



Stronger Base, Reaching Outward

2004 was a year of strengthening the VHL Family Alliance, increasing our capacity for growth, and broadening our reach. We now serve people across a greater expanse of the world, and are communicating and learning with a larger community of patients and physicians worldwide. In order to be able to reach out, we have taken the time to create a stronger base. We are pleased with the progress we have made, and look forward to building an ever stronger future.

Funding for all our activities comes from you, our members and friends. We depend on your generosity to support our educational programs and to fund research.

There is still work to do in making sure people **get a diagnosis** as early as possible. We continue to find people in the United States, newly diagnosed with VHL, who have had symptoms for quite a long time. According to a survey we conducted in September, one-third of the respondents with delayed diagnoses had waited more than 20 years to finally understand what was happening. That delay usually cost them a great deal of suffering and some long-term deficits.

This year we added a general practitioner to our **Medical Advisory Board**, to help us communicate better with the primary care physicians who are the first to help with a diagnosis. Our Medical Advisory Board reviews all the medical information we share, making sure it is correct and guiding us in serving the medical community.

Two new Clinical Care Centers joined the program: University of Pennsylvania in Philadelphia, and Vanderbilt University in Nashville. There are now 18 U.S. centers, and 10 in other countries, who have pledged to coordinate medical care for people with VHL.

The 2005 version of the **VHL Handbook** will be mailed about the end of this year to our entire membership and the health care professionals we serve. With this improved information available in print and on the internet, we hope that more people will find their symptoms listed and discuss the possibility of VHL with their physicians.

We held eight regional meetings this past year in various parts of the country -- from Tampa to Seattle, Los Angeles to New York -- hoping to make it possible for more people to attend.

This year's Medical Symposium was held in Kochi, Japan. Many physicians from Japan, Korea, and China were able to attend, learn, and share what they have learned in their countries about VHL.

Please join us!

We Need Your Help!

We are now reaching more than 14,000 people in 88 countries. Our website www.vhl.org served an average of 15,000 visitors each month, who used an average of 4500 pages per day.

This year, **thanks to you**, we awarded another \$80,000 in research grants, bringing the total to \$741,000 over the last eight years. **Let's do it again!**

Expenditures on Management and Fundraising were steady at 15% of our income. We are strengthening our core services so that we can build our capacity to manage further growth and exciting new projects.

For example, we have reserved some funds last year and this year anticipating some expenses in the distribution of the new Handbook, the creation of an improved tissue banking program and a rise in core staffing expense.

Call or write for a list of special projects in need of funding, where the project could be named by the donor.

Total Revenue for
Fiscal 2004 (ended
June 30, 2004) was
\$206,464.
Of this, \$80,000 was
allocated to research
funding.



39% Research
30% Education
and support
3% Fundraising
13% Admin
15% Reserve.

*We Depend on Your
Support! Thank you!*

Dr. Judith Frydman wins award

Decisions on which grants to fund are a combination of the ratings of the proposal itself, an evaluation of the probability that the team will carry through, and the value of the results to the VHL Family Alliance community. While many of the applications submitted proposals which were "good science," the Board and its advisors chose the one they felt has the greatest potential in leading to better therapies for VHL.

The Board approved a two-year grant to Dr. Judith Frydman of Stanford University for her study "Cellular Pathways leading to degradation of tumor-causing variants of the VHL protein."

As part of the body's self-repair mechanism, there are checks that ensure that each step in the process of cell division and replication is going right. If not, a process of "degradation" gets rid of the incorrect cells so that the process will succeed. Seen from this perspective, a tumor is caused by a failure of this quality-control process.

Dr. Frydman theorizes that instead of using a drug to work specifically on the VHL gene, we might use a drug to bolster this quality-control process and let the body take care of the problem normally — eliminating the cells that lose that second copy of the VHL gene.

We are excited at the prospects this project presents, and wish Dr. Frydman and her team all the best for the successful completion of this project.



