



Terms and Conditions

PLEASE READ THE FOLLOWING INFORMATION CAREFULLY. IN UTILIZING THIS SERVICE, YOU REPRESENT THAT YOU ARE OVER EIGHTEEN (18) YEARS OF AGE, AND YOU ACKNOWLEDGE THAT YOU UNDERSTAND AND ACCEPT THE FOLLOWING TERMS AND CONDITIONS. IN COMPLIANCE WITH THE CHILDREN'S ONLINE PRIVACY PROTECTION ACT, YOU MUST BE EIGHTEEN (18) YEARS OF AGE OR OLDER TO SUBMIT PERSONAL MEDICAL DATA AND INFORMATION. IF YOU DO NOT ACCEPT THESE TERMS AND CONDITIONS, YOU MAY NOT ACCESS THIS SITE OR UTILIZE ANY OF THE SERVICES PROVIDED ON OR THROUGH THIS SITE.

The CGIP Database is a project of the VHL Alliance to collect patient information and medical information concerning von Hippel-Lindau (VHL), Hereditary Leiomyomatosis and Renal Cell Cancer (HLRCC), and Birt-Hogg-Dubé (BHD) and related conditions, in order to accelerate research and find better treatments and ultimately a cure for these conditions. [%% this website is still in development]

1. General; Purpose and Acceptance of Terms and Conditions

a. General. Use of the CGIP Database website (the "Website") and the services associated with the CGIP Database Website (the "Services") is governed by the following terms and conditions herein (the "Terms and Conditions") and a privacy policy (the "Privacy Policy"), both of which you must read before using the Registry Website and the Services. All pages within the Website are owned and operated by the VHL Alliance. (The VHL Alliance together with its members, directors, and affiliated entities are referred to collectively herein as "VHLA").

b. Purpose. The purpose of the Website is to allow individuals, families and medical and research providers to register certain information on the CGIP database. The information provided by the registrant, during registration, is maintained in a secured database and will never be shared without the registrant's express consent. However, the Website may allow registrants to search de-identified information available on the Website.

c. Acceptance of Terms and Conditions. By using the Website, you represent that you accept and agree that you have read all of the Terms and Conditions and the Privacy Policy, understand them, and that you agree to and have the legal capacity to be bound by them. These Terms and Conditions constitute a legal agreement between you and the CGIP Database. The CGIP Database reserves the right to modify these Terms and Conditions at any time in its sole discretion, and without prior notice, by posting amended terms on this Website. We encourage you to review the Terms and Conditions periodically for any updates or changes. If you do not agree to be bound by the Terms and Conditions and the Privacy Policy, you may not use the Website.

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2. Ownership

a. All CGIP Database-generated content available at the Website, including without limitation, any information, software, photographs, images, video, audio, graphics, or text on the Website (“Content”), and all patent, copyright, trademark, trade dress, domain name, trade secret, and other proprietary rights therein are the sole property of the CGIP Database or used by the CGIP Database with the permission of the owner of such content. You agree to abide by all applicable intellectual property laws and any additional restrictions set forth on the Website in relation to the Content.

3. Use of the Website

a. Legal Capacity. You may use the Website or register to be included in or access and search the registry database, if you are at least eighteen (18) years old or older or possess legal parental or guardian consent; that you are fully able and competent to enter into the terms and conditions set forth in these Terms and Conditions and are otherwise capable of forming legally binding agreements under applicable law; and that you agree to be bound by these Terms and Conditions. If you are not competent to form legally binding agreements, do not use this Website.

b. True, accurate and complete information. If you register to use the Website, you agree to provide true, accurate and complete registration information.

