



VHL Family Forum



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Challenge Grant!

We -- all of us -- have an exciting opportunity to significantly improve the pace of research toward better management of VHL. We need your help. If every one of us would contribute just a little bit, we can move closer to solving the riddle of VHL.

As we discussed in the September issue of the *VHL Family Forum*, there have recently been important strides in understanding the basic chemistry of the VHL gene and the VHL protein. Nonetheless, a "cure," the ability to repair the genetic flaw, is at least a decade away.

Meanwhile, there are a lot of people dealing with a lot of tumors, and there are some approaches we can take alongside this research which may lead to better management in the short run.

For example, it is possible that some drug could be used to replace the function of the missing protein, or to bolster the body's other natural defenses to compensate for the missing protein.

Take diabetes as an example. There is no cure for diabetes either. Without insulin, diabetes is a terrible disease. But with insulin and diet they are now able to manage diabetes pretty well.

The VHL Family Alliance has been looking for research projects with affordable price tags, where we can make a difference, encourage additional research teams to participate in VHL research, and we think we have found a good one.

One very good approach to determining what drugs might emulate or replace the function of the missing protein is to create a model of the normal protein. This is a process called crystallography. Dr. Diana Griffith, a crystallographer at the Massachusetts General Hospital and Harvard Medical School, proposes to create a model of the VHL protein. In essence, she will take purified VHL protein, create a crystal from the protein, analyze the crystal using complex microscopic techniques, and build a model, like you would build a structure from a children's building toy.

Once a model exists, it is much more cost-effective

for pharmaceutical companies to undertake to try different drugs which might be effective in replacing the missing protein function. There is no guarantee of when or if we might get such a drug, but having a model should significantly increase competition, which improves the odds of finding one.

Once Dr. Griffith has gotten to the crystal stage, she would be able to qualify for a larger grant from a scientific source. But first she has to create a crystal. Her proposal to get to that stage is \$50,000.

The Murray Foundation is willing to pay half, if the rest of us will pay the other half. They have issued us a challenge -- they will match up to \$26,000 if we can raise the other \$26,000 by January 31, 1996..

We are asking everyone to participate. This is only the beginning, only one research project. With your help, we can offer 1-2 research grants each year to increase the pace and breadth of VHL research, to find new ways of controlling tumor growth, or of treating tumors with less invasive and less risky methods.

We are getting oh, so close! Please help us raise money to find the help we all need to manage our health, and which may be the key to solving tumor conditions and cancer for everyone. □

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Join us in Hawaii, June 17-21, '96

VHL in the Pancreas

Edited by Joyce Graff

Pancreatic lesions are generally considered to be the least symptomatic among the lesions of von Hippel-Lindau disease. Families report a number of subtle symptoms, though, which may be caused by pancreatic cysts.

There are three types of cysts and lesions which may be found commonly in the pancreas: cysts, serous microcystic adenomas, and islet cell tumors.

Pancreatic cysts are found in large numbers of people with VHL, with wide variation in families. The frequency of pancreatic cysts ranges from 0% in two large families to 93% in others.¹ The earliest they have been reported is at 15 years, found with ultrasound or CT.

Cysts may be found throughout the pancreas. Cysts are composed of epithelium-lined collections of serous fluid that vary in size from several millimeters to over 10 cm. (over three inches). The serous cystadenoma (or microcystic adenoma) is a grapelike cluster of multiple microscopic and macroscopic (2mm to 2 cm in diameter) cysts separated by thickened walls of stroma. These tumors are benign and usually do not cause symptoms. Occasionally (rarely) they can cause bile duct obstruction. The mucinous cystadenoma of the pancreas, a premalignant lesion, is not associated with VHL disease. Since cysts and cystadenomas of the pancreas are benign in patients with VHL disease, they generally need not be removed unless they are causing obstructions.

People with pancreatic lesions report a wide variety of symptoms, mostly relatively subtle. Fran experienced discomfort and bloating of the abdomen, and loss of appetite. In her case this was caused by a large number of cysts, which cause compression of her stomach, causing her to feel full. Fran says, "My greatest complaints are difficulty in digesting fats (they simply hurt for a while), and problems caused by the size of the enlarged pancreas, especially pressure discomfort when sitting or bending. It feels just like being nine months pregnant, only my stomach doesn't look it." She and Terry have found that walking helps to speed digestion and relieve the bloated feeling.

One member was told he was "full of pancreatic cysts and there was nothing they could do about them anyways." He was left with the mistaken impression that they were cancer that had spread. We were able to give him questions to ask his doctor and get the reassurance he needed -- they were in fact only cysts, and did not present a danger to him. "It is possible to have innumerable cysts without ever having a problem," Fran says. "Only three of mine have been troublesome, and that's because of their large size and particular location. I wouldn't even know the others

were there if it wasn't for the CT and ultrasound pictures." One of Fran's larger cysts was treated by a procedure called percutaneous drainage and hypertonic saline sclerosis, in which the cyst was drained, filled with hypertonic saline solution, and drained again to cause it to deflate and keep it from refilling.

In some infrequent cases the pancreas may become so replaced with multiple small cysts that it becomes nonfunctional, which may result in fatty stools and diarrhea. Symptoms may be relieved with pancreatic enzyme replacement. On rare occasions insulin-dependent diabetes may result. If lesions are placed so as to obstruct the bile ducts, there may be pain or inflammation or infection. Pain is your body's signal to you that there is something wrong which requires attention -- seek medical help immediately, as pancreatitis (inflammation of the pancreas) is a serious condition requiring medical attention.

