HealthCheckUSA will request personal information from you, like your name, mailing address, e-mail address, company name, or telephone number. Your response to these

inquiries is necessary to process the lab results back to you. In addition, HealthCheckUSA may use this information for other business purposes, such as to alerting you to future promotions and services that may be of benefit to your understanding of certain laboratory tests or the approval of other tests.

Laboratory Data

HealthCheckUSA recognizes the sensitivity of their personal health information. All client reports are mailed directly to the client only and copies are not retained. Under no circumstances will this information be made available to third parties such as insurance carriers or representatives of any health provider without the prior consent of the individual.

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Disclosure to third parties

In cases where we believe your health interests will be served, HealthCheckUSA may share your information (with the exception of account, credit card, and ordering information) with HealthCheckUSA Business Partners, who can alert you about new products and services in the offering. If you receive unwanted marketing materials from any of our Business Partners, please let them know that you wish to be removed from their contact list.

Email Information

If you choose to correspond with us through email, we may retain the content of your email messages together with your email address and our responses. We provide the same protections for these electronic communications that we employ in the maintenance of information received by mail and telephone.

Protecting Your Security

Information Security

We utilize encryption/security software to safeguard the confidentiality of personal information we collect from unauthorized access or disclosure and accidental loss, alteration or destruction.

Evaluation of Information Protection Practices

Periodically, our operations and business practices are reviewed for compliance with corporate policies and procedures governing the security, confidentiality and quality of our information.

Employee Access, Training and Expectations

Our corporate values, ethical standards, policies and practices are committed to the protection of customer information. In general, our business practices limit employee access to confidential information, and limit the use and disclosure of such information to authorized persons, processes and transactions.

You may request access to all your personally identifiable information that we collect online and maintain in our database by emailing info@healthcheckusa.com.

HealthCheckUSA Partners

We are not responsible for the practices employed by web sites linked to or from our web site nor the information or content contained therein. Often links to other web sites are provided as pointers to information on topics that may be useful to the users of our website.

HealthCheckUSA reserves the right to change, modify, or update this statement at any time without notice.

HIPAA Policy

HIPAA Notice of Privacy Practices for Personal Health Information

Effective Date: April 14, 2003

THIS NOTICE DESCRIBES HOW MEDICAL INFORMATION ABOUT YOU MAY BE USED AND DISCLOSED AND HOW YOU CAN ACCESS TO THIS INFORMATION.

PLEASE REVIEW IT CAREFULLY

Dear Customer of LifeScan, HealthCheck and HealthCheckUSA

We are required to provide you with this Notice of Privacy Practices and to explain our legal duties under the Federal Health Insurance Portability and Accountability Act (HIPAA).

By law, we are required to:

- maintain the privacy of your Personal Health Information (PHI)
- provide you this notice of our legal duties and privacy practices with respect to your PHI; and
- follow the terms of this notice.

How We Collect Information: We obtain most PHI directly from the Individual. The Information that an Individual gives us when registering for a services generally provides the Information we need. An individual's clinical information is forwarded directly to the individual and some form of record is either retained in secure hard copy file or with a laboratory's archival record for 3 years. If we need to verify information or need additional Information, we may obtain information from third parties such as adult family members or employers. Information collected may relate to an individual's demographics, employment, health, avocations or other personal characteristics which may assist us in evaluating the individual's healthcare. In most cases we do not retain the dates and locations where service was provided.

We **protect** your PHI from inappropriate use or disclosure. Our employees, and those of companies that help us service your health screening, are required to comply with our requirements that protect the confidentiality of your PHI. They may look at your PHI only when there is appropriate reason to do so, such as to administer the process of returning your health test results back to you.

We will **not knowingly disclose or sell** your PHI to any other individual or organization for their use in marketing products to you without your prior consent.

We will **not forward** by mail, fax or electronically your PHI to any healthcare provider without your prior written consent.

We will **not make available** your test results to your employer or 3rd party carrier without your prior written consent.

We May Use and Disclose PHI about You without Your Authorization unless you Object as described below, together with some examples.

- **Appointments and Other Health Information.** We may send you reminders for medical care or checkups. We may send you information about future health services that may be of interest to you as a health conscious individual. For example, we will make frequent mailings to you as a prior customer.
- **Research:** We may use PHI about you for studies and to develop reports. These reports do

not identify specific people. For example, we may want to determine how many individuals of a sex in an age range from a defined population have a cholesterol value over 240 mg/dl .

- **Future Business:** PHI may be disclosed as part of a potential merger or acquisition involving our business in order to make an informed decision regarding any such prospective transaction. Should a merger or acquisition take place, our database of names and addresses may be part of the process.
- **Where Required by Law or for Public Health Activities:** We may disclose PHI when required by federal, state or local law. Examples of such mandatory disclosures include notifying state or local health authorities regarding particular communicable diseases, or providing PHI to a government agency or regulator with health care oversight responsibilities. We may also release PHI to a coroner or medical examiner to assist in identifying a diseased individual or to determine the cause of death.
- **For Payment.** We may use or disclose PHI about you to get payment or to pay for health care services you receive. For example, we may provide PHI to bill your health plan for health care provided to you.
- **To Avert a Serious Threat to Health or Safety:** We may disclose PHI about you to law enforcement in order to avoid a serious threat to the health and safety of a person or the public.
- **For Law Enforcement or Specific Government Functions:** We may disclose PHI in response to a request by law enforcement official made through a court order, subpoena, warrant, summons or similar process. We may disclose PHI about you to federal officials for intelligence, counterintelligence, and other national security activities authorized by law.
- **When Requested as Part of a Regulatory or Legal Proceeding:** If you or your estate is involved in a lawsuit or a dispute, we may disclose PHI about you in response to a court or administrative order. We may also disclose PHI about you in response to a subpoena, discovery request, or other lawful process by someone else involved in the dispute, but only if efforts have been made to tell you about the request or to obtain an order protecting the PHI requested. We may also disclose PHI to any governmental agency or regulator with whom you have filed a complaint or as part of a regulatory agency examination.
- **Other Uses of PHI:** Other uses and disclosures of PHI not covered by this notice and permitted by the laws that apply to us will be made only with your written authorization or that of your legal representative. If we are authorized to use or disclose PHI about you, you or your legally authorized representative may revoke that authorization, in writing, at any time. We cannot take back any uses or disclosures already made with your authorization.
- **Disclosure to Family, Friends, and Others.** We may disclose PHI about you to your family or other persons who are involved in your medical care.
- **Directory.** We may use PHI about you to assist visitors at our facilities to locate you or to inform clergy about you.

Your PHI Privacy Rights

- **Right to See and Get Copies of Your PHI.** In most cases, you have the right to look at or get copies of your PHI. You must make the request in writing and include dates and location(s) of service.. You may be charged a fee for the cost of copying and mailing the PHI to you.
- **Right to Request to Correct or Update Your PHI.** You may ask us to change or add missing PHI if you think there is a mistake. You must make the request in writing and provide a reason for your request. However, there are conditions under which we may deny this request.
- **Right to Get a List of Disclosures.** You have the right to ask us for a list of disclosures made after April 14, 2003 and up to six years prior to the date you made the request. You must make the request in writing.
- **Right to Request Limits on Uses or Disclosures of Your PHI.** You have the right to ask us to limit how PHI about you is used or disclosed. You must make the request in writing and

tell us what PHI you want to limit and to whom you want the limits to apply. In your request, you must tell us (1) dates and location(s) of service (2) what information you want to limit; (3) whether you want to limit our use, disclosure, or both; and (4) to whom you want the limits to apply (for example, disclosure to your spouse or parent). To make a request, you must make your request in writing to Privacy Coordinator, HealthCheckUSA, 8700 Crownhill Blvd #110, San Antonio, Texas 78209. We will not agree to restrictions on PHI uses or disclosures that are legally required, or which are necessary to administer our business. While we will consider your request, we are not required to agree to it. If we do agree to it, we will comply with your request.

- **Right to Revoke Permission.** If you are asked to sign an authorization to use or disclose PHI about you, you can cancel that authorization at any time. You must make the request in writing. This will not affect PHI that has already been shared.
- **Right To Choose How We Communicate With You.** You have the right to ask us to share your PHI with you in a certain way or in a certain place. For example, you may ask us to send PHI about you to your work address instead of your home address. You must make this request in writing. You do not have to explain the basis for your request.
- **Right to File a Complaint.** You have the right to file a complaint if you do not agree with how we have used or disclosed PHI about you. All complaints must be submitted in writing. Your services will not be affected by any complaints you make. We cannot retaliate against you for filing a complaint or refusing to agree to something that you believe to be unlawful.
- **Right to Get a Paper Copy of this Notice.** You have the right to ask for a paper copy of this notice at any time.

ADDITIONAL INFORMATION

We reserve the right to change the terms of this Notice of Privacy Practices at any time. Any changes will apply to information we already have and any information we receive in the future. A copy of the new notice will be posted at www.healthcheckusa.com and provided to individuals upon request as required by law. You may request a copy of the current notice at anytime.

LifeScan, Inc. San Antonio, TX.
Effective: 4/12/2003

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Inherent Health

<http://www.inherenthealth.com/home.aspx>

INTRODUCTION

Please read this privacy policy (the "Privacy Policy") to learn more about how Interleukin Genetics, Inc. ("Interleukin," "we," or "us") treats personally identifiable information that you provide to us when you create a user account and order Services on our website www.inherenthealth.com (the "Website"). Unless otherwise defined herein, capitalized terms shall have the meanings assigned to such terms in the Terms and Conditions of Use Agreement for the Website found [here](#). If you have comments, suggestions, questions, or concerns about our Privacy Policy, please contact us at privacy@InherentHealth.com.

What This Privacy Policy Covers. This policy covers our treatment of personally identifiable information that we obtain from you when you register as a new customer and when you purchase Services that may be offered for sale on our Website. Personally identifiable information also includes health information that you disclose to us and information generated from tests that we conduct for you. We regard personally identifiable information as information that someone can use to identify or contact you in person, such as real name, telephone number, email address, physical mailing address, financial account information, Genetic Information, and certain medical information

you voluntarily provide to us such as your birth date, gender, and personal and family disease history. Information that we use internally to identify you as a customer in our system, such as your selected username or password, is not considered personally identifiable information.

What This Privacy Policy Does Not Cover. This policy does not cover the privacy practices of third parties that we do not own or control, such as our partners and advertisers. In addition, we may provide links to other services and on occasion to other sites that may interest you. All of these sites operate independently and they have their own privacy or security practices. We have no control over, do not review, and cannot be responsible for these outside websites or their content. Accordingly, we encourage you to review their policies before submitting any personal information to them.

HOW INFORMATION IS COLLECTED

1. Information You Provide.

Required Registration Information. When you register as a customer, we collect the following information from you: full name, email address, and the username and password you have created.

Required Information When You Order Products. When you order products on our Website, we collect your full name, your billing and shipping address, telephone number, credit card number, expiration date and security code.