c. Lawful Use. You agree to use the Website for lawful purposes only. You shall comply with all federal, state, and local laws applicable to the use of this Website and shall not use the Website to engage in any prohibited conduct. Prohibited conduct, broadly stated, is any conduct (i) that is unlawful, infringing, tortious, fraudulent, abusive, harassing or otherwise harmful to the CGIP Database or any other party or property; (ii) that violates another party’s intellectual property, privacy, or other rights; or (iii) that otherwise interferes with the operation, use or enjoyment of any service, system, or other property. Without limiting the generality of the foregoing, any information provided by you in connection with use of the Website: (1) shall not be false, fraudulent, inaccurate or misleading; (2) shall not be obscene or indecent; (3) shall not contain any viruses, Trojan horses, worms, time bombs, spiders, or other computer programming routines that are intended to damage, detrimentally interfere with, surreptitiously intercept or expropriate any system, data or personal information; (4) shall not infringe on any of the CGIP Database’s or other third party’s copyright, patent, trademark, trade secret or other proprietary rights or rights of publicity or privacy; (5) shall not be defamatory, libelous, unlawfully threatening or harassing; and (6) shall not create liability for the CGIP Database or cause us to lose the services of our Internet service providers or other suppliers. You may not take any action that imposes an unreasonable burden upon the infrastructure used to support the Website, including but not limited to unsolicited e-mail, also called spam.

d. Website for Allowable Activities (defined herein) only. The Website is for the use of registered users only. Specifically, individuals, families, or providers can use the Website to register and update a registration and, once registered, to search de-identified information (the “Allowable Activities”). Organizations, companies, and/or businesses may register as providers. The Website cannot be used in connection with any other endeavor outside of the Allowable Activities, including, but not limited to blogging. Specifically, users shall not disclose, post, publish, display, or transmit any of the Website content, without the written consent of the CGIP Database. Users also shall, at all times, maintain all de-identified information received from the Website in the strictest of confidence.

e. No Unauthorized Use. You may not attempt to gain unauthorized access to this Website or any services, other accounts, computer systems or networks connected to any server or to any of the Services, through hacking, password mining or any other means.

4. User Conduct and Responsibility

a. Security. You are solely responsible for the security of your password and your account, and are fully responsible for all activities that occur under your password or account with or without your knowledge. If you knowingly provide your login and password information to another person, your account privileges may be suspended temporarily or terminated. You agree to immediately notify the CGIP Database Coordinator of any unauthorized use of your password or account or any other breach of security. CGIP Database will not be liable for any loss or damage arising from your failure to comply. Certain portions of the Website and information contained on the Website may be accessible only to registered users or to affiliates, service providers or other business partners of the CGIP Database, or may otherwise be password restricted. You agree not to (i) gain or attempt to gain unauthorized access to such portions of the Website or to information contained in such sections of the Website; (ii) obtain or attempt to obtain confidential, proprietary and/or personal information stored on the Website; (iii) distribute passwords to unregistered or unauthorized users; or (iv) make any unauthorized use of the Website or information accessible on the Website. CGIP Database reserves the right to deny or revoke access to the Services, in whole or in part, if CGIP Database reasonably believes that you are in breach of these Terms and Conditions, or are otherwise using or accessing the Services inconsistent with the Terms and Conditions.

b. User Submitted Content. You acknowledge and agree that, upon creation of a profile on the Website and registration or registration as a provider, your submitted content (each submission individually, and all submissions, collectively, referred to herein as the “User Submission”) may be available for viewing by other registered users or to affiliates, service providers or other business partners of the CGIP Database, as de-identifiable data only, for research, statistical, study, and evaluation purposes. Notwithstanding the foregoing, however, the CGIP Database makes no representation or guaranty that your profile or provider information will be reviewed.

The CGIP Database is not in any way associated with or responsible for content posted on or transmitted to the Website by users, including, but not limited to, User Submissions. The CGIP Database has the right, but not the obligation, to monitor and verify content posted on or transmitted to the Website for any reason, and reserves the right to remove anything that is, in its sole discretion, unacceptable, inappropriate, or not in compliance with these Terms and Conditions; to disclose data to law enforcement agencies or authorities who may investigate reports of misuse or abuse of this Website; and to terminate any User’s access to the Website at any time, without prior notice.

Each user acknowledges and agrees that the CGIP Database is not required to edit or review any information or content posted, submitted, or otherwise transmitted by users. However, the CGIP Database reserves the right, in its sole discretion, to verify and correct any errors, inaccuracies, or omissions in any portion of the Website or content posted thereon or submitted or otherwise transmitted thereto, and all such content may be subject to CGIP Database approval. CGIP Database reserves the right, at any time, for any reason, to reject, suspend, cancel or remove content, and neither CGIP Database, nor its employees, consultants or other agents will have any liability for taking such actions.

