

Examples of Research Questions

- How do symptoms develop over time?
- Is there a link between the type of mutation a person has and the symptoms?
- Why do siblings sometimes have different symptoms?
- Are first in family mutations more aggressive?
- What is the role of environmental factors?
- What role does lifestyle play?
 - Anxiety/Stress/Depression, Nutrition/Diet, Exercise
- Do medications impact tumor growth?
- What affects tumor growth rate?
- Does oral health correlate with tumor growth?
- Does pregnancy change the course?
 - What about other sources of hormones?



To participate,
log on to
www.vhl.org/databank



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A member of



CANCER IN OUR GENES

International Patient (CGIP) Databank



Patient participation
helping to find a cure

**VHL
BHD
HLRCC
SDH**

*and other related
cancers*

A Partnership
between Patients
and Clinical
Researchers

www.vhl.org/databank



Goals of the CGIP Databank

- Create a single major source of information for researchers and patients
- Include a large number of patients to allow for more accurate research
- Give a complete “picture” of each patient with either VHL, HLRCC, BHD, SDH, or related syndromes
- Learn the natural history of these conditions
- Find links between lifestyle and these conditions
- Help to find good methods for treatment, possibly including over-the-counter products
- Match patients to clinical trials more quickly

Advantages of a Patient-Driven Databank

- Only the patient can give the correct “picture” of what it is like to live with these syndromes
- Provides insight into lifestyle and quality of life (i.e., nutrition, exercise, mental outlook)
- Includes usage of both prescription and non-prescription medications
- Shows family history (blood relatives)



Why Multiple Conditions?

- VHL, HLRCC, BHD, and SDH all increase the odds of getting kidney cancer.
- Each is caused by an alteration in a different gene
- If any one of these four genes can cause kidney cancer, what do they have in common?



Data Privacy and Confidentiality

- Your name, address, email, or other information that might identify you will **not** be shared
- The VHL Alliance controls who can use the research data

Reasons to Take Part

- Make clinical trials easier to match
 - VHLA will tell patients if a researcher thinks they might be right for a clinical trial. Patients will then be able to connect with the trial, if they want to take part
- You will be able to print out your medical history and medication list to give to doctors
- You can choose to have screening reminders sent to you

Share Your Experiences to Help Research

- Today researchers are limited to the information obtained by a single hospital or research team
- This provides only a limited picture of the disease, often focused on a single organ
- The CGIP Databank will allow researchers to see the complete picture of thousands of patients
- ***We need as many people as possible to help and provide their information!***



Global Rare Disease Initiative

- VHLA is working with NORD and others around the world for the CGIP databank
- Many sources of data will be included
- Consulted with the FDA on questionnaire design