Email Information. In addition to providing the foregoing information to us, if you choose to correspond with us through email, we may retain the content of your email messages together with your email address and our responses. We provide the same protections for these electronic communications that we employ in the maintenance of information received by mail and telephone. It will remain safeguarded and not be shared with any outside services or companies, except as necessary to provide the services that you have requested.

Access to Your Personal Information. In general, we make it easy for you to view the personally identifiable information we have collected from you in your customer profile, where you can add, edit, or delete it as you see fit.

2. Information We Track. Similar to other commercial web sites, our Website utilizes a standard technology called cookies and Web server logs to collect information about how our Website is used. Information gathered through cookies and Web server logs may include the date and time of visits, the pages viewed, time spent at our Website, and the websites visited just before and just after our Website. This information is collected on an aggregate basis. None of this information is associated with you as an individual.

Cookies are stored on computers to increase the security of your personal information and make it easier for you to navigate a website. Session cookies are automatically deleted when you close your web browser, while other cookies, called persistent cookies, remain on your computer for long periods of time. To remove persistent cookies from your computer, follow the instructions in the help menu of your web browser. If your internet settings block cookies altogether, you will not be able to log into an account on the Website.

INFORMATION WE DO NOT COLLECT

1. Personal Information of Children Under the Age of 13. You should be aware that our Website is not intended for, or designed to attract, children under the age of 13 and as such, we do not intentionally gather personally identifiable information of children who are under the age of 13. If you believe that we have collected personal information about a child who is under the age of 13, please contact us at privacy@InherentHealth.com and such personal information will be deleted.

HOW PERSONALLY IDENTIFIABLE INFORMATION IS USED, CONTROLLED, AND SECURED

1. Use of Your Personally Identifiable Information That You Provide To Us. We may use your personally identifiable information for the following purposes:

- To process and fulfill your order, including to send you emails confirming your order status and shipment.
- To generate and send you requested test results.
- To communicate with you and to send you information by email, mail, or other means about our products, new services, and special offers we think you will find valuable.
- To notify you about important changes to our Website.

As a customer, you will be given the opportunity, at least once annually to notify us of your desire not to receive promotional offers.

2. **Use of Information We Collect From Cookies.** We may use the information we collect from cookies for the following purposes:

- To analyze trends and statistics about the use of our Website
- To design our Website in the most user-friendly manner so that we can enhance your shopping experience
- To help us improve our Website, products and services and better serve our existing and potential customers

3. **Control of Your Personally Identifiable Information.** Except as otherwise described in this Privacy Policy, personally identifiable information you provide to us will not be shared outside of Interleukin and its controlled subsidiaries and affiliates without your permission.

4. **Security of Personally Identifiable Information.** To prevent unauthorized access to personally identifiable information, we have put into practice a number of procedures set forth below:

- User access is protected using personally assigned usernames and passwords.
- DNA samples are assigned a unique, anonymous barcode to track the Genetic Information independent of the user information.
- User information is always stored separately from Genetic so that Genetic Information remains anonymous to laboratory personnel.
- This Website is encrypted to secure personally identifiable information. All personally identifiable and transactional information is encrypted using industry standard SSL encryption where the consumer sends confidential personal and credit card information to us on our Website, a secure server software which we have licensed encrypts all information entered before it is sent to us. The information is scrambled en route and decoded once it reaches our Web site.
- Our network is secured using server firewalls. In addition, the Website will use firewall to protect information from unauthorized access, disclosure, alteration, and/or destruction.
- Archives containing personally identifiable information are securely stored on the database server which will be securely stored behind the firewall
- Employee and third party consultant access to personally identifiable information is limited to their needs related to provision of Services. Employees and third party consultants may only access this information using a password.

All employees and third party consultants with access to personally identifiable information are trained appropriately and are required to sign a confidentiality agreement that aligns with this privacy policy.

Please note that email correspondence that you may send to us may not be secure unless we advise you that security measures will be in place prior to your transmitting the information. For that reason, we ask that you do not send confidential information such as Social Security or financial account numbers to us through an unsecured email.

HOW INFORMATION IS SHARED AND DISCLOSED

1. **With Third Parties.** We may provide anonymous, aggregate information about our customers, sales, Website traffic patterns and related information to our affiliates, partners or reputable third parties, but this information will not include personally identifiable information.

2. **Linked Services.** In some cases, we may allow you to access or link to other products or services through our Website. In all of these cases, our partners may choose to collect your personal information as they deem appropriate. We are not responsible for or in control of how our partners collect, use, or disclose your information obtained through these linked services. We encourage you to be aware when you are using these partner services and, for your best online experience, we encourage you to review their policies before submitting any personal information to them.

3. **As Necessary In Certain Legal Circumstances.** We reserve the right to disclose your personally identifiable information as required by law and when we believe that disclosure is necessary to protect the rights, property or safety of Interleukin or others, respond to claims and/or to comply with a judicial proceeding, court order, or legal process served on us.

TEST RESULTS

Customer samples are processed in our state-of-the art CLIA-certified laboratory with the utmost standards of quality and according to government regulations.

Your DNA sample will only be tested for the information requested. Results will be provided by mail to the address designated or electronically via a secure, password protected Website. No one outside our laboratory will have access to the results unless directed to do so in writing. This includes family members.

To further protect your privacy, we will destroy samples within ten days after completing your requested test.

COMMUNICATION

We will contact customers using the method of communication they specify. Information will not be communicated to any other individual unless the customer directs us to do so in writing or it is required by law.

ACCOUNT TERMINATION

If a customer decides to terminate his or her account with Interleukin, we will delete the customer's user account, access and personally identifiable information from our system. However, we are required by law to archive and retain copies of the test report for 7 years.

FEDERAL LAWS PROTECTING YOU

Some people worry that once they know a genetic fact about themselves, they could be forced to share that information with an insurer or employer. The United States instituted a new law on May 21, 2008 called the Genetic Information Nondiscrimination Act (GINA), which protects Americans against unfair treatment from employers and insurers on the basis of genetic information. As a result, you are not required to disclose genetic information to an employer or insurer, nor can they legally discriminate against you.

STATE LAWS PROTECTING YOU

There are also state laws that prevent insurers, employers and others from using genetic test results for

discriminatory purposes. You may have additional protection under these laws, depending on where you are located.

NOTICE TO CALIFORNIA RESIDENTS

California Civil Code Section 1798.83 permits customers who are California residents and who have provided Interleukin with "personal information" (as that term is defined in Section 1798.83) to request certain information about the disclosure of that information to third parties for their direct marketing purposes. If you are a California resident with questions regarding this, please contact Interleukin at privacy@InherentHealth.com or at Interleukin Genetics, Inc., 135 Beaver Street, Waltham, Massachusetts 02452, U.S.A.

FOR OUR CANADIAN CUSTOMERS

Canadian citizens, except under circumstances defined by law, are entitled to access their own Personal Information collected by Interleukin by writing to: Interleukin Genetics, Inc., 135 Beaver Street, Waltham, Massachusetts 02452, U.S.A. We may ask you to pay an administrative fee for accessing or copying your information, but will inform you of the anticipated charges and confirm that you want us to proceed before processing your request. If you believe that the personally identifiable information about you that we have collected is incomplete or inaccurate, we will correct the information upon verification of the omission or error and of the identity of the person requesting the change. If you wish additional information about our personal identifiable management, to access, correct or have us investigate any matters in relation to your personally identifiable information, please contact us at the address provided above.

NOTICE TO VISITORS OUTSIDE OF THE UNITED STATES

You should be aware that the United States and other countries have not harmonized their privacy regulations. Because Interleukin and its servers is located in the United States, we have written our Privacy Policy to satisfy United States regulations. By registering as a customer, you expressly agree to the transfer into and out of the United States and the use of your personally identifiable information as necessary to provide the services that you request. You also agree to the level of privacy protection set out in this Privacy Policy.

LINKED WEBSITES

This Website contains links to third-party Websites operated by other organizations. We are not responsible for their privacy practices and we encourage our customers to read the privacy policies of each Website that collects personally identifiable information. We will not disclose our customers' personal information to these organizations.

BUSINESS TRANSITION

In the event that Interleukin undergoes a business transition such as a merger or an acquisition by another company, or if any personally identifiable information is transferred to another company, we will require the successor to comply with the terms of this policy.

CHANGES TO THIS PRIVACY POLICY

This Privacy Policy is subject to occasional revision, and changes will be posted on the Website. If we make any substantial changes in the way we use or disclose your personally identifiable information, we will notify you at the email address listed in your customer profile. If you object to any such changes, you may request that we delete your customer account.

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Inneova
www.inneova.com

INNEOVA CORPORATION DISCLAIMER AND PRIVACY POLICY

Welcome to Inneova Corporation Limited. To insure an informative, non-offensive, and fair environment for all of the users of our web site as well as for our customers, we have established certain rules and conditions for its use. By accessing any areas of the www.inneova.com web site or by purchasing our products and services, you agree to be legally bound to and abide by the rules and conditions set forth below:

1. Inneova Corporation Limited (hereinafter “ICL”) is committed to protecting your privacy. Any personal information, including your name, mailing address, telephone number, email address, sex, age, or medical condition that you disclose to us during your use of our web site will not be given, sold, licensed, or rented to any third party. Furthermore, any permission-based contact we undertake with you will provide you with the option to unsubscribe at any time.

ICL will also not disclose to third parties your identity, contact details, or test results obtained from you as part of an agreement for services rendered (except to its medical, scientific, and other service partners, subsidiaries and related business entities, legal advisors, agents, or appointees for the purpose of performing genetic testing or interpretation services, as well as any associated administrative transactions, as deemed necessary by ICL in the normal course of business) with the exception of cases where any legal action, court order, or legislation requires it to do otherwise.

2. ICL warrants that the results of the analysis of any biological samples provided to us by the customer are correct according to the lab findings and based upon the origin of the samples provided to us. The customer warrants that the he or she is legally entitled to possess and submit the samples provided to ICL. The customer agrees to indemnify ICL against any loss, damages, or liability suffered by ICL as a result of the customer providing ICL with samples not legally obtained or otherwise legally, ethically, or scientifically encumbered.
3. ICL uses a specific tracking system to identify your sample as soon as it enters our facilities. Molecular biologists in charge of your sample do not know who the actual sample belongs to, but only see each sample as a number. This tracking number is associated with your name and contact information only within our secure database, which is not accessible by the lab or anyone outside of our company.
4. The processing of each sample involves DNA extraction and analysis. The DNA is used only for the purpose of predictive genetics testing. Once processed, each DNA sample is discarded following a secure protocol.
5. All web site design, texts, images, graphics, other content, and any part or arrangements thereof, as well as all proprietary software or other features used on the web site are the property of ICL or are used by ICL under license. Any use of materials on this web site – including their reproduction, modification, distribution, or republication – without the prior written consent of ICL is strictly prohibited.
6. While ICL will make every reasonable effort to maintain the accuracy, completeness, and currency of the information published on this web site, this web publication is provided “as is” without a warranty of any kind, either expressed or implied, including, but not limited to, the implied warranties of merchantability, fitness for a particular purpose, or non-infringement. ICL will not be held liable for damages of any kind arising from the use of this site or the products or services purchased using this site, including but not limited to direct, indirect, incidental, punitive, and consequential damage. In addition, ICL does not represent or warrant that the information accessible via this site is accurate, complete or current.