In the medical literature there are a few rare mentions of adenocarcinomas of the pancreas. Based on his research, Dr. Neumann feels that the rare reports of adenocarcinomas "usually lack histopathologic documentation" and may have been mischaracterized.¹

The most worrisome pancreatic issue is tumors, not cysts, in the islet cell portion of the pancreas. These seem to be more frequent in people with pheochromocytomas. Most islet cell tumors are slow growing and do not cause symptoms. However, they can grow rapidly, cause bile duct obstructions, and can even metastasize to the liver or bone. Islet cell tumors should be watched carefully for signs of aggressive growth. Many thanks to Fran M., Michigan; Jay S., Florida; Tammy N., Mississippi; and Terry B., Wisconsin, for their assistance in the preparation of this article.

1. Neumann, Hartmut P.H. et al., "Pancreatic Lesions in the von Hippel-Lindau Syndrome," *Gastroenterology* (1991) **101**:465-471.
2. David M. Hough et al., "Pancreatic Lesions in von Hippel-Lindau Disease: Prevalence, Clinical Significance, and CT Findings," *AJR* (1994) **162**:1091-1094.
3. Choyke, Glenn, et al., "Von Hippel-Lindau Disease: Genetic, Clinical, and Imaging Features," *Radiology* (1995), **194**: 629-642.

The cookbook looks fantastic! Looks like my diet goes to pot as we try some of them. It appears Dr. Zbar has a great culinary repertoire. How does he stay so thin? -- Don Marshall, Mississippi

"I was quite taken with the new cookbook. It was like a family reunion for me seeing the names of people who had sent in recipes, people who had contributed blood samples to help identify the VHL gene." -- Dr. Berton Zbar, National Institutes of Health.



Perfect Recipes . . .

. . . Perfect Gifts !!

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Contacting an Adopted Child's Birth Family

by Ann Hege Hughes, Maryland

The need to gather medical information for oneself or for a VHL-affected child is but one of many worthy reasons adult adoptees and adoptive parents seek to contact birth families. Since most original birth records are sealed, look for support from the adoption reform movement -- a group of birth parents, adult adoptees and adoptive parents who have learned, through suffering, that truth and openness in adoption is the best course.

There's a pervasive myth in our society that an adoptive family can completely *replace* the adoptee's family of birth. The closed adoption system was built around this myth, which ignores the reality that adopted children are actually blessed with *two* families. The adoptee's primary family is, of course, the family who chose him and is raising him. But he or she is also genetically and spiritually tied to a family of birth. And in cases where a child's life and health are at stake, it can be deadly to pretend otherwise.

As for the birth mother, understand that she was told, at some point, that she wasn't needed any more and if she really loved her child she would gracefully disappear. Even if she surrendered her child of her own free will, every birth mother is left with a sense of emptiness and loss -- if not regret and resentment -- for it's impossible to "forget and go on as if it never happened." Isolated in secrecy, birth mothers have no way of knowing the emptiness they feel is "normal". So, thinking they have failed yet again, they hold this shame close to their heart in the same dark place where they hide their primal grief over the loss of their child.

To truly understand the dynamics of shame, guilt, disempowerment and loss upon which our system of closed adoption is built, I recommend that, before searching, you read books about adoption issues and how all members of the Triad -- child, birth parents, and adoptive parents -- have been affected. There are several outstanding ones written by Triad members. From Nancy Verrier, an adoptive mother and professional therapist, comes *The Primal Wound*, which contains a brilliant analysis of subconscious issues for adoptees. Betty Jean Lifton, an adoptee and therapist, has written *Lost and Found* and *Journey of the Adopted Self*, two books which examine the adoptee's experience. *The Other Mother* by birth mother Carol Shaefer will give you a glimpse into that world. Another adoptee, Jean Strauss, has written an excellent book about the reunion process called *Birthright*. All these books and many others are available from American Adoption Congress (AAC)¹ and Concerned United Birthparents (CUB).²

If you want a crash course in adoption issues,

attend one of the national or regional conferences sponsored by adoption reform groups such as AAC, Council for Equal Rights in Adoption (CERA),³ and others. Also, there will probably be a Triad support group of some kind in your local area.⁴ Attending a local group will help you put a human face on this. The group may be able to offer search suggestions and assistance as well.

Other things you can do are: contact your adoption agency, or the lawyer or doctor who helped arrange the adoption. Tell them you need to get in touch with the birth family. Put a release of confidentiality in your file, so that if the birth family is also looking for you, you can be connected.

There are also reunion registries, such as the International Soundex Reunion Registry (ISRR),⁵ and others maintained by various adoption reform groups or by the state in which the adoption took place. These registries may not accept information for minors, however. In this case, you can petition a judge where the adoption took place to open your child's records. Sometimes they will do this for a medical emergency.

Please note that there is a proposed law which would make it impossible to connect adoptees and birth families. The Uniform Adoption Act would close adoption records irrevocably for 99 years and make it illegal to search. You can help by contacting your legislators to vote "no" when the Bill is presented in your state.

In conclusion, finding your or your child's birth family can also be an opportunity to reshape outdated attitudes about adoption. By giving up the myth that one family can replace another, the adoptive family can embrace its rightful role as the "family of nurture." Then, in a brave new world of openness and truth, we can pull the family of origin from the shadows to stand beside the family of nurture, so each can make its own vital contribution to the special child they both deeply love.

Ann Hughes is the President of Gateway Press, a genealogical publishing house in Baltimore. In 1990, Ann sought and found her 24-year-old birth daughter. She has written a book about her search that she hopes to have commercially published. She will be happy to answer additional questions about this article.

1. American Adoption Congress (AAC), 1000 Connecticut Ave, N.W., Suite #9, Washington, DC 20036. 2. Concerned United Birthparents (CUB), 2000 Walker Street, Des Moines, IA 50317. 3. Council for Equal Rights in Adoption (CERA), 401 E. 74th Street, Suite 17-D, New York, NY 10021. 4. Local support groups are listed in the *Blue Book*, available from Blue Book, Box 230643, Encinitas, CA 92023-0643 (\$14.50). 5. International Soundex Reunion Registry (ISRR), P.O. Box 2312, Carson City, NV 89702.

