

## **Privacy Policy**

Updated August 2024

ClinGen's GenomeConnect is committed to protecting the privacy of our participants and those who visit our website. To better protect your privacy, we provide this notice explaining our practices. To make this notice easy to locate, we make it available as a link on our home page. We define personal information to include: name(s), email address, mailing address, survey responses, registry information and non-public information included in your correspondence with us.

GenomeConnect is part of the Clinical Genome Resource Project (ClinGen). ClinGen is funded by the National Institutes of Health (NIH). The website is owned and hosted by ClinGen. The registry system was developed and is hosted by Tempus Dynamics, a company specializing in patient registries. GenomeConnect welcomes participants who can read and understand English or Spanish. GenomeConnect is open to both adults (age 18 and older) and minors under the age of 18 who have the consent of a parent or legal guardian who have had genetic testing.

This Privacy Policy applies to all Sites where it is posted but addresses only the use and disclosure of Information we collect when you use the Sites as described in detail below. You should be aware that when you are on the Sites, you may find links to other websites that GenomeConnect does not control, and we do not determine the privacy practices of third parties or the content of their websites. You should read the posted privacy policy of any website before you access it.

### **Important Notice if You Are Not a United States Resident**

#### **CONSENT TO PROCESSING YOUR INFORMATION IN THE UNITED STATES**

GenomeConnect is located in the United States. Your personal information may be transferred to the United States or other locations outside of your state, province, country or other governmental jurisdiction where privacy laws may not be as protective as those in your jurisdiction. We are subject to the United States laws and regulations that govern the privacy and security of information, as well as consumer protection laws and regulations of the United States and its individual states, as applicable. If you are a citizen or resident of a different country, the data protection laws of your country may differ as to how your personal information is protected. We want you to understand that when you provide your personal information to us, or direct your healthcare provider to provide it to us, your personal information will be transmitted to and processed in the United States. In doing that, you will be giving GenomeConnect your consent to process your personal information in the United States, in accordance with United States law, for our legitimate purpose in fulfilling your request or addressing your healthcare needs.

Although participants are welcome from around the world, the GenomeConnect team is unable to process and submit data from participants in the European Union due to recent changes to the General Data Protection Regulation (GDPR).

## **Our Site Security**

PLEASE NOTE THAT, BY ITS VERY NATURE, A WEBSITE CANNOT BE ABSOLUTELY SECURE OR OTHERWISE PROTECTED AGAINST INTENTIONAL OR MALICIOUS INTRUSION ATTEMPTS. FURTHERMORE, GENOMECONNECT DOES NOT CONTROL THE DEVICES OR COMPUTERS OR THE INTERNET OVER WHICH YOU MAY CHOOSE TO SEND INFORMATION AND CANNOT, THEREFORE, PREVENT SUCH INTERCEPTIONS OR COMPROMISES TO YOUR INFORMATION WHILE IN TRANSIT TO GENOMECONNECT . GENOMECONNECT CANNOT AND DOES NOT GUARANTEE THE ABSOLUTE SECURITY OF ELECTRONIC INFORMATION, COMMUNICATIONS, OR TRANSMISSIONS. ANY TRANSMISSION MADE OVER THE INTERNET BY ANY ORGANIZATION OR ANY INDIVIDUAL RUNS THE RISK OF INTERCEPTION.

## **Types of Information We Collect**

When you use our Sites, we collect and store “Information” from or about you, as well as the device you have used to access the Sites, in a variety of ways, including (but not limited to) the following:

**Information you provide to us:** We collect and store Information that you provide directly to us on or through the Sites. For example, we collect Information about you when create an account or register for our Sites, subscribe to newsletters and publications, register or attend an event, use various features of the Sites,, fill out a survey,, conduct a search, call us, request support, email or otherwise communicate with us. **Depending on the Site, we may collect the following kinds of Information from you, and we may use this Information to contact you or combine that Information with other information we have about you or your device:**

- **Account and Contact Information:** such as your name, email address, password, postal address, phone numbers, age, date of birth, username, and password and any other Information you provide.
- **Information About Others:** such as the names and the contact Information of your representatives and any dependents in your care;
- **Health Information,** such as your past and present medical condition, medication information, genetic test results, and treatment history.
- **Other Information you Choose to Provide:** such as Information you provide to conduct a search; fill out a form; participate in a survey, use other interactive areas of the Sites such as participant matching feature or other communication features; provide your social media handles; or request technical or customer support.

- **Usage Information:** such as Information about how you use our Sites or interact with us, including information associated with any content you upload to the websites or otherwise submit to us, and information you provide when you use any interactive features of the websites.
- **Subscription information:** such as your preferences for receiving communications about our activities, events, and publications, and details about how you engage with our communications.

When you contact the GenomeConnect team at [info@genomeconnect.org](mailto:info@genomeconnect.org), your email address and other information included in your email may be forwarded to the appropriate person(s) within GenomeConnect for a response. A copy of your correspondence may be retained by GenomeConnect and also by the responding individual.

