WHAT IS VHL?

Von Hippel-Lindau (VHL) is a genetic condition involving the abnormal growth of blood vessels. The *vhl* gene controls cell behavior and prevents tumor formation. For people with von Hippel-Lindau, the *vhl* gene does not function properly, causing tumors to grow in up to 10 different parts of the body throughout a patient’s life. With no known pharmacological treatment, surgery is the only option for VHL patients.

VHL knows no boundaries. It affects approximately one in 36,000 people in every ethnic group. The prevalence of VHL is approximately the same prevalence as muscular dystrophy and one-half that of cystic fibrosis.

WHAT IS VHLA?

The VHL Alliance (VHLA) is a 501(c)3 non-profit organization founded in 1993. Today, VHLA is the world’s leading organization supporting von Hippel-Lindau Syndrome. VHLA funds research, increases awareness, and provides education and support to improve the lives of thousands of people living with VHL, and ultimately, find a cure.

WORK OF VHLA

The work of the VHL Alliance is about education, support, clinical care, research, and awareness. VHLA is the preeminent resource and clearinghouse for VHL patients, caregivers, and the medical community.

Core to its mission is empowering patients to actively manage their health by making educated decisions including seeking the best of care. The ups and downs of a chronic condition are taxing for all directly or indirectly impacted by VHL. VHLA addresses this need through services and incorporate a holistic approach to its service.

As a multi-organ disease, expert clinical care by multiple specialists with experience in treating VHL patients is essential to managing patient care. VHLA has created centers of care for VHL

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Mission: The VHL Alliance is dedicated to research, education, and support to improve awareness, diagnosis, treatment, and quality of life for those affected by VHL.
patients around the globe called Clinical Care Centers (vhl.org/ccc). Clinical Care Centers provide effective coordination of care, promote timely screenings and serve as a source of information and support.

VHLA provides education and support through many programs and resources—both one-on-one and in group formats, online and in person, printed and spoken. Enhancing education is essential to increase awareness, both within and outside of the VHL community. VHLA provides support and educational resources through:

- A toll-free hotline
- A peer mentoring program
- Staff monitored Social Media groups
- Quarterly newsletters
- Annual National Family Meetings
- Facilitated telephone discussion groups
- Regional meetings and gatherings
- Printed materials including the VHL Handbooks and VHL Vignettes
- Global VHL Clinical Care Centers

RESEARCH

The VHL Alliance is a leading funder of VHL research with over $1.7 million granted to support studies designed to find a cure. The vhl gene controls the major feeding pipeline of every tumor. Curing VHL is one step closer to curing many other forms of cancer, including: breast, kidney, colon, lung, pancreatic, prostate and adrenal.

VHLA envisions a cure for VHL and other forms of cancer, eliminating the need for patients to undergo multiple surgical interventions to control their tumors.

The VHL Patient Natural History Study (also known as Cancer in our Genes International Patient Databank—CGIP) provides researchers with knowledge of VHL directly from the patient. This will help expedite the pathway to getting new drugs approved for the treatment of VHL. Visit vhl.org/databank to do your part of the research!

GET INVOLVED

Together we are uncovering the cure for VHL and other forms of cancer. We are asking you to join us and continue your support. We simply cannot do it without you!

- **DONATE**
  It is only through the generosity of our supporters and our volunteers that we can offer so many different programs. Donate now at vhl.org/donate

- **FUNDRAISE**
  Gather together friends, family, and community members to help plan an event or create a virtual fundraising page at grouprev.com/vhlalliance

- **VOLUNTEER**
  Contact the VHL Alliance to find out about additional volunteer opportunities at info@vhl.org.