VHL Family Forum

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VHL Clinical Care Centers

We are very pleased to announce the inauguration of our Clinical Care Program for von Hippel-Lindau disease (VHL), under the coordination of Susan Warnick, R.N., of Reisterstown, Maryland.

The goals of the Clinical Care Program:

- To improve diagnosis and treatment of VHL
- To provide coordination of care across medical specialties
- To provide resource centers for patients and physicians who are new to VHL
- To provide a ready channel for communicating advances to these centers of expertise
- To provide a model which can be replicated elsewhere

The beginning model for our program is that of the National Neurofibromatosis Foundation for NF. Since we are a small population, a VHL Clinic is not a building, a department, nor even necessarily a designated day, but it is certainly a "state of mind." The Clinical Care Committee will work with the pilot centers over the coming year to define the standards for the program.

Each of the participating pilot institutions has agreed that they will designate a point-of-entry into the institution where the term VHL will be recognized, and staff will know how to assist. They will take responsibility for helping a patient find all the needed specialists, and check all the appropriate areas of the body which need screening. They will ensure communication among the specialists involved in a patient's care, and wherever possible will do their best to coordinate appointments to minimize the time the patient and family need to spend at the center.

These centers may also serve as a source of second-opinions, or referrals from Health Maintenance Organizations and physicians less familiar with VHL.

We need your help in identifying centers where expertise in VHL already exists, and tying those centers into the system. We need your help in identifying places where a new clinic might be developed. We need your suggestions for standards of care. And we need your help with the nuts and bolts of coordinating the program. Susan would like to have regional coordinators assisting with communications — please contact her to volunteer your help.

The initial pilot clinics are:

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

Albert-Ludwigs University Hospital, Freiburg, Germany. Dr. Hartmut Neumann, Nephrology, Tel: +49-761-270-3363; Fax: +49-761-270-3245.

Kapiolani Medical Center, Honolulu, Hawaii. Juliet Yuen, M.S., Tel: 808-973-8698; Fax: 808-973-2554.

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

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

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

Mount Sinai Hospital, New York City. Jane Halperin, M.S., Neurosurgery, Tel: 212-722-1784; Fax: 212-534-3163.

University of California, San Francisco. Siobhan Geary, R.N., Neurology, Tel: 415-476-3338; Fax: 415-476-8778.

University of Iowa Medical Center, Iowa City. Mary Curtis, M.D., Tel: 319-356-2674; Fax: 319-356-3347.

University of Kansas Medical Center, Kansas City. Debra L. Collins, M.S., Tel: 913-588-6043; Fax: 913-588-3995.

To volunteer your assistance with the Committee, or to enroll as a Clinical Care Center for VHL, please contact Susan Warnick, R.N., 16 Ridge Lawn Road, Reisterstown, MD 21136. Tel: (410) 526-6858. ❑

Inside this issue!

World Focuses Attention on VHL!

World Focuses Attention on VHL

Report from the International Symposium on Von Hippel-Lindau, Freiburg, Germany, May 27-28, 1994.

"In the last ten years, von Hippel-Lindau disease has gone from an obscure medical curiosity to a condition with far-reaching implications in oncology," said Dr. Alfred G. Knudson of Philadelphia, originator of the now widely accepted theory of tumor-suppressor genes, delivering the keynote address at the First International Symposium on von Hippel-Lindau (VHL) in Freiburg, Germany. He noted that study of VHL is helping scientists to understand the mechanisms of many kinds of cancer.

Eighty respected physicians and scientists gathered from Japan, the United States, England, Germany, France, Italy and the Netherlands. They shared the results of their research on the molecular genetics and clinical management of VHL. Dr. Knudson lauded the presentation of urologist Dr. Gyula Kovacs of Heidelberg, saying that he "has made an enormous contribution" to the field. Honored American attendees included Dr. Y. Edward Hsia of the University of Honolulu, and Dr. Nuzhet O. Atuk of the University of Virginia, whose studies of large VHL kindreds have provided key pieces of the VHL puzzle.

In the May issue of *Nature Genetics,* the VHL gene has been shown to play a role in 85% of kidney cancer cases which occur in the general population, affecting 23,000 people each year in the United States alone. [See page 7]

The meeting was hosted by Dr. Otmar Wiestler of Bonn, and Dr. Hartmut P.H. Neumann of Freiburg, who has spent the last twelve years concentrating on improving diagnosis and treatment of patients with von Hippel-Lindau disease. Dr. Neumann recently completed a tour of the United States, sponsored by the VHL Family Alliance, where he spoke on VHL in five cities. [See pages 8-9,10]

The principal questions for this symposium concerned diagnosis and therapy: how to improve diagnosis through clinical findings and/or through molecular genetics; how to reduce exposure to radiation in diagnostics; how to reduce the complexity of the diagnostic process. In the area of therapy, Dr. Neumann posed the question how to find the right balance between undertreatment and overtreatment. With improvements in diagnostics, tumors are now found at very early stages, but at what point should action be taken? The goal of the symposium was to make recommendations to physicians and to inform the decisions of the patients regarding their treatment.

Dr. Hartmut Neumann, Albert-Ludwigs University, Freiburg, Germany

Joyce Graff of Brookline, Massachusetts, and Peggy Graham of Warren, Michigan, attended the Symposium, representing the VHL Family Alliance. Both Joyce and Peggy have children affected with VHL. They met with families from Germany, and were interviewed on German television. They spent most of Saturday with Peter and Sylvine Z. from East Berlin, who send their best greetings to all the members of the VHL Family Alliance.

Nearly thirty talks and posters were presented.

The French National VHL Registry project under Dr. Stéphane Richard found hundreds of previously misdiagnosed cases of VHL. They found that 30% of all cases of cerebellar hemangioblastoma and 58% of cases of spinal hemangio-blastoma were in fact VHL. Among patients under the age of thirty, the percentages rose to 47% and 77% respectively. When tumors occur in young people, they are more likely caused by a hereditary condition.

On the last day, Dr. Neumann summarized the recommendations of the symposium regarding cerebellar hemangioblastomas. Screening is done with MRI with gadolinium. They can grow fairly large without symptoms. Early diagnosis is important to prevent loss of function. There was interest in the possible contribution of radiosurgery for cerebellar hemangioblastoma. Dr. Hsia noted that it is important to screen VHL women before childbearing because of the tendency of tumors to grow at a faster pace during pregnancy.