Research Digest

By Joseph Verdi, Ph.D.,
Director of Research

It has been an exciting and challenging year for the VHL Family Alliance Research Program.

We are very pleased with the grant we awarded this year. The remaining applications we received, while worthy, were predominantly in the area of more basic science. And while there is always more to be done in understanding how VHL ticks, it costs a great deal of money and we cannot hope to support it all.

I really believe that we should be more active in promoting immediate impact, high-risk, high-reward types of proposals -- things that have patient care at the forefront.

We want to focus on funding young scientists, helping them accumulate sufficient evidence so that they can go for larger grants from NIH, and encouraging them to study VHL. As a patient advocacy organization we want to fund things that will impact patients most rapidly: clinical trials, new strategies in constraining tumor formation, etc.

We are actively working toward a national repository for tissue and data which will facilitate research on VHL and assist in measuring the results of clinical trials. In addition to the Tissue Bank, if we also had a database where scientists could have easy access to valued reagents, it would greatly bolster and facilitate research.

All in all, I think the progress being made is great. Unfortunately I have the patience of a hyperactive school kid waiting for a cookie. With the help of donations from all our good friends, the guidance of our Medical Advisory and Research Review Boards, and the scientific contributions of our collaborators worldwide, we can do more to facilitate and sustain the pace of advancements.



Teamwork for Health

I have to admit to being surprised at how much brighter the future looks since I posted on the VHL online forum and cannot express how grateful I am for the replies I have received. — Ken C., Canada

We need more doctors able to give a proper diagnosis that it's VHL and not just the common cold. Keep up the great work on educating the medical world. You are priceless! -- Cindy P., Wisconsin

Thank you! We have learned so much from the newsletters! -- Frank C., Colorado

The Board has set these goals for the coming year:

- Strengthen our core services
- Expand our capacity for growth
- Support the existing clinical trials
- Seek out research proposals that lead more directly to improved therapies
- Distribute the revised **VHL Handbook**
- Reach out to under-represented populations
- Provide more convenient access for doctors to VHL information
- Build a better tissue bank to support research

Challenge! Your Gift Goes Farther!

Two families have challenged you to make a special pledge to VHLFA this season.

Special thanks go to the Greene family of Virginia and the Weinberg family of New York for their generous Challenge Grants! See how you can help us earn these challenge gifts!

Volunteers Making a Difference

Donations come in two major forms: money and time. It takes both to sustain an organization like this one. Altogether more than 90 volunteers donated more than 10,000 hours to this effort. Each and every donation was important.

We would like to recognize publicly here the very special efforts of a few of these people.

Altheada Johnson of New York chairs the Hotline Committee, coordinating the scheduling and training of all the hotline volunteers. She is also the lady who answers info@vhl.org, and reads and replies to messages sent to Contact Us on our website.

She helps to design our outreach to the medically underserved in the United States. One key activity is the redesign of our telephone access path, making it easier for people to get through to the Hotline in English and in Spanish.

Since 1993 she has chaired the New York State Chapter. In addition to these on-going activities, this year she organized and chaired the Annual Meeting in Queens, New York.

Altheada has served nine years on the Board of Directors, and is beginning her fourth term, more elected terms than anyone else on the Board. She serves as Secretary of the Board, on the Executive Committee.

Another of the Hotline volunteers is **Robin Kadlecek of Texas**. Robin was chosen this year as our Volunteer of the Year for her outstanding service and thorough, caring replies both on the Hotline and in the Online Discussion Group. Robin has learned about VHL "the hard way" through the experiences of her husband and two sons, for whom she is the family coordinator of appointments and care.

Altheada, Robin, and Audrey Clifton of North Carolina have staffed the hotline very ably this past year. Anyone interested in becoming a member of the Hotline Committee is asked to contact Altheada at 800-767-4845 ext.3.

The leaders of our Chapters are also essential personnel in this network of volunteers. They provide an very important link for people at the

local level, welcoming new members, and assisting them in finding services within the state. There are jobs of many sizes to fit people's busy schedules.

