

# Gene by Gene Privacy Policy

Your privacy is important to us. This privacy statement explains what personal data we collect from you and how we use it. We encourage you to read the summaries below.

This statement applies to all Gene by Gene products. References to Gene by Gene products in this statement include Gene by Gene tests, features or services offered by, and websites maintained under any of our subsidiaries.

Gene by Gene, Ltd., performs DNA testing for genealogy, ancestry, medical, research and paternity through our subsidiaries, including Family Tree DNA, DNA Findings, DNA Traits, DNADTC, and Gene by Gene.

Gene by Gene owns and runs its own lab, the Genomics Research Center in Houston, Texas.

In addition, Gene by Gene owns and operates the websites GenebyGene.com, DNATraits.com, FamilyTreeDNA.com, DNAFindings.com and DNADTC.com ("Gene by Gene websites").

**For the purposes of this policy, "Gene by Gene" ("we", "us", "our" "the Company") refers and applies to all subsidiaries and websites in the Gene by Gene corporate family, unless specifically stated otherwise.**

**PLEASE READ THIS AGREEMENT CAREFULLY TO ENSURE THAT YOU UNDERSTAND EACH PROVISION. THIS AGREEMENT CONTAINS A MANDATORY ARBITRATION OF DISPUTES PROVISION THAT REQUIRES THE USE OF ARBITRATION ON AN INDIVIDUAL BASIS RATHER THAN JURY TRIALS OR CLASS ACTIONS, TO RESOLVE DISPUTES. IT ALSO LIMITS THE REMEDIES AVAILABLE TO YOU IN THE EVENT OF A DISPUTE.**

**In addition to the PRIVACY POLICY below, Family Tree DNA also adheres to the Genetic Genealogy Guidelines as proposed by the Genetic Genealogy Standards Committee in January 2015.**

**Please note that the Family Tree DNA Website Terms of Service and Usage and the Family Tree DNA Refund Policy are listed separately from this document. Please see those respective pages for those details.**

## Gene by Gene and the EU-U.S. and Swiss-U.S. Privacy Shield

Gene by Gene complies with the EU-U.S. and Swiss-U.S. Privacy Shield Frameworks as set forth by the U.S. Department of Commerce regarding the collection, use, and retention of personal information transferred from the European Union and Switzerland to the United States. Gene by Gene has certified that it adheres to the Privacy Shield Principles of Notice, Choice, Accountability for Onward Transfer, Security, Data Integrity and Purpose Limitation, Access, and Recourse, Enforcement and Liability. If there is any conflict between the policies in this privacy policy and the Privacy Shield Principles, the Privacy Shield Principles shall govern. To learn more about the Privacy Shield program, and to view our certification page, please visit <https://www.privacyshield.gov/>

In compliance with the EU-US and Swiss-US Privacy Shield Principles, Gene by Gene commits to resolve complaints about your privacy and our collection or use of your personal information. European Union or Swiss individuals with inquiries or complaints regarding this privacy policy should first contact Gene by Gene at: [ombudsman@genebygene.com](mailto:ombudsman@genebygene.com).

Gene by Gene has further committed to refer unresolved privacy complaints under the EU-US and Swiss-U.S. Privacy Shield Principles to an independent dispute resolution mechanism, the BBB EU PRIVACY SHIELD, a non-profit alternative dispute resolution provider located in the United States and operated by the Council of Better Business Bureaus. If you do not receive timely acknowledgment of your complaint, or if your complaint is not satisfactorily addressed, please visit [www.bbb.org/EU-privacy-shield/for-eu-consumers/](http://www.bbb.org/EU-privacy-shield/for-eu-consumers/) for more information and to file a complaint.

Please note that if your complaint is not resolved through these channels, under limited circumstances, a binding arbitration option may be available before a Privacy Shield Panel.

## Contact Us

For all questions or comments on our privacy practices, or in the event of a complaint, please contact: [ombudsman@genebygene.com](mailto:ombudsman@genebygene.com).

## Purposes of this Document

This document (Gene by Gene Privacy Policy) is intended to explain how Gene by Gene manages the privacy of your personal data and other information that can be used to identify you, either alone or in combination with other information, including your DNA samples and test results (collectively, "Personal Information").

