



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

2001 Beacon Street, Suite 208, Boston, MA 02135-7787 USA
Tel: +1-617-277-5667 – Fax: +1-858-712-8712
<http://www.vhl.org> – info@vhl.org – 1-800-767-4VHL

Annual report, 2007-2008

We have continued to build a strong infrastructure in this exciting year, and have undertaken some pretty exciting public awareness projects which have brought VHL more into the public eye. Our programs fall into two major categories: Research and Education.

Education and Support Programs

Personal support is provided through telephone, e-mail, local chapters, and online support groups in eighteen countries. The newest member of our international affiliates program is South Africa.

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. In fiscal 2007, we moved the English-language group to a free platform known as ClincaHealth, a startup company providing free discussion group services to health communities like our own. We were one of their first groups.

In April 2008, ClinicaHealth changed its name to Inspire.com and released a new version of its software platform on the web. Although we had been clear about our needs for good communication around the release, they did not prepare the community (about 450 people) for the level of change they were putting forward, and many people were confused. Gale Lugo and Joyce Graff worked hard with members of the community, and Joyce negotiated with Inspire to provide documentation, make improvements, and generally get our community back to the level of comfort necessary to support the discussion activity we had enjoyed up to that point.

As of June 2008, the community is generally quite happy again, activity is up, and there are now more than 600 subscribers to the English language list. The German group has 63 members; there

are 90 in the French group (up 22%), and 95 in the Spanish group (up 17%). The Japanese group includes 47 people in Japan.

Chapters

The Chapters Program has been an area of focus this year. In most US states and 18 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. Mary Lou Linn, a retired reference librarian and mother of a young man with VHL, joined our team this year 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, and coaching, and acknowledgement of these key volunteers.

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. This e-mail list has grown 33% in the past year.

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 FY07 in
Greenwood, SC, November 2006
Dallas, TX, November 2006
Philadelphia, PA, April 2007
Boston, MA, June 2007

The Annual Meeting was held at the John Hancock Conference Center in Boston. Ten speakers gave excellent presentations. Handouts and video presentations of each talk are available on the internet at our new video/podcast library, <http://vhl.impactlearning.org>

Medical Education

Our Biennial Medical Symposium was 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. Researchers from 12 countries shared the current state of their research with one another, and with 30 patients and family members in attendance. The next Symposium will be held in September 2008 in Denmark.

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 we have continued to build our Tissue Bank and a Research Database.

Research Grants

During 2008 the Board of Directors approved the recommendations of the Research Advisory Board to fund three grants of \$40,000 each to the following scientists:

- **Thera P. Links, M.D., Ph.D.**, of the University of Groningen will do a project involving "Visualizing VEGF producing lesions in Von Hippel-Lindau."
- **James Handa, M.D.**, of the Wilmer Eye Institute of Johns Hopkins Medical Institute in Baltimore, will study the "Use of a novel genetic animal model to study the molecular pathogenesis of retinal hemangioblastomas in VHL disease."
- **Rupal Bhatt, M.D., Ph.D.**, of Beth Israel Deaconess Hospital and the Dana Farber/Harvard Cancer Center in Boston, will study the "Role of the Interferon Gamma Pathway in Resistance to Antiangiogenic Therapy." This grant is co-funded with the Renal SPORE at the Dana Farber/Harvard Cancer Center in Boston.

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 have moved our tissue banking to the National Disease Research Interchange (NDRI), where we can not only store tumors but also blood, 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. This is particularly important in studying some of the more rare tumors that occur in VHL. Without tissue to study, no researcher can undertake the project.

Research Database

With the help of a grant from the Alex's Lemonade Foundation we have created 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 are working to collect a sufficient number of stories and tissue samples 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 are working with members of our Medical Advisory Board to determine how best to collect information about the off-label use of drugs for VHL.

Building Income

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 2007 campaign will be received through payroll donations received by the end of calendar 2008.

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 volunteers Audrey Clifton (North Carolina), Emily Stevens (New Jersey), Evelyn Werner (New York) and Jody Herbst (South Carolina). 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 New York State 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

- Joyce Graff was appointed to the Director's Consumer Liaison Group (DCLG) which reports to Dr. John Niederhuber, Director of the National Cancer Institute. This is a five-year appointment to a 16-member committee of consumer advocates representing people with cancer that meets several times a year with Dr. Niederhuber.
- President Bush visited the laboratory of Dr. W. Marston Linehan at the National Cancer Institute and met personally with several VHL patients at the Clinical Center, including Dale M., our chairperson for Montana.
- Fred Turner, chairman for New Hampshire, organized a motorcycle rally and fundraiser in memory of his late wife Linda.
- The television program House featured an episode (#402) treating a patient who proved to have VHL. The case focused on some of the most rare issues that occur in VHL. Joyce wrote some program notes to clarify points for people with VHL. http://vhl.org/press/house_402.php
- Amanda Hutchison, our chairperson for Mississippi, made memory quilts for her step-children, to help them remember their mother who died of VHL. Their story was featured in her local newspaper and television, and accompanied by a charming video on the internet.
- Jenny Mathison, our chairperson for Washington state, and Kim Hall organized a group of walkers to raise money for VHL as part of the Bloomsday Marathon in Spokane. The team was covered by the local television station, with video on the internet.
- On September 21, 2008 staff of the VHLFA participated in the 20th Annual Boston Marathon Jimmy Fund Walk as Team Kidney Cancer-VHL. This group was lead by Team Captain Mary Lou Linn, along with fellow VHL Family Alliance staff, Joyce Graff, Hannah Costa, and Ranjana Sharma, who each walked the Boston 3-Mile. A new friend of the VHL Family Alliance, Carleen Gentry chose to walk the complete Hopkinton 26.2 Mile walk!
- On October 7, 2008, VHLFA ran an ad in the first Philanthropy Bonus section of USA Today, page 21E