You are responsible for any content you post, publish, display or otherwise transmit to the Website. You agree not to transmit or otherwise make available on the Website any personal information of any individual or any material protected by copyright, trademark, publicity, privacy or other proprietary right without the express permission of such individual or the owner of such rights, respectively. The burden of determining that transmission of the information is permissible, or that the material is not protected by such rights, is on you, the user. You shall be solely liable for and shall indemnify and hold CGIP Database harmless for any damages resulting from any infringement of copyrights, trademarks, proprietary rights, violation of privacy or publicity rights, or any other harm resulting from your submissions to, or transmission of information from, the Website.

By submitting material to any area of the Website, you expressly grant to CGIP Database the royalty-free, perpetual, irrevocable, non-exclusive right and license to use, reproduce, modify, adapt, publish, translate, and distribute such material (in whole or in part) worldwide, in accordance with the Privacy Policy.

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You further understand and acknowledge that you may be exposed to User Submissions that are inaccurate or otherwise objectionable, and you agree to waive and hereby do waive, any legal or equitable rights or remedies you have or may have against the CGIP Database with respect thereto, and agree to indemnify and hold the CGIP Database harmless to the fullest extent allowed by law regarding all matters related to your use of the Website, whether as a registered provider in submitting User Submissions and/or creating a profile, or as a representative of an institution using the Website for informational and educational purposes. Users may report abuses of the Website to the CGIP Database Coordinator with sufficient detail identifying the abusive conduct or content, so that the CGIP Database may determine, in its sole discretion, whether to take action with respect to such alleged abuse.

You are solely responsible for and will exercise caution, discretion, common sense and judgment in using and accessing the Website and all content contained therein. You are solely responsible for any equipment necessary to access and use the Website.

c. Cooperation. You agree to cooperate fully with the CGIP Database to investigate any suspected or actual activity that is in breach of these Terms and Conditions.

d. Research Studies, Clinical Trials, and Other Developments. It is the responsibility of all users to stay informed regarding clinical trials, research and other developments of interest. Although the CGIP Database will attempt to distribute relevant information regarding research studies and clinical trials to users based on the information provided in the user's profile, the CGIP Database assumes no responsibility for informing users regarding all such studies and trials, and makes no guaranty as to the completeness or accuracy of such information. The CGIP Database also assumes no responsibility for connecting any user with the provider of a research study or clinical trial, but will make every effort to inform users of upcoming research studies or clinical trials. Furthermore, the CGIP Database assumes no responsibility for ensuring the qualification of a user or participation of any user in any such study or trial. It is the responsibility of each user to contact the relevant investigators and pursue participation in a study or trial.

The value and relevance of the information provided by the CGIP Database is directly linked to the information provided by users in their respective profiles and registration. It is your responsibility to provide complete and accurate information, and to update your profile information as appropriate, so that you can receive relevant and current information.

e. Risk of Using the Website and the Internet. You assume total responsibility and risk for your use of the Website and the Internet. You acknowledge and agree that any uploads or transmission you make to, from or through the Website may be intercepted and used by an unauthorized third party and that all of the risk associated with these activities is solely yours.

f. Links to Other Websites. The Website may contain links to other Websites that are not under the control of the CGIP Database. The CGIP Database is not responsible for the contents of any linked website or any link contained in a linked Website, or any changes or updates to such websites. The inclusion of any link does not imply endorsement by the CGIP Database. It is up to you to take precautions to ensure that whatever you select for your use is free of viruses, worms, Trojan horses, and other items of a destructive nature.

5. Information Contained on Website

In the course of using the Website or Services, users may provide information about themselves, which may be visible to certain other users (see the Privacy Policy) learn more about information collected on the Website). You understand that by posting materials on the Website or otherwise providing materials to us, you are agreeing to allow us to aggregate your anonymized (or de-identified) data for use by the community and other third parties. You understand that all information publicly posted or privately transmitted through the Website is the sole responsibility of the person from which such content originated and that the CGIP Database will not be liable for any errors or omissions in any content. You understand that the CGIP Database cannot guarantee the identity of any other users with whom you may interact in the

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course of using the Website or Services. Additionally, we cannot guarantee the authenticity of any data that users may provide about themselves.