Dr. Dieter Schmidt of Freiburg summarized the recommendations for retinal angiomas. He screens the retina with contact glass and fluorescein angiography as needed, in an effort to find lesions when they are very small. He treats angiomas with laser, espe-

Left to right: Sylvine & Peter Z, E. Berlin; Peggy Graham, R.N., Michigan; Dr. Alfred G. Knudson, Philadelphia.

cially small ones in the periphery, treating them in multiple sessions to avoid blistering the retina. Conscientious follow-up is important, as additional lesions are not uncommon.

When lesions are close to the optic nerve or macula, treatment can be dangerous. He tends to observe these unless they are actively growing. He posed the question whether photon-beam therapy might hold promise for treatment of certain of these difficult lesions. Dr. Stéphane Richard of Paris noted that since retinal angiomas are indistinguishable under a microscope from cerebellar hemangioblastomas, we should refer to them as hemangioblastomas.

Luisa Guerra, head of Alleanza VHL, our Italian affiliate, sends greetings from Italy.

Dr. Peter Choyke of the National Institutes of Health, U.S., summarized the findings on renal cell carcinoma. CT scanning is recommended with 5 mm. slice depth and contrast. One should not only identify the presence of tumors, but their size and growth rate, but re-checking twice at 6-month intervals the first year. Once this information has been gathered and the risk calculated, watch the tumors up to a size of approximately 3 cm and then perform enucleation or partial nephrectomy. Total nephrectomy should only be performed when there are no other options. Several of those present recommended the use of MRI or ultra-sound during the surgery to maximize the benefit of each surgery. Continue a conscientious follow-up program because more tumors are not uncommon. The goals are to avoid frequent surgery, and reduce metastasis to a minimum.

Dr. Atuk summarized the recommendations on pheochromocytoma. Dr. Eamonn Maher of England recommends annual urine testing. Dr. Atuk uses CT, though some felt that MRI or MIBG were preferred. He feels that of the chemical indicators, urinary catecholamines are the most useful indicators. None of those present had experienced any malignancies among pheos. Therefore the recommendation is to enucleate the tumor whenever possible. Pheos can occur outside the adrenals, so even people with bilateral adrenalectomy should continue to be screened for pheo. The presence of a pheo must be ruled out before any surgery in VHL patients, to avoid surgical complications.

Professor J.-P. Grünfeld of Paris, in his concluding remarks, noted that VHL is often misdiagnosed in all countries, partially due to the risk of overly compartmentalized medicine. He noted that with the better information which is being gathered, with better training on VHL now available to physicians, better information for families, and with the participation of the families in the ongoing process of learning about VHL, progress will continue to be made.

Dr. Wiestler thanked everyone for coming, and for the enthusiasm generated at the meeting. ❑

Relatives in Italy?

Luisa Guerra requests your assistance in locating people with VHL in Italy.
Materials and telephone support in Italian.
Please contact:
M. Luisa Guerra, Chair, Italian Affiliate
Alleanza VHL
Loc Malvicina, 19
15066 Gavi (AL), Italy
+39 (143) 643572

Request for Assistance

from Eamonn R. Maher, M.D., Cambridge, England

I would be most grateful if you were able to help with a small study I was interested in performing. I wanted to compare the course of VHL patients who have been treated by dialysis or by transplantation following bilateral nephrectomy. To my knowledge there are few patients who have had a renal transplant and it would be helpful to try and pool the data.

If you or a close relative have had both kidneys removed and been treated with dialysis or transplant, and would be willing to answer some questions, please write to me or to the Alliance. I would also like to hear about any relatives who are now deceased who were treated in one of these ways.

Many thanks for your help.

Write to Dr. Maher, or call 800-767-4VHL

Eamonn R. Maher, M.D., M.R.C.P.
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L to R: Dr. Y. Edward Hsia, Juliet Yuen, M.S., Hawaii; Dr. Peter Choyke, Maryland; Dr. J. P. Grünfeld, Paris.

Living with VHL

by Linda and Fred T. and their daughter Stephanie, New Hampshire

I was adopted at birth into a loving family, and always thought that was a good thing all my life. That is, until I was an adult with medical problems and needed information.

I was healthy as a horse most of my life, except a little bit asthmatic as a child. Very strong at twenty-three, I got pregnant with my daughter, and from that time I began to have problems.

First I had cysts and tumors resulting in a hysterectomy before my daughter was six months old. At the time we didn't know about VHL, and the records are now unavailable, so we'll never know if that was related or not.

At age thirty-six I received a call from my long-lost natural sister. I was told we had some strange disease in our family. She didn't know much about it, except that it was diagnosed through the eyes and brain. With this little piece of information I went to a major hospital in New Hampshire. "The hospital staff asked us about VHL," Fred adds, "and we had nothing to tell them." They said they saw nothing in my eyes or brain, so I went away fat, dumb, and happy.

After that everything seemed okay except for a series of symptoms that my doctor did not seem concerned about. But my husband insisted that I wasn't right.

"The doctors just weren't taking her seriously," Fred says. "She had a number of unexplained aches and pains. They grew more serious as time went by, but the doctors told her, 'It's in your mind. These things you are describing come with aging,' etc. I know Linda is not a complainer. I asked my own doctor to take a look at her, and he agreed to run a series of tests."

Finally this doctor really listened to me. He found my kidneys loaded with tumors. "Well, Linda," he reported, "we have found that your kidneys are the size of very large grapefruit, and we are sending you to a specialist immediately. And by the way, Happy Birthday." It was on my fortieth birthday that I was introduced to VHL. The local urologist sent me to another specialist in Boston.

For two years I went through a series of surgeries. Fred adds the details: "They did a radical nephrectomy within days of the original diagnosis. We were very pleased with this doctor. The right kidney they were able to approach sparingly, removing only the tumors and part of the kidney. In a few years there were more tumors to remove. With so little kidney left, Linda began needing dialysis, and now life really changed. But after several tries at repair, God gave us a gift. The 5/16 of a kidney she had left began working more effectively, and she no longer needed dialysis! Thank you for your kindness, Lord!"

I was nearly ready to give up on the last bit of kidney, when it miraculously began to work. I have been off dialysis ever since, and happy to say I am doing well.

Through all this I set myself little goals and just kept fighting to reach each little one, trying not to worry about the big ones.

Things have been very good for me the last two years, though my daughter has had three surgeries. Like most people with VHL, I am happy for today and just wait for what happens tomorrow. Please God, grant us all the strength to fight back.

