“When you are studying about von Hippel-Lindau disease you are not just studying about [the] ... disease... you are also now touching other diseases as well where we can use the VHL gene to understand what is happening.”

William G. Kaelin, Jr., MD
2019 Nobel Prize Awardee for Medicine
WHAT IS VHL? The VHL gene is in all of us, helping to suppress the growth of tumors. Those with a flaw in this gene are prone to develop tumors throughout their bodies. Researchers are racing to identify and control the pathways that allow tumor growth in VHL and other cancers. Their progress provides hope for all of us by Curing Cancer through VHL.

WHO IS VHLA? Founded in 1993, the VHL Alliance (VHLA) is the world’s leading organization supporting von Hippel-Lindau Syndrome. We are a 501(c)3 nonprofit dedicated to improving the lives and optimizing the treatment of those affected by VHL while aggressively pursuing cure.

LIVING WITH VHL: ASHLEE’S STORY

With no family history or knowledge of VHL, Ashlee was diagnosed with VHL at age 15. Living in rural Canada, Ashlee and her parents struggled to find information on VHL. Unfortunately, her doctors did not have much information on the condition – only one paragraph! They could not answer many of the family’s many questions.

When Ashlee was 34 she was pregnant and also had a tumor on her brain. Immediately following a premature delivery, Ashlee was faced with the need for emergency brain surgery. The surgery was particularly difficult due to the tumor’s location and the doctors felt unprepared to tackle the challenge.

Ashlee’s parents knew where to turn; they reached out to the VHL Alliance. The VHLA staff responded immediately. Despite it being a holiday weekend, within hours, the VHLA connected Ashlee’s doctors with an expert in VHL neurosurgery, Russell Lonser, MD. Dr. Lonser consulted with Ashlee’s physician and care team, walking them through the pre-op preparation, surgery, and post-surgical procedures, ultimately saving her life.

Today, Ashlee, a proud mother of a young son, provides the VHLA Handbook to every doctor she meets, helping improve her care and the care of others by raising awareness about the disease. “By understanding VHL, I’ve become my own best advocate – and VHLA has supported me every step of the way,” explained Ashlee.
The VHL Alliance is a leading funder of VHL research, committing over $2.3 million to support studies seeking a cure. Since the VHL gene controls the major pipeline that feeds every tumor, its cure brings us closer to curing many other forms of cancer. Though surgery remains the only option for VHL patients, our ongoing research has resulted in approval for multiple cancer drugs in use today.

William G. Kaelin, Jr., MD, 2019 Nobel Prize in Medicine recipient for his research into VHL and the VHL gene.

The VHL Alliance fosters community, provides resources, and connects patients to expert clinical care with specialists experienced in treating VHL. Our initiatives include:

- Global VHL Clinical Care Centers (CCCs)
- The VHL Handbook, the preeminent reference guide to VHL
- Toll-free hotlines and facilitated telephone discussion groups
- Peer mentoring program
- Regional meetings and gatherings
- Programs for teens and young adults

With a chronic condition that affects multiple organs as VHL does, education is essential to ensure optimal outcomes. At VHLA, we empower patients to actively manage their health by making informed decisions and accessing expert care. We also serve as an educational resource for the medical community, evolving tools to guide diagnosis, screening and treatment.
The VHL Alliance is dedicated to RESEARCH, EDUCATION, and SUPPORT to improve awareness, diagnosis, treatment, and quality of life for those affected by VHL.