



Privacy Policy

%%Note: this document anticipates the development of a “portal” website interface to the CGIP Database. Not all sections are relevant to the beta test.

Overview

The Cancer in Our Genes International Patient Database (CGIP Database) is a project of the VHL Alliance. The Alliance is committed to protecting the privacy of our families. Your privacy and the security of the data you provide are of the utmost importance to us. Because we gather medical information, we feel you should fully understand the terms and conditions surrounding the use of that information. We understand your medical information is a very personal subject, and we want to make sure you are as comfortable as possible if you choose to share that information.

We provide this notice explaining our information 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, phone number, survey responses, registry information and non-public information included in your correspondence with us.

When you contact the CGIP Database Coordinator at registry@vhl.org, or you use the contact form, your email address and other information included in your email may be forwarded to the appropriate person(s) within the CGIP Database, the VHL Alliance, or one of our professional advisors for a response. A copy of your correspondence may be retained at the CGIP Database home office and also by the responding individual.

CGIP Database has established and maintains a mailing database. The mailing list includes families of affected individuals, friends, physicians, scientists, contributors and others interested in VHL, HLRCC, BHD and related tumor conditions. The CGIP Database will never release our mailing list or the names of our member families to any outside organization or third party. However, if an outside organization sends us information for distribution to CGIP Database families, we may mail it to you after the VHL Alliance (VHLA) Board approves the mailing.

Confidential information may only be released by written or verbal permission of the person or organization identified. Verbal permission can only be given for a specific release. Any general release, such as a release of information including personal identifying data, must be in writing.

Study Title: Cancer in Our Genes International Patient Database

The CGIP Database website provides links to other sites that may be of interest. The CGIP Database is not responsible for the privacy practices or content of other such web sites.

The CGIP Database is firmly committed to maintaining the confidentiality of your personal information in all of our activities and programs. Every reasonable effort will be made to maintain the privacy and security of all personal information in our possession. Access to personal information will be limited to CGIP Database Task Force members assigned to work on the CGIP Database and a small number of qualified and approved individuals who need to access such information in the course of their work on the Database. In all instances, this work will be directly overseen by a member of the CGIP Database Task Force. All individuals working for the CGIP Database will be instructed in the confidentiality requirements of the organization.

You must read this Privacy Policy (the “Privacy Policy”) and the CGIP Database Website terms and conditions (the “Terms and Conditions”) prior to using any portion of the CGIP Database Website located at <http://registry.vhl.org> (the “Website”). By using the CGIP Database Website, you agree to all the terms of the Privacy Policy and Terms and Conditions. If you do not agree with the terms of this Privacy Policy, you may not use any portion of the CGIP Database Website.

The CGIP Database Website is owned and operated by the VHL Alliance (www.vhl.org), a Massachusetts nonprofit corporation. CGIP Database respects your privacy and has written the Privacy Policy so that you are aware of the information CGIP Database collects from you, how that information is protected, and how it is used. If you have any questions or comments regarding the Privacy Policy, or you feel that the CGIP Database is not abiding by its posted Privacy Policy, please contact us at: registry@vhl.org.

1. General

a. The CGIP Database has the highest regard for your privacy. We realize that our service can only work if we build trust with our user communities. For that reason, our first priority is to make sure users are confident in the security of the data they share with us. This Privacy Policy outlines the type of information the CGIP Database collects from the users of the CGIP Database Website and how it is shared with other parties. We reserve the right to modify the Privacy Policy at any time, and without prior notice, by posting amended terms and conditions on the CGIP Database Website. We encourage you to review the Privacy Policy periodically for any updates or changes.