Being adopted complicated all of this in the beginning. It might have helped save my kidneys if I had known more about VHL and about the others in my family who had had kidney trouble. It might also have changed my mind about having children, knowing I could pass on such a disease. I have been blessed with a very strong daughter, and she handles life's problems very well.

"Since 1988 when our daughter Stephanie was 17," says Fred, "we had taken her to doctor after doctor for severe headaches and numbness in her left side, to which they all said, 'Just your average teenager with teenage problems!' Finally we found a neurologist, a great lady, and got her attention, and at last they did some testing. Our suspicions were confirmed — Stephanie had several brain and spinal tumors. It had taken two years to get a doctor to listen to our fears."

"I remember the day I went for that first test," says Stephanie. "I was afraid, and my boyfriend at the time was telling me that it would be fine.

"My Dad went with me to my MRI. I remember being given one of those oh-so-attractive hospital gowns. The technician told me to hop up on the table and lie down. They put my head into this cage-like device and the test began. The next thing I heard

through the noise of the test was the technician saying, 'Oh, my God!'

"The next day I was given the news — I had a brain tumor and would need surgery.

"That was in January 1990. It was my senior year in high school, the years which, as my parents say, are the best years of your life. Or so I thought!"

Stephanie was clear and doing well for three years, until six months after she began taking birth-control pills.[1]

"Since that first surgery I had another brain surgery in April 1993, and two days after I was home from the hospital I was rushed back to the hospital because my left leg was in such pain; it felt as though it had been driven over and crushed.

"Back to the trusty MRI truck[2] where it was discovered that I needed yet another surgery, this time on my spine.

"I have been told by several of my doctors that life as I have known it is over and I will now have restrictions and have to take life easy. Well, at the age of 21 I truly don't see myself as the take-it-easy type. I live a very active life, and don't let anything stop me, not even some of the pains caused by VHL.

> "Life may not be the party we hoped for, but while we're here we should dance.
> -- *Anonymous, submitted by Barbara H., Arizona*

"My life has changed a lot. Having VHL, I have learned so many things: how to be strong, and never give up, no matter how much it hurts. I have also learned not to take life for granted.

"I think the one and only thing that I hate, and I use that word with the strongest meaning, I hate the fact that there is nothing that will keep me from passing this on to the unborn children I would love to give birth to, but shouldn't.

"Being only 21 it is a very difficult decision that I have to make — it's one I'm just not ready to make just yet. On the one hand, I think I could have a child and raise him or her to have the outlook I have, just to accept it as a part of life and deal with it as problems come up; or is it unfair to pass something on that I know is harmful, and brings nothing but pain to someone that has no choice at all?

"Something very sad from all of this — it takes something as serious as having a surgery from VHL to see the true people in my life. I have Mom, Dad, one best friend in Florida who tries very hard to understand, and an old boyfriend who is now a great friend and has been there since day one. Anyone else that has been part of my life has been there for me until it gets rough, and I'm sick or need surgery, and then they're gone.

"So far, I don't let VHL bother me. I have it, can't get rid of it, so why dwell on it and be negative?

"I am too young and have too many goals in life just to lie down and give up.

"Watching my mother struggle every day with this really hurts me, one because I love her and two, I know that someday I may be in as much pain as she is, but like her, I won't give up without a fight.

"I live life for me, not for VHL."

"While Stephanie was in the hospital from the spinal surgery," Fred says, "Linda and I went to a VHL meeting on Plum Island, Massachusetts. Surprise! We are not alone in this strange and perplexing condition. There are many more people than we ever imagined, all there to discuss VHL. All agreed the best advice to someone with VHL is never to lose your sense of humor. An easy piece of advice to give, but sometimes very, very difficult to follow. Strong support from family and friends does ease the burden. Only another VHL patient can truly understand the experience. As much as I watch, and participate with, and love my wife and daughter, I know I only come close to understanding."

Recently we went to the National Institutes of Health for testing -- amazingly thorough and efficient! But the most amazing thing of all was that ALL the staff in each and every department was friendly and courteous. Not once was anyone rude or belittling. Even better than that, everyone -- every doctor, every technician -- knew about VHL, was concerned, and listened. It was our first pleasant experience.with the medical profession since my diagnosis. I hope that as more is known about VHL, the doctors as well as the patients will become more comfortable with it.

1. Many VHL women report accelerated tumor activity around shifts in hormone levels. Research is being conducted at the National Institutes of Health to quantify the problem. Meanwhile, there is reason to be cautious around times of hormone shift -- adolescence, childbearing, and menopause -- and it may be wise to avoid artificial shifts in hormone levels such as birth-control pills.

2. Since there is no major hospital nearby with an MRI machine, there is a mobile MRI unit which travels around the less populous parts of New England. ❑

Relatives in Australia?

Please help Jennifer locate more people with VHL in Australia.
Jennifer Kingston, Chair, Australian Affiliate
(photo page 16)

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Adoption and Medical History

-- Joyce Maguire Pavao, Ed.D., LCSW

It is estimated that adoption affects the lives of forty million Americans. This is startling, considering that there are approximately five million adoptees in this country. However, there are birthparents, adoptive parents, birth and adopted siblings, grandparents and a whole array of extended family members who are impacted by adoption. Adoption is becoming more prevalent in the 1990's.

Adoption has the potential of being a very positive way to create a family. One must remember, however, that there are feelings about having surrendered a child to adoption, about having a child -- especially when one cannot bear birthchildren -- and about being adopted that pose special concerns for those involved throughout their lives.

In my research and practice I explore the special issues and concerns that birthparents, adoptive parents and adoptees face. There are normal crises that occur. While all families and individuals go through developmental stages, the special circumstances that adoption creates add issues and complexity to the process of development. These issues are normal and healthy under the circumstances that surrender and adoption create. A systemic approach is needed in order to work with adoptive family systems. There is no identified patient in this model, but the whole system (from the wider context of adoption practices to the intricate relationships in the adoptive family and the birth family) is regarded as the client. Crises can be normal and can even lead to transformation. And when speaking of the adoptive family, the birthparents are included, whether or not they are known.

There are ongoing issues in adoption for the whole family: how to tell the child, what to tell the child, when to tell the child, how to deal with extended family members and neighbors, how to work with the schools and with professionals who have little or no experience with learning disabilities, attention deficit disorder and emotional difficulties in adopted children. Things that birthfamilies take for granted may pose serious dilemmas for adoptive families.