7. The above stated rules and disclaimers are subject to change by ICL at its sole and absolute discretion.
8. This site is created and controlled by ICL based in Canada. ICL operates under the laws of Canada, and any all uses and transactions conducted within the scope of this web site are subject only to the laws of Canada. Any disputes arising out of the use of or reference to this web site shall be settled by a court of law, by arbitration, or by mediation in Canada under the laws of Canada. Canadian legislation will govern all terms, conditions and disclaimers on this site, without giving effect to any principles of conflicts of laws.

Inneova also provides a Statement of Consent on its website:

Statement of Consent

As a client of Inneova Corporation Limited, a company incorporated under the Canada Business Corporations Act (CBCA), I expressly agree to the following:

I understand the basic concept of predictive genetics testing and how it may result in the discovery of genetic predispositions that could indicate an increased or decreased risk of developing certain medical conditions and diseases. I realize the possible far-reaching implications of the information obtained through predictive genetics testing in affecting my life choices as well as those of my relatives, children, and unborn children.

I voluntarily agree to provide Inneova Corporation Limited (hereinafter "ICL") with a biological sample of my DNA in the form of saliva or blood submitted to ICL in one or more test tubes or other approved containers (depending upon the test) in order to allow ICL to manage the process of performing a DNA test (or series of DNA tests) on this material. I hereby warrant that I am legally entitled to possess and submit for processing the samples provided to ICL, and agree to indemnify ICL against any loss, damages, or liability suffered as a result of my providing ICL with samples not legally obtained or otherwise legally, ethically, or scientifically encumbered.

I understand that upon receipt of payment for its services and receipt of my contact and/or personal details as well as my DNA sample, ICL is obligated to manage the process of performing a DNA test (or series of DNA tests if I have purchased more than one test) and subsequently provide me with predictive genetics test results, as well as an indicative, preliminary personalized report for each test performed based on statistical genetic research into the behaviour and interaction of genes with factors such as aging, nutritional and lifestyle choices, as well as various diseases and how they could affect my health and well being.

I hereby allow ICL to contact me by any or all of the means provided to ICL during the test registration process for services rendered via the www.inneova.com web site for the purpose of communicating to me any information relevant to the performance by ICL of its duties under this Agreement, for the delivery of my test results and preliminary, personalized interpretations of such tests, as well as to recommend to me additional tests or services as deemed appropriate and/or necessary by ICL at any time in the future.

Furthermore, I consent to ICL maintaining a database that includes my contact and limited personal details for the purpose of sending me periodic updates to its product and/or service line in the form of newsletters, special reports or offers, or other communications tools. I understand that I may, at any time, unsubscribe from such services by means of a written request to ICL by e-mail that includes my name, address, and e-mail address as provided to ICL during the registration process (as applicable), and that ICL will thereby be obligated to remove my contact details and any personal details from its database within 14 business days. The e-mail address for such requests shall be unsubscribe@inneova.com.

I understand that ICL will not disclose my identity, contact details, or test results to third parties (except to its medical, scientific, and other service partners, subsidiaries and related business entities, legal advisors, agents, or appointees for the purpose of performing genetic testing or interpretation services, as well as any associated administrative transactions, as deemed necessary by ICL in the normal course of business under the terms of this Agreement as well as under its [Disclaimer and Privacy Policy](#)). I understand that ICL will be absolved of this responsibility to a limited extent as stated in its [Disclaimer and Privacy Policy](#) in the case of any legal action, court order, or legislation requiring it to do otherwise.

I agree that ICL is in no way responsible for my full understanding of the test results nor their preliminary, personalized interpretation (or the results of multiple tests and their interpretations) provided to me by ICL. I further agree that, in order to help me to adequately interpret the results of my DNA tests upon receiving their preliminary interpretation from ICL, especially within (but not limited to) the context of my unique personal health status as determined by my family doctor or other physician during a face-to-face consultation (a status which is largely or completely unknown to ICL), I must consult with an appropriately-qualified medical professional.

I understand that ICL is not providing me with medical counselling under any of its legal definitions, but rather with predictive genetics testing services that I may subsequently use to consult with an appropriately-qualified practitioner in anti-aging or predictive medicine, either referred to me by ICL upon request or recommended to me by my family doctor. I understand that the information (preliminary or otherwise) provided to me by ICL does not constitute medical advice, but rather the provision of information about my genetic characteristics that should be considered a precursor to seeking medical counselling in a face-to-face meeting with a qualified physician in a clinical environment.

I agree that ICL assumes no liability for the accuracy or completeness of any of the predictive genetics tests conducted by or on behalf of ICL on my DNA beyond the obligation to repeat at no cost to me a test that has been deemed inaccurate or incomplete by an appropriately-qualified medical professional in the form of a written protocol, and that ICL will investigate the matter of any such test in order to determine why it may not have been conducted to meet the demands of its quality standards in order to avoid a repetition of such circumstances.

I agree that ICL assumes no liability for the accuracy or completeness of any interpretations of the predictive genetics tests conducted by or on behalf of ICL on my DNA (and which are based on statistical genetic research), and that ICL may provide me with an initial assessment of my genetic predispositions that may include general suggestions as to what measures would normally be recommended to prevent the onset or development of identified medical conditions or diseases to which I may be predisposed, but which I may or may not be affected by.

I agree that any such indications or recommendations provided to me by ICL are provided for the purpose of general, introductory information only, that this information does not and cannot replace a face-to-face clinical consultation with an appropriately-qualified medical practitioner, and that I will discuss the information provided to me by ICL with a qualified physician for a complete interpretation of my test results and their implications should I want to become fully informed on the subject and/or wish in any way to act upon the results or interpretations of the predictive genetics testing services performed by ICL on my behalf.

I agree that ICL (together with its medical, scientific, and other service partners, subsidiaries and related business entities, legal advisors, agents, or appointees) assumes no liability for any stress, strain, hardship, adverse medical condition, financial loss, or other circumstances that I may suffer as a result of the receipt or reference to any predictive genetics test results and/or interpretations thereof supplied to me by ICL. I understand that ICL is obligated under this Agreement to provide me with certain information concerning my DNA that I may use in any way that I deem appropriate, and that I

am aware of the strong recommendations of ICL to consult with an appropriately-qualified medical practitioner in order to adequately understand and benefit from it.

I understand that ICL is responsible for the delivery of a professional sample kit to me for each test or series of tests that I purchase from ICL, and that I am responsible for the quality and return shipment (at my expense) to ICL of my DNA sample.

I confirm that I am an adult over the age of 18 years (or over the age of consent in jurisdictions where such age is higher than 18 years), that I enter into this Agreement voluntarily, and that I am legally entitled to do so. As far as I am aware, I may engage the services of ICL for the purposes of any transaction under this Agreement without contravening the laws of my country of residence or citizenship, and I hold ICL harmless from any liability for misrepresentation or error on my part in this regard.

I understand that ICL operates under the laws of Canada, and that this Agreement and all transactions conducted within its scope is subject only to the laws of Canada. Any disputes arising out of this Agreement shall be settled by a court of law, by arbitration, or by mediation in Canada under the laws of Canada.

I confirm that I sufficiently comprehend the English language to understand my rights and responsibilities under this Agreement, the rights and responsibilities of ICL under this Agreement, the limitation on the responsibilities of ICL to providing me with a defined set of predictive genetics testing services as well as preliminary interpretations thereof, and to expressly agree with these Terms & Conditions and Statement of Consent as well as with the [Disclaimer and Privacy Policy](#).

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Knome Inc.
www.knome.com

Note: Website is under revision as of March 2010 and the information below is no longer accessible.

Frequently Asked Questions portion of the website has the following:

“We are dedicated to enabling our clients to remain completely anonymous if they so choose. We do so by implementing confidential information management processes that have been successfully applied in the defense industry and by architecting our technology in a manner that avoids structural weaknesses that may be vulnerable to attack. Our clients receive their genetic information on our proprietary GenomeKey, a fully encrypted portable storage device.”

In description of services, website provides:

“Core to the fundamental principles of the company, you retain full ownership of your personal genetic information. Our GenomeKey uses the latest and most secure encryption technologies to keep your personal information safe. The device ensures that only you can access your personal information and that your genetic data is never exposed. In order to reduce the risk of data exposure, we never store clients' sensitive information online. The genetic information stored on the GenomeKey is the only accessible version of your information and analysis, and you do not need to use the internet to review your data. The company's patent-pending network architecture prohibits Knome from providing third-party access to client information without explicit approval.”

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Matrix Genomics

www.matrixgenomics.com

One caveat: Once you give your results to your doctor, it becomes part of your medical record, and accessible to interested parties such as insurance companies.

Matrix Genomics Inc. is committed to maintaining the privacy of our clients. We use every safeguard to ensure your information is kept confidential. Your information is kept in a secure environment, inaccessible to anyone. We will only share your information with others if you authorize us to do so. The genetic material you send us is destroyed after testing. Public Law #110-233 protects the individual from discrimination in employment and health insurance coverage based on their genetic endowment.

Personal Information

You do not have to reveal any identifiable information about yourself when you contact us, even your name -- you are welcome to create an alias, a kit name. When you purchase a kit, you will be assigned a code that we will use to track your specific information. Our staff is trained in methods to protect the privacy of our clients, and your personal information is not shared with anyone else.

Our Lab

Our laboratory affiliate Clinical Reference Laboratories will ship DNA collection materials to you, requiring your name and address. You paste the identifying barcode onto the sample for shipment back to the lab for testing. No personal information follows the sample to the lab. Your sample is destroyed at the lab once tested.

Privacy Policy Changes

Matrix Genomics, Inc. reserves the right to change this policy statement as we deem necessary. We will post any changes to our policy here on our website.

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MediChecks

www.medichecks.com

MediChecks.com (MediChecks.com Ltd) respects the privacy of visitors to our site. Please read this privacy policy carefully so that you understand our privacy practices. Questions regarding privacy issues should be directed to MediChecks.com.

Children should always get permission from their parents before sending any information about themselves (such as their names, e-mail addresses, and phone numbers) over the internet, to us or to anyone else. We won't knowingly allow anyone under 18 to register with our site.

To make use of certain features on our website, visitors need to register and to provide certain information as part of the registration process. We may also ask for information from those who buy products or services or conduct other transactions on our website. (we may ask, for example, for your name, e-mail address, sex, age, post code or credit card number.