Gale Lugo of Florida has been a very active Chairman of the Florida Chapter since 1994. She tries to contact people in Florida once a year, reminding them that she is there, and helping people find good care for VHL in Florida. She holds a meeting in Florida every 1-2 years.

Since last fall she has helped as Acting Chair for the Southeast Region, and has assisted in recruiting and training new chapter leaders in South Carolina and Montana. She is working on creating a regional meeting in the Alabama area.

Gale has served since 1999 as one of the moderators of the English language Online Discussion group, vhlfa@yahoo.com, making sure people get the information and support they need.

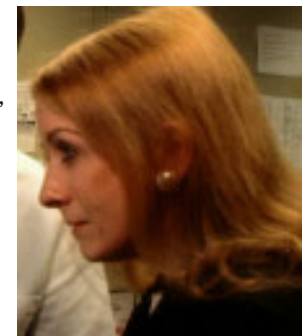
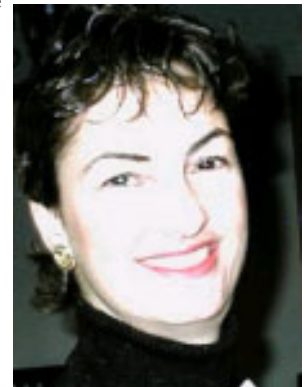
Fran Mott of Michigan is another of our most active chapter chairs. Fran stays in touch with members in Michigan, providing comfort, helping people find medical help when their doctors get stuck, and delving deeply into some of the more tricky medical issues we face.

She is in close touch with the Clinical Care Center at the University of Michigan, and with other hospitals in the Detroit area, offering her assistance to doctors for their patients with VHL, and also in making contact with VHL experts when the doctors themselves face a tricky situation.

We salute these very special people.

Won't you join the team? Whatever time or money you can contribute will be very much appreciated, and will go to raise hope and improve quality of life for all people affected by VHL.

Thank you!



Your Donation Goes Even Farther!

Thanks to the generous support of the Greene and Weinberg families, your donation this season will go even farther!

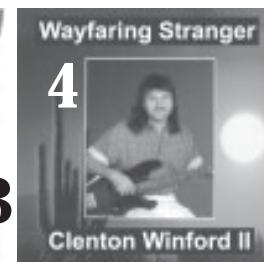
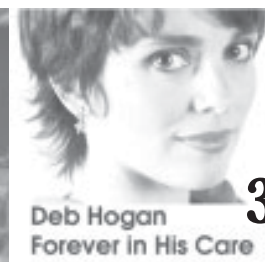
Sunny Greene has challenged us. She will match all contributions of \$100 or more that we receive by December 31, 2004, up to a maximum of \$10,000. Please help us earn this wonderful donation!

First-time donations in any amount received by December 31 will be matched by the Weinberg family, up to \$500.

We're offering you something you can't buy at any price -- life-saving information about VHL.

Gifts of the Artists:

Several talented members of our community have donated CD's and books. For a donation of \$150 or more, you can choose one of these wonderful performances as your free gift. Write in the item number on your donation form. **Thank you!**



Mail to: VHLFA, 171 Clinton Road, Brookline, MA 02445

or Canadian VHLFA, 4227 Hamilton Rd., Dorchester, ON N0L 1G3

Enclosed is my tax-deductible gift to support: ☐ VHLFA ☐ Research only

- ☐ \$25 ☐ \$50 ☐ \$100 ☐ \$150 ☐ \$500 ☐ \$1000 ☐ \$_____
- ☐ My employer will match my donation. I have enclosed the necessary forms.
- ☐ First-time member! The Weinberg family will match my gift.
- ☐ Gifts of \$100 or more will be matched by the Greene family.
- ☐ With my gift of \$150 or more, please send me item # _____ above

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- ☐ Send newsletter
- ☐ Audio version needed
- ☐ I would like to receive occasional alerts via e-mail from VHLFA only

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VHLFA is a non-profit corporation in the U.S. and a registered Charity in Canada

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