6. Disclaimer of Medical Advice

You understand and acknowledge that all users are responsible for their own medical care, treatment, and oversight. All of the Content provided on the Website, including text, treatments, dosages, outcomes, charts, profiles, graphics, photographs, images, advice, messages, forum postings, are for informational purposes only and are not intended to be a substitute for independent professional medical judgment, advice, diagnosis, or treatment. The Content is not intended to establish a standard of care to be followed by a user of the Website. You understand and acknowledge that you should always seek the advice of your physician or other qualified health provider with any questions or concerns you may have regarding your health. You also understand and acknowledge that you should never disregard or delay seeking medical advice relating to treatment or standard of care because of information featured on or transmitted through the Website.

7. Disclaimer of Warranties

a. THE WEBSITE AND THE CONTENT MADE AVAILABLE ON THE WEBSITE ARE PROVIDED ON AN "AS IS" AND "AS AVAILABLE" BASIS. THE CGIP DATABASE DOES NOT MAKE ANY EXPRESS OR IMPLIED WARRANTIES, REPRESENTATIONS OR ENDORSEMENTS WHATSOEVER (INCLUDING, BUT NOT LIMITED TO, WARRANTIES OF TITLE OR NON-INFRINGEMENT, OR THE IMPLIED WARRANTIES OF MERCHANTABILITY OR FITNESS FOR A PARTICULAR PURPOSE) WITH REGARD TO THE WEBSITE, THE CONTENT, ANY ADVICE OR SERVICES PROVIDED THROUGH THE WEBSITE OR ON THE INTERNET GENERALLY. SOME STATES MAY NOT PERMIT THE DISCLAIMER OF IMPLIED WARRANTIES, SO THE FOREGOING DISCLAIMER MAY NOT APPLY TO YOU. THE CGIP DATABASE DOES NOT WARRANT THAT THE WEBSITE WILL BE UNINTERRUPTED OR ERROR-FREE OR THAT DEFECTS IN THE WEBSITE WILL BE CORRECTED, THAT ANY INFORMATION CONTAINED ON OR TRANSMITTED THROUGH THE WEBSITE IS COMPLETE, ACCURATE OR CURRENT, THAT USER OR OTHER INFORMATION WILL BE COMPLETELY SECURE FROM UNAUTHORIZED ACCESS OR DISCLOSURE, OR THAT ANY INFORMATION IS FREE OF VIRUSES OR OTHER ROGUE PROGRAMMING.

8. Limitation of Liability

a. UNDER NO CIRCUMSTANCES SHALL THE CGIP DATABASE OR ANY OF ITS PARTNERS, CONTRIBUTORS, AGENTS, EMPLOYEES, OR ANY OTHER PARTY INVOLVED IN CREATING, PRODUCING, OR DISTRIBUTING THE WEBSITE OR PROVIDING CONTENT, ADVICE, PRODUCTS OR SERVICES THROUGH THE WEBSITE BE LIABLE FOR ANY DIRECT, INDIRECT, INCIDENTAL, SPECIAL, OR CONSEQUENTIAL DAMAGES FOR LOSS OF PROFITS, GOODWILL, USE, DATA OR OTHER INTANGIBLE LOSSES (EVEN IF WE HAVE BEEN ADVISED OF THE POSSIBILITY OF SUCH DAMAGES) THAT RESULT FROM: (I) THE USE OF OR INABILITY TO USE THE WEBSITE; (II) ANY INACCURACIES, ERRORS, OMISSIONS, OR LACK OF AUTHENTICITY IN THE CONTENT; (III) USE OF THE CONTENT; (IV) THE COST OF PROCURING SUBSTITUTE MERCHANDISE, ADVICE AND SERVICES RESULTING FROM USE OF THE WEBSITE; (V) ANY LOSS, MISUSE, OR UNAUTHORIZED ACCESS TO OR ALTERATION OF INFORMATION OR MATERIALS TRANSMITTED TO OR CONTAINED ON THE WEBSITE; (VI) STATEMENTS, ADVICE, WARRANTIES, GUARANTEES OR CONDUCT OF THE CGIP DATABASE OR ANY THIRD PARTY ON THE WEBSITE, OR (VII) ANY OTHER MATTER RELATING TO THE USE OF THE WEBSITE. YOU HEREBY ACKNOWLEDGE THAT THIS PARAGRAPH SHALL APPLY TO ALL CONTENT, ADVICE, MERCHANDISE, AND SERVICES AVAILABLE THROUGH THE WEBSITE. BECAUSE SOME STATES MAY NOT ALLOW THE EXCLUSION OR LIMITATION OF LIABILITY FOR CONSEQUENTIAL OR INCIDENTAL DAMAGES, IN SUCH STATES LIABILITY IS LIMITED TO THE LEAST AMOUNT PERMITTED BY LAW. THE LIMITATIONS OF LIABILITY PROVIDED IN THIS AGREEMENT INURE TO THE

