



Dedicated to improving diagnosis, treatment, and quality of life for people with von Hippel-Lindau disease.

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Annual report, 2008-2009

As the first decade of the 21st century draws to a close, we celebrate the achievements we have made in the first 16 years of the VHL Family Alliance.

Education and Support Programs

Personal support is provided through telephone, e-mail, local chapters, and online support groups in 26 countries on six continents.

Personal Support via telephone and e-mail

The Hotline team handles an average of 300 calls a month in English in the United States and Canada. Staffed entirely by volunteers from VHL families, they answer calls in their own homes. Backup is provided by lay experts in particular aspects of VHL, and our Medical Advisory Board, and the Expert Centers in the world with the highest concentration of knowledge about VHL.

E-mail inquiries can be sent to info@vhl.org, or to any of the chapters using a coded address (e.g. us-mt@vhl.org) which is forwarded to the volunteer on duty for the state represented by the 2-character postal abbreviation in the address. In this way the addresses remain consistent, while the staffing can be modified behind the scenes as needed.

Online Support Community

We have five online support communities in different languages: English, French, Spanish, German, and Japanese. All of these started in Yahoo!Groups; most have now moved on to better platforms that provide more privacy. Since 2007, the English-language group has resided on a free platform known as Inspire (formerly ClincaHealth). Volunteers Gale Lugo (Florida), Tina Gruner (Oregon), and Jennifer Kingston (Australia) serve as moderators of the group.

As of June 2009 there are 750 members of the Inspire community, an increase of 25% since June 2008. In addition, the German online support group has 63 members; there are 179 in the French group (doubled in one year!), and 95 in the Spanish group (up 17%). The membership of all these groups spans country boundaries and brings together by language group people with common concerns on multiple continents. The Spanish group, for example, includes people in the United States, Mexico, Spain, and ten countries of Central and South America. The Japanese group includes 47 people in Japan.

Facebook

In addition, there is an online discussion group in Facebook which has now reached 1600 people – having been started less than a year ago. This group tends to be less heavily medical than the Inspire group. It is “social networking” more than medical support.

Chapters

The Chapters Program has been an area of focus this year. In most US states and 26 other countries we have at least one designated contact who is able to speak with people in the local language about medical and social services available in their area, and to provide much needed morale support.

Mary Lou Linn, a retired reference librarian and mother of a young man with VHL, joined our team in 2007 primarily to work with the volunteers who lead the various U.S. Chapters around the country. She is able to focus her energy on recruitment, training, coaching, and acknowledgement of these key volunteers, and coaches the local volunteers in organizing regional meetings.

Some Highlights:

- Ann Riley, Chapter Chair in Connecticut, attended the New England regional meeting in October 2009 in Springfield, Mass.
- Amy Milor is co- chapter chair in Virginia.
- Beverly Angotti replaced Gale Lugo as chapter chair in Florida. Gale resigned for health reasons.
- Brian Dougherty resigned as Chapter chair in Kentucky . His new career placed too many demands on his time. Audrey Clifton is now chapter chair for Kentucky.
- Chasity Casey is the new chapter chair in Georgia. She was recruited at the annual convention in 2009.

Website

The Website (vhl.org) is one of our primary services. This year we served nearly 2 million pages of information to an average of 1900 people per day. 75% of our traffic is from North America, 9% from Latin America, 10% from Europe. A full 10% of our traffic is in Spanish, demonstrating the increasing importance of Spanish language services. We are working with key players in Spain and Latin America to create a medical symposium in Rio de Janeiro in October 2010, with translation between English and Spanish. In addition to pointers on www.vhl.org, an index of European country support groups is maintained by our German affiliate at <http://www.vhl-europa.org>.

Handbook**

The Handbook is now available in English, Spanish, French, German, Danish, Italian, Chinese, and Arabic, and is being translated into Hindi and Malayalam, languages of the Indian subcontinent. Copies are available for download free from our website. In a recent test month, 19% of our website traffic was for the Spanish pages, 5% for French, 5% for Chinese, and 1% for Arabic (about 10 copies a month of the Handbook in Arabic). Additional local language versions are in progress. All translation has been done by volunteers. Translation into Arabic was donated by Bioscientia, a research company in Germany which does a great deal of work with Middle Eastern nations. The translation was done by in-house staff and verified by physicians in the Middle East.

All versions of the Handbook are available free for download from the internet and on paper by request. In this fiscal year, more than 1000 copies of the English-language handbook were downloaded from the internet, 199 copies in Spanish, 204 copies in French, about 20 per month in Chinese, and 10 per month in Arabic. For those who do not have access to the internet, we send paper copies in the mail.