Additional resources: Adoptees Liberties Movement Association (ALMA) connects adoptees and birthparents. (212) 581-1568. Adoptive Parents for Open Records, 9 Marjorie Drive, Hackensack, NJ 07840.

Is Reading Hard?

Do you have trouble holding a book to read? Focusing your eyes to read? Making sense of the squiggles on the paper? You may even have good vision, and still have a "print handicap."

A print handicap is any condition which makes it difficult or impossible for you to read conventional printed materials. It may be a vision problem, a physical limitation which makes it hard to hold a book, or a cognitive problem temporarily resulting from a brain surgery.

Most states have programs to assist people who have print handicaps. Libraries for the Blind and Physically Handicapped lend audio books and players to people who qualify for the program.

Mrs. Betty B. from Tennessee has graciously volunteered to talk with anyone who has concerns about visual impairment or coping with printed materials in new ways. Betty has VHL and has been blind for many years. She has three daughters and two grandchildren, and is an active teacher of Braille.

Please call the hotline at 1-800-767-4VHL, and ask for an appointment to speak with Betty.

Vision and Independence

Question: I have a family member who is experiencing visual problems and needs help in everyday activities. Is there a place I can contact for assistance?

Answer: There are several organizations that can provide help including training for home activities, visual aids, work training, audio tapes and braille material. The American Council for the Blind (1-800-424-8666) can provide information including the contact number for your State Division of Services for the Blind, which you can then contact directly. The Lions Clubs of America can also be a resource. Contact your local Lions Club for information. Other sources would be:

American Foundation for the Blind (1-800-232-5463).

Catalogs may be ordered through The Lighthouse (1-800-829-0500), including Games in Large Print.

Maxi-Aids Catalog (1-800-522-6294) - Low and High Tech Products for challenged individuals

American Printing House for the Blind (1-800-223-1839) - tapes and other products

Independent Living Aids (1-800-527-2118).

You may also order *A Resource Guide for People with Sight Loss* through your local bookstore (ISBN 09-929718-14-3, \$43.95).

□

Champion Golfer

by Charles Mayo, California

In 1934, when I was nine years old, a doctor told my mother that my left eye condition was probably a lazy eye.

In 1953, while living in Paso Robles, California, a terrible pain started in my left eye and I was unable to see out of that eye. An ophthalmologist diagnosed the condition as glaucoma and removed the eye. When I was ready to leave the hospital, he told me that he had observed some lesions of von Hippel-Lindau disease (VHL) in my right eye and that my eye should be examined periodically.

At the time we did not know that VHL causes a series of tumors, or lesions, in the retina and other parts of the body.

While living in Long Beach, California, in 1956, the retina in my right eye detached. Dr. Dohrman Pischel, in San Francisco, performed the surgery and told me he opened a window so I would be able to see about 10% of normal vision. He told me he wanted to examine my children's eyes and to return in six months.

What he did not tell me then is that VHL is a hereditary disease. Each child has a 50/50 chance of inheriting it from an affected parent.

When I left the hospital I knew I would never have normal sight, so I began looking for rehabilitation programs for the visually impaired. Within three months, the retina detached again. The operation that followed was not successful and I realized I would never see again. I went into a state of mourning and my whole life passed before me, including what accomplishments I had made.

Only 31 years old, with three small children, my most important thoughts were how I was going to care for my family. I contemplated what solutions were available and what goals were the most important. I prayed for guidance and remembered that I had read "be prepared for all phases of life and your chance will come." I enrolled at Long Beach State College through the State Rehabilitation program and earned a Liberal Arts degree in 1960.

In 1961 I started to work as a social worker for the Santa Clara County Department of Social Services and in 1969 received a stipend to attend San Francisco State University where I received a master's degree in social work. I returned to work as a psychiatric social worker.

While listening to the radio in 1963, I heard an announcement that Claude Pattemore had won the U.S. Blind Golfers Tournament in White Plains, New York. After hearing this, I went outside with a broom and started a golf swing. I told myself I could play golf again. I practiced with a neighbor and my sons and

soon was playing in local tournaments with my son Steve as my coach. Steve was then twelve years old.

I learned to play golf as a teenager, while caddying at the San Gabriel Country Club. After I lost my sight it was an asset to me that I had the training and fundamentals of playing golf. One important characteristic for me is the "mind's eye" which makes a picture of the shot that I am going to play and the shots that I have made in the past. For example, the eleventh hole at San Gabriel is approximately 130 yards. I can see the eucalyptus trees on the sides, the creek and the bridge across the fairway and how the hole is trapped, with a small opening in front of the green and a big trap behind the green. It has to be a precise shot to hit that green. Now when my coach tells me that the shot is 130 yards, I make a mental picture of this hole and try to make a shot as though I was hitting for that green. I use the same technique for all my shots.

Still the most important person is my coach. Without his help I would not be able to play this wonderful game. My son Steve is still my Number One coach and has been for thirty years. Steve works at a golf shop and gives lessons. Daughter Peggy also coaches me and is an L.P.G.A. teaching professional in Palm Desert, California. My wife, Dorothy, coaches me at practice, on vacations and in some tournaments.

The question I am asked the most is: "How do you play golf?" My answer is that I have a coach who lines me up and sets me up at the tee so that I'm lined up toward the direction I want to go. He sees that my feet, shoulders, grip and the face of the club are in the correct position to hit the ball towards the flag. He asks me if I'm ready and when I tell him I am, he steps back and I swing at the ball and hope that I hit it toward the flag. Without the coach, who takes the place of my eyes, it would be impossible to play.

We're Going to . . .

The VHL Symposium Hawaii, June 17-21, 1996

For hotel reservations, call the Pacific Beach Hotel, (800) 367-6060 or (808) 922-1233

For flight arrangements, call your local travel agent or call Jacki Hunsberger at 610-489-0896 or 800-829-0022, Fax: 215-361-8008.