The information you supply will help us to offer you more personalised features, to tailor our site to your interests and make them more useful to you. If you don't supply the information we need, we

may be unable to provide you with services we make available to other visitors to our site. Even if you want to remain completely anonymous, you're still free to take advantage of the wealth of content available on our sites without registration.

To help make our site more responsive to the needs of our visitors, we invoke a standard feature of browser software, called a "cookie," to assign each visitor a unique, random number, a sort of user id, if you will, that resides on your computer. The cookie doesn't actually identify the visitor, just the computer that a visitor uses to access our site. Unless you voluntarily identify yourself (through registration, for example), we won't know who you are, even if we assign a cookie to your computer. The only personal information a cookie can contain is information you supply. A cookie can't read unrelated data off your hard drive.

Our advertisers and the third parties that provide products or services through our site may also assign their own cookies to your browser, a process that we don't control. We use cookies to help us tailor our site to your needs, to deliver a better, more personalised service.

Our web servers automatically collect limited information about your computer's connection to the internet, including your ip address, when you visit our site. (your ip address is a number that lets computers attached to the internet know where to send you data -- such as the web pages you view.) Your ip address does not identify you personally to us. We use this information to deliver our web pages to you upon request, to tailor our site to the interests of our users, and to measure traffic within our site.

To make our site more valuable to our visitors, we offer some features in conjunction with other providers. We share with these third parties such information as is necessary to provide the products or services. Our site includes links to other websites, and provides access to products and services offered by third parties, whose privacy policies we don't control. When you access another website or purchase products or services or conduct other transactions through our website, use of any information you provide is governed by the privacy policy of the operator of the site you're visiting.

The provider's privacy policy may differ from ours. If you can't find the privacy policy of any of our provider partners via a link either from the site's home page or from the pages on which the products or services are offered, you should contact the provider directly for more information.

If we need to change our privacy policy at some point in the future, we'll post the changes before they take effect. By visiting our site, you agree that your visit, and any dispute over our privacy practices, is governed by this privacy policy and our visitor agreement.

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My Gene Profile

www.mygeneprofile.com

Note that the following policy is virtually identical to Navigenic's privacy policy.

Your privacy is extremely important to us. This privacy policy will explain how we collect and use the information that you provide to us.

Collection and use of information

My Gene Profile collects a variety of information regarding your use of our Web site and services, including personally identifiable information. The "personally identifiable information" in this policy refers to the following:

- "Your Genetic Data" means the genotyping results that we generate for you through our services (namely, the set of "A"s, "G"s, "T"s and "C"s at particular locations in your genome) to the extent such results are sufficient in quantity to uniquely identify you.
- "Your Phenotype Information" means the personal information that you voluntarily provide to us, which may include your gender, your birth date, your ethnicity/ancestry, the geographic regions where you or your ancestors have lived, any diseases or other health conditions that run in your family, and personal traits such as height and weight.

We collect and use Your Account Information and other personally identifiable information about you to authenticate your use of our Web site and services, to process your purchase transactions, to provide you with the services you have requested, to communicate with you and to send you relevant information and materials. However, we will not, without your explicit consent, disclose or share personally identifiable information about you with third parties except as required to provide the services you have requested, or as otherwise required by applicable law.

My Gene Profile may freely collect, use and disclose any non-personally identifiable information collected on our Web site, unless otherwise prohibited by this privacy policy or applicable law. This information may include your computer's internet protocol (IP) addresses and cookies which are placed on your computer when you access our Web site (see the cookies section below), as well as the date and time, your computer's operating system and Web browser type, the identity of your internet service provider, and a list of Web pages you have visited. In some cases, this information is collected automatically and stored in log files.

Research

My Gene Profile believes in bringing you the highest quality service available and helping further scientific and medical research. To that end, we may analyze our members' genetic data and associated phenotype information on an aggregated basis and de-linked from any member account information, to:

- Improve the quality and features of our Web site and services
- Provide our members with new and more accurate analysis of genetic data
- Discover or validate associations between certain genetic variations and certain health conditions or traits, as well as other insights regarding human health
- Publish our findings and insights without disclosing Your Genetic Data in a quantity sufficient to uniquely identify you, and without otherwise disclosing your identity

As the number of our clients grows, potentially surpassing the size of currently available public data sets that we use to calculate risk estimates, our ability to study the aggregated genetic data and phenotype information we have collected from our clients, and to publish our findings and insights, will help us to further the advancement of scientific and medical research and fulfil our mission to help you live healthier, longer.

We may also give you the opportunity to contribute your genetic information to science. If you elect to contribute your genetic information to science through the My Gene Profile service, you allow us to share Your Genetic Data and Your Phenotype Information (de-linked from Your Account Information) with not-for-profit organizations who perform genetic or medical research, and you allow such not-for-profit organizations to separately or jointly publish study results that include Your Genetic Data and Your Phenotype Information (but not Your Account Information), in peer-reviewed scientific and medical journals and otherwise, and to deposit such data and information into public data repositories or otherwise make them publicly available to the extent required by such journals.

If you elect not to contribute your genetic information to science through the My Gene Profile service, we will not share Your Genetic Data or Your Phenotype Information with such organizations.

Communications from us

We may be sending at least three types of e-mails: e-mails required to provide you with services you have requested; alerts giving you relevant and new information about service updates; and e-mails informing you about promotional services. Alerts and promotional e-mail messages sent will contain a link that will allow you to opt out of future mailings.

Privacy practices of third-party Web sites

This Web site may contain links to other Web sites. My Gene Profile is not responsible for the privacy policies or practices of any third-party Web sites, including Web sites of any sponsors, collaborators or linked Web sites, or for the privacy policies or practices of any other third parties. To the extent that you disclose personally identifiable information to any collaborator Web sites, linked Web sites or other third parties, different rules may apply to their use or disclosure of any personally identifiable information you disclose to them, and we encourage you to review their privacy policies before disclosing personally identifiable information to them.

Legally required disclosure

We may be legally compelled in the future to disclose personally identifiable information about you to satisfy a court order, subpoena, government order, law, regulation or other legal process. We will use reasonable and lawful efforts to limit the scope of any such legally required disclosure, and we will make every attempt to notify you in advance insofar as we are legally permitted to do so.

In the event that My Gene Profile is acquired by or merges into another company, any personally identifiable information or other information owned or possessed by My Gene Profile may be transferred to the successor,

Changes to this Privacy Policy

My Gene Profile reserves the right to modify or amend this privacy policy at any time. Any material changes will be conspicuously posted on this Web site, and we will notify members by e-mail. Changes will be effective 30 days after posting to this Web site.

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MyGenome

www.mygenome.com

In the description of its genetic testing service, the website states: “You control your private genetic information. Your information will not be available to anyone, or used for any purpose, not explicitly authorized by you.” **This company also states the following advisory on its website:** **“WARNING:** Please do not send any private medical information by email at this time. This is not currently a secure, HIPAA-compliant medium for communicating medical information.” No explanation is given for the reference to a “HIPAA-compliant medium”.

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Navigenics

www.navigenics.com

Collection and use of information

Navigenics collects a variety of information regarding your use of our website and services, including personally identifiable information. The "personally identifiable information" addressed by this policy refers to the following:

- **"Your Account Information"** means the information that you or your physician provide to us when creating or updating your Navigenics account, or purchasing our services, that can be used to uniquely identify you, such as your name, telephone number, email address, billing/shipping address or credit card number.
- **"Your Genetic Data"** means the genotyping results that we generate for you or your physician through our services (namely, the set of "A"s, "G"s, "T"s and "C"s at particular locations in your genome) but only to the extent such results, by themselves or when linked to other personally identifiable information, are sufficient to uniquely identify you.
- **"Your Phenotype Information"** means your gender, your birth date and, optionally, other personal information about you that you or our physician may voluntarily provide to us, which may include your ethnicity/ancestry, the geographic regions where you or your ancestors have lived, any diseases or other health conditions that run in your family, and personal traits such as height and weight.

We collect and use Your Account Information and other personally identifiable information about you to authenticate your use of our website and services, to process your purchase transactions, to provide you with the services you or your physician have requested, to communicate with you or your physician, and to send you or your physician relevant information and materials. However, we will not, without your explicit consent, disclose or share personally identifiable information about you with third parties except as required to provide the services you have requested, in the event Navigenics is acquired by or merges into another company, or as otherwise required by applicable law. We limit access to Your Account Information and other personally identifiable information about you to appropriate Navigenics personnel on a need-to-know basis.

Navigenics may freely collect, use and disclose any non-personally identifiable information collected on our website, unless otherwise prohibited by this privacy policy or applicable law. This information may include your computer's internet protocol (IP) addresses and cookies which are placed on your computer when you access our website (see the cookies section below), as well as the date and time, your computer's operating system and web browser type, the identity of your internet service provider, and a list of web pages you have visited. In some cases, this information is collected automatically and stored in log files. Navigenics contracts with third-party web analytics companies to help us use this information, which is not intended to uniquely identify you, to track and analyze aggregate usage volume and patterns regarding our website. Under certain circumstances, we may need to review this information in combination with Your Account Information to identify and resolve an issue regarding your access to our website.

Research

Navigenics believes in bringing you the highest quality service available and helping further scientific and medical research. To that end, we may analyze our members' genetic data and associated phenotype information on an aggregated basis and de-linked from any member account information, to:

- Improve the quality and features of our website and services
- Provide our members with new and more accurate analysis of genetic data
- Discover or validate associations between certain genetic variations and certain health conditions or traits, as well as other insights regarding human health
- Publish our findings and insights without disclosing Your Genetic Data in a quantity sufficient to uniquely identify you, and without otherwise disclosing your identity

As the number of our members grows, potentially surpassing the size of currently available public data sets that we use to calculate risk estimates, our ability to study the aggregated genetic data and phenotype information we have collected from our members, and to publish our findings and insights,

will help us to further the advancement of scientific and medical research and fulfill our mission to help you live healthier, longer.

We may also give you the opportunity to contribute your genetic information to science. If you elect to contribute your genetic information to science through the Navigenics service, you allow us to share Your Genetic Data and Your Phenotype Information (de-linked from Your Account Information) with not-for-profit organizations who perform genetic or medical research, and you allow such not-for-profit organizations to separately or jointly publish study results that include Your Genetic Data and Your Phenotype Information (but not Your Account Information), in peer-reviewed scientific and medical journals and otherwise, and to deposit such data and information into public data repositories or otherwise make them publicly available to the extent required by such journals.

If you elect not to contribute your genetic information to science through the Navigenics service, we will not share Your Genetic Data or Your Phenotype Information with such organizations.

Cookies

Navigenics uses a combination of session and persistent cookies to track your navigation and use of our website, and your web browser must be configured to accept cookies in order for you to create a Navigenics user account and access many of the features on our web site. Cookies are small pieces of information that are stored by your web browser on your computer's hard drive. Our cookies enable us to facilitate access to different aspects of your account across our website, and to enhance your experience on our website. For example, by showing when and how you and other users visit our website, cookies help us to see which pages of the website are particularly helpful to customers for providing information. This helps us improve our website, because we can eliminate pages that are unpopular and update and improve those pages that are visited frequently. Cookies also improve your ease of using our website, for example, by remembering your address or ordering information when you request information or services on our website. We also use cookies to securely link your Navigenics account with the computer you used to set up your account; if you choose to access your account from another computer, you will be asked to follow additional steps to verify your identity.