VHL Handbook: Kids' Edition

Since 2006 a committee of parents and professionals has worked to create a version of the Handbook designed for children. The demographics of our community have changed significantly since 1993. With increased availability of DNA testing and increased awareness among physicians, a growing number of children are being identified with VHL. 80% of these are children of a parent with VHL, but a full 20% are children who are the first in their families ever to have VHL.

Our goal in producing this book is to help children and their families understand what VHL is, and learn to manage their health. It is important for children to take ownership of making healthy choices and participating in the management of their health. This book presents VHL – what it is, what kinds of things can occur, how we monitor to find problems early, and how the child can make a difference and cope with the stresses of this condition.

Newsletter

The Newsletter (paper and electronic) remains our key framework for delivering information. In addition to the paper readership, many people access the information on the web. With the help of a network of volunteer translators, articles from the newsletter and original local information is available on the web in English, Spanish, German, French, Japanese, Danish, Italian, Flemish, and Dutch.

On the website people can sign themselves up for our e-mail newsletter. We moved the list to a different billing and list management platform where we can verify subscribers more carefully and weed out inactive addresses. We now have more than 1573 verified e-mail subscribers in this list.

Regional Meetings

In an effort to make it possible for more people to attend face-to-face meetings, we held another series of Regional Meetings this year, in a one-day format (10:00 AM to 4:00 PM), allowing people to commute to the meeting. A modest donation is requested to cover the cost of lunch and facilities. Local doctors provide most of the "talent", with the occasional addition of an expert from outside the area, and a representative of the VHLFA Board.

Meetings were held in FY09 in
Bellevue, WA, June 2008
Houston, TX, November 2008
Hoboken, New Jersey, March 2009
Austin, TX, March 2009
Windsor, Ontario, Canada, April 2009

The Annual Meeting was held at Hyatt hotel in Anaheim, California, in June 2009. Ten speakers gave excellent presentations. Handouts and video presentations of each talk are available on the internet at <http://vhl.org/videos>

Medical Education

Our Biennial Medical Symposium was held in Roskilde, Denmark, in September 2008. 125 physicians and researchers from all over the world gathered to share their findings, form connections, synergize, and move VHL research forward. The Center was shared with the first medical symposium on Birt-Hogg-Dubé disease, a one-day symposium dedicated to BHD which preceded the VHL 3-day meeting. The Danish VHL Family Alliance organized and hosted the meeting.

Clinical Care Centers

Three more institutions joined our Clinical Care Centers program this year:

- University of California at Los Angeles (UCLA)
- Mayo Clinic, Jacksonville, Florida
- University of Miami, Florida

Through this program we have created two-way communications with the physicians most knowledgeable about VHL at major institutions in ten countries. They provide us with a single point of contact, and we maintain a listing on the internet of how people can reach them. Each institution is required to provide all the services needed to manage VHL, and to assist patients in navigating the institution to find the right specialist at the right time and successfully manage their health.

Research

The goal of our research program has been to encourage more young researchers to undertake the study of VHL. With our seed money grants, younger researchers are able to compile the proof-of-concept data and findings that make it possible for them to obtain larger grants from major funders. More precious than money is the availability of biomaterials for study. This year two new areas were added to our Research Program: expanded Tissue Banking and a Research Database.

From an “obscure” disease in 1993, “VHL” is on the tip of the tongue of every researcher in kidney cancer, angiogenesis, and cancer in general. The VHL protein is the primary controller of the process of angiogenesis – a benefit in wound healing or rerouting blood around clots in the heart, but a problem in the formation of hemangiomas, hemangioblastomas, and the food supply that feeds cancer tumors.

Since 1998, the VHL Family Alliance has awarded more than \$1.4 Million in research grants.

Research Grants

During 2009 the Board of Directors approved the recommendations of the Research Advisory Board to fund one additional research grant of \$18,000 for a one-year commitment to:

- Rachel Giles, M.D., Ph.D., Associate Professor, Laboratory of Experimental Oncology, University of Utrecht, the Netherlands, to support her work using Zebrafish as a model to understand the workings of von Hippel-Lindau disease. Zebrafish are transparent, allowing us to watch the development of a VHL tumor in a living organism.
- Thera Links, M.D, Ph.D., University of Groningen, the Netherlands, has been granted a no-cost continuation of the grant awarded 2007-2008 to complete the project “Visualizing VEGF producing lesions in von Hippel-Lindau” by scanning 30 patients using a radioactive labeled antibody, based on Avastin, to see if these PET scans can correctly depict the level of tumor activity.

