

von Hippel-Lindau Alliance Annual Appeal

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Help Strengthen Our Alliance for a Cure

by Jan Capinegro, VHLA Board of Directors

Merriam-Webster defines Alliance as:

A bond or connection between families or individuals; an association to further the common interests of the members; the state of being joined in some activity or effort; a relationship in which people agree to work together.



This could not be truer of the VHL Alliance (VHLA). For our family, VHLA was the bond, the connection that helped us navigate a very frightening time in our lives. Our 15 year old son, an avid high-school athlete was in peak physical condition. After complaining about neck pain, our family physician recommended an MRI which revealed tumors in his brain and spinal cord. Words no parent ever is ready to hear. After a whirlwind of events, doctors at Children's Memorial Hospital in Chicago performed surgery to remove the tumors. His surgeon suspected the tumors were related to von Hippel-Lindau (VHL), which was later confirmed through genetic testing. After our family was tested, we learned that our son had a mutation of the VHL gene. He is one of the 20% of VHL patients who are "first in family" or a new mutation.

While at the hospital with our son, a colleague researched VHL and connected us to the VHL Alliance. As a family, we were spinning with fear and confusion over this rare disease and overwhelming diagnosis. The connection to VHLA helped center us, provide direction for managing VHL and gave us hope that there was indeed a strong future for our son. It was clear that VHLA was committed to support, research,

and education. VHLA reassured us that a cure was in our future. It was exactly the lifeline we needed. Fifteen years later, our son is happily married to his high-school sweetheart and has a growing career. He is committed that VHL will begin and end with him.

VHLA is an invaluable resource that educates, supports, and gives hope to so many individuals and families who are going through similar experiences, many with very young children. Together, we are joined in an effort to find a cure; working together with a community of patients, caregivers, volunteers, researchers, and healthcare providers ensures that anyone who comes to VHLA will be given hope for a strong future.

Thanks to research and the new patient registry (**Cancer in Our Genes International Patient Database**, pages 2-3), we have even more reason to be hopeful. Just over 20 years ago, researchers identified the VHL gene. This discovery has led to ongoing research on how the VHL gene affects the formation of tumors in the body, be it related to von Hippel-Lindau or many other forms of cancer including kidney, breast, adrenal, colon, liver, pancreatic, and lung.

Will you join our effort? By working together we can make a difference in the fight against cancer. Whether you volunteer, host a fundraiser, donate a little, or a lot—every effort will strengthen our alliance...

...We know that the cure for cancer IS in our genes and, by strengthening VHLA, we are certain to find a cure.

Quotes from Great Nonprofits

"I'm a family member of a VHL Warrior. We found VHLA earlier this year when going through another surgery. What a relief! First, the resources available (especially the handbook) have been invaluable! In addition to improving our own knowledge, we've been able to educate doctors in our area thanks to VHLA. Second, they have a connection to a community of caring, kind, knowledgeable, and driven people is extremely comforting. Each person I've had interaction with from VHLA has responded promptly and with genuine care of my personal interest. I feel grateful we have them! If you have to have VHL (or have a family member with VHL), at least you get VHL Alliance too!" — LizW

"I was diagnosed with VHL in 1993 and became part of the VHLA shortly thereafter. The VHLA has been the hub for patient education on the symptoms and monitoring of VHL and the backbone into research and establishing Clinical Care Centers. The VHLA is not only an organization but also a "community" where people can feel like they are not alone in the fight against VHL." — LUNAR



<http://greatnonprofits.org/organizations/browse/search:VHL+family+alliance>



Strengthening Clinical Care Centers

by Sarah Nielsen, MS, CGC, Chair, VHLA Clinical Advisory Council; VHLA Board of Directors



VHL patients are true warriors! Not many others can 'boast' being able to lie still for up to 6 hours in a MRI tube (even before listening to iPods was an option), or say that they have a group of healthcare providers large enough to be a football team! However, it is this unique aspect of VHL, the fact that the disease can affect so many different parts of the body, which makes coordinated medical care one of the biggest challenges individuals with VHL face. Screening for VHL begins at birth and thus requires that individuals navigate a wide variety of medical specialties throughout their lifetime. This is precisely why the Clinical Care Center (CCC) Program was initiated in 1994 at the inception of the VHL Alliance. We realized early on how important it is to be an empowered patient, through education of both yourself and the medical community. The National Institute of Health (NIH) began as the single hub for VHL care, but now most care is dispersed across the country, with 25 established CCCs in the United States, and 11 worldwide! As Chair of the Clinical Advisory Council, it is my job to ensure that these Centers are providing as high-quality, coordinated and compassionate care as possible. There are many new and exciting efforts currently taking place in order to strengthen the CCC's.

