

## RESEARCH

The VHL Alliance is a leading funder of VHL research with over \$1.6 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, eliminating the need for patients to undergo multiple surgical interventions to control their tumors.

The Cancer in Our Genes International Patient Databank ("Databank") provides researchers with a natural history of VHL. This will help expedite the pathway to getting new drugs approved for the treatment of VHL. Visit [vhl.org/databank](http://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](http://vhl.org/donate)

- **FUNDRAISE**

Gather together friends, family, and community members to help plan an event or create a virtual fundraising page at [groupnev.com/vhlalliance](http://groupnev.com/vhlalliance)

- **VOLUNTEER**

Contact VHLA to find out about volunteer opportunities in your region

For additional opportunities, please call or email the VHLA office.



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Find us on



## VHL Alliance

# WHAT IS VON HIPPEL- LINDAU OR VHL?

*The VHL Alliance is dedicated to research, education, and support to improve awareness, diagnosis, treatment, and quality of life for those affected by VHL.*

[vhl.org](http://vhl.org)



## WHAT IS VHL?

Von Hippel-Lindau (VHL) is a genetic condition involving the abnormal growth of blood vessels in up to 10 parts of the body. It is caused by a flaw in one gene, the VHL gene, which regulated cell growth causing patients to battle a series of tumors throughout their life. With no known pharmacological treatment, surgery is the only option for VHL patients. Even children as young as one, need to be monitored for VHL lesions.

VHL knows no boundaries. It affects approximately one in 36,000 people (approximately 10,000 people in the U.S. and 200,000, worldwide) 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 THE VHL ALLIANCE (VHLA)?

The VHL Alliance (VHLA) is a 501c3 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.

The VHL Alliance is about:

- Education
- Support
- Diagnosis
- Treatment
- Research
- Patients
- Caregivers
- Clinicians
- Researchers
- Awareness



## WORK OF THE VHL ALLIANCE

The VHL Alliance connects patients with others living with VHL, answers questions for medical personnel, or fields questions to the appropriate experts. Resources provided through VHLA include:

- A toll-free hotline
- Personal conversations including a mentor program
- Staff monitored Social Media groups
- Quarterly newsletters
- Annual National Family Meetings
- Professionally facilitated telephone discussion groups
- Regional Meetings and Gatherings
- VHL printed materials including the VHL Handbook, VHL Vignettes, and the VHL Handbook, Kids Edition
- National and International VHL Clinical Care Centers

VHLA is a member of



A member charity of the Combined Federal Campaign and many other workplace campaigns  
CFC #10934