



Minor Child Assent to Participate in the Cancer in Our Genes International Patient Database

This Assent form is for people ages 7 to 17 who wish to participate in the Cancer in Our Genes International Patient Database (CGIP Database) to help us learn about VHL, HLRCC, BHD, and other related medical issues.

This assent form may contain information that you do not understand. Please ask to have any information that you do not clearly understand explained to you. You may print a copy of this assent form to think about or discuss with family or friends before making your decision.

Will you participate in the CGIP Database?

The CGIP Database is inviting you, and other children, to give information about yourself, the history of your medical condition and how it affects you, to help us learn more about genetic diseases. We are also asking you to ask your parents or legal guardian to allow your doctor to add medical information about your medical condition to the CGIP Database. The information you contribute to the registry will supply medical researchers with information they need to discover more about early detection of genetic disease, new methods for diagnosis, and development of effective treatments. However, we cannot predict if, or how, the research done using your information will help people with genetic diseases now, or in the future.

In order to be a part of the CGIP Database, you and your parent (or legal guardian) will read "*Understanding Your Participation*", a document that provides information about the Registry. You should ask any questions that you have and may contact the CGIP Database coordinator at registry@vhl.org or by calling 800-767-4945 ext 4. Then to join the Registry, your parent or your legal guardian must agree, in writing, that you will take part. We are also asking you to agree to take part, and you can do this by signing your name on your parents' form. If you decide to take part in this study, and later change your mind, you may choose to stop at any time.

Do you need to be in the CGIP Database to benefit from research findings in the future?

Providing information about your medical condition is your choice and the choice of your parent or guardian. If at some time in the future information is found that will help your health, you will benefit from that information whether you participated in the CGIP Database or not.

What kinds of things will you do if you participate in the CGIP Database?

Your parent or guardian will help you fill out an on-line registration questionnaire. If you need help, you may contact the CGIP Database coordinator at registry@vhl.org or by calling 800-767-4845 ext 4. Your parent or guardian may also ask your doctor to add medical information to your record in the CGIP Database.

When will my participation in the CGIP Database end?

We will be using the information you provide for many years to come. We will be allowing researchers who are designing projects to study genetic diseases to use some of the medical information you and your doctors provide. However you may choose to end your participation at any time.

Who will see this information?

Your personal and medical information will be kept confidential (private) and only be accessible to you, your parent or guardian and the CGIP Database personnel. You may choose to allow your doctor to access your personal information in the registry but you are not required to do so. You may also choose to allow some of your medical information to become part of the CGIP Database research database to be used by

Study Title: Cancer In Our Genes International Patient Database

researchers who are designing medical research studies. Researchers who receive access to some of your medical data will not know who you are.

I understand this information and agree to participate in the CGIP Database

Print name of minor child

Date

Signature of minor child

Date

Print name of parent or legal guardian

Date

Signature of parent or legal guardian

Date

Please print, sign and return this form by mail, fax or email (PDF) to:

Email: registry@vhl.org

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

Paper mail:

Suzanne Nylander, Coordinator

CGIP Database

VHL Alliance

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