



2001 Beacon Street, Suite 208, Boston MA 02135-7787

Tel: +1.617.277.5667 or toll free +1-800.767.4845 • Fax: +1.858.712.8712 or toll free +1-866-209-0288

<http://www.vhl.org> / E-mail: info@vhl.org

What is von-Hippel Lindau or VHL?

- von Hippel-Lindau (VHL) is a disease caused by a genetic mutation of the VHL gene
- The VHL gene is involved in many other forms of cancer; it controls the major feeding pipeline to every tumor cell
- The disease causes the development of multiple tumors in a number of sites throughout a patient's lifetime, from early childhood through adulthood
- Sites at risk include: kidney, retina, spinal cord, brain, pancreas, adrenal gland, and inner ear
- Studies of the VHL gene have resulted in approval of multiple cancer drugs
- Particularly in the case of the kidney and pancreas, if not treated correctly, tumors can advance to malignant forms of cancer
- Currently, there are no approved drugs for treating of VHL
- The VHL mutation is a dominant inherited trait: offspring have a 50% chance of inheriting the mutated VHL gene
- 20% of people with VHL are the first person in their families with this disease
- VHL affects people of all ethnicities in every country of the world
- The prevalence of VHL is approximately one-half of that of cystic fibrosis (1 in 32,000)
- Approximately 10,000 people in the United States are affected by VHL and 200,000 worldwide
- ***The VHL gene controls the major feeding pipeline of every tumor. Curing von-Hippel Lindau brings us one step closer to curing many forms of cancer!***



2001 Beacon Street, Suite 208, Boston MA 02135-7787

Tel: +1.617.277.5667 or toll free +1-800.767.4845 • Fax: +1.858.712.8712 or toll free +1-866-209-0288

<http://www.vhl.org> / E-mail: info@vhl.org

What is the VHL Alliance (VHLA)?

Mission Statement:

The VHL Alliance is committed to improving diagnosis, treatment, and quality of life for individuals and families affected by von Hippel-Lindau disease.

- VHLA is the preeminent resource and clearinghouse for patients, caregivers, researchers, and the medical community. VHLA is about:
 - Education
 - Support
 - Diagnosis
 - Treatment
 - Research
 - Patients
 - Caregivers
 - Clinicians
 - Researchers
 - Building Awareness
- VHLA was founded in 1993.
- VHLA is connected to approximately 90% of all diagnosed VHL patients, worldwide.
- VHLA provides guidelines for VHL management
- VHLA is an educational and support resource through:
 - A toll-free hotline
 - Personal conversations
 - The Internet: VHLA website, social networking (Facebook, Inspire, etc.)
 - Quarterly newsletters
 - Regular e-mail bulletins
 - Annual family/caregiver meetings
 - Regional meetings
 - VHLA Handbooks
 - VHL Affiliates in 28 countries around the world
 - VHL Clinical Care Centers in the U.S. and around the world



2001 Beacon Street, Suite 208, Boston MA 02135-7787

Tel: +1.617.277.5667 or toll free +1-800.767.4845 • Fax: +1.858.712.8712 or toll free +1-866-209-0288

<http://www.vhl.org> / E-mail: info@vhl.org

The work of the VHL Alliance has led to:

- Over \$1.3 million for VHL research
- Clinical Trials Task Force working to create drug and imaging trials at multiple centers for a scattered population
- International Patient Registry designed to provide data on genetic and environmental factors contributing to VHL and other forms of kidney cancer
- A 16-year rise in the average life expectancy for a person with VHL over the past 20 years
- Enhanced quality of life
- Approved targeted therapies for other forms of cancer, including kidney cancer and breast cancer
- Clinical Care Centers, hubs of VHL care
- Tissue bank for surgically-removed VHL tissue for VHL research
- Strong international support community that breaks through feelings of isolation
- Understanding of the underlying bio-logical mechanism responsible for many other forms of cancer
- VHL Clinical Advisory Council
- VHL Research Council