Families: Learn the latest advances in managing your health

Doctors: Share ideas with other doctors and researchers to advance diagnosis and treatment for people with VHL.

For more information, contact Dr. Ted Hsia or Ms. Janet Brumblay, at (808) 956-8331.



VHL has greatly affected my life, as two of my children also have VHL. My older son died at the age of 38 of leiomyosarcoma, a type of cancer in the spine, not connected to VHL.

Editor's Note: At 70 years of age, Chuck Mayo is currently ranked number 5 with the the United States Blind Golfers Association, although he has held the number 2 ranking for many years in the past. He plays U.S. Tournaments in Orlando in November, Phoenix in April, and New York in June. He also travels to foreign countries, such as England, Canada, and Australia, for other tournaments. He is organizing a West Coast blind golfers' association which will also include people who are partially sighted because he would like to see more visually impaired people participate in golfing competition.

Clinical Care Centers

For additional information, please contact Susan Warnick, R.N., 16 Ridge Lawn Road, Reisterstown, MD 21136. Tel/Fax (410) 526-6858. Maryland. (* = new or changed since March 1995)

Canada: Memorial University of Newfoundland, St. John's, Newfoundland. Jane Green, M.S., Medical Genetics, Tel: 709-737-6807; Fax: 709-737-3374.

***France:** Necker Hospital, Paris. Stéphane Richard, M.D., Neuro-Oncology, Tel/Fax: +33-1-4449 5421.

***Germany:** Albert-Ludwigs University Hospital, Freiburg. Hartmut Neumann, M.D., Nephrology, Tel: +49-761-270-3363; Fax: +49-761-270-3245; E-mail: Neumann@mm41.ukl.uni-freiburg.de.

***Israel:** Hadassah Hospital, Jerusalem. David Gross, M.D., Chief, VHL Clinic, Endocrinology, Tel: +972-2-777648; Fax: +972-2-437940; E-mail: Gross@vms.huji.ac.il.

Netherlands: University Hospital, Utrecht. Dr. Cornelius J. M. Lips, Dept. of Internal Medicine. Tel: +31-30-509-111; Fax: +31-30-518-328.

United Kingdom:

England: Addenbrookes Hospital, Cambridge. Eamonn Maher, M.D., Tel: +44-223-216446; Fax: +44-223-217054.

Wales: University Hospital, Cardiff. Dr. Diana Wheeler, Institute of Medical Genetics. Tel: +44-222-743922; Fax: +44-222-747603.

United States:

California: University of California, San Francisco. Siobhan Geary, R.N., Neurocutaneous Clinic, Tel: 415-476-3338; Fax: 415-476-7965.

Hawaii: Kapiolani Medical Center, Honolulu. Y. E. Hsia, M.D., Tel: 808-956-8331; Fax: 808-956-5518.

Illinois: Northwestern Memorial Hospital, Northwestern University, Chicago. Maureen O'Connor, R.N., Daniel Dalton, M.D., 312-943-5353; Fax: 312-908-0376.

Iowa: University of Iowa Medical Center, Iowa City. Ann Muilenberg, Coordinator. Tel: 319-356-2674; Fax: 319-356-3347.

Kansas: University of Kansas Medical Center, Kansas City. Debra L. Collins, M.S., Tel: 913-588-6043; Fax: 913-588-3995; E-mail: Collins@ukanvm.cc.ukans.edu.

Maryland: Johns Hopkins Medical Center, Baltimore. Jill Hennessey, M.S., Medical Genetics, Tel: 410-955-3122; Fax: 410-955-0484.

Massachusetts: Lahey Clinic, Boston. John Libertino, M.D., Urology, Tel: 617-273-8420; Fax: 617-273-5246.

Michigan: University of Michigan, Ann Arbor. Wendy R. Uhlmann, M.S., Molecular Medicine & Genetics. Tel: 313-763-2532; Fax: 313-763-7672.

Minnesota: Mayo Clinic, Rochester. Mary Kelly, Clinic Coordinator, Tel: 507-284-8198; Fax: 507-284-0161.

New York: Albert Einstein Medical College of Medicine/Montefiore Medical Center, Bronx. Robert D. Burk, M.D., Tel: 718-430-3720; Fax: 718-918-0857.

Mount Sinai Hospital, New York City. Jane Halperin, M.S., Neurology, Tel: 212-722-1784; Fax: 212-860-6629.

Find information about VHL on the World Wide Web! Connect to the VHLFA Home Page, at URL
<http://kumchttp.mc.ukans.edu:80/instruction/medicine/genetics/vhl/vhlhomep.html>
 or <http://neurosurgery.mgh.harvard.edu:80/vhl-fa.html>

Ohio: Cleveland Clinics, Cleveland. Dr. Andrew C. Novick, Dept of Urology. Tel: 216-444-5584; Fax: 216-445-7031.

Texas: Baylor College of Medicine, Houston. Michael Frazier, B.S., Manager, Genetics Clinic, Texas Children's Hospital. Tel: 713-770-4280; Fax: 713-770-4294.

Washington: University of Washington, Seattle. Robin L. Bennett, M.S., Division of Medical Genetics, Tel: 206-548-4030; Fax: 206-543-3050. □



Hawaii, Here we Come!

I hope you can all attend the VHL Conference June 17-21, 1996, in Hawaii.

All those time zones! Do your mind and body a big favor and stay a few extra days, and save money on your airfare. By staying 2-3 nights (or longer) before or after the conference, you could save hundreds of dollars. With a custom package you could see as much as possible in the time you have.

Rent a car? See another island? Or several? Will you be joining friends or family? A condo would be more economical and much more comfortable. All special pre- and post-conference additional nights can be arranged for departures from all over the U.S. If you are using frequent flier awards, I can still arrange a special "land only" package for you.

You may call me anytime.

Jacki Hunsberger, CTC

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Online Services

by Fred Johnson, Computer Committee

The VHLFA Web site is very popular!