We use your Personal Information to provide you with Gene by Gene services, customized reports and features. Customers who use certain services provided by Gene by Gene are offered an opportunity to sign a Consent Form, also referred to as a Release, specific to each subsidiary which allows them to take full advantage of those services.

In the absence of a specific Consent Form, this Privacy Document will prevail.

By using the Gene by Gene websites and the services offered, you consent to the collection, use, storage and disclosure of your Personal Information by Gene by Gene in accordance with this Privacy Document. It should be read in conjunction with the Gene by Gene Terms of Use and Gene by Gene Consent Agreement.

## Our Commitment to You

Gene by Gene collects, processes, stores and shares your Personal Information in a responsible, transparent and secure environment that fosters our customers' trust and confidence. To that end, Gene by Gene respects your privacy and will not sell or rent your Personal Information without your consent. Personal Information includes, but is not limited to names, phone numbers, physical or mailing addresses, email addresses, and genetic test results.

## How We Use Personal Information

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Gene by Gene collects data to operate effectively and provide you the best experiences with our products. You provide some of this data directly, such as when you create a Gene by Gene record. Additional data is provided when we deliver your test results or other Gene by Gene products.

Gene by Gene uses the data we collect to provide you the services we offer, including improving and personalizing your experiences. We may also use the data to communicate with you about your test progress, your account, and to provide product information including occasional marketing offers. You may opt out of receiving marketing communication at any time.

## **Storage and Processing**

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When you provide us with any Personal Information, that Personal Information will be stored and processed at the Company's headquarters adjacent to the Genomics Research Center in Houston, Texas. If you are located outside the USA and still choose to order a DNA Test kit and provide a DNA sample, by providing us with Personal Information, you specifically consent to the transfer, storage and processing of Personal Information to and in the United States, which you recognize may provide a different level of protection for Personal Information and personal data than in your country of residence.

## **Security**

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Gene by Gene places great importance on the security of all our customers' User Submitted Content. We have reasonable and adequate security measures in place to attempt to protect against the loss, misuse, or alteration of customer data under our control.

For example, our security and privacy practices are periodically reviewed and enhanced as necessary and only authorized personnel have access to Personal Information. We use secure server software to encrypt financial information you input before it is sent to us and we only work with third parties who have met and commit to our security standard. While we cannot guarantee that loss, misuse or alteration of data will not occur, we use commercially reasonable efforts to prevent this.

## **Use and Disclosure of Personal Information**

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When you order an individual test online, we primarily use your Personal Information to provide your test results, to verify and carry out financial transactions relating to payments you make online, and to communicate with you.

Gene by Gene discloses your Personal Information to third parties in very limited circumstances as set out below.

To third party service providers, under the protection of appropriate agreements, so that the third parties may perform various tasks for us. For example, we use third parties to process payments from you. These third parties are only given access to that information needed to perform their services, and are prohibited from using it for other purposes. Processors may include affiliated and unaffiliated service providers in the United States, Europe and in other jurisdictions. If Gene by Gene wishes to transfer personal information to a third party that is acting as an agent, we will do so only if we enter into a written agreement with such third party requiring that the third party provide at least the same level of privacy protection as is set forth in this policy.

To the different Gene by Gene divisions, so that they may use Personal Information for the purposes described in this Privacy Document. Additionally, we might restructure, buy, or sell business units. In these transactions, customer information is often one of the transferred assets, remaining subject to promises made in then prevailing Privacy Documents. Also, in the event that Gene by Gene, or substantially all of its assets or stock, are acquired, transferred, disposed of (in whole or part and including in connection with any bankruptcy or similar proceedings), Personal Information including test results will as a matter of course be one of the transferred assets.

We may disclose your Personal Information

with your knowledge and any relevant permissions

as described in this Privacy Document

as may be required by law, regulatory authorities, legal process or to protect the rights or property of Gene by Gene or other Users (including outside your country of residence)

to enforce our terms and conditions

to protect our rights, privacy, safety, confidentiality, reputation or property, and/or that of Gene by Gene, you or others

to prevent fraud or cybercrime

to permit us to pursue available remedies or limit the damages that we may sustain

**We also may be required to disclose an individual's personal information in response to a lawful request by public authorities, including to meet national security or law enforcement requirements.**

Gene by Gene's accountability for personal data that it receives under the Privacy Shield and subsequently transfers to a third party is described in the Privacy Shield Principles. In particular, Gene by Gene remains responsible and liable under the Privacy Shield Principles if third-party agents that it engages to process the personal data on its behalf do so in a manner inconsistent with the Principles, unless Gene by Gene proves that it is not responsible for the event giving rise to the damage.

