

## The CGIP Databank: Viewpoint from a User

*By Deb Hogan, VHLA Board of Directors*

Back in February, Suzanne Nylander, Director of Wellness for the VHLA, sent me a link to test and offer thoughtful feedback for the **Cancer in our Genes International Patient Databank** (CGIP Databank). I have to admit that I was busy, like so many of you are, and I didn't get a chance to respond. When Ilene Sussman asked if any of the board members would write an article on the databank, I knew I had to say yes. And I am glad that I did!

Let me first explain what a patient databank is. It is a place where medical information, family history, lifestyle, and other pertinent factors are collected and stored for medical research. The CGIP Databank collects information for VHL, HLRCC, BHD, SDH and other related diseases in hopes of finding a cure. The survey participant's data is initially collected then updated at least annually due to the fact that the research is longitudinal, following the progression of disease over time. Agreeing to participate authorizes the use of "de-identified" information (does not show name, address, or other identifying information) contributed in scientific studies.

So, I followed the link to the portal and entered my name, email and selected a password. There

was an extensive section on Informed Consent where I had to agree to Terms and Conditions. I was then asked about Contact Preferences. Did I want to be contacted regarding participation in clinical trials or would I agree to be a tissue donor? Next I was asked to add myself or someone else as a survey participant, including my preferred method of contact—phone, email or address. Data encryption is used to protect the privacy of the participant and information is shared only with the VHL Alliance. I also learned that to further ensure the protection of the patient's rights and welfare, an independent ethics committee, Chesapeake IRB, has approved the CGIP data collection.

I was then given the opportunity to select a survey such as "Genetics" or "Nutrition and Exercise". Imagine researchers using our information to answer questions such as, "Why do siblings, with the same genetic alterations, present with different symptoms?" or "What effects do diet and nutrition have on tumor growth?" I enjoyed answering the questions in each survey and I found it very user friendly. Questions regarding the databank can be sent via email to [databank@vhl.org](mailto:databank@vhl.org) or via phone at 800-767-4845 x4. So pour yourself some coffee or tea and enroll in the CGIP databank to find a cure!



**REGISTER HERE: <https://databank.vhl.org/>**

## A Participant's Perspective on the CGIP Databank

*By Jule Fobert, VHLA Board of Directors*

It wasn't until VHL patients shared symptoms and diagnosis of endolymphatic sac tumors (ELSTs) with the VHL Alliance that doctors learned that the inner ear was also a site of VHL tumors. It was through your input that VHLA informed doctors rather than the doctors informing us. Now, ELSTs are included in the recommended VHL screening guidelines.

VHLA works with researchers, doctors and VHL patients and caregivers to gather, share, and research information in a collective effort to find a cure for VHL. As we work towards the cure, we are looking for ways to better manage testing, lifestyle choices, and the disease itself. None of the work we do can be done without your sharing information about you and your family's experiences.

VHLA has built a worldwide databank to house all of the information about your VHL experience, which includes sharing your genetic testing, scans and other information such as your diet and oral care. Your

information will help researchers, doctors and other VHL patients and their families around the world learn more about VHL and make it easier to answer many of the questions we currently have.

We know a lot about VHL because you share with us your struggles (and triumphs) with VHL. But there is still more we need to understand and only you can help.

Lend your voice to help find the cure. Sign up today for the CGIP (Cancer in Our Genes International Patient) Databank at <https://databank.vhl.org/>. **We need you!**

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