Special thanks to Dr. Stephen Tatter, our volunteer Web Master at the Massachusetts General Hospital, for creating and maintaining this invaluable service. See the address at the bottom of this page.

The chat circle has been cancelled for lack of interest. Please use the BBS instead.

VHLBBS/UMC available on the Internet

The VHLBBS free bulletin board sponsored by the Global Ministries of the United Methodist Church may be reached at 1-212-222-4724 or

telnet hwbbs.gbmg-umc.org

or through the menu option on our home page.

VHL on the Net

Write to vhl@pipeline.com to ask any questions about VHL or the VHL Family Alliance. A volunteer family member will reply. □

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If you think you are beaten -- you are.	
If you think you dare not -- you don't.	
If you'd like to win but think you can't,	
It's almost a cinch you won't.	
If you think you'll lose, you're lost.	
For out in the world we find	
Success begins with a person's will.	
It's all in the state of mind	
Life's battles don't always go	
To the strongest or faster hand;	
but sooner or later the person who wins	
Is the one who thinks "I can."	
-- Anon. Shared by Clay Castleberry, California	

Page 8

Original art work by Sherri D., Tenn.

Introducing our Medical Advisory Board

There are seventeen medical professionals listed on page 14 who may not always be very visible to you as readers, but who are very visible to the members of the Board of Directors. They very generously lend us their expertise as consultants on difficult questions from members, in the writing or reviewing of material for this newsletter, in presenting or helping design presentations for our annual meeting, and in advising us on various aspects of our programming. We continue here their introductions. We have purposely sought out people with depth and breadth of experience with VHL — people whose formal training has been enriched by working with a number of patients with VHL over a number of years.

Stéphane Richard, M.D.

Dr. Richard is Professor and Chairman of the Laboratory of Neuro-Oncology at the École Pratique des Hautes Études in Paris. He earned his M.D. from the Medical School of Angers and completed postgraduate training with Paris, with a Ph.D. in Histology. He was a French national champion discus thrower. He holds

board certification in Pathology and obtained degrees in Endocrinology, Reproductive Biology, and Genetics. His primary research interests are morphology and genetics of brain tumors.

Since 1990 he and Dr. François Resche, Professor and Chairman of Neurosurgery in Nantes, a French National Registry of VHL patients, consisting of 480 patients with von Hippel-Lindau disease. He works regularly with more than 200 patients and their families. His efforts have contributed greatly to bringing a new level of attention to VHL throughout the medical community in France.

Through 1994 he worked at the La Salpêtrière hospital, in the Laboratory of Neurohistology, chaired by Dr. Foncin, who is well known for his contribution to the genetics of Alzheimer's disease. He has recently joined the Necker Hospital, where many other physicians of the French Clinical Care Center are based.

Dr. Richard has a special interest in the clinical and genetic epidemiological aspects of VHL. One major tool of genetic epidemiology is genealogy, consulting municipal and parish registers of births, marriages, and deaths in order to identify even distant relatives of patients, and by studying the records of various departments of neurosurgery, ophthalmology, pathology and especially neuropathology, dating back in some instances more than 60 years. In a number of

*VHL France is on the Minitel! Instead of printing telephone books in France, every home has a small computer terminal with an 8-inch screen to look up telephone numbers. The service has grown to include plane and train schedules, commercial advertising, personal ads, and games. Here Michel Proux, co-chair of VHL France, demonstrates that you can find VHL France on the Minitel by dialing 3615 code CNA*VHL. You would find two pages of information about VHL, and could send a message to Michel. Or on the Internet, write to Michel or any other VHLFA member or volunteer in care of uhl@pipeline.com.*

instances Dr. Richard was able to connect so-called "sporadic" cases to previously known VHL families, such as the large "Sancerre" family with 28 affected people, and to identify "founders" more than 100 years back. This work has made it possible to identify large groups of patients who are genetically identical by descent, allowing for more precise research. It has also enabled Dr. Richard to alert the physicians caring for people who are not aware of being at risk, so that they can take appropriate precautions.

He has participated in almost 60 scientific papers and books including "Hemangioblastomas, hemangioblastomatosis and von Hippel-Lindau disease" (*Advances and Technical Standards in Neurosurgery* (1993) **20**:197), "Renal Lesions and pheochromocytoma in von Hippel-Lindau disease" (*Advances in Nephrology* (1993) **23**:1), and "Pheochromocytoma as the first manifestation of von Hippel-Lindau disease" (*Surgery* (1994) **116**:1076). He also published many articles in French such as "Do hemangioblastomas exist outside VHL disease?" (*Neurochirurgie* (1994) **40**:145, selected by the 1995 issue of the *Year Book of Neuroradiology*).

In December 1994 Dr. Richard was awarded the Yvonne Dumonteil Prize by the French National Cancer League (*Ligue Nationale contre le Cancer*) for his "outstanding contribution to the clinical and epidemiologic genetics of von Hippel-Lindau disease." He is a founding member of our affiliate VHL France, and serves on its Medical Advisory Board. □

In Memoriam

The families of Carolyn and Clay, whom we remembered in the September issue, were kind enough to share their stories with us. We celebrate their lives and send our heart-felt wishes of love and comfort to these families. If you would like to write to either family, we will be happy to pass your notes along.

Carolyn Flanagan

-- Mark Flanagan

In the roughly 15 months between the time my sister Carolyn was diagnosed in March and April of 1994 as having renal cell cancer and von Hippel-Lindau, she led a life on two parallel courses.

On one, she was totally committed to recovery. She was willing to do whatever it would take. If the CAT-scans, MRIs and such provoked severe anxiety in her, her response was to say, "Fine, I'll meditate, take a valium, wear a blindfold and get through it." If most of the doctors she dealt with were ignorant about VHL, she was willing to do the research, explain the condition to them, carry copies of medical literature about VHL to their offices. She was very grateful to the VHL Family Alliance for help on this account.