Please note that session cookies expire automatically when you close your computer's web browser, whereas persistent cookies are stored on your computer's hard drive until deleted. If you set up or access your Navigenics account from someone else's computer, or a publicly accessible computer, we recommend that when your session is complete you delete any persistent cookies on the computer by following the web browser's instructions and then close the web browser.

Communications from us

We will be sending at least three types of emails: emails required to provide you with services you have requested; alerts giving you relevant and new information about service updates; and emails informing you about promotional services. Alerts and promotional email messages will contain a link that will allow you to opt out of future mailings.

Advertising

The Navigenics Health Compass is not an advertising-subsidized service. Navigenics does not derive revenue from the use of banner advertisements. However, we may describe our collaborators' products and services on our website or in our communications to our members from time to time, and we may feature links to our collaborators' websites.

Privacy practices of third-party websites

This website may contain links to other websites. Navigenics is not responsible for the privacy policies or practices of any third-party websites, including websites of any sponsors, collaborators or linked websites, or for the privacy policies or practices of any other third parties. To the extent that you disclose personally identifiable information to any collaborator websites, linked websites or other third parties, different rules may apply to their use or disclosure of any personally identifiable information you disclose to them, and we encourage you to review their privacy policies before disclosing personally identifiable information to them.

Minors

This website is not directed toward minors under 18 years of age. Given the ethical, privacy and informed consent considerations regarding genetic testing of minors for predisposition or carrier status of adult-onset genetic disorders, Navigenics does not knowingly collect or use information from minors under the age of 18.

Legally required disclosure

We may be legally compelled in the future to disclose personally identifiable information about you to satisfy a court order, subpoena, government request, law, regulation or other legal process. We will use reasonable and lawful efforts to limit the scope of any such legally required disclosure, and we will make every attempt to notify you in advance insofar as we are legally permitted to do so.

Termination of your account

If you do not renew your account subscription with Navigenics, or if at any time you request us to terminate your Navigenics user account, we will delete Your Genetic Data and Your Phenotype Information within 90 days from all operational Navigenics systems, and Your Genetic Data and Your Phenotype Information will not be included in any future archive of these systems, unless we are required by applicable law to retain any such data and information, in which case we will do so only for so long as required, and only for the purposes of such law. However, we will not be obligated to delete your Genetic Data or Your Phenotype Information from historical archives of our systems.

Upon account termination, you will be given an opportunity to withdraw your consent for us to use Your Genetic Data and Your Phenotype Information (de-linked from Your Account Information) for our internal research purposes as described above. If you previously have elected to contribute your genetic information to science through the Navigenics service, you will also have the opportunity upon account termination to withdraw your consent for not-for-profit organizations to begin new studies using Your Genetic Data and Phenotype Information after the 90-day period. However, Your Genetic Data and Your Phenotype Information will not be removed from any ongoing or completed studies or publications in which Your Genetic Data or Your Phenotype Information was utilized.

Finally, we may retain Your Account Information solely to the extent required for our accounting and compliance purposes, and as otherwise required by applicable law.

Changes to this Privacy Policy

Navigenics reserves the right to modify or amend this privacy policy at any time. Any material changes will be conspicuously posted on this website, and we will notify members by email. Changes will be effective 30 days after posting to this website and email notification.

Viewing and changing your Personal Information

As a Navigenics account holder, you may view or change Your Account Information online by signing into your account at www.navigenics.com and clicking on the Manage Profile link in the top right corner of the page. You may also correct Your Account Information by sending email to Navigenics Member Service at memberservice@navigenics.com, or by phoning Navigenics Member Service at (866) 522-1585.

Contacting Us

If you have any questions or concerns regarding this Privacy Policy, or if you wish to have access to or request corrections or updates to personally identifiable information in our records, please contact:

Chief Privacy Officer
Navigenics, Inc.
(650) 585-7700
privacy@navigenics.com

EFFECTIVE DATE: June 19th, 2009

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New Hope Medical Center

www.newhopemedical.org

Royal Center for Advanced Medicine is committed to protecting your privacy and developing technology that gives you the most powerful and safe online experience. This Statement of Privacy applies to the Royal Center for Advanced Medicine Web site and governs data collection and usage. By using the Royal Center for Advanced Medicine website, you consent to the data practices described in this statement.

Collection of your Personal Information

Royal Center for Advanced Medicine collects personally identifiable information, such as your e-mail address, name, home or work address or telephone number. Royal Center for Advanced Medicine also collects anonymous demographic information, which is not unique to you, such as your ZIP code, age, gender, preferences, interests and favorites.

There is also information about your computer hardware and software that is automatically collected by Royal Center for Advanced Medicine. This information can include: your IP address, browser type, domain names, access times and referring Web site addresses. This information is used by Royal Center for Advanced Medicine for the operation of the service, to maintain quality of the service, and to provide general statistics regarding use of the Royal Center for Advanced Medicine Web site.

Please keep in mind that if you directly disclose personally identifiable information or personally sensitive data through Royal Center for Advanced Medicine public message boards, this information may be collected and used by others. Note: Royal Center for Advanced Medicine does not read any of your private online communications.

Royal Center for Advanced Medicine encourages you to review the privacy statements of Web sites you choose to link to from Royal Center for Advanced Medicine so that you can understand how those Web sites collect, use and share your information. Royal Center for Advanced Medicine is not responsible for the privacy statements or other content on Web sites outside of the Royal Center for Advanced Medicine and Royal Center for Advanced Medicine family of Web sites.

Use of your Personal Information

Royal Center for Advanced Medicine collects and uses your personal information to operate the Royal Center for Advanced Medicine Web site and deliver the services you have requested. Royal Center for Advanced Medicine also uses your personally identifiable information to inform you of other products or services available from Royal Center for Advanced Medicine and its affiliates. Royal Center for Advanced Medicine may also contact you via surveys to conduct research about your opinion of current services or of potential new services that may be offered.

Royal Center for Advanced Medicine does not sell, rent or lease its customer lists to third parties. Royal Center for Advanced Medicine may, from time to time, contact you on behalf of external business partners about a particular offering that may be of interest to you. In those cases, your unique personally identifiable information (e-mail, name, address, telephone number) is not transferred to the third party. In addition, Royal Center for Advanced Medicine may share data with trusted partners to help us perform statistical analysis, send you email or postal mail, provide customer support, or arrange for deliveries. All such third parties are prohibited from using your personal information except to provide these services to Royal Center for Advanced Medicine, and they are required to maintain the confidentiality of your information.

Royal Center for Advanced Medicine does not use or disclose sensitive personal information, such as race, religion, or political affiliations, without your explicit consent.

Royal Center for Advanced Medicine keeps track of the Web sites and pages our customers visit within Royal Center for Advanced Medicine, in order to determine what Royal Center for Advanced Medicine services are the most popular. This data is used to deliver customized content and advertising within Royal Center for Advanced Medicine to customers whose behavior indicates that they are interested in a particular subject area.

Royal Center for Advanced Medicine Web sites will disclose your personal information, without notice, only if required to do so by law or in the good faith belief that such action is necessary to: (a) conform to the edicts of the law or comply with legal process served on Royal Center for Advanced Medicine or the site; (b) protect and defend the rights or property of Royal Center for Advanced Medicine; and, (c) act under exigent circumstances to protect the personal safety of users of Royal Center for Advanced Medicine, or the public.

Use of Cookies

The Royal Center for Advanced Medicine Web site use "cookies" to help you personalize your online experience. A cookie is a text file that is placed on your hard disk by a Web page server. Cookies cannot be used to run programs or deliver viruses to your computer. Cookies are uniquely assigned to you, and can only be read by a web server in the domain that issued the cookie to you.

One of the primary purposes of cookies is to provide a convenience feature to save you time. The purpose of a cookie is to tell the Web server that you have returned to a specific page. For example, if you personalize Royal Center for Advanced Medicine pages, or register with Royal Center for Advanced Medicine site or services, a cookie helps Royal Center for Advanced Medicine to recall your specific information on subsequent visits. This simplifies the process of recording your personal information, such as billing addresses, shipping addresses, and so on. When you return to the same Royal Center for Advanced Medicine Web site, the information you previously provided can be retrieved, so you can easily use the Royal Center for Advanced Medicine features that you customized.

You have the ability to accept or decline cookies. Most Web browsers automatically accept cookies, but you can usually modify your browser setting to decline cookies if you prefer. If you choose to decline cookies, you may not be able to fully experience the interactive features of the Royal Center for Advanced Medicine services or Web sites you visit.

Security of your Personal Information

Royal Center for Advanced Medicine secures your personal information from unauthorized access, use or disclosure. Royal Center for Advanced Medicine secures the personally identifiable information you provide on computer servers in a controlled, secure environment, protected from unauthorized access, use or disclosure. When personal information (such as a credit card number) is transmitted to other Web sites, it is protected through the use of encryption, such as the Secure Socket Layer (SSL) protocol.

Changes to this Statement

Royal Center for Advanced Medicine will occasionally update this Statement of Privacy to reflect company and customer feedback. Royal Center for Advanced Medicine encourages you to periodically review this Statement to be informed of how Royal Center for Advanced Medicine is protecting your information.

Contact Information

Royal Center for Advanced Medicine welcomes your comments regarding this Statement of Privacy. If you believe that Royal Center for Advanced Medicine has not adhered to this Statement, please contact Royal Center for Advanced Medicine at droyal@royalmedicalclinic.com. We will use commercially reasonable efforts to promptly determine and remedy the problem.

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Nimble Diagnostics

www.nimblediagnostics.com

No privacy policy but website states on the ‘Frequently Asked Questions’ page: “Privacy guaranteed - Your privacy is of utmost importance to us. Any genetic or other information generated by us or provided by you or will NEVER be shared with a third party, such as an insurer, employer, or medical practitioner without your express written permission. Any and all personal data can be destroyed on request.”

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Pathway Genomics

www.pathway.com

SUMMARY INTERNET PRIVACY STATEMENT

Effective Date - December 21, 2009

THIS NOTICE DESCRIBES HOW MEDICAL INFORMATION ABOUT ME MAY BE USED AND DISCLOSED AND HOW I CAN GET ACCESS TO THIS INFORMATION. PLEASE REVIEW CAREFULLY.

A Note to Non-U.S. Users

You expressly consent to the processing of your personal information in the United States in accordance with the Full Privacy Statement. United States privacy laws and regulations may be less stringent than the laws in your country.