2. Collection, Use and Disclosure of Information

- a. **De-identified and identifiable information.** Information collected on the CGIP Database can be categorized as either de-identified or identifiable. De-identified information is information that cannot be traced to a specific individual. Identifiable information tells us exactly who you are. This information allows you to access your registry and allows the CGIP Database to communicate with you.
- b. **Collection of Information.** All of the information you provide to CGIP Database will be maintained in a secure database, and any information that could identify you will not be shared without your express written consent, unless otherwise required by law.
- c. **Use and Disclosure of Information.** The goal of this registry is to make the information you provided searchable, while protecting your identity. De-identified data (information where all personal identifiers such as name, address, social security number has been removed) gathered from this profile will be made available to registrants of the CGIP Database Website in the hope that analyses of a substantially larger database will support breakthroughs and clinical trials that could lead to better treatments and care management. The CGIP Database will perform the searches for specific questions within the registry and provide de-identified reports back to you or

Study Title: Cancer in Our Genes International Patient Database

the requesting party.

De-identified information (information where all personal identification such as name, address, telephone has been removed) gathered from this profile will be made available to participants of the CGIP Database and to NORD in the hope that analyses of a substantially larger database will support breakthroughs and clinical trials that could lead to better treatments and care management. The CGIP Database will perform searches for specific questions within the CGIP Database and provide reports back to you and to the medical research community. Use of the de-identified data is governed by the Terms and Conditions.

Any information you provide to third party genetic counselors or other professionals whom you have contacted through the CGIP Database Website will be subject to their policies with respect to privacy and nondisclosure of information. We encourage you to familiarize yourself with those policies.

The CGIP Database may employ independent contractors, vendors and suppliers (“Outside Contractors”) to provide specific services and products related to the CGIP Database Website or to the services provided on the CGIP Database Website, including but not limited to, performing general statistical analysis, maintaining an email suppression list as may be required by state and/or federal law, fraud screening, testing and implementation of special services to users, and developing applications for the CGIP Database Website and the services provided on the Website. These Outside Contractors may have limited access to information collected on the CGIP Database Website, including protected health information and personally identifiable information. In the course of providing such products or services, Outside Contractors will be contractually obligated to protect the privacy and security of all protected health information and personally identifiable information.

3. Withdrawal of Information

At any time, you have the right to withdraw your information from the Website registry database. You may exercise this right by contacting the CGIP Database coordinator at registry@vhl.org and your profile will be removed. De-identified data shared with the other global rare disease database repositories such as GRDR will also be removed. However, de-identified data cannot be retrieved from researchers that have already accessed it prior to your request for removal.

4. Protection of User Information

All users are required to review and abide by the CGIP Database Website Terms and Conditions and the Privacy Policy. The CGIP Database takes steps to ensure that your information is treated securely and in accordance with this Privacy Policy. We use commercially reasonable methods to protect the security of information and data submitted to the CGIP Database Website. We employ best practices from our networking to our secure servers to protect data from intrusion. Users should keep in mind, however, that no internet transmission is ever 100% secure or error-free. Where you use passwords, ID numbers, or other special access features on the CGIP Database Website, you should take special care to safeguard them. It is also important for you to help protect against unauthorized access to your information. You are solely responsible for signing off of our CGIP Database Website each time you finish using it and for securing your login information and security responses. Any transactions using your login and security responses will be deemed to be authorized by you.

5. Ownership of Information

All of the information you provide to the CGIP Database in connection with the CGIP Database Website is owned by the CGIP Database. Your information may contribute to the development of inventions or commercial products from which others may derive economic benefit. You will have no rights to any inventions, commercial products or other such discoveries and you will receive no economic benefit.

7. Cookies

a. A cookie is a small data file that some websites write to your hard drive when you visit them. When you visit the CGIP Database Website, we may send one or more cookies to your computer that will uniquely identify your browser. These cookies cannot collect or store your identifiable information. They are used to keep your place while you are logged in, and can track and target the interests of users to enhance their experience on the website. Usage of a cookie is in no way linked to any personally identifiable information while on the CGIP Database Website. If users reject the cookie, they may still use the CGIP Database Website.