If the treatment involved radiation treatments, a hip replacement, removal of parts of her adrenal glands and kidneys, interleukin II therapy, she was ready to endure that. Her last instructions to a doctor were given on June 8, at a time when she had been in severe pain for weeks: resuscitate me if necessary and continue treatment if possible. She died June 10. She was 48.

The other course was to prepare friends and family for the event recovery might not be possible. I don't think I can adequately express the difficulties she was willing to overcome to make trips to Washington and Florida to spend time with a couple of her closest friends, or later just to meet for breakfast with a friend visiting from California. Upon her death, I initially felt at a loss as to how to satisfy the obligations she had left to me as her next of kin. As each specific challenge arose, however, I realized that she had been very subtly giving me a fairly complete set of instructions.

It was quite a balancing act, but she was quite a person. Catherine Power, head of the Rhode Island Department of Mental Health, Retardation and Hospitals, where Carolyn was employed as a habilitative services manager, described her at her

memorial services as "steel wrapped in grace." Carolyn was equally gentle and determined.

She was a helluva big sister and a helluva social worker and social work administrator. The Superior Peer Award given quarterly to outstanding employees at MHRH has been renamed the Carolyn Flanagan Superior Peer Award in her honor.

If disease had not intervened Carolyn would about now be counting down her last year toward semi-retirement. She would be looking ahead to travel and a part-time career as a counselor, consultant, teacher.

A long life should have been hers. She exercised, dieted, had the annual checkup and saw a physician whenever an ailment warranted it. For all the doctors she saw, none added up the "mystery headaches" she had had since age 10 to the high blood pressure that came on at age 21 as possible indicators of VHL. It would seem that few, if any of them, were familiar with VHL. By the time she was diagnosed, renal cell cancer had already spread to her hip.

Carolyn's family is very appreciative of the support she received from the VHL Family Alliance. We wish the Alliance continued success in promoting awareness and early detection of VHL. □

Clay Castleberry

-- Leah Castleberry

My brother, Clay Trevor Castleberry, departed our lives on July 4, 1995. He was returning to California from Maine and died suddenly on the plane. Our family had gathered in Maine to celebrate our mother's 50th birthday.

In March of 1990, Clay was diagnosed with a midline cerebellar hemangioblastoma. The removal of the hemangioblastoma was complicated by its size (the tumor was twice the size of the medulla) and a tumor that was later discovered on his adrenal gland (a pheochromocytoma). The pheo caused Clay to experience sudden extreme variations of his blood pressure. Unable to stabilize his blood pressure, Clay spent the rest of 1990 in the hospital until the discovery and removal of the pheo.

Rehabilitation was a very long and difficult process for Clay, but he never gave up. Told he would never walk again, Clay struggled and often stumbled to prove them wrong. Learning to walk again began with small successes such as being able to stand for 4 seconds without fainting. When he fell he simply got right back up on his feet. In May 1993 he gave his wheel-

chair to someone who needed it.

Another obstacle was learning to communicate without a voice. He had no gag reflex so a tracheostomy was performed for breathing purposes. Our mother, a speech therapist, taught Clay how to communicate with the nurses. Sign language can, at times, be more meaningful than actual words.

Without a voice Clay's expressions became more animated to portray his feelings. His laughter, although silent, is one of my fondest memories. A valve was later implanted in Clay's trachea which, when occluded with his thumb, diverted air by his vocal cords providing voice for speech.

“ *There is nothing in the world so much admired as a person who knows how to face challenges with courage.* -- Seneca ”

Clay had always been a strong, independent person. Having to rely on others for assistance was very difficult for him. Becoming independent again, physically and financially, was his goal. He first achieved mobile independence with a driver's license and a car, then he enrolled in an intensive computer program. He was attending college, five short months from graduating with honors, when he left us.

Clay's desire and pursuit to become independent was succeeding. Clay spent the last two years in his own apartment without assistance. My brother Donovan, my mother and I are very proud of Clay and his accomplishments. He was our shining star and taught us about courage and determination. Clay's absence from our lives will always be felt. We are, however, grateful for all the precious memories he has given us in his too short life. We cherish them.

Our mother, Charlotte, having undergone numerous surgeries and obstacles herself, gave Clay the strength he needed to carry him through the past five years. The von Hippel-Lindau disease has contributed to a close-knit family. We share a unique and special relationship. I thank Clay and my mother for showing us that no obstacle is too big to overcome.

He was so strong,
stirring along.

He could not crumble,
and was sweetly humble.

Stubborn as hell,
He tore out of his shell.

He loved to live,
And had everything to give.

Clay was stronger than steel,
and he made us feel,
even we could do anything.

-- Written for Clay by Carrie. □

Diamond Dig

-- Melissa Minster, Delaware

The Delaware Valley Chapter of the VHL Family Alliance held its First Annual Diamond Dig to raise funds for research on von Hippel-Lindau disease. The event was held during Community Day in Newark, Delaware. Fred and Altheada Johnson came from New York.

In return for a donation of \$5, people earned the right to dig for 15 seconds in the "diamond mine" (a plastic wading pool filled with sand and gemstones) to look for a 1/4 carat diamond valued at \$500 or one of 300 cubic zirconias. The gemstones were donated by J. J. Minster's Jewelers.

The Diamond Dig was well received the the community. We were able to hand out over 700 of the "What is VHL?" brochures and raise over \$400.

It was interesting to see that the information was read and we received many questions concerning VHL, not only from community members but doctors and nurses as well.

Through this event we were able to learn new ways to make next year's Diamond Dig even better. □

Our Family is Growing!