SCOPE

The Full Privacy Statement that follows tells you how we collect, protect, use, and share the information you provide us and the choices you have regarding our use of, and your ability to correct, that information. The Summary Privacy Statement is intended to introduce the Full Privacy Statement, not replace it. Later, it also serves as a quick reference guide to key information. By using our services, you acknowledge that you have reviewed and agree to the terms of the Full Privacy Statement and the Terms of Service.

INFORMATION WE COLLECT

By accessing or using this Website or other services, purchasing a DNA collection kit, or activating a Pathway Genomics account and submitting a sample, we will collect and store your personal information. This information identifies you or can be linked to your identity and Account Information. The following describes the types of personal information that we collect and store:

- **Account Information** (contact and payment information, and information in Personal Settings)
- **Genetic Information**
 - Sample and DNA Extract
 - Type of Genetic Test(s) (health or ancestry genetic test)
 - Genetic Testing-Based Health Information
 - Health Risk (at risk diseases and health related conditions)
 - Carrier (recessive diseases)
 - Pharmacogenetic (drug response)
 - Ancestry Information (genealogical and ethnic)
- **Survey-Based Information** (Health, Family History, and Other Surveys)
- **Other Customer Provided Information**
 - Friend's Name and Email
 - Genetic Counseling and Customer Service Notes
- **Online Profile Information** (computer IP address and non-personal information, such as browser types, web page views)
- **Aggregate Information** (summarized information unlinked to name or Account Information)

When you visit our site, use our services, or view our online advertisements, we use cookies and other technologies to collect Online Profile Information about you.

HOW WE USE YOUR INFORMATION AND YOUR CHOICES

- Pathway Genomics collects and uses your Account Information, Genetic Information, Survey-Based Information, Other Customer Provided Information, and Online Profile Information to provide you our services.
- Third Party Service Providers may have access to and use Account Information and Survey-Based Information to deliver these services to you on our behalf. They will have no access to Genetic Information, other than Type of Genetic Test.
- You cannot opt-out from transactional communications that are essential to delivering our services to you, unless a marketing message or advertisement is included.
- We analyze and use Aggregate Information (unlinked from your name or Account Information, and Online Profile Information (your computer IP address and non-personal information) to track and monitor aggregate usage of our website and to improve the quality and features of our website and services. You can delete cookies as described in Cookies, under the Online Profile Information section of Information We Collect.
- We use your Account Information, Genetic Information, and Survey-Based Information to offer the right products and services from Pathway Genomics and Trusted Partners to you. In this case, we maintain control of your personal information. You can opt-out from receiving each of these marketing communications (see the "How To Exercise Your Choices" section

that follows). You can also delete cookies as described in Cookies, under the Online Profile Information section of "Information We Collect."

- If you elect to use our Refer-A-Friend service, we will send a one-time email to your friend inviting them to visit our website. We will not share this information with any marketing partners. Your friend may request, using the email or physical address identified in the Contact Us section, the removal of his name and email address from our database.

HOW WE SHARE YOUR INFORMATION AND YOUR CHOICES

- Pathway Genomics will NOT share your Genetic Information or any other personal information with your employer or health insurance issuer, unless you expressly authorize us to do so.
- Any reseller of our products or services will not collect personal information from you.
- We may provide your Genetic Information and Survey-Based Information, unlinked from your name and Account Information, to research collaborators to conduct Pathway Genomics-authorized scientific research and development. You cannot opt-out from this research. We also may pass on to you a research collaborator's request that you volunteer additional information or participate in a study. No name or Account Information is shared with a research collaborator without your express consent.
- We may provide Aggregate Information, unlinked to your name or Account Information, to our advertisers to deliver individualized advertising to you. You can delete cookies as described in Cookies, under the Online Profile Information section of Information We Collect. Your express consent is required before your Account Information, Ancestry Information, Survey-Based Information, and Online Profile Information, is disclosed to our Approved Trusted Partners for Ancestry Information Sharing. No other Genetic Information will be disclosed. Pathway Genomics may receive information from the Approved Trusted Partner concerning the service requested by you, including contact and other personal information that you may have inputted on its website, with your express consent. See Approved Trusted Partner Qualification Requirements in the Full Privacy Statement.
- If you are a customer as a result of participating in your employer wellness program, Pathway Genomics only provides your employer Aggregate Information unlinked to your name.
- We may disclose or report your personal information when we believe in good faith that the disclosure is required or permitted by law or regulation, a court order or other judicial or legal process or proceeding, or to cooperate with regulators or law enforcement authorities to resolve consumer disputes.
- If Pathway Genomics enters into a business transaction, such as a merger, acquisition by another company, or selling some or all of its assets, your personal information will, in most instances, be part of the assets transferred. We will require the acquiring company to comply with the material provisions of the Full Privacy Statement.

HOW TO EXERCISE YOUR CHOICES

- **Opt-outs** - To the extent you are permitted, you may exercise your right to opt-out by either a) clicking the unsubscribe link in the footer of any Pathway Genomics' email or replying with unsubscribe in the subject line, or b) writing to us at the address in the Contact Us section at the end of this Privacy Statement.
- **Opt-ins** - You may exercise your right to opt-in when expressly presented with this choice prior to the indicated personal information being shared.

ACCESSING YOUR INFORMATION

- Pathway Genomics will not be responsible for any liability caused by you sharing your personal information with others.

- You have the right to request an accounting of all disclosures, other than for treatment, payment, or healthcare operations. You can make this request using the contact information at the Contact Us section of this Privacy Statement.
- If your Account Information changes (such as email address, street address, or phone number), you can log into your account and change the appropriate information.
- At your written request and according to your instructions, we can destroy your remaining sample and DNA obtained from it, and delete your Account from our systems. However not all personal information can be removed from our systems. We are required by law and standards of medical practice to preserve medical records, some contact information, and disclosure records for specified time periods. Information archived on data backup media also cannot be deleted, however is protected by encryption. Aggregate Information and information in logs cannot be deleted. You can request that your sample and DNA extract be destroyed and/or your account deleted by contacting by either email or mail as identified in the Contact Us section.
- We may deny access when denial of access is authorized by law, when granting you access would have an unreasonable impact on other people's privacy, or to protect Pathway Genomics' rights and property.

HOW WE STORE AND PROTECT YOUR INFORMATION

Pathway Genomics has adopted administrative, physical and technical security measures to protect your personal information. However no method of transmission over the Internet or method of electronic storage is 100% secure. Therefore, while we use commercially reasonable and appropriate means to protect your personal information, we cannot guarantee its absolute security.

PRIVACY OF CHILDREN ONLINE

- If a child activates an account and completes any surveys, we shall send two emails, as identified by children during the activation process, to obtain verifiable consent to maintain collected information from children under the age of 13. If we are unable to obtain parental or guardian consent, we will erase such information from our records, except for information that may be archived on encrypted data back-up media.
- We will not knowingly market products or services to children under 18.

YOUR CALIFORNIA PRIVACY RIGHTS

California customers can request a list of personal information categories disclosed to third parties for their direct marketing purposes and the names and address of such third parties.

CHANGES OF THE PRIVACY STATEMENT

Material changes to this Privacy Statement that affect your rights will be emailed to you and will be posted on our website at least thirty (30) days before the effective date of the Privacy Statement.

CONTACT US / COMPLAINTS

If you have questions or comments regarding our privacy practices or have a complaint about our use or disclosure of your personal information or our privacy practices, you may contact us either by mail, email, or phone as follows:

privacy@pathway.com

(877) 505-7374

Chief Privacy Officer

Pathway Genomics Corporation
4045 Sorrento Valley Blvd.
San Diego, CA 92121

You may also file a complaint with the Secretary of the U.S. Department of Health and Human Services and/or the California Department of Public Health. Pathway Genomics will not take retaliatory action against you for filing a complaint about our privacy practices.

FULL INTERNET PRIVACY STATEMENT

Effective Date - December 21, 2009

THIS NOTICE DESCRIBES HOW MEDICAL INFORMATION ABOUT ME MAY BE USED AND DISCLOSED AND HOW I CAN GET ACCESS TO THIS INFORMATION. PLEASE REVIEW CAREFULLY.

A Note to Non-U.S. Users

You expressly consent to the processing of your personal information in the United States in accordance with this Full Privacy Statement. United States privacy laws and regulations may be less stringent than the laws in your country.

SCOPE

This Full Privacy Statement tells you how we collect, protect, use, and disclose the information you provide us and the choices you have regarding our use of, and your ability to correct, that information. By using our services, you acknowledge that you have reviewed and agree to the terms of the Full Privacy Statement and the Terms of service.

INFORMATION WE COLLECT **ACCOUNT INFORMATION**

We collect Account Information from you when you purchase a DNA collection kit, or activate a Pathway Genomics' account and submit a sample. Account Information includes:

- Name, email address, billing and shipping address
- Username and password
- Phone number or mobile number
- Date of birth, height, weight, and other personal information
- Payment information (such as a credit or debit card)
- Preference communication settings regarding your choices
- Parental or guardian approval, if applicable

Some of this information is editable in your Account's Personal Settings.

GENETIC INFORMATION Sample and DNA Extract

We analyze DNA in your sample to determine the presence of Single Nucleotide Polymorphisms (SNPs, pronounced Snips) at locations within your genome. This information, which is called your "genotype," is stored in our database. Our on-site laboratory personnel are privacy trained and your DNA is stored in our secure DNA Lockbox™.

Type of Genetic Test(s)

In our database, we identify the type of genetic test(s), such as health, ancestry, or combo package, that is ordered.

Genetic Testing-Based Health Information

You can access this information by using the user ID and password provided to you to activate your account.

- **Health Risk Information**
This is information about diseases or health related conditions that you have or may be at risk for based on your Genetic Information. Pathway Genomics uses published research, which meets Pathway Genomics' criteria, that links genetic information to the risk of having a disease in order to provide your Genetic Testing-Based Health Risk Information.
- **Carrier Information**
This is information about recessive disease genes that you may carry and could possibly pass to children based on your Genetic Information.
- **Pharmacogenetic Information**
This is information regarding how you might metabolize and respond to certain kinds of drugs based on your Genetic Information. This information can provide guidance to you and your physician when considering various medications and treatments.

Ancestry Information

This is genealogic and ethnic information based on your Genetic Information. Ancestry Information includes information about your ancient ancestors, your racial ancestry and your genetic similarity to various individuals, such as family members or famous people.

SURVEY-BASED INFORMATION

Pathway Genomics may request information from you via questionnaires or surveys.

- **Health Survey** participation is required as it provides information necessary to complete and present your results analysis or to screen your results for medically appropriate communications. Examples include, ethnicity, and sex.
- **Family History Survey** participation is not required, however is recommended to deliver more informed results. Family History Survey information is helpful for completing a family Health Tree, a feature in your Member Account, and to genetic counselors and medical professionals who may provide you advice. Examples include questions about diet, exercise, smoking, history of disease among family members, height/weight, and ethnicity, your personal traits and characteristics (for example, height or hair color) and your family history (for example, whether other family members have the same health condition).
- **Other Surveys** are completely voluntary and you therefore have a choice whether or not to disclose this information. Examples may include information about you and your family, such as gender or product use preferences and/or behaviors.

