Do you want to help find a cure?

Blue eyes. Black hair. Cancer. What else runs in your family?

Learn more about your von Hippel-Lindau disease and help researchers unravel the mysteries of the disease. Your information and input can help researchers better understand VHL – contributing to more promising research to improve the quality of life for patients living with VHL and ultimately, leading to a cure.

“Now that I have filled out MyVHL, I know that my grandchildren will have an easier time dealing with VHL. It is so comforting to know.”

By the numbers...

- People worldwide living with VHL: 200K
- People in the US living with VHL: 10K
- New VHL patients born in the US every year: 125
- VHL Clinical Care Centers worldwide: 49
- Path forward: 1
What is MyVHL?

MyVHL is a multi-patient database which helps researchers identify patterns across VHL patients. MyVHL provides you – and researchers – with more complete information about VHL, like how your lifestyle, medications, and other factors impact the disease and quality of life. These insights help you better understand the condition and help researchers know where to focus their efforts.

Due to its rarity, there is less understanding of VHL and the factors that may have an impact. The data individuals provide in MyVHL helps researchers identify and uncover factors that may increase risk, inhibit or slow tumor growth, or lead to an effective cure.

DISCOVER How your unique journey can help others

Help find a CURE for cancer through VHL

Be a part of progress in RESEARCH

Register for MyVHL today! Learn more about your VHL and contribute to finding a cure. And, when you complete the survey and upload your scans (or submit a Records Release form), you will be eligible to receive a $50 Amazon Gift Card (US-based participants only). All of the information shared in MyVHL will remain secure and confidential.

REGISTER NOW!
vhl.org/MyVHL

The success of MyVHL – and breakthroughs in treatments and ultimately a cure – require collaboration between researchers, doctors and VHL patients – YOU! Please take the time to complete the study.