## **Non-Personal Information**

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When you visit our Gene by Gene websites, we may automatically collect non-personal information about you, such as the website from which you have come to our Gene by Gene websites, your Media Access Control address, your computer type, screen resolution, Operating System version and Internet browser. We may also collect non-personal information such as demographic data, for example your geographic area. Non-personal information also includes personal information that has been aggregated in a manner such that the end-product does not personally identify you or any other user of the Gene by Gene websites.

## **Additional Consent**

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Your use of any of Gene by Gene's services constitutes your consent to allow Gene by Gene to use your Personal Information for purposes of quality control and internal research and development activities.

Additionally, your consent will be sought for research purposes. Much of the genetic information resulting from DNA testing has not been clinically validated, and the technology we use, which is the same technology used by the research community, to date has not been widely used for clinical testing. For these reasons, our customers are encouraged to participate in Gene by Gene's research initiatives that may contribute to a better understanding of the results of genetic testing. **Your participation in these initiatives is entirely voluntary and your DNA test results will not be used or disclosed without your consent. Once given, however, consent cannot be revoked.**

We will ask for your consent in several ways. For example:

A general consent document will be offered to you as part of your decision to participate in any of the Gene by Gene services offered by any of the websites owned and operated by Gene by Gene. Your consent will allow Gene by Gene to share your test results, anonymized and aggregated with those of others who have consented, with our third-party research partners for the purposes of general scientific research intended to lead to publication in peer-reviewed scientific journals.

From time to time, we may ask for explicit consent to participate in specific research, and upon this consent we may allow our research partners to access your individual test results, which will be kept anonymous, for the purposes of general scientific research intended to lead to publication in a peer-reviewed scientific journal.

From time to time, we may ask for explicit consent to participate in specific research, and upon this consent we may allow our research partners to access your individual test results, which will be kept anonymous, for the purposes of scientific research aimed at advancing genetic knowledge and creating, commercializing, or undertaking activities toward the practical applications that may lead to the improvement of health care.

From time to time, we may ask for explicit consent to allow our research partners to access your non-anonymized individual test results in connection with a specific research project.

Research partners may include commercial or non-profit organizations that conduct or support population genetic studies, scientific/medical research, or the development of drugs or devices to diagnose, predict, or treat health conditions.

### **Gene by Gene account**

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With a Gene by Gene account you can sign into the specific Gene by Gene service you purchased. Signing into your account can enable improved personalization, and allows you to access your results. When you sign into your account to access a product, we create a record of that sign-in.

Having an account with any of the subsidiaries does not automatically create an account in other subsidiaries. Each business unit maintains separate databases and customer interfaces. For example, ordering a genealogical test from Family Tree DNA does not give you an account with Gene by Gene for medical testing.

### **How to Access & Control Your Personal Data**

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You can view or edit your personal data, with the exception of test results, online by logging into your personal page with the kit number and password that you have been provided. Family Tree DNA also provides privacy and security settings that allow you to control the visibility of your personal data to your matches and in any group project you have joined. Please read the [Settings – Privacy & Sharing Page](#) in our Learning Center for more information regarding your privacy settings and permissions.

Gene by Gene acknowledges that individuals have the right to access the personal information that we maintain about them. An individual who seeks access, or who seeks to correct, amend, or delete inaccurate data, should direct his query to **ombudsman@genebygene.com**. If requested to remove data, we will respond within a reasonable timeframe.

We will provide individuals with an opt-out choice before we share their data with third parties other than our agents, or before we use it for a purpose other than which it was originally collected or subsequently authorized. To limit the use and disclosure of your personal information, you may submit a written request to [ombudsman@genebygene.com](mailto:ombudsman@genebygene.com).