Research Infrastructure

With help from the Alex’s Lemonade Stand Foundation we established a tissue bank at the National Disease Research Interchange (NDRI). We were the first voluntary health organization to join their Rare Disease Initiative, a program funded in part by the Office of Rare Disease Research at the U.S. National Institutes of Health. Ranjana Sharma is the Research Coordinator working with this program, recruiting people into the program, assisting them in filling out forms, and interfacing with NDRI.

In FY09 we piloted a program aimed at “genotyping” the tissue samples in our bank. We offered to reimburse one-half the cost of DNA testing if people would register as tissue donors and provide a copy of their DNA report to the bank. Thus researchers can learn, before obtaining a sample, which VHL mutation type is in the sample. This makes our samples more useful to researchers.

The program has been very successful. At the end of FY09 the Board of Directors voted to continue the program indefinitely, establishing it as a key service we offer to our community.

Research Database

As part of our Research Infrastructure project we improved the Research Database questionnaire and the Access Database used to store this information. This work was done in collaboration with our German affiliate, under Gerhard Alsmeier. Our goal is to gather and store a significant amount of information about hundreds of people with VHL so that we can begin to understand the early signs of future problems, and any other accompanying signals that may appear in people with VHL. One thing we have learned is that this kind of data collection requires a greater effort than we are currently able to afford.

Gerhard Alsmeier in Germany has obtained a grant from the Robert-Bosch Foundation in Stuttgart to automate the database as a web-based tool that could be used by the physician or indeed by the patients themselves to enter a detailed medical history and track the state of the health of this person over time. This program is being implemented in Germany in February 2010. We are currently seeking funding to implement this program in the United States as well.

Tracking Drug Development

When we began in 1993, we all were hoping for the day when there would be a pill to take to prevent the formation of new tumors. We projected that it would be at least ten years before such drugs came on the scene, and probably another ten before they were approved. This year two drugs were approved for use with metastatic kidney cancer (not VHL), which may have some applicability to VHL. These are not the ultimate drugs we are still hoping for, but it’s a start.

Once drugs are approved, doctors can prescribe them for conditions other than the ones on the label. This “off-label use” is legal, but of course is entirely untested. It also means that insurance companies will likely decline to reimburse for the drug, and these new drugs are often quite expensive. It therefore behooves us to determine, through careful scientific studies, whether these drugs are effective for VHL. If we can gather sufficient evidence, the drug company can apply to the Food and Drug Administration to put VHL on the label which would then allow insurers to reimburse for the drug.

We are in conversation with a number of researchers to determine the best way to track off-label use. This would be a natural branch of the research infrastructure project. With a web-based tool, we might be able to gather information from patients who are taking “off-label” drugs under the guidance of their local doctors

Building Income

We experimented with a number of new funding channels this year. Alex Anderson of New Jersey proposed that we have one designated international fundraising day in May, where

everyone would work to raise the visibility of VHL and raise money to expand our research initiatives.

This combined effort did result in much increased awareness. The net gain in funding was disappointing, as the level of effort was sometimes greater than the revenue warranted. We are reviewing these efforts and will be attempting to “work smarter” in the coming year.

Staffing

During this fiscal year our staff consisted of:

- Executive Director, Joyce Graff, full-time
- Research Coordinator and Office Manager, Ranjana Sharma, part-time
- Membership Coordinator, Mary Lou Linn, part-time
- Development Coordinator, Anita Kalathara, full-time (ended May 2009)
- Publications Assistant, Robin Cochrane, part-time
- Bookkeeper, Pamela Bracken, part-time (10 hours/month)
- and a large number of wonderful volunteers throughout the United States and the world.

Each of our Board members and committee chairpersons contributes some time to the management of the organization. Altheada Johnson manages info@vhl.org and the hotline staff, which are our primary lines of contact with the membership and the world. She has been assisted this year by Jody Herbst (South Carolina), Audrey Clifton (Kentucky), Kathy Miner (Arizona), and Emily Stevens (New Jersey). Dr. Myriam Gorospe (Maryland) who answers the Spanish hotline, and Joyce Graff (Massachusetts) answers the French hotline.

Complementing this core staff are Copilevitz & Canter (state registrations) and Independent Charities of America and the CancerCURE Federation (CFC applications and promotional events). Linda Berk volunteers to help prepare CFC state registrations.