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BENEFIT OF THE CGIP DATABASE AND ITS RESPECTIVE AFFILIATES, PARTNERS, CONTRIBUTORS, OFFICERS, DIRECTORS, EMPLOYEES, ASSIGNS, ATTORNEYS AND AGENTS.

9. Indemnification

You agree to indemnify and otherwise hold harmless the VHL Alliance, its officers, employees, agents, subsidiaries, affiliates and other partners from any and all liability, including any and all direct, indirect, incidental, special, consequential or exemplary damages, and any and all costs and/or expenses (including reasonable attorneys' fees) resulting from (i) your use of the Website, including, but not limited to, your access to, submission of, or distribution of, information to or from the Website; (ii) any misuse, unauthorized access to, disclosure, alteration, or destruction of the Website, information contained in the Website, and/or your communications with or through the Website, or (iii) any other matter relating to the Website. You understand and agree that the CGIP Database may disclose information provided if in its good faith belief such disclosure is required by applicable law.

10. Copyright and Copyright Agent

a. The Website and the compilation (meaning selection, composition, and arrangement) of all of the content on the Website is the exclusive property of the CGIP Database and protected by U.S. and international copyright law. The CGIP Database reserves the right to remove any content, from any source, at any time, for any reason (including, but not limited to, claims or allegations made by third parties relating to such content). Users of the Website agree to not take any action with respect to content of the Website that would violate the intellectual property rights of the CGIP Database or the individual rights of other users. Content contained on the Website may not be modified, copied, distributed, framed, republished, downloaded, displayed, or sold in any form or by any means, in whole or in part, without the prior written consent of the CGIP Database or, in the case of user-submitted content, any other appropriate party or parties. It is the sole responsibility of the user to secure all necessary rights and permissions before downloading, reproducing, modifying, distributing, or otherwise using user-submitted content. The CGIP Database respects the intellectual property of others and asks that users do the same. If a user or any other party feels that its work has been copied in a way that constitutes copyright infringement, that person should provide the CGIP Database with the following information:

1. A physical or electronic signature of a person authorized to act on behalf of the owner of an exclusive right that is allegedly infringed; 2. Identification of the copyrighted work claimed to have been infringed, or, if multiple copyrighted works at a single online Website are covered by a single notification, a representative list of such works at that Website; 3. Identification of the material that is claimed to be infringing or to be the subject of infringing activity and that is to be removed or access to which is to be disabled, and information reasonably sufficient to permit the service provider to locate the material; 4. Information reasonably sufficient to permit the service provider to contact the complaining party, such as an address, telephone number, and, if available, an electronic mail address at which the complaining party may be contacted; 5. A statement that the complaining party has a good faith belief that use of the material in the manner complained of is not authorized by the copyright owner, its agent, or the law; 6. A statement that the information in the notification is accurate, and under penalty of perjury, that the complaining party is authorized to act on behalf of the owner of an exclusive right that is allegedly infringed.

Users may contact the CGIP Database for notice of claims of infringement on this Website as follows:

By phone: +1-617-277-5667 or 800-767-4845 (toll-free USA and Canada)

By fax: +1 858-712-8712 or 866-209-0288 (toll-free USA and Canada).