## Changes

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Gene by Gene may make changes to this Privacy Document from time to time. If we do so, we will publish the updated version of this Privacy Document on the Gene by Gene Website (and/or notify you via email or by other appropriate means), with the date on which it changed, so that you will be aware of what information we collect, how we use it and under what circumstances we disclose it in accordance with applicable law. If you do not consent to any changes to our Privacy Document, you may notify us [ombudsman@genebygene.com](mailto:ombudsman@genebygene.com). At Gene by Gene's discretion and on a case-by-case basis, we will either continue to apply the previous Privacy Document or delete your information and/or account.

## Enforcement

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Gene by Gene is subject to the investigatory and enforcement powers of the Federal Trade Commission (FTC).

## Privacy and Confidentiality Specific to Family Tree DNA

If you signed the release form, whether physically or electronically, we use your genetic data for matching purposes and we share your email address with relevant matches. We do not share phone numbers, physical or mailing addresses, though we may contact you on behalf of a match if your email address appears to be invalid.

A "Relevant Match" as stated in the Family Tree DNA [release form](#) is one of the following:

### RELEVANT MATCHES

Test	Genetic Distance of Relevant Matches
Y-DNA 12	<a href="#">Exact Matches and (within a project) a genetic distance of 1</a>
Y-DNA 25	Genetic distances of <a href="#">0 through 2</a>
Y-DNA 37	Genetic distances of <a href="#">0 through 4</a>
Y-DNA 67	Genetic distances of <a href="#">0 through 7</a>
Y-DNA 111	Genetic distances of <a href="#">0 through 10</a>
mtDNAPlus (HVR1 & HVR2)	<a href="#">Exact Matches excluding positions 309 and 315</a>
mtFull Sequence (HVR1, HVR2 & Coding Region)	<a href="#">0 through 3, including heteroplasmy, but excluding positions 309 and 315</a>
Family Finder	<a href="#">Persons sharing a certain amount of centimorgans, and listed under Family Finder matches</a>

\*\* Note: When a Y-Chromosome STR marker comparison differs by more than one, the matching program takes genetic distance rather than the number of mismatching markers into consideration. This is because for most STR markers, each step difference is as meaningful as mismatches on additional markers.

## Your Commitment to Privacy

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You agree that your Password is not to be disclosed publicly alongside your Kit Number, as this disclosure may lead to others having access to names and emails of your matches, thus violating the privacy of other customers. If Family Tree DNA becomes aware that a customer's kit number and password has been disclosed in any way to the public, it reserves the right of changing the password. Kit numbers may be used as identifiers on the pages of group projects, so long as the person's password is not displayed.

## 3rd Party Payments and Account Access

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If a person consents to testing that is paid for by another party, that person is consenting to allow the other party, whether an individual or a group project, access to their results and information, even if they order and pay for additional testing later. The purchaser of a test cannot deny access to the account and raw results of the test taker. The test taker cannot deny access to the purchaser of the test without reimbursement of the purchase price.

Should the test taker no longer want to allow the purchasing individual or group to have access their account, the test taker may reimburse the purchasing individual or group the full amount of the purchase price to return sole access to that account to the test taker only. Once the test taker has provided documentation to Family Tree DNA that they have provided a full reimbursement of the purchase to the original payor, we will be able to return access to test taker alone. **Please note that although a test taker may reclaim ownership of the record and DNA stored with Family Tree DNA, they cannot undo or retrieve any prior data downloads or sharing outside of Family Tree DNA.**

## Beneficiary Information

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The owner of an account is responsible for naming a beneficiary to that account, should the test taker pass away. If no beneficiary is named on the account, Family Tree DNA retains ownership of the record and DNA. If a family member or heir presents documentation of relationship to the deceased test taker, Family Tree DNA may, at its discretion, allow the family member or heir access to the account.

## Project Participation

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Family Tree DNA provides the option to participate in one or more projects. This participation may help you learn more by working with others who may share similar ancestry. If you choose to participate in a project, the Project Administrator will be able to view your results and contact information so that he or she may best help members of the project learn about their ancestry.