GenomeConnect has established and maintains a mailing list for emails. The mailing list includes families of affected individuals, friends, physicians, scientists, contributors and others. We do not release our mailing list or the names of our member families to any outside organization or third party unless required to do so by law. However, if an outside organization sends us information for distribution to registry participants, we may email it to you after proper approval.

**Browser or Device Information:** We also collect, and may transmit, certain technical Information automatically when you use or navigate our Sites, and traffic between GenomeConnect and the Internet at times will be recorded for analysis (technical and physical). We do this to, among other things, help diagnose problems with our servers, collect Site usage statistics, and administer our Sites. This includes, but may not be limited to, the following types of Information:

- **Log Information:** Our systems may record certain log file and usage Information such as your Internet Protocol (“IP”) address, browser type and language, operating system, referring URLs, date and time of your visit, pages viewed, links clicked, movements through the Sites, and other Information about your activities on our Sites.
- **Device Information:** Device information such as the device used to access or use the Sites, including the hardware model, operating system and version, unique device identifiers, and mobile network Information. If your device settings permit, we may also collect Information about the location of your device to facilitate your use of certain features of the Sites.

**Pixels, cookies, and similar tools:** We may use cookies, pixel tags, web beacons, embedded scripts, local objects, and other tracking technologies (collectively referred to as “Cookies”) to automatically collect the types of Log and Device Information described above, which may include third-party Cookies. By using our Sites, you consent to our

use of Cookies. See the Cookies Notice below for additional information about our use of Cookies.

**Third Parties and Their Tools:** We may allow others to provide analytics, marketing, or other services using Cookies to collect Information about your use of our Sites.

**Aggregated Statistics:** We may collect statistics about the behavior of users on the Sites. For instance, we may monitor the most popular forums or participant interactive features on the Sites. We may display this Information publicly or provide it to others.

### **How We Use the Information We Collect**

We may collect and use Information in the following ways, depending on the Site, including:

- To communicate with you
- To provide you with information or services, including personalized Information
- To make features and functions on the Sites available for your use
- To optimize your web experience
- To provide or improve customer service
- To conduct surveys, research, analysis, and generate reports
- To promote events and GenomeConnect tools
- To establish and manage your accounts
- To operate, evaluate, and improve GenomeConnect's services and operations
- To monitor and analyze trends, usage, and activities in connection with our Sites
- To comply with applicable laws, regulations, and court orders

The above list is not comprehensive and may change without notice.

### **How Your Information Is Shared**

We may share Information we collect about you in the following ways: with our service providers, consultants, and vendors to maintain, improve, monitor, provide, protect, and promote our Sites and services; with other entities that are affiliates or subsidiaries of GenomeConnect; in the course of legal proceedings or in response to legal orders or government requests, and as otherwise required by law; as needed to support compliance, operations, and corporate governance functions; and in connection with a transfer of ownership or assets, a corporate reorganization, merger, or acquisition.

**Please note:** Information you have shared with others or that others have copied may also remain visible after you have closed your account or deleted the information from your own profile. In addition, you may not be able to access, correct, or eliminate any Information about you that other Site users copied or exported out of the Sites, because this information may not be in GenomeConnect's control.

For registry participants, Tempus Dynamics will store information we receive from you on its computer systems, which have tight security measures in place to protect

participant information. Before your genetic and health data are shared, we will remove your personal information such as name, date of birth, and address, and replace it with a unique number code. This unique code is only known by approved staff involved with GenomeConnect. This code is stored in a secure place on the Tempus Dynamics server and protected with a password. If there are any breaches, federal and state laws, including the Genetic Information Nondiscrimination Act (GINA), have been put in place to protect you against some types of genetic discrimination. If we think you may have been affected by a breach in the registry's computer system or identified by any of your information, we will notify you.

### **Third Party Information Sharing**

As a routine part of some business processes, we may share some Information from the Sites with third parties. We may disclose Information to such third parties that perform services for us in the processing of the Sites and/or the services made available thereon. For example:

- **Service providers:** We may engage trusted third-party companies and individuals to facilitate or provide services on our behalf or to perform Site-related services and analysis.
- **Legal orders:** We may disclose user Information if required by any applicable law or government agency to comply with a legal order. We may also disclose or use user Information in order to defend or enforce our legal rights and in accordance with any applicable law.
- **Corporate transfers:** We may disclose, share, or transfer user Information in connection with a merger, acquisition, reorganization of our assets.

Participants' genetic and health data will be deidentified before it is shared. This means that this data will be separated from your personal information like your name and email. We will NEVER share your personal contact information without your permission. Deidentified data will be shared with the following groups so that it can be studied to improve health care:

- **Open-access databases:** These are available to anyone with internet access. General information, such as de-identified health and genetic information, age, race, or sex may be shared with these types of databases. One example is [ClinVar](#), a database of genetic changes and their relationship to health.
- **Controlled-access databases:** These are only available to approved users. More detailed information such as a complete list of all changes found in your genes during testing, may be found in these databases.
- **Clinical Genome Resource (ClinGen):** ClinGen may have access to this deidentified data for ClinGen related activities. ClinGen activities may be displayed on the ClinGen [website](#).