By e-mail: registry@vhl.org

By mail: 2001 Beacon Street, Suite 208, Boston, MA 02135

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11. Trademarks

The name CGIP Database, the CGIP Database logo, and other VHL Alliance logos and names are trademarks of VHL Alliance. You agree not to display or use these trademarks in any manner without VHL Alliance's prior, written permission. The section titles of these Terms and Conditions are displayed for convenience only and have no legal effect. If any provision of these Terms and Conditions are to be unenforceable for any reason, the remaining provisions will be unaffected and remain in full force and effect.

12. International Users

The CGIP Database makes no claims that information on the Website is appropriate or may be downloaded outside of the United States. Access to the Website may not be legal in certain countries or for certain persons. If you access the Website from outside of the United States, you do so at your own risk and are responsible for compliance with the laws of your jurisdiction regarding online conduct and acceptable content. User personal information ("Information") that is submitted to this Website will be collected, processed, stored, disclosed and disposed of in accordance with applicable U.S. law and our Privacy Policy.

If you are a non-U.S. user, you acknowledge and agree that CGIP Database may collect and use your Information and disclose it to other entities outside your resident jurisdiction. In addition, such Information may be stored on servers located outside your resident jurisdiction. U.S. law may not provide the degree of protection for Information that is available in other countries. By providing us with your Information, you acknowledge that you consent to the transfer of such Information outside your resident jurisdiction to the U.S. or other jurisdictions with different, and in some cases, lower levels of protection for your Information. If you do not consent to such transfer, you may not use the Website.

13. General Practices Regarding Use and Storage.

You agree that CGIP Database has no responsibility or liability for the deletion or failure to store any messages and other communications or other Content maintained or transmitted by the Website. You acknowledge that CGIP Database reserves the right to log off accounts that are inactive for an extended period of time. You further acknowledge that CGIP Database reserves the right to modify these general practices and limits from time to time.

14. Privacy

You agree that you have read and understand the terms of the Privacy Policy. This policy governs the collection, use and sharing of personal and non-personal information from you when using the Website.

15. Termination

You agree that CGIP Database may, with or without cause, immediately terminate your account and access to the Website or the Services without prior notice. Without limiting the foregoing, the following will lead to a termination by CGIP Database of a user's use of the Website or the Services (a) breaches or violations of these Terms and Conditions or other incorporated agreements or guidelines, (b) requests by law enforcement or other government agencies, (c) a request by you (self-initiated account deletions), (d) unexpected technical issues or problems, and (e) extended periods of inactivity. You agree that all terminations shall be made in CGIP Database's sole discretion and that CGIP Database shall not be liable to you or any third-party for any termination of your account or access to the Website or the Services.

16. Communications from CGIP Database

From time to time, CGIP Database or other related entities will notify users of updates and other valuable information about CGIP Database, the Website and related clinical and research information (see our Privacy Policy to learn more about communications). By using the Website, or registering or subscribing for services provided on or through the Website, users consent to being contacted by the CGIP Database

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and related entities, and to receiving such updates and information. Users acknowledge and agree that users must always accept email transmissions from the CGIP Database, in order, to continue to use the Website or the Services.

17. Fees

Signing up for an account is free.

18. Governing Law

a. Any disputes arising out of the use of the Website or the Services or these Terms and Conditions will be governed by the law of the State of Massachusetts, regardless of conflict of law principles. Sole and exclusive jurisdiction and venue over any dispute arising out of or relating to these Terms and Conditions shall lie in the appropriate federal or state court in Massachusetts.

19. Statute of Limitations

Any cause of action you may have with respect to use of the Website must be commenced within one (1) year after the claim or cause of action arises.

20. Contacting the CGIP Database Coordinator

If you have any medical, research, treatment or patient referral questions, contact a nurse educator or staff member at the VHL Alliance home office or hotline, 800-767-4845 ext 1 or 4.

If you have questions about the CGIP Database, or to report violations of these Terms and Conditions, please email the Registry Coordinator at: registry@vhl.org.