OTHER CUSTOMER PROVIDED INFORMATION

- **Friend's Name and Email** - When you provide us this information for Refer-a-Friend messages, we use it only to send the message you request.
- **Genetic Counseling and Customer Service Notes** - Physicians, genetic counselors and customer service representatives may make private notes of conversations with you. Genetic counseling notes become part of your medical record.

ONLINE PROFILE INFORMATION

Pathway Genomics also collects, stores and uses your computer IP address and non-personal information through cookies, log files, and clear gifs to create an online profile unlinked from your name and other Account Information. Your profile details your viewing preferences, activities and interactions with Pathway Genomics, for example, browser types and web page views.

Cookies A **browser cookie** is a piece of data tied to information about the user and stored on the user's computer. We may use session cookies, which terminate when a user closes his or her browser, and persistent cookies, which remain on the user's computer until manually deleted or expire based on a date set within the cookie. You can set your browser not to accept browser cookies. Remember though, without browser cookies, you may not be able to take full advantage of all our website features.

We may also use **flash cookies** on our website to enhance your online experience and present online ads from Trusted Partners or other third parties. Flash cookies are similar to browser cookies, except that they can store data more complex than simple text. Flash cookies, by themselves, cannot do anything to or with the data on your computer. In addition, flash cookies cannot access or remember your email address or other personal information unless you provide the information on this site. We use flash cookies to provide you with a better user experience. Currently you cannot delete flash cookies with your browser, however you can manage and disable flash cookies by clicking [here](#).

Logs

Like most standard website servers, we use log files. We may log internet and computer protocol (IP) addresses, type of web browser, internet service provider (ISP), referring/exit pages (links you click), type of operating system, date/time stamp, and pages visited. Information contained in a log, such as computer IP addresses, cannot be deleted when an individual requests Account deletion.

Clear GIFs We also use pixel tags, also called clear gifs, in HTML-based emails that show us when emails have been opened by the recipients and, in conjunction with our cookies, provide information to help us better manage content on our site and promotional emails. We work with online advertising agencies and networks to display retargeted ads to our site prospects, on our behalf, across the Internet. They collect your computer IP address and non-personal information about your visits to our website, and your interaction with our products and services. This information is collected through the use of a pixel tag, which is industry standard technology used by most major websites. These services are a benefit to you, and create a customized experience for you while you surf the Web. There may be a link in a retargeted display ad to the advertiser's privacy policy which you should read. If you do not want the advertiser to collect this information, you may opt out of their service. Opting out will not in any way affect your use of our site. You can also set your email program to only receive text-based emails which do not include clear GIFs.

AGGREGATE INFORMATION

Aggregate information is summarized information unlinked from your name and Account Information. Certain business functions can be performed using such limited data sets. This security control reduces the risk of unauthorized access.

HOW WE USE YOUR INFORMATION

Providing Our Services

When you activate your account and submit a sample to Pathway Genomics, we collect and store Account Information that is used to administer the Pathway Genomics' services provided to you. We use your Account Information to provide our genetic testing services, including processing your purchase, tracking your submission, allowing you to access the results, and authenticating your use of

our services. Pathway Genomics will make available to you information based on your Genetic Information, Survey-Based Information, and Other Customer Provided Information.

Pathway Genomics' privacy-trained customer service personnel will have access to your Account Information and customer service notes and records to assist you, but not to your Genetic Information, Survey-Based Information, or genetic counseling notes or records. In addition, Pathway Genomics' privacy-trained genetic counselors and physicians may have access to your Account Information, Genetic Information, Survey-Based Information, and Other Customer Provided Information, to provide you counseling and guidance. Pathway Genomics screens the results of the genetic testing and then provides an appropriate medically approved method of informing our customers about sensitive test results, which may include contact by a genetic counselor or physician. Information about our counseling session with you will not be shared with any third parties unless you grant us express authorization to do so.

As part of delivering our services to you, Pathway Genomics' purchasers and account-activated users will occasionally receive transactional email updates and alerts containing information related to their testing results or information about your purchase. You do not have the choice to opt-out of transactional communications, which are essential to delivering our services to you, unless a marketing message or advertisement is included.

Third Party Service Providers

Pathway Genomics uses third parties, companies and individuals, to perform functions on our behalf. Examples include fulfilling orders, delivering packages, sending postal mail and email, removing repetitive information from customer lists, analyzing data, providing marketing assistance, providing search results and links (including paid listings and links), processing card payments, systems development and managed technology services, and providing customer service. These third parties may have access to and use Account Information and Survey-Based Information to needed to perform their functions our behalf. However they may not retain, share, store or use it for any other purposes and must maintain strict confidentiality of this information. They will have no access to Genetic Information, other than Type of Genetic Test. All such third party service providers agree to responsibly use your personal information in an authorized manner and to comply with all legal requirements.

Improving Our Services

Pathway Genomics analyzes and uses Aggregate Information (unlinked to your name or Account Information), and Online Profile Information (computer IP address and non-personal information) to improve the quality and features of our website and services. This information allows us to administer our website, track website usage (in the aggregate), analyze trends about use of the website and referral websites. You cannot opt-out, however you can delete cookies as described in Cookies, under the Online Profile Information section of Information We Collect.

Pathway Genomics and Trusted Partners Email Marketing - Managed by Pathway Genomics

Privacy-trained Pathway Genomics personnel may also use Account Information, Genetic Information, and Survey-Based Information to understand individual browsing and purchase trends and deliver the right offers, products and services from Pathway Genomics and Trusted Partners to you. We believe it is more customer-friendly to personalize our services and offers to you based on your interests and geographic location than to send general information which may have no relevance. The arrangements with non-profit or commercial Trusted Partners may involve a referral fee received by us for the provision of services or products to our users. In this case, Pathway Genomics maintains control of your personal information. We explain how you may opt-out in the How To Exercise Your

Choices section. You can also delete cookies as described in Cookies, under the Online Profile Information section of Information We Collect.

Refer-A-Friend

If you elect to use our referral service to inform a friend about our website and services, we will ask you for the friend's name and email address. Pathway Genomics will automatically send a one-time email to your friend inviting them to visit our website. Pathway Genomics stores this information for a period of six months for the sole purpose of sending this one time email and tracking the success of our referral program. We will not share this information with any partners for marketing purposes. Your friend may contact Pathway Genomics at privacy@pathway.com or the address in the Contact Us section at the end of the Full Privacy Statement to request the removal of this information from our database.

Misuse of our refer-a-friend service by providing false email addresses or posing as someone else when sending an email may result in legal action and the disclosure of information about you, including your computer's IP address, as part of any investigation into your actions.

HOW WE SHARE YOUR INFORMATION

Employers and Health Insurance Issuers

Pathway Genomics will NOT share your genetic information with your employer or health insurance issuer unless you expressly authorize us to do so. The Genetic Information Nondiscrimination Act (GINA) prohibits employers from discriminating against employees based on their own or their family members' genetic information, effective November 21, 2009. GINA also prohibits group health plans and health insurance issuers offering health insurance coverage in connection with such a plan from discriminating against individuals based on genetic information, effective May 21, 2009. There is an exception for certain wellness programs (See Employer Wellness Programs later in this section).

Resellers

Any reseller offering our products or services may provide you a DNA collection kit with an activation number or a discount coupon. The reseller will not collect any personal information from you. You will directly provide us all the necessary personal information. Physicians cannot be resellers.

Research Collaborators

Pathway Genomics believes in furthering responsible scientific and medical research to improve our understanding of genetics and to assist physicians and other health care professionals to provide better health care. Collaborations between Pathway Genomics and non-profit or commercial research organizations will be guided by a research advisory committee established by Pathway Genomics. Any research collaborator will first need to obtain permission from an appropriate Institutional Review Board.

Pathway Genomics may share your Genetic Information and Survey-Based Information that is unlinked from your name and Account Information for purposes of conducting scientific and medical research and development authorized by Pathway Genomics. We require any such research collaborator that receives this information to agree not to attempt to re-identify and/or contact the individuals it belongs to.

We also may pass on to you a research collaborator's request that you volunteer additional information or participate in a study. No name or Account Information is shared with a research

collaborator without your express consent and the research collaborator agreeing to comply with all appropriate privacy and information security laws and regulations to protect such personal information.

Advertisers

Pathway Genomics may use Aggregate Information (unlinked to your name or Account Information) to deliver customized advertising to you. You cannot opt-out, however can delete cookies as described in Cookies, under the Online Profile Information section of Information We Collect.

This Privacy Statement applies solely to information collected by Pathway Genomics' website. This website may contain links from and to other websites that are not owned or controlled by Pathway Genomics. Please be aware that Pathway Genomics is not responsible for the privacy practices of other such websites. We encourage you to be aware when you leave our website and to read the privacy policies of each and every website that collects personal information.

Approved Trusted Partner's Qualification Requirements

Our Approved Trusted Partners have either: a) an independent audit certifying privacy and information security compliance; or b) attested to being compliant to Pathway's information security due diligence questionnaire and agreed to only authorized use of any personal information. We believe this provides practical assurance that our Approved Trusted Partners will exercise reasonable and appropriate protection of your personal information.

Approved Trusted Partner for Ancestry Information Sharing

Your express consent is required before Account Information, Ancestry Information, Survey-Based Information, and Online Profile Information, is disclosed to our Approved Trusted Partners for Ancestry Information Sharing. No other Genetic Information will be disclosed, other than Ancestry Information. Pathway Genomics may receive information from the Approved Trusted Partner concerning the service requested by you, including contact and other personal information that you may have inputted on its website, with your express consent.

Employer Wellness and Incentive Programs

If you are a customer participating in your employer wellness and/or incentive program, Pathway Genomics only provides your employer aggregate information unlinked to your name. This information allows your employer to evaluate the effectiveness of its employee wellness and incentive programs for reducing employee healthcare expenses.

Legal Obligations

Pathway Genomics may disclose or report your personal information when we believe in good faith that the disclosure is required or permitted by law or regulation, a court order or other judicial or legal process or proceeding, or to cooperate with regulators or law enforcement authorities to resolve consumer disputes.

Purchase or Sale of Business

If Pathway Genomics enters into a business transaction, such as a merger, acquisition by another company, or bankruptcy, your personal information will, in most instances, be part of the assets transferred. Pathway Genomics will require the acquiring company to comply with the material provisions of this Privacy Statement, as amended from time to time.