Financial record-keeping is done by staff in Boston, with records shared with our Treasurer in California through a service called QuickBooks Online, a service of Intuit on the internet, that allows people in multiple locations to log in and look at the same set of books simultaneously.

Public Awareness

- Alice Coday of Washington State was awarded the Lance Armstrong LIVESTRONG Challenge award. This means that she was chosen by the Lance Armstrong Foundation as the person in Seattle who has made the most significant impact on the fight against cancer.
- Alex Anderson of Margate, New Jersey, and a number of his teen-age friends staffed awareness booths around town on one weekend in May, selling VHL wristbands and talking with people about VHL.
- The Maryland Chapter, under Kelley Mackesey, held a CrabFeast and raised awareness and funds for VHL.
- Anita Kalathara organized a music event on Boston Common to raise awareness of VHL.
- Three teams of walkers participated in the Jimmy Fund Walk to raise money for kidney cancer research at Dana Farber, specifically focused on VHL.
- Kim Hall completed two triathlons (New York and Seattle), raising money for VHL.
- Beth Smith and two friends completed their second Triathlon in Massachusetts, raising money for VHL.
- The Norcross family in Iowa was interviewed in their local newspaper in hopes of raising awareness of VHL. Larry, the father, subsequently passed away. Family and friends donated money in his memory to VHLFA..
- Malinda Sagrestano (Pennsylvania) shared her story of delayed diagnosis of a

pheochromocytoma with Mystery Diagnosis. The show broadcast in May 2009. It proved to be particularly useful for training physicians. We showed the episode at the Anaheim meeting and discussed how a patient might be able to work with the doctors get to a correct diagnosis in a timely manner.

- Jeff Romanoff (Pennsylvania) received a kidney transplant at Cleveland Clinic from a fellow member of a Star Wars re-enactment group. This gained significant press coverage in Pennsylvania and Ohio.
- President Obama toured the VHL research laboratory of Dr. Marston Linehan. Press coverage did not include the name of the disease, but did include photographs of Dr. Linehan.
- Blythe Graziano (age 8, New Jersey) asked her friends to donate to VHL instead of giving her birthday presents. He father and sisters and many family members have VHL. Her guests donated \$180, which her family matched, for a total of \$360.
- Amy Lynn Budd presented her play in Providence, Rhode Island for a fund raising event in June. "The thing that ate my brain almost" is the first play ever about VHL!

In-Kind Donations

In addition to the support of so many wonderful donors and volunteers, we have been gifted with valuable in-kind donations from the following vendors:

	<u>Value</u>
MailWise Spam and Virus Protection Services for all vhl.org accounts	\$1800
Dr. Backup Offsite Backup Service for the Boston office	\$ 659

Special projects in need of funding:

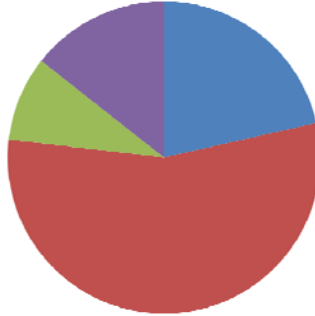
These projects could bear the name of the donor:

- Funding creation of a "cell line" to be part of our research infrastructure (\$800 each)
- Outreach to the medically underserved - (radio spots at \$1000 each)
- Funding for more local meetings for members (\$1000 each)
- Smaller and more accessible Continuing Medical Education training events for physicians via webcast or teleconference (\$1000 each)
- Clinical Care Bulletins in support of the Clinical Care Centers (\$2000 per year)
- Distributing the *VHL Handbook: Kids' Edition* to families through our clinical care centers program (\$3000)

Financial Report

for Fiscal 2009 (ended June 30, 2009) – Audited Financial Data

Total Revenue for Fiscal 2009 (ended June 30, 2009) was \$284,613. Of this, \$61,020 was allocated to the research program, for grants and tissue banking.



Of our Expenses:
\$61,020 (21%) Research
\$157,705 (56% Education and support
\$25,029 (9%) Fundraising
\$40,859 (14%) Admin

Liabilities and Net Assets:

Accounts payable and accrued expenses	\$13,217
Grants payable	\$18,000
<i>Total Current Liabilities:</i>	<u>\$31,217</u>
Unrestricted net assets	\$105,639
<i>Total net assets</i>	<u>\$105,639</u>
<i>Total Liabilities and Net Assets:</i>	<u>\$136,856</u>

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