[You can view a list of projects here.](#)

While FTDNA has strict Project Administrator guidelines that requires administrators to abide by our [Group Administrator Guidelines for FTDNA Projects](#), Family Tree DNA is not responsible for anything that the individual administrator does that is against those guidelines, other than admonishing or removing a group administrator from his or her role, if he or she is found to have breached or infringed on those guidelines. **Family Tree DNA may modify the Group Administrator Guidelines at any time and such modification shall be effective upon posting on the Family Tree DNA Website and a reasonable attempt to notify Group Administrators of changes.**

Group Projects often have a public website displaying member results so that members can share information more easily. Most groups will also have a member list that is available to members of the project. The list may include name, email address, and haplogroups. You may opt out of this list through the Privacy Settings on your account.

The free website that Family Tree DNA provides to projects may list member results by kit number. Results tables and maps on the free public website may include a participant's oldest known ancestor, the ancestor's country of origin, surname, and full name. Note that any changes you make to your permissions or privacy settings can experience a delay when updating on such public pages. Projects may have a webpage hosted on a different website, either in addition to or in place of the free website Family Tree DNA provides. Those pages should conform to the same privacy assurances as the ones on the Family Tree DNA website. You may wish to discuss with a project administrator what information will be available on the project's website before joining a project.

You may join or leave projects at any time at no charge. Please note that any information or data downloaded by a Project Administrator for analysis cannot be retrieved and the Project Administrator may still have access to your downloaded results even after you have left a project.

It is important to note that while Family Tree DNA does not impose a limit to the number of projects one can join, we will not tolerate customers joining multiple projects with the purpose of data mining or finding information that is not relevant to one's personal ancestral origins. Family Tree DNA reserves the right to remove people from projects at our sole discretion or if it feels that a participant is abusing the system in a way that may infringe another participant's privacy.

The mtDNA (mitochondrial) full sequence test contains some genes in the Coding Region (CR). By default, these results are unavailable to the project administrators. You may choose to allow your Project Administrators to view your coding region results on the My Account – Results Display Settings page of your myFTDNA Account (personal page).

## **Arbitration of Disputes and Governing Law**

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**Arbitration:** In the unlikely event that Gene by Gene has not been able to resolve a dispute after attempting to do so informally, we each agree to resolve any claim, dispute, or controversy (excluding any Gene by Gene claims for injunctive or other equitable relief) arising out of or in connection with or relating to this Agreement, or the breach or alleged breach thereof (collectively, "Claims"), by binding arbitration by the American Arbitration Association ("AAA") in the city of Houston, Texas under the commercial rules then in effect for the AAA, except as provided herein. The award rendered by the arbitrator shall include costs of arbitration, reasonable attorneys' fees and reasonable costs for expert and other witnesses, and any judgment on the award rendered by the arbitrator may be entered in any court of competent jurisdiction. Nothing in this Section shall be



deemed as preventing Gene by Gene from seeking injunctive or other equitable relief from the courts as necessary to protect any of Gene by Gene's proprietary interests. ALL CLAIMS MUST BE BROUGHT IN THE PARTIES' INDIVIDUAL CAPACITY, AND NOT AS A PLAINTIFF OR CLASS MEMBER IN ANY PURPORTED CLASS OR REPRESENTATIVE PROCEEDING. YOU AGREE THAT BY ENTERING INTO THIS AGREEMENT, YOU AND GENE BY GENE ARE EACH WAIVING THE RIGHT TO A TRIAL BY JURY OR TO PARTICIPATE IN A CLASS ACTION.

**Disputes and Governing Law:** You agree that: (i) the Services shall be deemed solely based in Texas; and (ii) the Services shall be deemed a passive one that does not give rise to personal jurisdiction over Gene by Gene, either specific or general, in jurisdictions other than Texas. This Agreement and any dispute regarding the Services shall be governed by the laws of the State of Texas, USA, without regard to conflict of law provisions and you agree to exclusive personal jurisdiction and venue in the state and federal courts of the United States located in the State of Texas, City of Houston for any actions for which we retain the right to seek injunctive or other equitable relief in a court of competent jurisdiction to prevent the actual or threatened infringement, misappropriation or violation of a our copyrights, trademarks, trade secrets, patents, or other intellectual property or proprietary rights, as set forth in the Arbitration provision above.

## Questions

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**If you have any questions about this Privacy Document, the practices of the Gene by Gene Website, or your dealings with the Gene by Gene Website, you can contact us by either calling 1-713-868-1438 or by emailing [ombudsman@genebygene.com](mailto:ombudsman@genebygene.com).**