# VHL Alliance (VHLA)

*The Cure for Cancer is in Our Genes*

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

**VISION:** The VHL Alliance envisions a cure for VHL

## What is VHLA?

*VHL or von Hippel-Lindau disease is a genetic form of cancer. VHL patients battle a series of tumors throughout their lives. The VHL gene controls the major feeding pipeline of every tumor. Curing VHL is one step closer to curing many other forms of cancer.*

The VHL Alliance is a 501c3 non-profit organization founded in 1993 by three families with VHL to share experiences, learn from one another, support one another, and help the doctors understand and treat VHL, and make life for patients. Today, the VHL Alliance is the preeminent resource and clearing house of patients, caregivers, researchers and the medical community. VHLA is connected with approximately 90% of all diagnosed VHL patients throughout the world.

The VHL Alliance is about:

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

## What We Do

The VHL Alliance empowers patients and their health care teams to manage the health of the patients. Central to patient care is the *VHL Handbook: What You Need to Know About VHL*, written and published by VHLA. The Handbook, also available in a children's version, is the only document in patient-accessible language that offers tips on diagnosis and treatment while providing constructive ways of living with VHL.

The VHL Alliance connects patients with others living with VHL, answers questions for physicians, or field questions to appropriate experts. In other words, VHLA is an educational and support resource through:

- A toll-free hotline
- Personal conversations including a mentor program
- The Internet: VHLA website, social networking (Facebook, Inspire, etc.)
- Quarterly newsletters
- Monthly Wellness E-news
- Annual National Family Meetings
- Regional Meetings
- VHL Handbooks
- VHL affiliates in 28 countries around the world
- VHL Clinical Care Centers in the U.S. and around the world

## Research

The VHL gene, discovered in 1993, holds the code for the production of the VHL protein. When the normal supply of the VHL protein is interrupted, the normal regulation of cell growth is also disrupted kicking off a process known as angiogenesis, the growth of new blood vessels. This is a normal process gone out of control. It can lead to formation of a knot of unnecessary blood vessels, or one of a variety of tumors in different organ systems. Angiogenesis is this same process which takes place in all cancers, and is necessary to fuel the growth of a cancer tumor. Research on VHL and the VHL protein are therefore key to solving cancer for everyone, not only for people with VHL. By following the clues given by VHL, we are developing new strategies for dealing with cancer.

The VHL Alliance is a leading funder of VHL research with over $1.4 million granted to support studies designed to find a cure. While these funds have not yet uncovered an effective pharmacological treatment for VHL, the supported research has resulted in approval of multiple cancer drugs for other cancers including kidney and breast cancers. VHLA envisions that a cure will be found, eliminating the need for patients to undergo multiple surgical interventions to control their tumors. To help expedite the process, the VHL Alliance established a Clinical Trials Task Force comprised of some of the leading VHL clinical researchers in the world.

At the suggestion of VHLA's Research Council, in the spring of 2014, VHLA launched a state-of-the-art patient registry. The Cancer in Our Genes International Patient (CGIP) Databank is an innovative and comprehensive clinical research effort that will expand strategies for treating many forms of cancer. For example, not yet fully understood is the impact that lifestyle has on tumor pathogenesis and progression. The CGIP Databank is designed to provide insight into many unanswered questions, including:

- Do commonly available over-the-counter medication impact tumor growth rate?
- What about diet or nutrition?
- Is there a correlation between anxiety, stress or depression and cancer?
- Can exercise help decrease the rate at which tumors develop and grow?
- Does pregnancy or changes in hormone levels put woman at greater risk for tumor progression?
- Does oral health influence cancer severity? (Oral hygiene has been tied to cardiac disease; evidence is accumulating for a link to pancreatic disease.)

## Who We Serve

VHL affects approximately one in 32,000 people (approximately 10,000 people in the U.S. and 200,000, worldwide) in every ethnic group, worldwide. The prevalence of VHL is approximately the same prevalence as muscular dystrophy and one-half that of cystic fibrosis. As a genetic disorder, VHL is primarily inherited from a parent, yet 20% of patients are "new mutations" – an event that occurs randomly to a child in a family with no prior history of VHL. Once this change occurs, a child of an affected person has a 50% chance of having the condition.

The VHL Alliance serves families with VHL, people pursuing diagnoses and treatment options or in need of support, and physicians seeking current information about differential diagnosis, screening, and treatment as well as researchers searching for a cure.

VHL Alliance
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