One example is medical history. Physicians say that dealing with an adoptee is like dealing with a coma victim in the sense that critical and current family history information is often missing and impossible to get. For this reason I have come to recommend leaving at least a channel open in all adoptions for the updating of medical information. Even where a "closed adoption" is desired, it is good to have a method for the birthparents to notify the adoption agency when family medical information changes, so that if the adoptee or the adoptive family needs this information there is a possibility of obtaining it.

There are also issues regarding the adoptee as parent, the birthparents' future parenting, the complexities (and concrete possibilities) of open adoption, the myriad reproductive technologies and the issues of adoption that are present for generations, as we look at family histories through genograms with a family systems approach.

Adoption is an ongoing issue through the lifecycle and beyond, affecting not only the generations past but those to come as well. With empathy and understanding, there is opportunity for the empowerment of individuals and families affected by the issues of adoption.

Adapted from "Normative Crises in the Development of the Adoptive Family: A Model for Professionals Working with Adoptive Families" by Joyce Maguire Pavao, Ed.D., as published in the *Journal of Marriage and Family Therapy*. Reprinted with permission. Dr. Pavao, an adoptee herself, founded and heads PACT (Pre- and Post Adoption Consulting Team), 385 Highland Avenue, Somerville, MA 02144 (617) 628-8815. ❑

Having Babies

-- Hannah N., Iowa

Genetic counseling of prospective parents is quite important. It is important for them to know that each child born to an affected person has a fifty percent change of developing the disease. In the case of my family, my father had von Hippel-Lindau disease and my mother and he had four children, including myself, all of whom have the disease. Whether those who have the disease should have children is a very personal decision which only they can make, but they should be made aware of the risks.

As for myself, I have a 16 month old baby boy; and although I hadn't planned on having children, the thought of terminating the pregnancy never entered my mind. I've lived a normal healthy childhood, I climbed trees, played football with my brothers, did everything a normal child would do and my life continues to be rewarding. I am working on a bachelors degree in journalism and am enjoying every aspect of motherhood.

There are no guarantees in life; you just do the best you can. I am not suggesting that it's O.K. for everyone with VHL disease to have children. I am merely pointing out my own personal viewpoints on the subject. You and you alone are responsible for the decisions you make.

From the booklet *Von Hippel-Lindau Syndrome: a booklet for patients and families,* written by Johannah N. and published 1992 by the University of Iowa Department of Medical Genetics, Dr. Mary Waziri Curtis, Chief.

VHL Gene Linked to Kidney Cancer

reviewing "Mutations of the VHL tumour suppressor gene in renal carcinoma"[1]

A study published in the May issue of *Nature Genetics* shows that the VHL gene plays a role not only in the formation of tumors in people who inherit a flaw in the VHL gene, but also in 85% of the kidney cancers in the general population as well. The cancer, called sporadic (non-familial) clear cell carcinoma, accounts for about 23,500 newly diagnosed cases of kidney cancer each year in the U.S. alone.

"With identification of this kidney cancer gene, it will be possible to develop new methods to improve the diagnosis and treatment of the disease and potentially to find ways to prevent it," said W. Marston Linehan, M.D., of the Surgery Branch, National Cancer Institute (NCI). "The finding also will make it possible to develop a blood or urine test that can detect kidney cancer early when it is most treatable." When detected in its earliest stages, the survival rate is 86%.

The damaged or mutated gene responsible for sporadic clear cell carcinoma of the kidney is a tumor suppressor gene located on the short arm of chromosome 3. The protein produced by the gene appears to normally restrain growth. The researchers found that this gene is mutated (inactivated) in a high percentage of tumors (57%) from patients with sporadic, non-familial cancer.

This is the same gene that was identified last year as the cause of the inherited cancer syndrome von Hippel-Lindau (VHL) disease.

"The disease appears to fit the two-hit model for development of cancer, where both copies of the critical gene are damaged or mutated," said co-investigator Berton Zbar, M.D., chief of NCI's Laboratory of Immunobiology.

Everyone has two copies of the VHL gene, as they do of every gene — one from the mother and one from the father. When we say that a person has VHL, that means that they inherited the faulty copy of the VHL gene from the parent who has VHL. One normal copy of a gene is sufficient to prevent development of a tumor. If both copies are damaged or mutated — the two-hit model — cancer may develop.

In people in the general population, the two copies of the VHL gene they inherit are both healthy. In order for a tumor to form, both copies of this gene must become deactivated. There are numerous theories of how genes get changed — environmental factors, water pollution, cigarette smoke, radiation, free radicals, etc. — we don't understand just what happens, but step by step the process is becoming clearer.

From the work on the VHL gene previously reported by Latif, Lerman, Zbar, et al.[2] we know that the VHL gene is on chromosome 3p. This article reports that the gene has been cloned by the same team[3] and that an article reporting the cloning has been submitted for publication. Now that the gene has been cloned, scientists can make greater headway in understanding how the gene operates. The gene appears to be important in encoding a functional protein. The next step is to understand what this protein does in the body, and what occurs when it is not present.

It is as if it takes two occurrences for a tumor to grow and become cancerous. First, the brakes have to be off; second the accelerator has to be on. The disabling of the VHL gene takes off the brakes. But what puts the accelerator on?

The researchers also found that the kidney cancer gene is affected early in the development of the disease. This finding is important, Dr. Linehan explained, because its early presence makes it possible to consider development of treatments to halt or reverse the progression of the disease in its early stages.

All this implies that exposure of the kidney to environmental carcinogens may lead to mutation of the VHL gene and subsequent tumor formation. This demonstration that mutations in the VHL gene foster tumor growth in renal cell carcinoma "should lead to a better understanding of how renal epithelial cell growth is regulated and should aid in methods of diagnosis and treatment of patients with this malignancy."[4]

For people with VHL, what do we learn from this?

We learn that VHL kidney tumors are indeed closely related to renal cell carcinoma. But we also learn that there is more to be learned. Dr. Linehan tells us, for example, that while he can get 80% of sporadic renal cell carcinoma tissue to grow in the lab, he has been unable to get VHL kidney tumor tissue to grow there. He still does not understand why. We know that VHL takes the brakes off, but what presses the accelerator? The same environmental factors which cause the VHL gene to change affect both people with VHL and people with sporadic kidney cancers.

