



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

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## **Annual report, 2004-2005**

The greatest achievement of this fiscal year was the third major revision and redistribution of the VHL Handbook. The Handbook is the distillation of twelve years of learning accumulated by the coalition of families, physicians, and researchers, intended specifically to improve the quality of life of people with VHL. Explanations of the aspects of VHL increase people's understanding of what they are dealing with, the screening guidelines tell patients and doctors what to look for and how, and the discussion helps people explore the available options for treatment. We are grateful to our Medical Advisory Board, our chapters and affiliates, and our entire community for this remarkable achievement.

### ***Medical Advisory Board***

Our Medical Advisory Board continues to provide the firm foundation on which we stand, ensuring that the medical information we share is correct, and guiding us in serving the medical community.

### ***The VHL Handbook***

Beautifully published copies of the 2005 VHL Handbook in English were distributed to members and other newsletter subscribers with the December 2004 edition of the newsletter. The Handbook is also available free on the internet in the following languages:

- Spanish, translated by Pierre Jacomet, Chile, with Dr. Karina Villar, Spain
- French, translated by Paul Bonneau, Canada, with Dr. Stéphane Richard, France
- Chinese, translated by Dr. Kan Gong, Beijing, China
- Arabic, translated by Dr. El Moeiz Ahmed Saad, Bioscientia Institute, Ingelheim & Amal Ahmed Saad and Omaira Ahmed Saad, Abu Dhabi, and sponsored by Dr. Jochen Decker, Bioscientia Institute

Additional translation teams are working to make this information available in Dutch, Italian, Portuguese, Hebrew, Croatian, Ukrainian, and Japanese.

A Danish handbook was prepared by a patient/provider committee in Denmark under the leadership of Vibeke Harbud in 2003. A German language handbook was prepared by Dr. Hartmut Neumann in 2003.

While the leading scientists all speak English as a requirement for advancement in their profession, most local doctors and patients do not speak English. Until this information is available in local language, it is unavailable to most of the people in the world who need it. A group of dedicated volunteers has worked hard to make this critical information available in local language within their own countries. The Spanish and French translations were done by bi-continental teams, to ensure that they would be usable on both sides of the Atlantic.

All versions are available free for download from the internet, and on paper by request. In the six months since we opened this service, 274 copies of the Handbook have been downloaded, including 199 English, 38 Spanish, and 37 French.

### ***Distributing Information***

The Newsletter (paper and electronic) remains our key framework for delivering information. In addition to the paper readership, more than 20,000 people per month visited our website, coming from about 107 countries, reading an average of 2662 pages per day. With the help of a network of volunteer translators, information is available on the web in English, Spanish, German, French, Japanese, Danish, Italian, Flemish, and Dutch. 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).

This year we added a system of periodic "alerts" via e-mail. People can sign up for our e-mail service on our website. We now have more than 1900 e-mail subscribers to this list.

As one example of the effectiveness of our electronic information delivery, one family called us to say that one of their family members was brain-dead from an accident, and they had one kidney they really wanted to donate to someone with VHL. We sent out an alert, and within two hours we had four candidates for this time-sensitive donation. The kidney was shipped to a gentleman in New York State who had been on dialysis for five years.

### **Online Meetings**

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 37% this year to 494 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 54 members; there are 70 in the French group, and 79 in the Spanish group. 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 40 people in Japan.

### **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 FY05 in  
    Memphis, Tennessee, November 2004  
    Boston, Massachusetts, April 2005  
    San Antonio, Texas, May 2005  
    Binghamton, New York, June 2005

The Annual Meeting was held at the Union League Club in Chicago, Illinois, where the meeting was organized and run by Tom and Nancy Lusk, Ellen and Bob Lydon, and Eric Lipp. They assembled an excellent agenda, the speakers were wonderful, and the attendees felt very well taken care of.

## **Medical Education**

Our Biennial Medical Symposium will be held in Toronto, Canada, in May 2006, hosted by our Canadian affiliate organization and the University of Toronto, and chaired by Dr. Michael Ohh.

