



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

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Annual report, 2005-2006

In this year of exciting developments, we have increased the capacity of the organization and have begun to build a stronger research infrastructure, to attract more researchers to study VHL. As always, our activities fall into two major groups: Education & Support and Research.

We moved!

For the first 14 years of our existence we occupied space in a private home, growing from one room to 2 ½ rooms in the house. In June of this year we moved to a three-room suite in an office building, giving us more space and a business atmosphere to welcome visitors and volunteers. We have added two additional part-time staff and several volunteers to form a solid base for our expanding programs, and to expand our capacity to serve.

Education and Support Programs

From the beginning, we realized that it would take some time – measurable in decades – before there would be a drug that would magically fix VHL. In the near term, we set out on a program to educate both families and physicians, to get more rapidly to an accurate diagnosis, and to help them determine the optimal treatment. This program of early diagnosis and better treatment has been successful in breast cancer and prostate cancer, and it has also been very helpful for VHL. Our job is far from done, but we have made a good start.

Education begins with the Handbook, the website, and public awareness initiatives, aimed at getting good information about VHL available in local language to the thousands of people around the world who are affected by VHL and their local physicians. Personal support is provided through telephone, e-mail, local chapters, and online support groups.

Personal Support via telephone and internet

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.

Chapters

The Chapters Program has been an area of focus this year. In most US states and 16 other countries we have at least one designated contact who is able to speak with people in local language about the medical and social services available in their area, and to provide morale support. Alex Lewis, our Program Assistant, undertook focused central administrative support for this group of key volunteers, and has worked to increase interaction among the chapters and with the staff. With the help of volunteers Gale Lugo (Florida) and Fran Mott (Michigan)

She has assembled additional support materials and goals for each of the chapters to accomplish over the coming year.

Website

The Website (vhl.org) is one of our primary services. This year we served over 1 million pages of information to an average of 1700 people per day – 1,140,000 successful page requests for the year, or an average of 95,000 per month. 75% of our traffic is from North America, 9% from Latin America, 10% from Europe. A full 10% of our traffic is in Spanish language, demonstrating the increasing importance of Spanish language service. We are working with key players in Spain and Latin America to add a professional meeting in Spanish language in 2007. In addition to pointers on www.vhl.org, an index of European country support groups is maintained by our German affiliate at www.vhl-europa.org.

Handbook

The Handbook is now available in English, Spanish, French, German, Danish, Italian, Chinese, and Arabic. 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 will send paper copies in the mail.

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 now have more than 2839 e-mail subscribers to this list, an increase of 33% over the previous year.

Online Support Groups

VHLFA provides *online discussion groups* in five languages on the internet, based at Yahoo Groups. These internet-based conversations provide support 24 hours a day, worldwide, in communities based on common language. The English language group has grown another 7% this year to 528 members. This group has been an excellent source of support for those going through new procedures as well as those newly diagnosed. The German group has 63 members; there are 90 in the French group (up 22%), 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.

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 (10-4), 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 FY06 in

Bethesda, Maryland, October 2005
Little Rock, Arkansas, November 2005
Boston, Massachusetts, October 2005
San Francisco, California, January 2006
St. Louis, Missouri, May 2006
Salt Lake City, Utah, June 2006

The Annual Meeting was held at the University Guest House, on the campus of the University of Utah, in Salt Lake City. Dr. Russell Lonser of the U.S. National Institute for Neurological Disorders and Stroke gave an outstanding talk on endolymphatic sac tumors which has been recorded and is being prepared for the internet.

Medical Education

Our Biennial Medical Symposium will be held in London, Ontario, Canada, in October 2006, hosted by our Canadian affiliate organization, the University of Western Ontario, and the Robarts Research Institute, and chaired by Dr. Stephen Pautler, Urologist at Western.

In order to make it more convenient for doctors to obtain current information, such as that presented in Salt Lake by Dr. Lonser, we are arranging for streaming video presentations to be housed on our website. We have a commitment also from the Office of Rare Diseases of the U.S. National Institutes of Health to link from their website to ours for the videos of the symposium. This should give much greater prominence and distribution to this critical information on VHL.

