



Family, Friends, Physicians, & Researchers dedicated to improving diagnosis, treatment, and quality of life for people affected by von Hippel-Lindau.

Hope - Strength - Community

What does this Alliance do for families living with VHL? It's probably easiest if we tell you a story -- the story of Troy and Alison and their children Chloe and Caleb. For Troy and Alison, their challenge each day is to keep their own and their children's lives happy and normal.

VHL has had a profound impact on Chloe and Caleb. Caleb was diagnosed at the tender age of four with three pheochromocytomas (pheos) on his aorta. He recently had two more surgeries to remove pheos and is now dealing with a sixth. Chloe had a pheo removed when she was eight, and a second one this fall.



Pheos not only occur in VHL, they also occur in the general population and in people with any of four other genetic flaws. VHL accounts for only 10% of pheos. But because we know that people with VHL are at risk for pheos, we are less often surprised by them. "Pheochromocytoma is still the most treacherous, deceptive tumor on the planet," says Dr. William Manger of New York University. "Missing the diagnosis almost invariably results in devastating cardiovascular complications or death." More than half of pheos are not found until after death. The autopsy of President Eisenhower revealed that he had a pheo, provoking his heart condition.

The Cancer Research Fund / VHL Alliance funds research into pheochromocytoma, and provides



bbb.org/charity

support for individuals and families struggling to get a diagnosis and find appropriate management for a pheo. Alison is an active participant in our Online Support Group, giving freely to others the support she has been glad to receive. Few doctors have much experience with pheos. She is often asked to make decisions that she feels totally unprepared to make. It helps so much to hear the experiences of others who have been

down the same road.

In addition to the pheos, Chloe has also developed several tumors in both of her eyes. Retinal angiomas are fairly common in people with VHL. Unfortunately, her tumors are in bad locations, making them particularly hard to treat without damaging vision. Chloe, like so many others, is literally waiting on the leading edge of medical research, experimenting with new treatment methods in hopes of preserving her vision. Again, sharing thoughts and experiences with experts and other patients has been invaluable.

Despite their battles with this disease, Chloe and Caleb are very normal, happy children. Caleb loves to go swimming, fishing, and just hang out with his buddies. Chloe is a competitive cheerleader with amazing tumbling skills, and thrives in the usual teenage social atmosphere.

Their parents are strong advocates for early DNA testing, as this probably saved the life of each of their children. Knowing early that their children were at risk for VHL, and



knowing that Troy had had two pheos and retinal lesions in his youth, they began preventive screening early and were on the lookout for symptoms.

Most importantly, the family relies on their strong faith in God, knowing that He will get them through this hurdle in their lives, and thriving on the joy that He provides despite these challenges.

You can help too, by helping to fund research. Research on the VHL gene is particularly important because of the critical role the gene plays in controlling tumor growth in many cancers. Please help us find a cure for VHL, and ways to halt tumor growth for everyone.



Researchers you are supporting 2006-2007

Research is the primary pathway to finding a cure for VHL. We received seven very strong proposals this year. Of these, the Research Advisory Board recommended these three, which we hope will help accelerate the development of new treatments for VHL.



Dr. Bin Teh of the Van Andel Research Institute in Michigan and his team examined the many changes that occur in the genes in clear cell Renal Cell Carcinoma (ccRCC). The most common change is the loss of chromosome 3p, which includes the VHL

gene. The VHL gene plays a biological role in the development of ccRCC -- not only in people with the condition VHL, but also in more than 60% of all kidney cancer. Most drug development so far has concentrated on VHL and angiogenesis. The second most common alteration, which occurs in 90% of the samples studied, is an increase in the expression of chromosome 5q which they call the 5qRCC gene.

Dr. Teh's team is studying the implications of this 5qRCC gene. Their intention is to understand its relationship to VHL and to the development of cancerous tumors in ccRCC. By understanding the interaction of VHL and 5qRCC, they hope to find ways to make better drugs to counteract these effects.



It is very helpful in studying a human disease to have an "animal model" so that we can do early drug testing on mice rather than humans. In other words, if a mouse were to lose VHL protein function, it would be ideal if it would develop the same tumors - retina, brain, spinal cord, kidney, pancreas, and adrenal

glands - as found in humans with this same genetic alteration. So far, the "VHL knockout mouse" models - mice with altered VHL genes - get liver hemangiomas rather than kidney ones.

Dr. Pause's team is breeding mice that get changes in their kidneys, by introducing mutations also in

other genes that have been shown to be important in the development of human RCC. This research team has created the first ever VHL mouse model in which cyst and tumor development can be observed in the target organs most commonly affected by VHL disease. In the breeding alone they are learning about the interaction of VHL with other proteins that are involved in the development of ccRCC and the acceleration of tumor growth. The team is also working to find combinations that will result in the development of tumors of the central nervous system (CNS). These models will serve an important role in testing new drug treatments to select the best candidates for human trials.



Most of us know about vaccinations that protect us from infectious diseases like polio and smallpox, but is it possible to be vaccinated against cancer? Or can we use cancer vaccines to treat existing disease? Vaccines work by introducing the infectious agent to the body to help the body develop

its own defenses against the agent. Ironically, cancer tumors deceive the immune system into thinking they are not dangerous, so that the body does not mount its full defenses.