1. J. Gnarra et al, "Mutations of the VHL tumour suppressor gene in renal carcinoma," published in *Nature Genetics,* May 1994, pages 85-90. This research was conducted by Drs.Berton Zbar, Michael I. Lerman, and Marston W. Linehan of NCI in collaboration with the Urology Departments of New York Hospital; Cornell University Medical Center, New York; University of Michigan, Ann Arbor; and Johns Hopkins Medical Institutions, Baltimore; Laboratory of Molecular Pathology, Technical University Munich; University Clinic of Surgery, Heidelberg.
2. F. Latif et al, "Identification of the von Hippel-Lindau disease tumour suppressor gene." *Science*, 260, 1317-1320 (1993). Reported in *VHLFF*, June 1993. 3. F. Chen et al, manuscript submitted. 4. Gnarra et al, p. 90. ❑

Teamwork for Health -- Report from the

Proclamation

WHEREAS, Von Hippel-Lindau (VHL) is a genetic disease, that primarily causes tumors in six parts of the body: the eyes, brain, spinal cord, kidneys, pancreas, and adrenal glands; and

WHEREAS, VHL does not discriminate by race or gender and is a dominant gene; therefore the children of one affected parent have a 50% chance of inheriting VHL; and

City of Fountains symbol

WHEREAS, A person with VHL can lead a normal productive life if careful screening for potential problems is carried out annually and problems are taken care of in a timely manner, and

WHEREAS, An International team of medical doctors and researchers from a variety of specialties, including neurology, urology, ophthalmology, nephrology and endocrinology, will convene in Kansas City April 16 and 17 to share new research in the diagnosis and treatment of Von Hippel-Lindau (VHL) Disease at the first annual VHL Conference co-sponsored by VHL Family Alliance and the University of Kansas Medical Center, and

NOW, THEREFORE, I, EMANUEL CLEAVER II, Mayor of Kansas City, Missouri, do hereby officially proclaim April 10-16, 1994 as

"VHL AWARENESS WEEK" in Kansas City, Missouri.

Done this 10th day of April, 1994.
Emanuel Cleaver II, Mayor

We are still glowing from the Kansas City meeting.

One hundred thirty people came together in Kansas City from 20 states in the continental United States, plus four people from Hawaii, two from Germany, and two from Australia. Most were people with VHL and their families; twenty physicians and medical professionals. Some nurses from Kansas City joined us on Sunday, and members of a high school biology class and their teacher came for Ms. Boehm's presentation on genetics.

The medical professionals joined together on panels which displayed more than one opinion on the same subject. They engaged in discussion with one another and with the audience to help us understand the many ways of looking at the same information. The families were not looking for simple answers -- we know there are none -- but rather for help in working through the options and engaging in constructive discussions with their own medical teams to work out the optimal health plan for their own unique situations. All the presenters got very strong thank-yous for their willingness to help us do that.

A very nice spot was broadcast on NBC News in Kansas City the Friday before the meeting.

Best of all, we met more than one hundred new friends! If you missed this one, perhaps you can join us ***next year in Boston!***

> "I really enjoyed this -- I learned a lot and it gave me peace of mind." "The mix between affected members, lay staff and medical community was perfect.
> -- *participant comments from feedback sheets*

*"**Fantastic!**"*

*"**Historic!**"*

Col. J. M. Lamiell, Tx

*"**Excellent!**"*

An Award

was presented to J. Michael Murray and the Murray Foundation for Eye Research, Inc. for courage and initiative, for creative connections, and for inspiration of innovation in working to conquer von Hippel-Lindau disease.

*"**Invaluable!**"*

> Teamwork: The ability to direct individual accomplishments toward organizational objectives. . . . The fuel that allows common people to attain uncommon results.
> -- *Anonymous, submitted by Patti K., California*

*"**Outstanding!**"*

Hetty DeVroom, R.N., Md,

Professionals Benefitted Too

by Hetty L. DeVroom, R.N., B.S.N., CNRN, Clinical Research Nurse, Surgical Neurology Branch, National Institute of Neurological Disorders and Stroke, Bethesda, Maryland

Just a short note to say how much I enjoyed attending the meeting and presenting our data. I learned about VHL in regards to the kidney and eye first hand from the patient's point of view. Many of the patients told me that they are looking forward to the audio tapes so that they can share the information with their family and friends. I would imagine that the patients and families that could not come will benefit the most. I enjoyed sharing my nursing and medical knowledge with those sitting around me. From my point of view, every nurse, and possibly a few physicians, can benefit from a patient's point of view in a setting outside of the hospital or office. You can be very proud of the way the meeting was managed and the turnout of the attendance.

Annual Meeting, Kansas City, April 15-17

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Teamwork for Health

1994 Annual Meeting

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Spreading the Word

by Melissa M., Delaware

This was an extraordinary event. We have lived with VHL in our family since the 1960's. Nonetheless, in two days we learned more about VHL than we had ever known. Not only did we learn from the doctors, but we learned as much from the other VHL patients and family members and their experiences. We learned most of all that you can live with VHL and it does not have to be tragic. You can live a long and happy life as long as you are monitored and treated early.

It is very important to make people and physicians aware of the disease because it is so under-diagnosed. We need to be more aware of VHL so that the correct diagnoses can be made and treated early. VHL can be controlled with proper monitoring and treatment.

VHL is not as rare as we were led to believe. VHL patients want to be as informed as possible and we want our doctors to be as informed if not more informed as we are. Part of the problem is that very few doctors know much about VHL or associate it with the problems their patients may be having, causing it to be missed over overlooked in diagnoses.

I am writing to my local papers, television stations, and some national programs too. I am working to do what I can to improve diagnosis, treatment, and quality of life for people with VHL. ❑

Miracles

by Don and Peggy M., Miss.

We have attended too many meetings where we have had to search for a positive learning experience. But this conference was different. It met every expectation we had and is rated as the best we have ever attended. We wish to thank Cindy Dearing, Lois Erickson, Joyce Graff, the University of Kansas Medical Center, and all associated with the Conference. There is no doubt in our minds that the "TEAMWORK" in evidence will achieve our goal of making VHL as manageable as diabetes in five years.

Debra Collins, M.S., Ks

If we were to find one aspect of this meeting that stands out foremost in our minds, it would be the caring and sharing that permeated the entire meeting. We are not alone, but are part of a large caring and sharing family. Although each person has their own story, we all share a common bond. It was apparent that we all have the same goals, albeit expressed in many different ways. We personally saw new friendships begin, not only between families living in close proximity but nationally and internationally. This Conference brought the highest meaning to a "Family Alliance." The interpersonal relationships established will last a lifetime.