-- by *Peggy Marshall, Chair, Chapters Committee*

As chair of the Chapters Committee for the VHLFA, my goal was to see five new chapters added to our "Family" this year. I'm delighted to say we have exceeded that goal and are still experiencing a great interest in additional chapters in the near future. I felt a great sense of deep caring about others, sincere warmth and exhilarating enthusiasm from each of them. We send a big welcome to our new State Chapter Chairs in Illinois, Iowa, Kentucky, North Carolina, Oklahoma, Texas, Vermont, Virginia/D.C., and Washington State, bringing the total to 21 State Chapters covering 28 states.

More than 15 State Chapter meetings were held across the nation adding an average of three new VHL affected members each. Local activities have helped to locate more, an average of 10 new VHL affected people per chapter.

Chapters have also helped with local fund-raising events, and sales of T-shirts, sweat shirts, cookbooks, and pins. Our chapters participated in "Make a Difference Day" in October, sponsored by *USA Today*.

In this article we begin introductions of some of the State Chapter chairs, volunteers who have taken on the challenge and the privilege of raising the visibility of VHL in their areas, working to increase the likelihood of an early diagnosis, and to provide that special empathy that only another VHL family can provide. We are very grateful for their willingness to share themselves and their time.

Juli Malfatti, Vermont Chapter

Juli is an Administrative Assistant in the Safety Department of a petroleum company located in rural Vermont and presently taking a course to complete a degree in Medical Transcription.

Juli is a member of a family that has known about VHL since the early 1960's. Her father was diagnosed with renal cell carcinoma, related to VHL, in July

1993. He passed away after eight weeks of treatment. At that time, he was under the impression that his family was only one of nine worldwide with this rare kidney condition and apologized for leaving his daughters to live with VHL.

When she attended the Burlington Conference and heard Joyce announce that we were looking for Chapter Chairs, she decided this was one way to make her father's death less pointless.

Juli says, "I understand first hand the need for

information and support so that we can meet each daily challenge. I am hoping to bring the awareness of VHL to as many local medical professionals and medical facilities as possible, so that families living in Vermont don't have to feel they are only one family in nine in the world. They will know they are part of a large and growing worldwide family."

Audrey Clifton, Lonzo E. Hayes, Jr, Co-Chairs, North Carolina

Audrey resides in Fayetteville, North Carolina. She is especially interested in church and directs the Adult Ministries and homeless program, along with volunteer work with Hospice of Cumberland County of N.C. She was diagnosed with VHL in 1970 and has had several brain and kidney surgeries. She says, "I feel that I am presently in good health and thank the Lord for being able to get around and enjoy life."

Audrey recently learned her oldest daughter and grand-daughter were diagnosed with VHL. She became involved with the VHLFA to provide support and information for her family and other VHL patients, so they would know they are not alone facing VHL. She says, "My goals for our Chapter are to educate the public in promoting awareness about VHL, and raising funds for research and finding a cure for VHL."

Lonzo is a member of a large VHL family (four generations) that includes his sisters, Peggy M. and Eva L. He is a volunteer firefighter and Emergency Medical Assistant who dedicates a large portion of his time to helping others. He resides in Sunset Beach, N.C. Lonzo was diagnosed with VHL at age 15 and has had several eye, brain and kidney surgeries.

Lonzo is dedicated to assisting in any way to help with promoting awareness, patient support and encouraging VHL research.

Mark and Cindy Boyd, Texas Chapter

Mark first learned he had VHL in August 1990, when he had kidney surgery. Their children are screened yearly. His dad passed away eighteen years ago from VHL complications. He has a sister, niece and nephew diagnosed with VHL. His brother recently went to NIH for complete screening.

Cindy says, "It was through the VHL Family Alliance and talking with Peggy Marshall that we learned of Dr. Zbar and the screening of new families at NIH. Our family wants the VHLFA to know how much we appreciate the hard work the Board Members and Medical Advisory Board are doing to help each of us."

"Two of the things we hope to accomplish in our Chapter are: (1) yearly screening for children at an early age, and (2) never think you don't need the VHL Family Alliance. We are very grateful for the knowledge and research that the VHLFA has given our family."

“All the volunteers of the VHL Family Alliance are doing a wonderful job of reaching out to many people. We are grateful to you for all you have done. Thanks so much to everyone who donates their time to the VHL Family Alliance for making a dream come true. -- Betty B., Tennessee”

Fran Dickson -- Virginia and Washington, D.C., chapter

Fran and her husband Bill Dickson (VHLFA Board and Research Management Committee Chair) recently retired from careers in the Federal Government. Fran worked in Personnel, interviewing applicants for highly sensitive positions with the Joint Chiefs of Staff.

Fran and Bill have two children and one grandchild. Their son-in-law and grandson have VHL. Their son-in-law had both kidneys removed, and recently had a successful kidney transplant. Fran and Bill were ready to relax in retirement but have now devoted their efforts in support of the VHL Family Alliance. Fran says, "Our goal is to help the VHL Family Alliance encourage researchers to find better forms of diagnosis, treatment, and an eventual cure for the disease."

Alice Minster Coday, Washington State

Alice is 40 years old and the oldest of three siblings. "I considered myself the lucky one! I originally joined the Alliance to support my brother and sister, both of whom have had various serious manifestations of VHL." Twelve years ago she was diagnosed with cysts on the pancreas and kidney, but no other symptoms. In 1986 she experienced unexplained hearing loss and vertigo, diagnosed as everything from ear wax to hypochondria to Minieres disease.

After agreeing to chair the Washington chapter, she learned that hearing loss can sometimes be associated with VHL. In August she went through four days of extensive testing at the National Institutes of Health and found that her hearing loss was the result of endolymphatic sac tumors, one on each side. The right side with the large tumor is the ear which still hears.

"I am sure that many of you have experienced the same agonizing frustrations of going from one place to another to get the proper diagnosis of what is happening to you. Because of the Alliance's networking and education, I now have peace of mind and know other people who care about me and understand my concerns. Thank you, VHL Family Alliance! I really am the lucky one!"

The Perfect Gift

What better gift than to surround someone with VHL with the love and comfort of the VHL Family Alliance!