YOUR CHOICES

Information Use or Sharing	Does Pathway share Personal Information?	Your choices to limit sharing
Providing Our Services	No	N/A
<ul style="list-style-type: none"> to process transactions and maintain accounts 	Yes	N/A
<ul style="list-style-type: none"> utilizing third party service providers 	Yes	Cookie Deletion
<ul style="list-style-type: none"> improving and individualizing our services 	Yes	Cookie Deletion
Pathway Email Marketing		
<ul style="list-style-type: none"> to offer our products and services to you 	No	Opt-out
Trusted Partner Email Marketing Managed by Pathway		
<ul style="list-style-type: none"> to offer their products and services 	No	Opt-out
Refer-A-Friend		
<ul style="list-style-type: none"> to send one time email to friend 	No	Friend May Opt-out
Employer / Health Insurer		
<ul style="list-style-type: none"> no disclosure provided unless authorized by you 	No	N/A
Research Collaborators		
<ul style="list-style-type: none"> without name and Account Information 	Limited	None
<ul style="list-style-type: none"> with name or other Account Information 	Yes	Opt-in
Resellers		
<ul style="list-style-type: none"> No personal information collected 	No	N/A
Advertisers		
<ul style="list-style-type: none"> only aggregate information shared 	No	None
Approved Trusted Partner Ancestry Information Sharing		
<ul style="list-style-type: none"> to display your haplogroup and related information and genetic share ethnicity 	Yes	Opt-in
Employer Wellness Programs		
	Aggregate Information	None

- health plans participation earn discounts / incentives for preventive health care

Legal obligations

- to respond to court orders and legal investigations Yes N/A

Purchase or sale of business Yes None

HOW TO EXERCISE YOUR CHOICES

- **Opt-outs** - To the extent you are permitted, you may exercise your right to opt-out by either a) clicking the unsubscribe link in the footer of any Pathway Genomics' email or replying with unsubscribe in the subject line, or b) writing to us at the address in the Contact Us section at the end of this Privacy Statement.
- **Opt-ins** - You may exercise your right to opt-in when expressly presented with this choice prior to the indicated personal information being shared.

ACCESSING YOUR INFORMATION

Information Sharing Authorized by You

The Pathway Genomics website allows you to share your personal information with other individuals, including family members, friends, physicians and other health care providers. It is your decision whether to allow these individuals to have access to your personal information. Pathway Genomics recommends that you carefully consider whether to grant these individuals access to your personal information, which individuals you will allow access, and what information you will make available to these individuals.

Pathway Genomics will not be responsible for any liability caused by you sharing your personal information with these individuals or other third parties, such as an employer or insurance company.

Accounting of Disclosures

You have the right to request an accounting of all disclosures, other than for treatment, payment, or healthcare operations. You can make this request using the contact information at the Contact Us section of this Privacy Statement.

Updating or Deleting Information

Pathway Genomics provides a means for you to access, correct, update or delete/deactivate your personal information. If your Account Information changes (such as email address, street address, or phone number), you can log into your account and change the appropriate information.

If you no longer desire to use our service, at your request which must be in writing and according to your instructions, we can destroy your remaining sample and DNA obtained from it, and delete your Account from our systems. However not all personal information can be removed from our systems. We are required by law and standards of medical practice to preserve medical records, some contact information, and disclosure records for specified time periods. Information archived on data backup media also cannot be deleted, however is protected by encryption.

You can request that your sample and DNA extract be destroyed and/or your account deleted by contacting our Chief Privacy Officer at privacy@pathway.com or Pathway Genomics Corporation, 4045 Sorrento Valley Blvd., San Diego, CA 92121.

Denial of Access to Personal Information

Your rights to access your personal information are not absolute. We may deny access when denial of access is authorized by law, when granting you access would have an unreasonable impact on other people's privacy, or to protect Pathway Genomics' rights and property.

HOW WE STORE AND PROTECT YOUR INFORMATION

Protecting Your Personal Information

You should not disclose your password or other information used to authenticate your identity to any family member, friend or other individual. You should immediately notify Pathway Genomics if any third party has access to your password or you learn of any unauthorized access to your information.

Despite the reasonable and appropriate efforts of you and Pathway Genomics, there is always some risk that an unauthorized third party will access without permission our systems or intercept transmissions of your information.

Security

The security of your information is important to us. Pathway Genomics follows generally accepted industry standards to safeguard the privacy of and protect the information that we collect, use and store. However no method of transmission over the Internet or method of electronic storage is 100% secure. Therefore, while we use commercially reasonable and appropriate means to protect your personal information, we cannot guarantee its absolute security.

Pathway Genomics has adopted administrative, physical and technical security measures to protect your personal information. We control facility and laboratory access through a card reader access system. We store your DNA in our secure DNA Lockbox™ located on-site to enable us to retest if scientific and medical advances provide a basis for retesting it.

Your password is stored in an encrypted manner. We use Secure Socket Layer ("SSL") to encrypt our website pages that collect personal information from you. (We recommend that you use a 256-bit SSL capable browser, such as Microsoft's Internet Explorer 7.0 or higher or Mozilla's Firefox 3.0 or higher, to enable this technology. Notice that the address bar starts with https: which indicates your connection is taking place via a secure server.)

We limit systems access to personal information only to personnel who reasonably have a need to know this information to provide our services. We maintain records of personnel logon access to databases and monitor and periodically review access to personal information. We use firewalls to protect our networks.

PRIVACY OF CHILDREN ONLINE

In accordance with the Children's Online Privacy Protection Act ("COPPA"), if a child activates an account and completes any surveys, we shall attempt to contact the child's parent or guardian, identified during the activation process, to obtain verifiable consent to maintain collected information from children under the age of 13. If we are unable to obtain parental or guardian consent, we will erase such information from our records, except for information that may be archived on encrypted data back-up media.

We will not knowingly market products or services to children under 18.

YOUR CALIFORNIA PRIVACY RIGHTS

Under California law, in certain circumstances California customers are entitled to request a list of personal information categories disclosed to third parties for their direct marketing purposes and the names and addresses of such third parties during the prior year. This request must be responded to within 30 days if made to the addresses below. As stated in this Privacy Statement, Pathway Genomics will not share your Personal Information with non-Pathway Genomic companies for their direct marketing purposes without your express consent. California customers who wish to request the list indicated above, further information about our compliance with this law, or have questions or concerns about our privacy practices and policies may contact us at the email or physical address in the Contact Us section below.

CHANGES OF THE PRIVACY STATEMENT

We reserve the right to change this Privacy Statement at any time. Material changes to this Privacy Statement that affect your rights will be emailed to you and will be posted on our website at least thirty (30) days before the effective date. Please check this Privacy Statement periodically for changes. At the top of this Privacy Statement we indicate the date it was previously updated. The continued use of any Pathway Genomics services following the effective date of posted changes to this Privacy Statement will mean that you accept those changes.

CONTACT US / COMPLAINTS

If you have questions or comments regarding our privacy practices or have a complaint about our use or disclosure of your personal information or our privacy practices, you may contact us either by mail, email, or phone as follows:

privacy@pathway.com
(877) 505-7374
Chief Privacy Officer
Pathway Genomics Corporation
4045 Sorrento Valley Blvd.
San Diego, CA 92121

You may also file a complaint with the Secretary of the U.S. Department of Health and Human Services and/or the California Department of Public Health. Pathway Genomics will not take retaliatory action against you for filing a complaint about our privacy practices.

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The Genetic Testing Laboratories

www.gtldna.com

How We Protect Your Privacy and Security

GTL [Genetic Testing Laboratories] is dedicated to your privacy and security. We know that you care how information about you is used and shared, and we appreciate your trust that we will do so carefully and sensibly. This notice describes our privacy policy. By visiting www.gtldna.com, you are accepting the practices described in this Privacy Notice.

To learn more about our privacy practices, see our Privacy Policy Details. GTL believes in protecting your privacy. When we collect personal information from you on our website, we follow the privacy principles of A2LA [American Association for Laboratory Accreditation], AABB [American Association of Blood Banks], ISO [International Organization for Standardization], NATA [National Association of Testing Authorities], and the BBB [Better Business Bureau] and comply with the U.S.-EU Safe Harbor Framework as set forth by the U.S. Department of Commerce regarding the collection, use and retention of personal data from the European Union. These are our promises to you:

1. Notice. When we collect your personal information, we'll give you timely and appropriate notice describing what personal information we're collecting, how we'll use it, and the types of third parties with whom we may share it.
2. Choice. We'll give you choices about the ways we use and share your personal information, and we'll respect the choices you make.
3. Relevance. We'll collect only as much personal information as we need for specific, identified purposes, and we won't use it for other purposes without obtaining your consent.
4. Retention. We'll keep your personal information only as long as we need it for the purposes for which we collected it, or as permitted by law.
5. Accuracy. We'll take appropriate steps to make sure the personal information in our records is accurate.
6. Access. We'll provide ways for you to access your personal information, as required by law, so you can correct inaccuracies.
7. Security. We'll take appropriate physical, technical, and organizational measures to protect your personal information from loss, misuse, unauthorized access or disclosure, alteration, and destruction.

You may also view the BBB EU/US Safe Harbor Dispute Resolution Participants.

Information We Gather

GTL is dedicated to your privacy and security and will not share your information with others except at your request. GTL does not sell information to others under any circumstances.

What personal information does GTL gather?

We collect only the information you provide to us, and we use the information you enter on our Web site, provide by telephone, or include by email strictly to provide you with the services you request in the manner in which you request them.

When is this information ever provided to others?

Delivery of Services: Legally Binding DNA tests and Immigration tests, for example, involve a release of your information within the guidelines you establish: we provide the results of DNA tests to third parties only at your request, and strictly within the parameters necessary for legal compliance.

Protection of GTL and Others: We release account and other personal information when we believe release is appropriate to comply with law; enforce or apply our Terms of Use and other agreements; or protect the rights, property, or safety of GTL, our users, or others. This includes exchanging information with other companies and organizations for fraud protection and credit risk reduction.

Our safe shopping guarantee

Our promise to you: we use the most advanced technology available to protect you and your transactions.

How Secure Is Information About Me?

We work to protect the security of your information during transmission by using 128-bit Secure Sockets Layer (SSL) encryption software, which encrypts information you input.

We reveal only the last four digits of your credit card numbers when confirming an order. Of course, we securely transmit the entire credit card number to the appropriate credit card company during order processing.

It is important for you to protect against unauthorized access to your password and to your computer. Be sure to sign off when finished using a shared computer.

Our Safe Shopping Guarantee

1. **Safety.** The GTL Safe Shopping Guarantee protects you while you investigate DNA tests at GTL, so that you never have to worry about credit card safety.

We guarantee that every transaction you make at GTL will be 100 percent safe. This means you pay nothing if unauthorized charges are made to your card as a result of shopping at GTL.

2. **Security.** We protect the security of your information during transmission by using 128-bit encrypted Secure Sockets Layer (SSL) software, the highest level of protection available for all your Internet communications, including credit card use and financial transactions, and which encrypts information you input.
3. **Discretion.** We reveal only the last four digits of your credit card numbers when confirming an order. Of course, we transmit the entire credit card number to the appropriate credit card company during order processing.
4. **Prudence.** It is important for you to protect against unauthorized access to your password and to your computer. Be sure to sign off when finished using a shared computer.