Do you see patients with VHL, BHD, HLRCC, SDH or other related genetic diseases?

ASK THEM TO PARTICIPATE IN THE DATABANK!

This study complements your own research and can help you answer questions both you and your patients have.

For example:
- What is the long-term impact of new or experimental treatments?
- Does pregnancy or other hormonal changes impact new tumor formation and/or tumor growth?
- Are there any lifestyle (diet, exercise, sleep, medications, nutritional supplements, oral health, and mood) changes that may affect tumor formation or growth?
- How does emotional health affect disease progression?

How can you use the data for your research?

- Apply to the VHL Alliance for access to de-identified data
- Match participants with your specific research criteria
- Provide baseline clinical data for your research

Quick facts about the Patient Natural History Study

- Created as a partnership between patients and clinical researchers, including assistance from a global research council of medical specialists
- IRB approved as a longitudinal study
- Includes information on lifestyle that only patients can provide
- Participants are located around the world; not restricted by geography or medical institution
- Information from patients updated annually

Patient Natural History Study

Please direct any questions about the Databank, including research you may be interested in conducting and requests for patient brochures to: databank@vhl.org or phone the Databank Coordinator at 617.277.5667 x 4.

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