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:

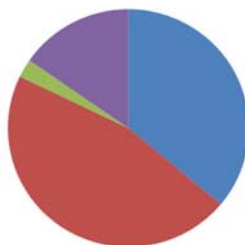
These projects could bear the name of the donor:

- 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 2008 (ended June 30, 2008) – Audited Financial Data

Total Revenue for Fiscal 2008 (ended June 30, 2008) was \$320,993. Of this, \$111,152 was allocated to the research program.



Of our Expenses:
 \$111,152 (36%) Research
 \$142,121 (46%) Education and support
 \$7,761 (3%) Fundraising
 \$47,369 (15.0%) Admin

Liabilities and Net Assets:

Accounts payable and accrued expenses	\$15,040
Grants payable	\$100,000
<i>Total Current Liabilities:</i>	<u>\$115,040</u>
Unrestricted net assets	\$114,117
Temporarily restricted	\$ 0
<i>Total net assets</i>	<u>\$114,117</u>
<i>Total Liabilities and Net Assets:</i>	<u>\$229,157</u>

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Neurology, National Institute of Neurological
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Hôpital Kremlin-Bicêtre, Paris, France

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R. Neil Schimke, M.D., *Dir. of Genetics*
University of Kansas Med Center, Kansas City,
Kansas

Robert B. Welch, M.D., *Chair Emeritus,*
Ophthalmology, Greater Baltimore Medical
Center, Baltimore, Maryland

International Affiliates

AUSTRALIA:
Jennifer Kingston
36 Refinery Parade
New Farm, QLD
4005 Australia

BELGIUM:
Ms. Chris Hendrickx
Dorpstraat 127A
Emblem
2520 Belgium

BRAZIL:
J. C. Casali da Rocha, Medical Director
National Tumor Bank
INCA Rua Andre Cavalcanti,37-2andar
Rio de Janeiro,RJ Brazil

CANADA:
Jill Shields
4227 Hamilton Rd
Dorchester ON
N0L 1G3 Canada

CHILE:
Pierre Jacomet Ollivet
Santa Luisa 295 - apt. 41
Renaca
Vina del Mar Chile

CHINA:
Kan Gong, MD, Ph.D., Urology
First Hospital, Peking University
No. 1 Da Hong luo Chang Street
Xicheng District, Beijing
100034 P.R. CHINA

DENMARK and the Nordic countries:
Richard & Vibeke Harbud
Fiskervejen 10
Veddelev
Roskilde, 4000 Denmark

ENGLAND, U.K.:
Mary Weetman
297.Holcombe Rd.
Greenmount/Bury
BL8 4BB England, UK

FRANCE:
Gilles Brunet/Guy Allegre, Genet-Oncologie
EPHE FacMed Paris-Sud
63 rue Gabriel PERI
LE KREMLIN-BICETRE
94276 France

GERMANY:
Gerhard Alsmeier
Rembrandtstrabe 2
Meppen
D-49716 Germany

HUNGARY:
Dr. Helga Süli-Vargha
H-1518, P.O. Box 32,
Budapest
112 Hungary

IRELAND:
Ms. Gloria Proby
Riverfield Farmhouse
Inch Gorey
County Wexford, Ireland

ITALY:
Francesco Lombardi
Corso Siccardi 11
Torino
IT-10122 ITALY

JAPAN:
Dr. Taro Shuin, Urology
Kochi Medical School
Kohasu Okoh-cho
Nan-kocho Kochi, 783-8505 Japan

THE NETHERLANDS:
Henny Berisha
Madeliefstraat 11
Gouda
2802 ZK The Netherlands

NEW ZEALAND:
Jon & Valerie Johnson
3B Luana Way
Howick, Auckland New Zealand

POLAND:
Dr Wojciech Lubinski, GENETICS
Pomeranian Ac of Medicine
ul.Powstancow Wlkp. 72
Szczecin
70-111 Poland

SPAIN:
Dr. Karina Villar
Plaza Platanos N°1 Galeria 2 Puerta 8
08207 Sabadell
Barcelona Spain

SWITZERLAND:
Frau Erika Trutmann
Alte Kantonstrabe 6
Brunnen
CH-6440 Switzerland

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