The CCC program has now developed to the point where it is clear that extended and redefined standards are necessary, both for the CCC's as a whole and for individual specialties. Dr. Armand Rodriguez, member of the Clinical Advisory Council, VHL patient, and internist at Imperial Medical Group in Fort Lauderdale, has agreed

to spearhead this effort. We are currently in the process of reviewing CCC renewal applications, and this is process we will repeat biennially to ensure that the CCC continue to meet the needs of the VHL community.

We are fortunate to have access to the leaders in VHL-related care, who form our Clinical Advisory Council and will be crucial in bringing their subspecialty-specific expertise to the table. We encourage open communication among our VHL care providers both within and amongst institutions and we recently created list-serves for each specialty in order to further open and focus the lines of communication and allow providers to learn from each other. The VHL Alliance has also adopted HLRCC (Hereditary Leiomyomatosis and Renal Cell Cancer) and BHD (Birt-Hogg-Dube) into its CCC umbrella and we are working to ensure the Centers are able to provide the necessary care for these individuals.

Two overarching areas with room for improvement have arisen in feedback regarding CCC's: coordination of care and incorporation of emotional health. Our renewal application now includes a question inquiring how the institution will define and implement coordinated care. Along these lines, we will continue to enforce the need for a point of contact who can address scheduling and logistical questions and a coordinating physician, the "quarterback" of the team, to decide when referrals to specialists are necessary and to make sure the patient is up to date on their annual screening. In regard to emotional health, we realize that coping with VHL can be an emotional rollercoaster for the patient and their loved ones. We are currently exploring how we can best address this important issue and are looking for your input! Please email us at clinics@vhl.org!

VHLA Groundbreaking Research Collaboration: Cancer in our Genes International Patient Database

November 2013 will mark the launch of the VHL Alliance's most momentous project: the **Cancer in Our Genes International Patient Database (CGIP)** for VHL (plus HLRCC and BHD). The VHL Alliance's Research Council has strongly recommended that we invest in ourselves and create this resource for both researchers and constituents. In partnership with the National Organization of Rare Disorders (NORD) and the FDA, and in collaboration with clinical researchers, this extremely important project will have great impact on our understanding of VHL.

A patient-driven registry will provide more than just a natural history of the disease and its various manifestations; it will also yield insights into how lifestyle and quality of life (diet, nutrition, exercise, mental outlook), family history (multiple family members can be easily compared), and environmental factors impact tumor growth and disease progression. Medication, including both prescription and over-the-counter, will also be analyzed to determine their impact on patient

outcomes. This is exciting, uncharted territory providing the quality of life insights that can only be found in a patient-driven database. The CGIP database is unlike the NIH database or other databases where limited information is entered by clinicians; it contains a complete "picture" of each patient with insights and observations only a patient can give.

Detailed responses to questions on a wide range of organs will reveal correlations between known VHL tumors and other possible effects in the body. Information obtained from this database will likely be relevant to other forms of cancer or diseases as well. Just as oral health has been shown to be related to cardiac disease, what are now considered unrelated conditions may be found to be related to VHL tumors in particular organs. Cross-disease analysis will also be possible with the CGIP database to find possible associations of genetic variations with other conditions, as has been done with autism and auto-immune disorders.

Another important function of the CGIP database will be to help expedite matching patients with clinical trials

Groundbreaking Research Collaboration—International Patient Database *(continued)*

as drugs become available for FDA or other international clinical testing. **Names and identifying information of participants will not be provided to researchers, nor will they be made public.** In the event that a researcher wants to contact a registrant regarding participation in a clinical trial, use of a tissue sample, or interview to obtain further information, the registrant will be asked by the VHL Alliance whether they wish to contact the researcher. There will also be direct benefits to each database participant. The medical history and medications sections will allow the participant to download and print out documents that can be used for their own medical appointments.

This unique database should prove to be an exciting resource for cancer researchers worldwide. The data will also stimulate scientific enquiry by geneticists, nutritionists,

physiologists, and environmental or population scientists.

The CIGP database is an ongoing study tool that will increase in value over time. VHL patients have already participated in research resulting in 8 new drugs to treat cancer; the power of this database will bring a number of new therapies, eventually resulting in a cure for VHL. The most important and costly piece is validation and updating of data to ensure that patient information is both accurate and current. Database information will also be linked to tissue sample and imaging data, providing further avenues of insight for researchers; VHL Alliance staff will work to obtain annual updates from the linked clinical data. The VHL Alliance needs your support both as a participant and as a donor for this valuable project and will provide suitable recognition for all donors. Be a part of our landmark effort to find a cure!

VHLA in its Third Decade

by Gayle Greene, VHLA Board of Directors

Have you noticed that something looks and sounds different? Our Board decided to update our name and logo to reflect the growth of our organization. The VHL Family Alliance was established 20 years ago as a support network for families, and while we are still that, we have expanded our focus. Besides families, our community includes dear friends, scientists, and doctors. To reflect our goals and community, we changed our name from the von Hippel-Lindau Family Alliance to the **von Hippel-Lindau Alliance**. Instead of the VHLFA, we are now the **VHLA**.