- Geisinger Institutional Review Board: The committee that oversees this project. To learn more where data is shared, select here.

### **Withdrawal of Information**

An individual who has registered for an account with us may review, update, correct or delete the personal information in their account profile by logging into their account.

You can choose to stop participating in the GenomeConnect registry at any time. If you want to withdraw your participation, please contact the registry at 570-214-1721 (toll-free 855-322-7683) or email [info@genomeconnect.org](mailto:info@genomeconnect.org). We will stop sharing your genetic and health data. We will stop all invitations for additional surveys and requests for patient or research contact. Data that has already been shared cannot be removed. Your account will be deactivated and the identifying information in your profile removed.

### **Cookies Notice**

This Cookies Notice describes how we collect, use, and store information through Cookies on our Sites, the reasons we use Cookies, and how you can manage settings related to Cookies.

**What are Cookies and Why Does GenomeConnect Use Them?** A Cookie is a text, image, or other file stored on your computer, mobile, or other device by your web browser when you visit or use a Site, and that your browser provides to us each time you return to the Site. Almost every website uses these files. Cookies may store certain Information such as your IP address, operating system, device information, browser type and language, referring URLs, access times, pages viewed, links clicked, movements through the Sites, and other information about your activities or use of the Site.

Cookies are used to identify the content you view, the content you provide so that you do not have to re-enter it each time you visit our Sites, and your preferences and settings. Cookies also help us provide you with customized content; speed navigation through our Sites; allow us to learn about your visit and use of our Sites. Cookies vary in duration. Session Cookies, for example, last for a defined amount of time such as while your internet browser is open. Persistent Cookies are stored on your device for longer periods. Both types of Cookies can create an identification that is unique to your device.

**What types of Cookies does GenomeConnect use?** We may use different types of Cookies, depending on the Site. We classify Cookies into the following main categories, described in detail below: (1) necessary cookies; (2) performance cookies; (3) functional cookies; and (4) analytics cookies.

- **Necessary Cookies:** Necessary Cookies are needed to make the Site work. These Cookies are used for technical purposes such as enabling better navigation on the Sites.
- **Performance Cookies:** Performance Cookies can be used for various performance purposes, including tracking the number of visitors to the Site and information such as the number of views a page gets, how much time a user spends on a page, and other pertinent web statistics. These Cookies improve the performance of the Sites and the user experience.
- **Functional Cookies:** Functional Cookies enable the Sites to save Information already entered (such as user names, language choices, and your location), so that it can offer you improved and more personalized functions. Functional Cookies are also used to enable features you request, such as playing videos.
- **Analytics Cookies:** Analytics Cookies collect Information such as IP address, device ID, browser information, geolocation, content viewed, or other Information for the purpose of analyzing and measuring how visitors use the Sites and specific functions and features.

**How to Manage and Disable Cookies.** You can see various Cookies used on websites accessed through browsers like Google Chrome or Microsoft Edge by right clicking on the webpage, selecting the Inspect tool, and clicking on the word Cookies under the Application tab. You can also manage or disable certain Cookies by adjusting your browser or device settings. Browsers and devices are different, so refer to the settings menu of your browser or device control settings for instructions on how to see or change your Cookie preferences. If you choose not to receive Cookies, our Sites, or portions of our Sites, may not function properly or be available to you. You may also learn more about managing and disabling Cookies, and more information on Cookies generally at [www.allaboutcookies.org](http://www.allaboutcookies.org).

### **How Long Do We Keep Your Information? (Data Retention)**

We may retain your collected Information for an indefinite period of time or as otherwise required by law.

### **Changes to this Privacy Policy**

We reserve the right to change, modify, add, or remove portions of this Privacy Policy at any time in our sole discretion and without prior notice. Updates will be posted here and be effective immediately upon posting. Please check the Site regularly for updates to this Privacy Policy.

### **Children**

The Children's Online Privacy Protection Act of 1998 (COPPA) addresses how information is gathered and used from children under the age of 13. While GenomeConnect is a non-commercial, nonprofit organization not subject to COPPA, GenomeConnect's Sites are directed at an adult audience and are not intended or designed to attract children under the age of 13.

If you learn that your child has provided us with personal information through our Sites without your consent, you may alert us at [info@genomeconnect.org](mailto:info@genomeconnect.org) . If we learn that a child has provided such personal information, except as required and authorized by law, we will take steps to delete such information.

#### Contact Information

Should you have any questions or want more information regarding GenomeConnect and our Sites, please send an email to: [info@genomeconnect.org](mailto:info@genomeconnect.org).