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.

In 1992 there were only 8 articles written in the medical literature about VHL. In 2002, 145 new articles on VHL appeared. So far in 2006, there are 326 new articles about VHL in the medical literature. This is an astounding building of momentum in research on VHL, which we want to strengthen and expand.

Research Grants

During 2006 the Board of Directors approved the recommendations of the Research Advisory Board to fund three grants of \$35,000 each for a one-year commitment to:

- Dr. George V. Thomas, Department of Pathology, UCLA, Los Angeles, CA - Individualizing mTOR inhibitor therapy in kidney cancer.

- Dr. Susanne Schlisio, Dana-Farber Cancer Institute, Boston, MA – Neuronal apoptosis by the prolyl hydroxylase Egln3: oxygen sensing and cancer.
- Dr. Donald Bellgrau, Professor of Immunology and Medicine, University of Colorado, Cancer Center, Denver, CO – Mutant VHL targeted molecular immunotherapy.

As one example of the success of our Research Grants program, Stanford University, in their Annual Report for 2005, lists VHLFA as one of their donors, and announced that Judith Frydman (one of our awardees, who finished her second year of funding from us during FY06) has been awarded a grant from NIH: “NIH Awards Funding for Protein Folding Machinery Center.” Stanford University was one of six institutions awarded funding by the National Institutes of Health to establish the Center for Protein Folding Machinery. Judith Frydman, associate professor of biological sciences, will serve as co-director of the project, and faculty in the chemistry, structural biology, and bioengineering departments also will participate. The mission of the center is to understand how proteins called chaperones guide other proteins through the folding process. The research could lead to advances in the treatment of diseases such as Alzheimer’s and cancer.”

Tissue Banking

It has become clear from our conversations with researchers that in addition to grant funding, the next greatest inhibitor of research on VHL is the availability of tissue for study. We spent this year evaluating options for expanding our Tissue Banking effort. The Board approved at the June meeting a proposal to move our existing Tissue Bank to the National Disease Research Interchange (NDRI), where we can not only store tumors but also blood, urine, saliva, and cell lines, creating a rich resource for researchers. One of the major hurdles in studying rare diseases is the availability of tissue for study. With a repository of tissue on hand, it becomes much more feasible to undertake a study of VHL.

Research Database

As the year ends, we have also been awarded a grant from the Alex’s Lemonade Foundation to create a research database to collect data which will also help to inspire researchers to undertake VHL research. As one example, we have been unable to get a researcher interested in epididymal cystadenomas or the corresponding tumor in women. Because these are “benign” tumors, no one has yet collected scans or tissue to study them. We will make an effort to collect a sufficient number of stories and tissue samples over the next two years to form the basis for a study. Our goal is to understand better how to do a differential diagnosis between these benign tumors and similar-looking more dangerous tumors, and prevent the significant over-treatment going on today.

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 and get insurers to reimburse for the drug.

We have begun conversations with two drug companies and our clinical care centers and will be working in fiscal year 2007 to set up multi-center studies with Sutent (Pfizer) and Nexavar (Bayer) to determine their effectiveness for VHL.

Building Income

We changed our method of calculating donors versus members this year. While in the past, anyone who gave at least \$25 was considered a "member," this year we are distinguishing between one-time donors to various fundraising events and "members" who want the newsletter and will likely be with us over time. This caused the membership number to seem to drop, but in fact we believe it is a number more reflective of the number of people who consider themselves "members." Recalculating last year's figures in the same way, we met this year's goal of increasing the paying membership by 10%. We would like to do the same in the coming fiscal year. While our membership dues are quite modest (\$25 domestic, \$35 international), it establishes an important base.

Individual members have helped greatly this year by creating Personal Fundraising Pages at Firstgiving.com/VHL. Pages celebrate events, remember loved ones, or simply tell a person's story and ask friends to participate in finding a cure for VHL and for cancer. More than \$15,700 was raised by members through this channel.