Brooke McLaurin, Miss Fayetteville, North Carolina, co-sponsored with the VHLFA a Continuing Medical Education event in Fayetteville for physicians and hospital staff, taught by Dr. Gladys Glenn of the National Cancer Institute and Audrey Clifton of the VHLFA.

In the March 2005 issue of our newsletter, we ran a patient survey on stereotactic radiation. Fifty-seven people responded, from all over the United States and six other countries. The results of that survey are reported in the September 2005 issue. It is clear from this data that 20% of the respondents had bad outcomes. That means there is considerable education to be done among patients and physicians, to improve the "qualification" of tumors -- are they good candidates for the procedure? -- and thus to improve outcomes. Many of those tumors should never have been treated using SRS. We all have much to learn from both the good and bad outcomes of the past about the benefits and the limitations of this technology. This is one example of how we can organize the information of our members in ways that are useful both to patients and physicians.

## ***Improving Clinical Care***

We are refreshing our Clinical Care Program, providing easy access to a number of large institutions through a single point of contact. In addition, we are working with several research teams to utilize this valuable network in creating multi-center clinical trials, and in collecting samples to facilitate research.

## ***Guiding Research***

Increased focus was placed this year on monitoring the progress of research and drug development for the primary issues of VHL. We are focusing on developing consortia and organizing information about our membership in more useful ways. By making information and tissue available for research, and making available some development grants, we hope attract more young researchers into VHL research.

We have been shifting the focus of our research funding efforts to projects that have a higher chance of "translating" into real patient therapies in the next several years. We received 16 grant applications this year, including six quite worthy projects.

## **Research Grants**

The Board approved the recommendations of the Research Advisory Board to fund four grants for a one-year commitment to:

- W. Kimryn Rathmell, MD, PhD, Oncology, University of North Carolina, Lineberger Cancer Center, Chapel Hill, NC "Models of VHL Tumorigenesis"
- Ian Frew, Ph.D., Institute of Cell Biology, Zurich, Switzerland, "Cooperation between loss of pVHL function and activation of the P13K signaling pathway in the progression of Renal Cell Carcinoma"
- Pei-Yin Lin, Graduate Student Researcher in the laboratory of Dr. Robert H. Weiss, Nephrology, University of California, Davis "P21 as a novel molecular target in renal cell carcinoma"

- Andreea Schmitzer, Ph.D., and Shawn Collins, Ph.D., Département de Chimie, Université de Montréal, Montréal, Québec, Canada "Inhibiting telomerase activity by helical drugs to prevent cancer progression"

In addition, we will be continuing a second year of funding awarded in June 2004 to:

- Dr. Judith Frydman, Stanford University, "Cellular Pathways leading to degradation of tumor-causing variants of VHL." \$80,000 over two years, 2004-2006

By providing seed money grants to young researchers, we are able to help them assemble the data they need to validate the concept of their line of research, and to help them obtain even larger grants from major funders. These four grants represent a total of \$120,000 or more than half our total budget for the year, demonstrating clearly our commitment to make the future better for us all.

## **Clinical Trials for VHL**

Some additional clinical trials have opened this year for people with VHL, notably the use of angiogenesis inhibitors in the eye under Dr. Emily Chew at the U.S. National Eye Institute, NIH.

Most other trials are still focusing on people with metastatic kidney cancer, and often exclude people with VHL due to concerns about side-effects on the other aspects of VHL. We continue to watch closely these trials, and suggest participation for qualified candidates.

We have also encouraged members to participate in research projects looking to find biomarkers for kidney cancer. Notably, fifteen people participated in a project under Dr. John Heymach of Dana Farber Cancer Institute in Boston, evaluating the use of Circulating Endothelial Cells (CEC's) as an indication of the amount of kidney cancer activity in the body. Several such projects are under way, looking to find the most inexpensive and efficient way to evaluate whether kidney cancer activity is going up or down, to indicate whether additional scans might be needed, or to check on the effects of drug therapy.

## ***New Telephone System***

We implemented a new "virtual" telephone system that knits together our many offsite volunteers while appearing to callers as a single office with a menu of telephone extensions. The new system has an "Operator" extension, which receives calls from dial telephones, and offers service in English, Spanish and French. The new system gives us more options for routing, helping us to increase the odds that the caller will reach a human being on the first try.