It was readily apparent that much thought was put into inviting knowledgeable speakers and coordinating sessions with the goal of teamwork between patient and provider. Each session was well prepared and orchestrated to address specific needs.

The Conference was a "Miracle" in the creation of a family of Sharing, Caring, and Education. Our love and thanks to everyone who is a part of the VHL Family Alliance. ❑

Craig Warnick, M.S., Md

Our thanks to everyone who made the Kansas City meeting possible!

Dr. John Adler, California
Dr. I. Jay Barrish, Kansas
Corinne Boehm, M.S., Maryland
Kim Coffman, Missouri
Debra L. Collins, Kansas
Dr. Mary Curtis, Iowa
Delta AirLines, Georgia
Hetty DeVroom, R.N., Maryland
Marion Merrell Dow, Kansas
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Dr. R. Neil Schimke, Kansas
David Torres, Hawaii
United Methodist Church, New York
Craig Warnick, M.S., Maryland
special thanks to everyone at the University of Kansas Medical Center
and most of all, to our wonderful chairpersons for an excellent job:
Cynthia Dearing, Missouri
Lois Erickson, Minnesota

When to Watch; When to Act?

Both the panel in Kansas City and the Symposium in Freiburg addressed this key question: When to watch a kidney tumor, and when to act? With today's better diagnostic methods, we are able to see tumors when they are very small, but at what point should action be taken?

There is no simple formula on which all physicians agree. But the evidence is mounting that VHL tumors have different behavioral characteristics than sporadic renal cell carcinoma: they tend to grow more slowly, are less aggressive, are more numerous, and have a 50% chance that there will be more after some years in the future.

There are no definite rules to guide patients or physicians, and our speakers were divided on this subject. Dr. Mark J. Noble of the University of Kansas Medical Center said that most urologists familiar with VHL now agree that you need not remove kidney tumors less than 2-3 cm. in size. He then removes the tumors and saves as much functioning kidney as possible. Dr. Craig Hawkins shared that in the experience of the Mayo Clinic they did have one patient who seemed to have a metastatic cancer from a tumor smaller than 2 cm. While they also practice renal sparing surgery whenever possible, they tend to operate on smaller tumors and cysts. Dr. Hartmut Neumann and his colleagues at the University of Freiburg do not operate for cysts alone, but only for larger tumors. His experience is that the safety limit may be higher than 3 cm. He generally waits until 4 cm.

Because no one can be sure, it is important that the patient be involved in making the decision about when to remove the tumors. With today's surgical techniques it is unlikely that the kidney can be operated upon more than 3 times before it will need to be completely removed, so operating too soon may result in loss of the kidney earlier in life. On the other hand, waiting too long may result in the cancer spreading to another place in the body. Dr. Neumann works with his patients to evaluate the position of the tumors, their tissue densities and growth patterns, the family kidney history, and the risk the patient is willing to live with. He has ten patients with tumors ranging up to 4 cm. without metastasis.

New kidney treatments may make it possible to operate more often on the kidney with less damage to kidney function, but they still entail surgery. The best hope is that research such as Dr. Linehan's work on the genetics of kidney cancer will lead to non-surgical therapies which will constrain the growth of kidney tumors and prevent or reverse the spread of kidney cancer.

For additional kidney information, see pages 2-3, 7. ❑

Experimental Therapy Hopes to Shrink Kidney Tumors

by Richard B. Alexander, M.D., Baltimore, MD

A new experimental therapy for kidney tumors in patients for whom the preservation of normal functioning kidney tissue is of paramount importance has been started as a joint project between the University of Maryland School of Medicine, Division of Urology and the Surgery Branch, National Cancer Institute. The experimental therapy is based upon the use of Tumor Necrosis Factor (TNF), a normally occurring biologic material which appears to have antitumor activity in animals and humans, and which is perfused through the isolated kidney in a surgical procedure.

The procedure involves isolation of the kidney and the blood vessels supplying the kidney and the connection of the isolated kidney to a heart lung machine identical to that used in open heart surgery. The kidney is then perfused with a solution of blood and saline and high doses of Tumor Necrosis Factor are injected through the isolated circuit of blood vessels in the kidney itself.

The major goal of this experimental protocol is to determine if this form of therapy can result in shrinkage of kidney tumors while preserving the normal functioning kidney tissue and delaying the time when removal of the kidney is necessary because of the risk of cancer.

This type of therapy has been applied to other cancers. The largest experience is with isolated perfusion of limbs in patients with melanoma or sarcoma of the limb that are not amenable to surgical therapy. Using combinations of different agents including tumor necrosis factor substantial response rates have been observed in isolated perfusion of the limb with this technique.

Patients with VHL and kidney tumors are of particular interest to us for this trial as we feel that such patients could benefit from a delay in the need to remove all functioning kidney tissue and begin hemodialysis. We are particularly interested in evaluating patients with VHL who have been informed that they require removal of a kidney because of renal cell carcinoma.

For more information, please contact Richard B. Alexander, M.D., Division of Urology, University of Maryland School of Medicine, 22 South Greene Street, Baltimore, Maryland 21201, (410) 328-5544.

Editor's Note: **Experimental** means we don't know yet if it works, or how well it works, or what the longer-term side effects may be. Because of the experimental nature of this treatment, people for whom conventional treatment options are still good choices are encouraged to use conventional treatment. People for whom conventional treatment means loss of all kidney function may wish to discuss this experimental option with Dr. Alexander. ❑

Resources

Singular Vision Outreach is a non-profit support organization for people with vision in only one eye. They have a very interesting publication which provides helpful driving tips for people with Singular Vision. For information or a copy of "Driving Tips," write to SVOR, P.O. Box 1451, Maryland Heights, MO 63043.

Planning your vacation can be as important as buying the tickets. If you can't walk very far without tiring, or use a wheelchair, you may wish to contact the visitors' bureau in the cities you will be visiting, to ask for tips for accessible travel. Major tourist attractions themselves often have guidebooks, wheelchairs to rent or lend, or other accommodations for visitors who tire easily. Walt Disney World, for example, has a "special assistance pass" which can be used to obtain preferential access to many attractions. See "An Exceptional Visit to Disney," *Exceptional Children Magazine,* April 1994, pages 25-27.

