


DETACH AND RETURN TO:



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

www.vhl.org / info@vhl.org
Phone: +1-800-767-4845 x4
Fax: +1-858-712-8712

Enclosed is my tax-deductible gift to support:

☐ VHLA ☐ Research only

Amount ☐ \$ _____

☐ My employer will match my donation. I have enclosed the necessary forms.

(Please make checks payable to VHL Alliance)

Name: _____

Address: _____

City: _____ State: _____ Zip: _____

Country if not U.S.: _____

Phone: _____

E-mail: _____

I am a ☐ Person with VHL ☐ Family member
☐ Friend ☐ Health professional _____
(specialty) _____

Card number _____

Name on card _____

Exp Date _____

Address _____

☐ One-time payment of \$ _____ OR:
☐ Twelve monthly payments of \$ _____ each

VHLA is a non-profit corporation in the U.S.

Donation is **in honor of** or **in memory of** (circle one)

Please send an acknowledgment card to:

Address _____

- 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 biological mechanism responsible for many other forms of cancer
 - VHL Clinical Advisory Council
 - VHL Research Council

Vision:
VHLA envisions a cure for VHL

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.



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A member of



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

Find us on



THE CURE FOR CANCER IS IN OUR GENES

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



Carter, Age 5

- Sites at risk include: kidney, retina, spinal cord, brain, pancreas, adrenal gland, and inner ear



Chloe and Caleb

- 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!**



Keith, Poet/Musician

What is the VHL Alliance (VHLA)?

- 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

What people are saying about the VHL Alliance?

• DOCTORS

"I am a physician working with VHL patients and patients with many other genetic diseases. The VHLA is the most helpful and best organized genetic support group of any kind. I wish patients with other genetic disorders had a support group as well organized and useful as the VHLA."—VHLMD

"This organization does a fantastic job of informing its members and providing clinicians with critical information. The VHLA has made a major contribution to the care of VHL patients worldwide by creating and certifying treatment centers of excellence in which patients can receive coordinated and expert care for all of the manifestations of VHL."—Dr. M. Gorin

• PATIENTS

"I am impressed at how responsive, compassionate, and effective this group is. They are a lifeline to individuals and families coming to terms with this rare genetic disorder."—Eileen B

"VHLA...the most amazing organization. Questions are answered, support given freely and with care. If you or someone you love has VHL, you will never walk alone as long as you are a part of this group." —Myway



Intergenerational VHL Family

How can I help?

It takes teamwork and money to realize our dream of finding a cure for VHL. The VHL Alliance relies on its constituents to work toward this vision.

Volunteers are needed to help grow our efforts of education and support for those with VHL, their family members, the healthcare community and the general public. Dollars are needed to expand VHL research efforts – efforts that will lead to a cure.

Manuel,
First in Family



• VOLUNTEER

We need your help! Call the office at 1-800-767-4845 x4 or write to office@vhl.org.

• DONATE

- ❖ Send a check with the form on the back and mail it to:

The VHL Alliance
2001 Beacon St., Suite 208
Boston, MA 02135-7787

- ❖ Donate online at vhl.org/helpnow/
- ❖ Call the office with your credit card information at +1-800-767-4845 x4

• OTHER WAYS TO HELP

There are many other ways to contribute. Visit vhl.org/help/