Dr. Don Bellgrau of the University of Colorado in Denver, with his collaborators Richard Duke and Alex Franzusoff, has developed a method for tricking the immune system into seeing a dangerous situation worthy of its full defensive action. This full response then causes the body to destroy the tumor. With grant funding from VHLFA, Dr. Bellgrau will provide proof of the principle that individualized vaccines can be made for specific VHL mutation types, and develop a preclinical roadmap for the rapid use of this approach to treat renal cell carcinoma in humans. Dr. Bellgrau presented an excellent talk in Boston to report on his first year of work. See the meeting report at vhl.org and a video of the complete talk at vhl.impactlearning.org

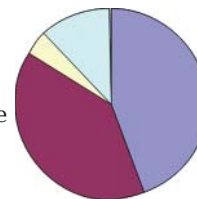
Thank you for your support of these projects!

Teamwork for Health

To support the work of the many researchers studying VHL, people with VHL can make the most important gift of all. Tissue removed during surgery is critically needed to find a cure. Call or write to the VHL Tissue Bank to give permission to deposit surgically removed tissue in the Bank, and help speed the day when we will have a cure for VHL. *Thank you!* write to bank@vhl.org or phone 877-221-6374 (24 hours a day) or see <http://vhl.org/bank>

Report for Fiscal 2007 (ended June 30, 2007)

Total Revenue for Fiscal 2007 was \$287,605. Of this, \$121,040 was allocated to the Research program, for grants and Tissue banking.



Of our Expenses:
 Research - \$121,040 (44.2%)
 Education & Support - \$108,710 (39.7%)
 Fundraising - \$11,564 (4.2%)
 Management - \$32,804 (12.0%)

Please help us cure VHL!

Challenge! Your Gift Goes Farther!

Three families are challenging you to make a special pledge to VHLFA this season. They will double your gift, up to \$30,000! and help us raise money for research. Special thanks go to Sunny Greene, the Lusk Family, and the Karal family in memory of Carol Karal for their generous Challenge Grants!

Family Album

In 2007 we honor several of our families who are helping this community in some new and creative ways.



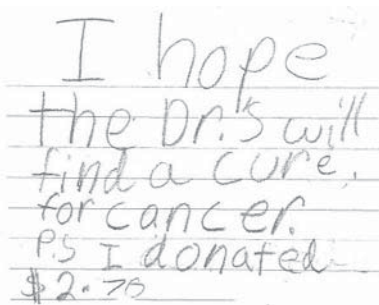
José and Alex Morais

Alexandra Morais, our Volunteer of the Year, shown here with her husband and strong supporter José, has helped with support for members in Spanish language since 2001. She is

one of the volunteers who answer messages sent to info-es@vhl.org. Originally from Colombia, she has a special place in her heart for Latin America. She is currently working to expand services in Mexico.

Dakota D. of Massachusetts sent us a sea shell from the beach and a donation of \$2.70 with her wish for a cure for cancer.

Beth S. attended the Boston meeting in June. "I signed up for the conference this year with mixed emotions. I want to learn as much about the disease as possible for myself and my children, but I was very scared to hear about all the possible things that could happen to us. After the first lecture, I was still a little overwhelmed, but my guard came down. As the weekend progressed, my attitude went from scared to very hopeful. I came away from the conference with so much hope for my future and my son's future. I was so happy to hear about all of the progress that is being made with research. The treatments are different now from when my brother was



from Dakota



Beth's children: Wynter and



Jeanne and Ellison McCoy with children Brooks, Ford, and Emmy

receiving them only three years ago. I also felt really connected to the other families in the room, seeing them all there in different states of health, all with such a positive attitude. I am having my screening done this week and next and for the first time, I don't feel overwhelmed with anxiety. I feel empowered with the knowledge that I learned from the weekend and for that I would like to thank you."

Jeanne McCoy of South Carolina has joined our Board of Directors this year. Jeanne has appeared on television for Comcast Newsmakers, and has done public relations work for the National Cancer Institute's VHL program. See her video at vhl.org.

Jeanne's mother was diagnosed late and is battling metastatic cancer. Jeanne's message is: "Early detection is the key!" She and her husband Ellison and their three children make a special effort to support the VHL Family Alliance. Every other year they celebrate their children's birthdays together, and ask friends and family to donate money to VHLFA in their honor.

All of these people are working together to improve diagnosis, treatment, and quality of life for everyone with VHL and related cancers.

Won't you please help too?

Your Donation Goes Even Farther!

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

Sunny Greene, the Lusk family, and the Karal family have challenged us. They will match all contributions of \$100 or more that we receive by December 31, 2007, up to a total of \$30,000. Please help us earn these wonderful donations!

We're offering you something you can't buy at any price -- life-saving information to help you stay healthy with VHL, and targeted research projects working for a cure for VHL.

Special blue wristbands are available on request for your donation of at least \$5 each. In the spirit of living strong, they proudly proclaim "Hope ... Strength ... vhl.org"

Gifts of the Artists: Several talented members of our community have donated CDs and books. For a donation of \$150 or more, you can choose one of these wonderful performances as your free gift.

Thank you!

**** Write in the item number on your donation form.**

1. *New York Times* Best-Selling book, "How Full is Your Bucket" by Donald O. Clifton and Tom Rath, Gallup Press
2. CD, Bach, "Goldberg Variations" for Piano, by Pierre Jacomet
3. Music CD, "Forever In His Care," by Deb Hogan
4. Music CD, "Wayfaring Stranger," by Clenton Winford II



Mail to: VHLFA, 2001 Beacon St, Ste 208, Boston, MA 02135-7787 USA
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.
- Please send me ___ VHL wristbands (minimum donation \$5 each).
- Gifts of \$100 or more will be matched by the Greene and Lusk families.
- With my gift of \$150 or more, please send me item # _____ above **

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- 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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