Do you need information on adapting a job or workplace to accommodate special needs from a disability? Call the **Job Accommodation Network,** a program of the President's Committee on Employment of Persons with Disabilities, at 1-800-526-7234 (8:00 a.m. - 8:00 p.m. EST). Trained consultants are available to help employers, disabled people, and vocational rehabilitation personnel with just about any question concerning employment and disabilities. JAN also has a database of products for independent living, with user feedback. JAN's address: P.O. Box 6080, Morgantown, WV 25606.

General Motors has a reimbursement program of up to $1,000 toward the cost of adapting or modifying a GM vehicle (new, dealer demo, or leased) for a disabled person. For specific guidelines, contact: GM Mobility Assistance Center, P.O. Box 9011, Detroit, MI 48202. (800) 323-9935.

Volkswagen has a Mobility Access Program which provides $1,000 in purchase assistance directly to anyone who buys a EuroVan to transport a full-time wheelchair user, or $500 in purchase assistance on any model Volkswagen for any buyer who requires adaptive driving equipment. See your Volkswagen dealer, or call 1-800-444-8987.

Apple Computer announced the opening of "Aisle 17," the **Apple Computer Disability Solutions Store**. Since 1985, when Apple Computer established its Worldwide Disabilities Solutions Group under the direction of Alan J. Brightman, Ph.D., Apple has been a leader in technology accessibility for children and adults with disabilities. In 1987, Apple collaborated with consumer groups to establish the Alliance for Technology Access (ATA), a nationwide network of community-based assistive technology resource centers. Now, with input from children and adults with disabilities, parents and professionals, Apple has created "Aisle 17," a mail-order disability solutions store dedicated to computing without boundaries. "Aisle 17" is the first one-stop source for bundled computer solutions designed specifically for children and adults with disabilities. For a complete shopper's guide, call 1-800-600-7808. TTY access: 1-800-755-0601.

National Kidney Cancer Association has a **new computer bulletin board** for those with an interest in kidney cancer: (708) 332-1052, IBM (compatible) PC, DOS, 2400/1200/300-baud modem, 8 data-bits, 1 stop-bit, full duplex, no parity/echo. Voice phone: (708) 332-1051. Free user guide available.

Educating the Child with Cancer, a new publication from Candlelighters Childhood Cancer Foundation, discusses issues of communication between families, school educators, and treatment centers, school re-entry, cognitive late effects, legal rights, and siblings. While VHL kids rarely deal with cancer, they do sometimes deal with chronic illness, extended absences from school, and the learning and family issues discussed in this booklet. Candlelighters Childhood Cancer Foundation, 7910 Woodmont Ave, Suite 460, Bethesda, MD 20814-3015. $7.50 to health professionals, free to families of children with cancer. ❑

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Ask the Family

Dear Family,

My family has learned so much through the Alliance. We are working with our medical teams to manage our health.

I am worried about my late husband's brother. He is "hiding out" from VHL, believing that if he doesn't go to the doctor he won't have to deal with VHL. I've tried to talk with him about it, but he doesn't want to hear it. I don't want to be a nag, but I really feel he should go for check-ups.

-- *Signed, Concerned*

Dear Concerned,

Every family has at least one person who "hides out" at some time. I would give him lots of material to read. Hand him brochures, the Handbook, pass him copies of the newsletter.

Say that you feel he has nothing to lose by simply reading about it. You know he is an intelligent person, you're simply asking him to read for himself with an open mind, and make his own decision.

Let him know about the 800 number. He can call anonymously and ask any questions he wants to ask.

Most of all, let him know that you care about him very much,

-- *Peggy M., Mississippi*

To the Editor:

I found especially useful, enlightening, and interesting "The Many Masks of Adrenal Involvement" [*VHLFF* 1:4, Dec. 1993] as I do have high blood pressure, diabetes, and am very intolerant of heat and break out in sweats. Let's hear more on Pheochromocytomas!

- *Barbara S., New Jersey*

Dear Barbara,

Thanks for your positive feedback on the article. We will be glad to share more personal stories and medical information about pheochromocytomas in future issues.

Don't forget that your best source of advice for your own situation is your own medical team. We can alert you here to the kinds of issues which may arise, and provide information to assist your medical team in learning from the experience of other families and doctors. If you feel that you could be affected, please share the article with your own physicians and get it checked out.

- *Joyce Graff, Editor*

A patient is a PERSON in a strange environment on an involuntary basis going through one of the most unpleasant experience of his life with persons not of his own choosing.

-- Anonymous, a quoted in Orphan Disease Update, X:3, Spring 1993. National Organization for Rare Disorders, New Fairfield, CT.

Time to Speak Up!

by Polly Arango, Co-founder of Family Voices

We must learn about the various health care reform plans being presented in our states and to Congress because . . .

- Most of them do not include the basic principles of universal coverage, flexible benefits, comprehensive family-centered care, family and professional partnerships, cost-effectiveness, and quality assurance that Family Voices believes must be present for all people with chronic illness.
- Without universal coverage, and with DNA testing, insurance companies will be able to systematically exclude people with disease genes from coverage, whether or not they have symptoms. Already there have been incidents where people with a recessive gene like cystic fibrosis -- people who themselves will never be ill from the disease -- have been discriminated against.
- At this point, President Clinton's Health Security Act (S. 1757 and H.R. 3600) and Senator Wellstone's American Health Security Act (S. 491 and H.R. 1200), also known as the single-payer plan, contain the fewest barriers to care for people with special health care needs. Most others do not include universal coverage and do not spell out benefits!
- The architects of the Clinton Plan have offered to continue working with Family Voices and other advocates to make necessary changes, especially on outpatient rehab, durable medical equipment, and copayments.
- Health care reform is happening very fast -- too fast to sit back and wait.

Health Care Reform must include all children, including children with special health care needs. That's the Family Voices mission. To that end we work with Congressional committee staffs and advocates in Washington almost weekly. Our partners include Children's Defense Fund, March of Dimes, United Cerebral Palsy, National Assoc. of Child Advocates, Assoc of Maternal and Child Health, Academy of Pediatrics, Natl Assoc of Children's Hospitals and Related Institutions, George Washington Center for Health Policy Research.

Learn everything you can. For comprehensive information, write to Family Voices, P.O. Box 769, Algodones, NM 87001 (505) 867-3159; Fax: (505) 867-6517. Ask for their *Facts and Questions.*

Tell your story. Write your Senators and Representatives. (If you don't know who they are, call the Congressional Switchboard at (202) 224-3121.) Include a family picture. Call their local offices and make arrangements to meet with them.