Our income through the Combined Federal Campaign increased 400%, but it's still a relatively small number (\$15,000) and we are working to increase our visibility and appeal through this channel. This is the primary way we reach out to the general public. Monies pledged in the fall 2006 campaign will be received through payroll donations received by the end of calendar 2007.

We received the second half of the grant from the Kendall Foundation for Project Outreach, working to identify more people with VHL among the "medically underserved," especially in the New York area. This money helped in the completion of a package of materials in Spanish language, and in the production of a Public Service Announcement, featuring rapper Keith Richards from New York. Uptake of this PSA has been disappointing, but we are still working with Keith to broaden distribution. His song, "Staples," has been very well received on the VHL website.

We are working to identify additional Corporate Partners and Foundations to assist us in our funding goals. We welcome any input from the membership in helping us grow and succeed in this area of fundraising.

Staffing

Our staff now consists of

- Executive Director, Joyce Graff, full-time
- Project Assistant, Alexandra Lewis, part-time (10 hours/week)
- Donations and Gifts Assistant, Cassie Désir, part-time (15 hours/week)
- Publications Assistant, Robin Cochrane, part-time (10-15 hours/week)
- 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 Audrey Clifton (North Carolina), Emily Stevens (New Jersey) and Evelyn Werner (New York). Alexandra Morais (New Jersey) answers the Spanish hotline, and Paul Bonneau (Québec) 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).

Financial record-keeping is done by staff in Boston, with records shared with our Treasurer in Michigan 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

- Derik Hodges of Connecticut told his story as part of VHL Awareness Month, May 2006. A press release was sent out, and our chapters worked with Derik's and their own stories to make inroads into the local press where they were.
- Brooke McLaurin, Miss North Carolina 2005, toured and spoke about VHL and brain tumors at every opportunity during the year of her reign. She sponsored a golf tournament, and a medical education event in Fayetteville, North Carolina. Even though she did not win the Miss America contest in 2006, she did a great deal to expand awareness of VHL.
- Joyce spoke at Wilton High School in Wilton, New Hampshire, for DNA Day on Monday, April 17, co-teaching with Courtney Nichols, genetic counselor from the Human Genome Institute.
- Pei-Yin Lin (one of the researchers we are funded in FY05) gave two oral presentations at the Young Investigators Forum in San Francisco April 29. She sent us thanks for the support from VHLFA.
- Alice Coday of Washington State was interviewed by the Wall Street Journal for an article published May 23, 2006.
- Alex Anderson of Margate, New Jersey, put up a Lemonade Stand at a local event in Atlantic City, and raised \$10,000 for VHL. This was matched by the Alex's Lemonade Stand foundation, to provide \$20,000 to VHL Family Alliance to help build a research database to accompany our new Tissue Bank and further strengthen our research infrastructure. This project begins in December 2006.

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

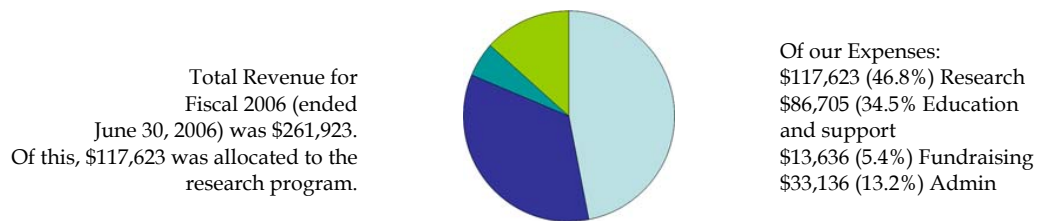
Special projects in need of funding:

These projects could bear the name of the donor:

- 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)
- Funding creation of a "cell line" to be part of our research infrastructure (\$800 each)

Financial Report

for Fiscal 2006 (ended June 30, 2006) - Audited Financial Data



Liabilities and Net Assets:

Accounts payable and accrued expenses	\$10,269
Grants payable	<u>\$105,000</u>
<i>Total Current Liabilities:</i>	\$115,269
Unrestricted net assets	<u>\$88,040</u>
<i>Total Liabilities and Net Assets:</i>	\$203,309

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