## **Building Income**

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.

In addition, we need effective ways to reach beyond our core constituents and develop a base of income from others. This year we further expanded our participation in the Combined Federal Campaign, joining CancerCURE, a Federation of cancer-related charities within the Health and Medical research field, which will bring greater visibility to our cause in the coming campaign. We expect the Fall 2005 campaign to go well, and are hoping to at least double our income through the CFC in the coming season. Monies pledged in the fall 2005 campaign will be received through payroll donations received by the end of calendar 2006.

Melissa Gokey-Thomas of Texas competed in the USA Ironman Triathlon in Lake Placid, New York, July 24, 2005. She completed the course in 13.5 hours, well within her goal of 17 hours. She also raised the second-highest amount for a charity among the athletes, and winning second place in the Janus Fund challenge. The Janus Fund will donate an additional \$8,000 to VHL in fiscal 2006.

We were awarded \$10,000 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, which will air on New York radio stations in fall/winter 2005/06.

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 an Executive Director, Joyce Graff; one faithful volunteer in the office, Rachael Morgenstern, who has served us 10-20 hours a week since 1993; a part-time Project Assistant, Robin Cochrane, three days a week; a part-time bookkeeper, 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). Two new hotline volunteers join the corps for FY06: 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).

We continue to work in "virtual" space - we use donated office space in Brookline, and leverage telecommunications technology to collaborate and provide our community of support via telephone and internet. As we continue to grow, however, we anticipate that we will grow out of our existing space within the next 1-2 years. We will make every effort to grow carefully and with strength, ensuring that our expenditures remain a very modest percentage of our income, and remaining true to our charter to improve diagnosis, treatment, and quality of life for individuals and families affected by VHL.

Financial record-keeping is now done by staff in Brookline, 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.

Robert Cochrane joined our staff as the Project Assistant to the Executive Director, assisting with distribution of materials and summarizing activities. We are very glad for his help in the office, which has significantly expanded our capacity to serve.

## **Public Awareness**

Several members were able to get articles in their local papers this year, including Kathy Sladky of Wisconsin, who addressed several thousand people in Green Bay, Wisconsin, on Cancer Survivorship Day.

Brooke McLaurin, Miss Fayetteville 2004, became Miss North Carolina 2005. She will reign through May 2006, when she will compete for Miss America. Brooke is using as her platform Brain Tumor and VHL awareness.

Melissa Gokey-Thomas was featured in a number of articles in Tomball and Houston, Texas, and Jamestown and Buffalo, New York.

Our new Public Awareness Team, headed by Dr. Judi Cook of Salem State College in Massachusetts, is helping us hone our messages and get the attention of the general public.

***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	\$1500
Dr. Backup Offsite Backup Service for Brookline office	\$1500

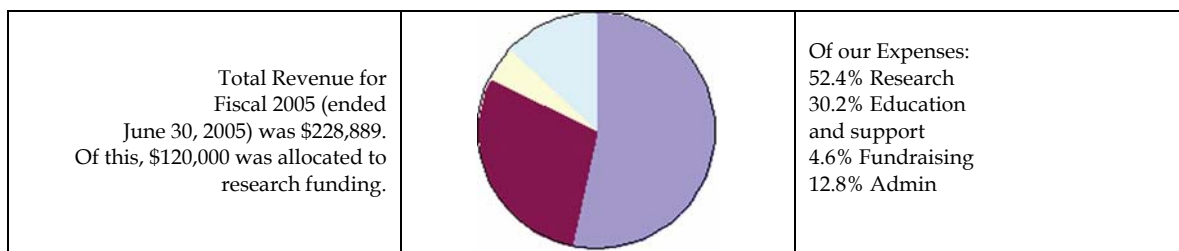
***Special projects in need of funding:***

These projects could bear the name of the donor:

- Outreach to the medically underserved
- 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)
- Support the Clinical Care Centers with CCC Bulletins (\$2000 per year)
- Research biobank repository to facilitate research on modifier genes and therapies (25,000 per year)

***Financial Report***

for Fiscal 2005 (ended June 30, 2005) – Audited Financial Data



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