



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](mailto:info@vhl.org) – 1-800-767-4VHL

## Annual report, 2006-2007

With the help of our many members and friends, we are building a stronger research infrastructure, and expanding our information services.

The rented office space we occupied beginning in June 2006 has given us room to spread out and grow. We have added two 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

Feedback on the Handbook has been overwhelmingly positive – from families, and also from the medical community. People appreciate the clear and concise explanations of the kinds of tumors that can occur in the VHL, how to diagnose and monitor them, and references for doctors to papers and experts that can guide them in determining treatment options for the patient.

With the addition this year of Japanese, the Handbook has been translated into nine languages, bringing this information to populations who do not read English. If needed, we will gladly print a paper copy and mail it anywhere in the world. To keep someone with VHL healthy, it is critical to shape the conversation between the patient and the local doctor. While medical experts and top researchers worldwide tend to speak English, that is not true for patients and their local doctors. Thus to really make a difference, it is imperative that this information be available in local language. Through the efforts of volunteers, these materials are rising in availability worldwide.

This year we have undertaken a more concerted program of public awareness initiatives, aimed at making VHL more of a household word. Joyce has appeared on more than 20 radio shows in the United States and Canada.

Personal support is provided through telephone, e-mail, and local chapters in thirty states and seventeen countries. Online support is available in English, Spanish, French, German, and Japanese.

#### ***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. This year we devised a way of increasing the capacity of our hotline to meet special times when an article hits the press. We invoked this plan when the McCoy article was published in April 2007, and we were able to handle calls from nearly 100 families in less than two weeks.

## **Chapters**

*The Chapters Program* provides local support and networking, sharing information about local resources. In most US states and 17 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. Cassie Désir provided support and an outline of activities for chapter chairs, encouraging and assisting these volunteers in carrying out their duties. New Chapters were added in four states.

## **Website**

*The Website (vhl.org)* is one of our primary services. Website traffic continues to grow. 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. In addition to pointers on [www.vhl.org](http://www.vhl.org), an index of European country support groups is maintained by our German affiliate at [www.vhl-europa.org](http://www.vhl-europa.org).

## **Handbook**

*The Handbook* is now available in English, Spanish, French, German, Danish, Italian, Chinese, Japanese and Arabic. All translation has been done by volunteers.

All versions of the Handbook are available free for download from the internet, and on paper by request. In this fiscal year, more than 900 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 and local group leaders, articles from the newsletter and original local information is made 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 provides us with a communications channel between newsletters, allowing us to distribute “breaking news” at a low cost.

## **Online Support Groups**

VHLFA provides *online discussion groups* in five languages on the internet. This year we moved the English language group from YahooGroups to a new provider, ClinicaHealth, which provides a framework that is more modern and has much better privacy characteristics – and no spam! The one unfortunate side effect is that one of our users who has WebTV, is not able to access the new list technology. A major benefit is that the discussions are now categorized, so that new members to the group can find answers to many of their questions using the topic headings and search utility.

## ***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 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. In 2006 there were 617, and so far in 2007 there are over 900 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 2007 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. Donald Bellgrau, Professor of Immunology and Medicine, University of Colorado, Cancer Center, Denver, CO – Mutant VHL targeted molecular immunotherapy (second year of funding).
- Dr. Arnim Pause, McGill University, Montreal, Quebec, Canada –
- Dr. Bin Teh, Van Andel Research Institute, Michigan –

## ***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. With the move to the National Disease Research Interchange (NDRI) we have a much more solid infrastructure for our tissue bank, and have been able to add blood samples and expanded medical data to

accompany samples. With NDRI's help, we are tracking the new standards for biospecimens coming out of the National Cancer Institute.

### **Research Database**

With help from a grant from the Alex's Lemonade Stand Foundation, and with the kind cooperation of our members, we have been able to build a research database recording medical profile information.

### **Tracking Drug Development**

In FY06 we opened conversations with two drug companies in hopes of setting up multi-center trials of some of the new drugs approved for advanced kidney and colon cancer, to determine whether they are effective against VHL. Until we can get VHL on the product label, insurance companies and other payers are likely to decline to pay for them.

It has not yet proven feasible to set up a multi-center study for such drugs. There is a trial of Sutent with VHL at M.D. Anderson in Houston which has not had great success in recruiting patients. One of the major barriers to enrollment seems to be the cost of transportation and housing to get to the center 1-2 times a month for the duration of the study.

We are therefore taking a different approach in FY08, working to obtain a grant to cover travel expenses incurred in participating in a clinical trial.

### **Building Income**

Our membership increased another 10% this year. While our membership dues are quite modest (\$25 domestic, \$35 international), it establishes an important base.

Individual members have helped greatly again this year by creating Personal Fundraising Pages at [Firstgiving.com/VHL](http://Firstgiving.com/VHL) and in Facebook. Two cars were donated, for a net income of \$2157.

Our income through the Combined Federal Campaign increased 36% to \$20,360. We continue to work 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.