Along with our name change, we have updated our logo. We kept the knot graphic which depicts a stylized bird's eye view of four people holding hands, but we also enlarged our name and added a tagline—**"The Cure for Cancer is in Our Genes"**. We hope that the tagline will help new friends understand how finding effective treatments for VHL-related problems has widespread application outside of our rare disease community. Many, many VHL lesions are benign, of course. Nonetheless, our genes hold a key to treating tumors in individuals without VHL, as well.

The guiding principles for our organizational growth and work for the next 3-years have been outlined in our new Strategic Plan, which you can find on the VHL website, still www.VHL.org. For instance, in the strategic plan (www.vhl.org/wordpress/library/VHLA-Strategic-Plan), for instance, you can see that patients remain the

primary impetus for all that the VHLA does. Supporting patients and the institutions that make their lives better is why VHLA exists. In order to advance this goal, we have focused more than in the past on our fundraising efforts. We need to raise funds to keep the Alliance strong and in perpetuity, and we want to raise funds to support researchers and broaden awareness of VHL in our communities. Fundraising will allow us to maintain and grow our patient support services. With adequate funds, our Executive Director, Ilene Sussman, and our Director of Wellness, Suzanne Nylander, will be able to travel to conferences, stay abreast of clinical studies, and stay connected with doctors and patients. In that way, they will be ready to answer questions for patients and families who reach out to them. Fundraising will allow us to build the **Cancer in Our Genes International Patient Database** that you can read more about on pages 2-3. Eventually, fundraising will allow us to fund research that will ameliorate VHL forever.

Our hope is to lead our organization into its third decade with grace—allowing it to grow and flourish without changing what's made it an integral resource for all of us over its first 20 years.



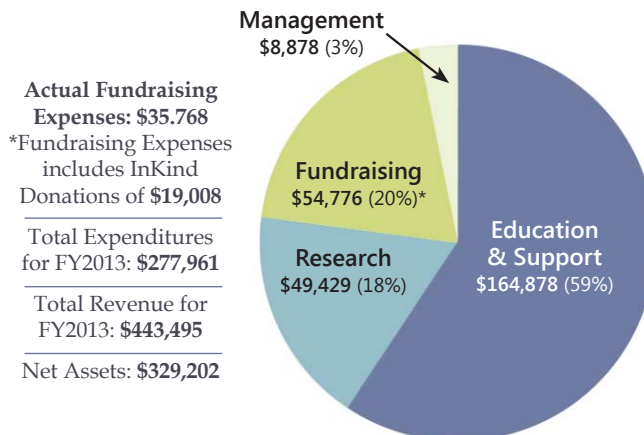
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Report for Fiscal Year 2013 (ended June 30, 2013)



Help Us Raise \$170,000 Between Now and December 31st!

Your help is needed to reach our joint vision of finding a cure for VHL! But until that time, VHLA is dedicated to research, education, and support to improve diagnosis, treatment, and quality of life for those affected by VHL.

Your donation today can be effectively doubled!

Thanks to a challenge grant from the Buckley, Greene, Horwitz, and Lusk Families, all donations received through the end of 2013 up to the amount of \$44,000 will be matched dollar-for-dollar! Support us with your tax deductible contribution.

Your contributions directly support VHL patients and medical research.

Here are some other ways that you can make a difference:

COMBINED FEDERAL CAMPAIGN: All federal employees may designate the *Alliance for Cancer Research and Support—VHL* as the recipient of their

generous gift by indicating our five-digit charity number 10934. Many states have state-level campaigns as well. See the brochure for our number.

FUNDRAISING EVENTS: You can organize an event to raise funds for VHLA. A group in Canada organizes a softball tournament every year to raise funds. This year, they raised over \$30,000! See a list of ideas at www.vhl.org/ways-to-help/fundraising-ideas/.

CREATE A LEGACY: Consider making a bequest of cash or property to VHLA in your will. Call our office to obtain our charitable non-profit information.

ATTEND VHLA EVENTS: See our calendar www.vhl.org/patients-caregivers/get-involved/calendar-of-events-and-meetings/.

Thank you in advance for your generous contributions to VHLA; we can't do it without YOU!

Mail to: VHLA, 2001 Beacon St, Ste 208, Boston, MA 02135-7787 USA
or Canadian VHLA, c/o Melanie Braaten, 602 Cowan Circle, Pickering, ON L1W 3K7

Enclosed is my tax-deductible gift to support: ☐ VHLA ☐ Research only

☐ \$25 ☐ \$50 ☐ \$100 ☐ \$150 ☐ \$500 ☐ \$1000 ☐ \$_____

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(Please make checks payable to VHL Alliance)

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- ☐ Send newsletter
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☐ Printed version
☐ Audio version needed
- ☐ I would like to receive occasional alerts via e-mail from VHLA only

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

Please charge my ☐ Visa ☐ MasterCard ☐ Amex Card number _____

Name as it appears on the card _____ Exp Date _____

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