Even if you've never done anything like this in your life, you can do it, and it's no big deal! Keep in mind this motto: *If I don't do it, who will??* ❑

Disability and Challenge

by Fred J., New York

I'm a VHL Spouse. My wife was diagnosed with VHL in 1988 after the first of six spinal cord surgeries. She has been using a wheelchair since 1989. For the past six years, life for us has changed drastically. Her recent disability has changed our lives and challenged us to alter our day to day activities radically.

During the process we've wondered why these circumstances have fallen upon us? Why the creator has chosen us? This situation has challenged my belief in God, his power over the universe and our individual lives.

I'd like to share with you the belief that sustains me, and allows me not to be angry at God, and maintain my faith. My belief centers around my concept of Normalcy and Disability, and my concept of God.

My concept of Normalcy and Disability can be expressed in a passage entitled, "Holy and Without Blemish before God: Disability and Normalcy" by Walter Wink:[1] "So the world is divided up into two groups after all -- not, however, the normal and abnormal, or the able and disabled. Rather, the line is drawn between those who are aware of their disabilities and those who are blind to them."

We are all disabled in significant ways, and who is to say what is the more severe disability? Those who are disabled are a reminder to us all that we too have disabilities. We are challenged to focus on our abilities rather than our disabilities. No one is perfect! The concept of perfection itself is misleading, for everyone on this earth has a disability of some sort. We all rely in part on others to overcome our disabilities. Physically disabled people are more obviously dependent than others. It is our disabilities as well as our abilities that tie us to others on this earth.

God has created a universe with a tremendous amount of diversity of living things. All things in the universe have a purpose, be it physical or spiritual, which gives it a life force. All life forces are different and complex. It is the diversity of living things that make the world. No two things on God's earth are exactly the same. What we view as normal varies from one person to another. Depending on where we live physically, emotionally, and spiritually we see things differently. God the Creator has allowed the diversity of the world to develop, and with it comes good, bad, health, and sickness. God expresses himself within all of these life situations.

Let me share with you a passage from a book entitled, *God Plays Piano, Too: The Spiritual Lives of Disabled Children,*[2] by Brett Webb-Mitchell who has interviewed several disabled children. This passage is about an autistic boy named Joshua. Joshua has a special gift. While Joshua is unable to speak clearly, work, or learn much more than an elementary education, his gift allows him to play the piano with great skill.

"The One who seems to be conducting and playing through Joshua's life is the Creator. We read in Genesis of God's creating man and woman in God's own image, which means, in part, that we too have been made with the innate ability to create or to construct: to take the elements of God's creation and blend and mold them until we fashion something unique in praise and service to God.

It is this aspect of creation that appears to be the driving, brilliant force in Joshua's young life. God's creative spirit, alive within us all, has made it possible for Joshua to play the piano.

Perhaps Joshua is not so disabled after all. Joshua sings and plays music in celebration of God's love for us all. Who knows? It may be God whom we hear playing the piano through Joshua."

The following quotes symbolize one aspect of God, Pain and Suffering. These quotes were shared by people on a Computerized Network called Ecunet™[3] in an electronic forum called "Disability Concerns" where people share philosophies, resources, and information on coping with disabilities.

"Sometimes God calms the storm; Sometimes God allows the storm to rage and calms the child."

"Pain can drive us in two directions. Either it can make us curse God for allowing our misery, or drive us to him for relief."

"If you don't have a disability now, you will. If you live long enough, there will come a time when you have to keep going though your heart is pierced through."

Remember the words of Dr. Martin Luther King, "The real measure of a person is not where he stands in times of comfort and convenience, but where he stands in times of trials and tribulations."

1. Walter Wink, "Holy and Without Blemish before God: Disability and Normalcy," as printed in *And Show Steadfast Love: A Theological Look at Grace, Hospitality, Disabilities, and the Church,* edited by Lewis H. Merrick. Louisville, Kentucky, Presbyterian Publishing House, 1993.

2. Brett Webb-Mitchell, *God Plays Piano, Too: The Spiritual Lives of Disabled Children* (New York, The Crossroad Publishing Co., 1993).

3. Ecunet™ is a computerized network sponsored by a large group of Protestant Christian denominations. Costs $11 per month plus connection costs. For information call 1-800-733-2863 or 1-203-673-7776.

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...Dr. Leo Rauch to celebrate a speedy recovery

...Curtis Smith, on his graduation from Southern Illinois University

...Jessica Sorkin, on her graduation from U. Mass. Amherst

...Patricia Stepper, on her retirement from the Department of the Army

...David & D. J. Torres, by Edgar D. & Neva J. Sullivan

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...Darlene Young, in celebration of her service to the VHL Family Alliance

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... and to all the Members of the VHL Family Alliance

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❑ My employer will match my contributions. I have enclosed the appropriate forms.

All Members receive a membership certificate, 3-4 issues of the Forum this year, and copies of all Alliance publications. Free subscriptions are available where the dues are a hardship. Donations greater than $250 receive a special sponsor certificate.

❑ Audio version available if needed for a handicapped member

I am a ❑ VHL patient ❑ VHL family member ❑ Supporting Friend
❑ Professional (physician, nurse, dietitian, social worker, etc.)
❑ Other (please specify)_____ _____
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❑ My occupation is _____

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In Italy, send to Alleanza VHL, Loc Malvicina, 19, 15066 Gavi (AL), Italy
In Australia, send to VHL Family Alliance, 2/51 Musgrave St, Yarralumla 2600, Camberra, ACT, Australia

Photos from Kansas City (see story pages 8-9). L to R, Top row: Eva Lou R., MO; Dr. R. Neil Schimke, KS, Tom R., MO, Dr. Mary Curtis, IA; Corinne Boehm, MD. Middle row: Ken and Patti K., CA; Gale L., FL; Dr. John Adler, CA; Dr. Hartmut Neumann, Germany; Bob W., NY; Beryl S., Australia. Bottom row: David, D.J., and Sally T., HI; Evelyn W., NY; Dr. James M. Lamiell, TX; Dr. Haring Nauta, TX; Eva L., GA; Patti K., CA; Jennifer K., Australia; Lois E., MN; Dr. Jay Barrish, KS. Photographers: Joyce G., MA; Vernon H., PA.

VHL Family Forum

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