### **Staffing**

Our staff now consists of

- Executive Director, Joyce Graff, full-time
- Membership Coordinator, Cassie Désir, part-time (15 hours/week)
- Research Coordinator, Jessica Costa, part-time (10 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](mailto: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), 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 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**

- Jeanne McCoy was featured on Comcast Newsmakers in the Philadelphia area. This spot is on the internet at <http://www.vhl.org/power>
- Joyce Graff was a guest on more than thirty radio shows. See [vhl.org/power](http://vhl.org/power)

Reports on many of the following are listed at <http://www.vhl.org/press>

- President Bush visited the laboratory of Dr. W. Marston Linehan and was briefed on his research into VHL and kidney cancer. Bush also visited three VHL patients in the clinical center, including Dale Miller, our chapter leader from Montana.
- Dr. *House* diagnosed VHL on his television show. The show was a depiction of some of the most rare aspects of VHL, not at all a common picture. Joyce Graff prepared a handout to accompany the show, posted on [vhl.org](http://vhl.org), to help people with VHL understand the lung cysts and the unusual presentation of pheochromocytoma included in the script.
- Vanderbilt University Medical Center released a story of one of their patients who claimed descent from the McCoy's of Hatfield-McCoy feud fame. In it, one doctor was quoted as saying that VHL is characterized by spurts of adrenaline, and the patient said that in her family "VHL is a rage disease." The Associated Press picked it up, and the story was covered in newspapers worldwide. Joyce Graff and a number of others wrote letters to the editor and responses in blogs and reader feedback lists all over the web to counter these negative statements. On the positive side, the AP article listed [vhl.org](http://vhl.org) as a resource, and we received more than 100 calls from people looking for more information about VHL.
- Julie D. of British Columbia was featured in her hometown newspaper with a very nice article about her and her three daughters, all of whom have VHL.
- Wheatley C., of Michigan was featured in an article in the tri-county newspaper near her home, stressing the need for and benefits of monitoring.
- Alice Coday and Jeanne McCoy were interviewed for an article in the CCR journal of the National Cancer Institute.

### **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 <a href="http://vhl.org">vhl.org</a> accounts	\$1800
Dr. Backup Offsite Backup Service for the Boston office	\$ 659

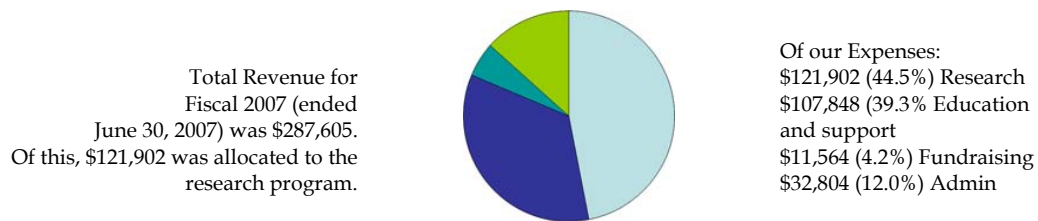
## Special projects in need of funding:

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 2007 (ended June 30, 2007) - Audited Financial Data



### *Liabilities and Net Assets:*

Accounts payable and accrued expenses	\$12,948
Grants payable	\$105,000
<i>Total Current Liabilities:</i>	<u>\$117,948</u>
Unrestricted net assets	\$101,527
Temporarily restricted	\$ 11,844
<i>Total net assets</i>	<u>\$113,371</u>
 <i>Total Liabilities and Net Assets:</i>	 <u>\$231,319</u>

## **FY07 Board of Directors**

Thomas D. Rodenberg, Esq., Chairman  
Bruce S. Weinberg, J.D., Vice Chairman  
Altheada L. Johnson, MS., R.D., Secretary  
Robert E. Schoenhals, Treasurer  
Sunny Greene

Eric I. Lipp  
Thomas A. Lusk  
Tom Rath  
Joseph M. Verdi, Ph.D.  
Clenton G. Winford II, Ph.D.

## **FY07 Medical Advisory Board**

Lloyd M. Aiello, M.D., *Beetham Eye Inst*  
Joslin Diabetes Center, Boston, Mass.

Debra L. Collins, M.S., *Division of Genetics*  
Univ. of Kansas Med Center, Kansas City, KS

Yujen Edward Hsia, M.D., Professor of  
Genetics, Retired, Honolulu, HI

Col. James M. Lamiell, M.D., *Clinical Invest.*  
*Regulatory Office*, U.S. Army AMEDD Center  
& School, Fort Sam Houston, TX

John A. Libertino, M.D., *Chief, Institute of*  
*Urology*, Lahey Clinic Medical Center,  
Burlington, MA

Richard A. Lewis, M.D., M.S., *Ophthalmology*  
Baylor College of Medicine, Houston, TX

Joseph A. Locala, M.D., *Psychiatry &*  
*Psychology*. Cleveland Clinic Foundation,  
Ohio

Eamonn R. Maher, M.D., University of  
Birmingham, Edgbaston, Birmingham,  
England

Virginia V. Michels, M.D., Chair, Medical  
Genetics, Mayo Clinic, Rochester, Minnesota

Haring J. W. Nauta, M.D., *Chief of*  
*Neurosurgery*, University of Texas Medical  
Branch, Galveston, Texas

Hartmut P. H. Neumann, M.D., *Nephrology*  
Albert-Ludwigs University, Freiburg, Germany

Andrew C. Novick, M.D., *Chair, Urology*  
The Cleveland Clinic, Cleveland, Ohio

Edward H. Oldfield, M.D., Chief, Surgical  
Neurology, National Institute of Neurological  
Disorders and Stroke, Bethesda, Maryland

Stéphane Richard, M.D., *Neuro-Oncologie*  
Hôpital Kremlin-Bicêtre, Paris, France

Armand Rodriguez, M.D.,  
Internist, Florida

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-koku 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

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](mailto:info@vhl.org) – 1-800-767-4VHL