8. Log Files; Web Beacons

a. The CGIP Database may use log file information sent by your web browser (which may include information such as your web request, Internet Protocol (“IP”) address, browser type, browser language, referring/exit pages and URLs, platform type, and other information) to analyze trends, administer the CGIP Database Website, track the movement of users, and gather broad statistical information for aggregate use. IP addresses are not linked to personally identifiable information. The CGIP Database may also employ “web beacons” (also known as clear gifs) to track online usage patterns of users. This information is not linked to personally-identifiable information. Web beacons may also be employed for tracking and receipt purposes in connection with web-based emails we send to users.

9. Website Links

The CGIP Database Website may contain links to other web sites. This Privacy Policy applies solely to information collected on or submitted to the CGIP Database Website. The CGIP Database is not responsible for the privacy practices of other sites linked to the CGIP Database Website or third party advertisements served on the CGIP Database Website. The CGIP Database encourages users to read the privacy policies of websites and third party advertisers when they connect to them through the Website.

10. Communications from CGIP Database

From time to time, the VHL Alliance or other related entities will notify users of updates and other valuable information about the VHL Alliance, the CGIP Database Website and related clinical and research information. By using the CGIP Database Website, or registering or subscribing for services provided on or through the CGIP Database Website, users consent to being contacted by VHL Alliance and related entities, and to receiving such updates and information. The VHL Alliance encourages related entities, including its business partners, to follow best practices with respect to email communications, security and privacy. However, the VHL Alliance cannot control, and assumes no responsibility for, any contact of users by related entities, including its business partners. In the case of emails coming directly from the VHL Alliance such emails will clearly be from the VHL Alliance and will include instructions on how to unsubscribe from future emails.

11. Required Disclosures

You understand and agree that the CGIP Database may disclose information provided by you if in its good faith belief such disclosure is required by applicable law.

12. Contact Us; Member Accounts

If a participant elects to contact the CGIP Database through contact information provided on the CGIP Database Website, or register for an account, you may be asked for any of the following: name, password, e-mail address, e-mail subject and a message containing your inquiry (in the case of a “contact us” inquiry), and certain profile and account information (in the case of a member account registration). The CGIP Database stores this data in order to reply to the submitted inquiry or to establish and service the member account. The submitted information is then subject to the terms detailed in this Privacy Policy.

13. Children Under the Age of Thirteen (13)

The CGIP Database is unable to prevent children under the age of thirteen (13) from visiting the CGIP Database Website; however, no part of our CGIP Database Website is directed at or intended for persons under the age of thirteen (13). If you are under the age of thirteen (13), please do not access the CGIP Database Website at any time or in any manner. In order to comply with the Children's Online Privacy Protection Act, the CGIP Database will not knowingly collect personally identifiable information from children under the age of thirteen (13). By providing personal identifiable information through the CGIP Database Website including, but not limited to, your name and e-mail address, you represent and warrant that you are at least thirteen (13) years of age and that you agree to comply with the Privacy Policy. If, at any time, the CGIP Database learns that personally identifiable information has been collected from persons under the age of thirteen (13) without verified parental consent, the CGIP Database will take the appropriate steps to delete such information.

14. Notification of Changes

Please review the Privacy Policy whenever you use the CGIP Database Website in order to be aware of the ways that your information is used. The CGIP Database reserves the right to change the Privacy Policy at any time, without prior notice.

15. Sharing Personal Information Online

Please keep in mind that whenever you voluntarily disclose personal information online – for example on message boards, through e-mail, or in chat areas – that information can be collected and used by others. In short, if you post personal information online that is accessible to the public, you may receive unsolicited messages from other parties in return.

Date effective: September 15, 2013

Contact information:

Registry Coordinator

E-mail: registry@vhl.org

Telephone: 800-767-4845 or +1-617-277-5667

Fax: 866-209-0288 or +1-858-712-8712

Paper mail:

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