Symbols of that comfort include beautiful 1-inch pins in silver or gold designed by member Melissa M. of Delaware; T-shirts and sweatshirts designed by member Altheada J. of New York; cookbooks prepared by members Gale L. and Altheada J. and the Florida chapter. Or make a donation in their honor and show how much you care. Send brochures asking your friends and relations to contribute. See p. 15 for information.

Best of all, give the gift of your own love and caring by being a volunteer. We have jobs in all sizes, beginning with a single phone call or delivering brochures to a medical meeting. We are all volunteers -- your gift of time or money is what makes it all work.

William C. Dickson, +1 (703) 759-3665
Research Management Committee
 10613 Creamcup Lane, Great Falls, VA 22066
Lois P. Erickson, Vice-Chair, +1 (612) 884-2794
Fund-Raising Committee
 9532 10th Avenue South, Bloomington, MN 55420
Joyce Wilcox Graff, Chair, +1 (617) 232-5946
Editor, VHL Family Forum
 171 Clinton Road, Brookline, MA 02146
Peggy Graham, R.N., Int'l. Liaison, (810) 979-8563
Professional Education Committee
 32049 Cambridge Drive, Warren, MI 48093
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Chair, Alleanza VHL
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Altheada L. Johnson, Secretary, +1 (718) 622-2457
Membership Committee
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Chair, VHL Family Alliance, Australia
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Public Relations Committee
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Chapters Committee
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Hazel Murfitt, Britain, +44 (353) 861308
Chair, VHL Patient and Family Support Group
 114 Longfield Road, Littleport, Ely, Cambs CB6 1LB England U.K.
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In France, send to VHL France, 87, rue de la République, 95240 Corneilles-en-Parisis, France

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E-mail: vhl@pipeline.com; Phone: 1-617-232-5946; Fax: 1-617-734-8233

Toll-free in the United States and Canada: 1-800-767-4VHL

Editor: Joyce Wilcox Graff, 1-617-232-5946 (eve)

Adviser: Debra L. Collins, M.S., U. Kansas Med. Center, 1-913-588-6043

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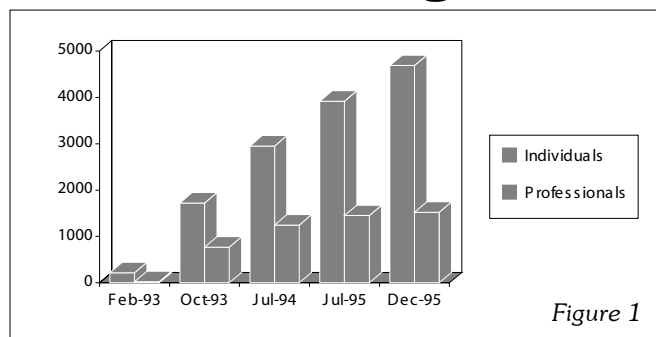
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Every
contribution
helps!
Thank you



We're Growing!!!

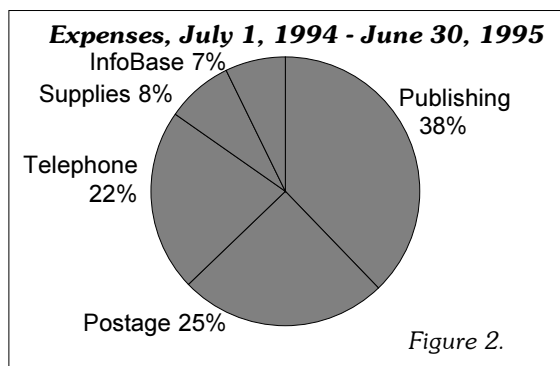


Thanks to all of you, the VHL Family Alliance continues to grow at an amazing rate. We are encouraged and inspired by your interest and participation.

We "broke even" for fiscal 1995! That's a victory! We spent \$32,219.02, allocated as shown in Figure 2.* The Boston conference was self-supporting.

We are all volunteers. We pay no staff; we do not rent office space.

Just to continue our current activities will cost \$35,400 this year. In addition, the revised Handbook will cost \$5,000 to print and distribute; setting up a VHL Registry will cost \$5,000 a year; and our goal for fund-raising for research is \$35,000. We can only



*A complete annual report is available on request.

spend what we have.

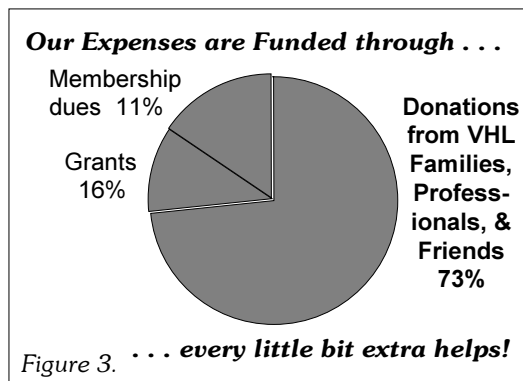
We need your help. We realize that not everyone can contribute money, and we want to make sure that everyone has the information they need. This organization is not about money, it's about helping one another. We will *always* give our help and send literature to whoever needs it, regardless of their ability to pay.

So if you can afford to give, please give a little extra for the person who can't. And if you can't afford to give at this time, perhaps you might suggest to a friend or relative that they contribute in your honor instead of buying you that holiday gift.

As you can see in Figure 3, the membership dues fund only a portion of the budget. Those extra donations you send with your membership, the T-shirts and pins and cookbooks you buy, and the honor cards you send to your friends, all help to make this organization work.

If you value the 800 number, the Web service on the Internet, the Clinical Care Centers and this newsletter ... and want them to continue, please, please give what you can. Together we will find better management, and a cure for VHL. And you will be a partner in this work. **Thank you!**

We send love and blessings at this holiday season and always. -- VHLFA



VHL Family Forum

Newsletter of the VHL Family Alliance
171 Clinton Road
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