

## Dogs do More than Bark

Adeline V. from Belgium went blind from VHL at the age of 14. It was several years later that she came to know what the cause of her blindness was — and what the longer term consequences could be. She informed her seven sisters and two brothers of the situation but only a few were prepared to undergo an examination.

Faced with a serious handicap yet young and with a love of life, Adeline picked herself up and continued her studies in special education. After completing her education, she went to work in a library for the blind and took additional course work in library studies, and later in management.

She was promoted to a management position in a production center where books are transcribed into braille, large print and audio format.

Her career has suffered two serious interruptions for operations for the removal of cysts in her kidneys and brain..

When she got her job with the National Production Center in Brussels, and needed to travel long distances to work, she knew that a guide dog would make it possible for her to travel more rapidly, more independently and more safely than she could with only a cane. She began to look for a guide dog school where she could obtain a dog.

She visited guide dog schools in England, Switzerland and France, and her first guide dog was a Labrador Retriever born in England and trained in France. It was difficult to be accepted into the guide dog program, and then to travel the long distance to France, and to train in French, when her native language is Dutch. But it was worth the effort. She found it wonderfully freeing to work with a dog. The dog is trained to watch out for obstacles. Paving stones in the street, curbs, building sites, traffic lights, cars — all are obstacles to the blind person who ventures into the jungle of towns, armed only with a white cane. Thanks to the dog, all these traps became less threatening. Guided by her companion, Adeline quickly achieved greater mobility and autonomy in her daily life and recovered a great deal of security and confidence.



In Belgium, there are narrow streets, unrecognizable sidewalks, and strange traffic patterns. The dog made it much easier to navigate her way across the open squares of Antwerp. In areas where there are crowds of people shopping, and no cars to provide directional clues, the training and memory of the dog become extremely important.

Adeline felt that Belgium needed its own guide dog school. She and her husband set out to raise

*cont'd, page 2*

### ***Inside this issue!***

Clinical Trials - Early Results	Dr. Richard Lewis
Taking Part in Trials	Ask the Family: Dandelions and Cancer
Tribute to my Mom	Regional Meetings Coming Up: Tampa, Los Angeles, New York, Dallas, and Everett, Washington
Ask the Experts: Pancreas	Symposium in Kochi, Japan, May 2004
Regional Meeting Notes	
10 Warning Signs of Caregiver Stress	
Eugen von Hippel	
Clinical Care Center in Philadelphia	



*Adaline at home with her best friend.*

money for a location, a trainer, and for the operation of a school in Belgium. They founded The Belgian Centre for Guide Dogs in Belgium in 1990 and still play an active role in the management of the Center.

Not every dog can become a guide dog. Out of ten dogs tested, only six can become good guides. The process begins with careful breeding. Candidate puppies are then placed in homes where they are reared through puppy-hood. Experience has shown that a dog reared in a family with children is always a better, more sociable and more affectionate guide than a dog that has been raised in a cage or kennel.

During this time the puppies come to “puppy school” to learn basic commands, discipline, and socialization. They have to learn to circulate in the human world, undistracted by sounds, people, and other animals. They wear special a special jacket

identifying them as a guide dogs in training. When they are returned to the Center at the approximate age of 12 months, they need to have essential qualities such as obedience, balance, quietness and self-possession. They then undergo a very demanding training course that lasts for 6 to 8 months. You cannot force the dogs to work; they have to start the training when they feel ready to “learn the job”. The trainer is there only to correct them and to help them develop their intelligence.

The initial training takes place at the Center on a set course where the dog learns to deal with a great number of obstacles which it will meet in real life – open manhole covers, construction detours, overhanging branches, and such. After that, it starts to work in quiet streets where it is immediately confronted with the realities of the outside world.

After six to eight months of intensive training, the dog can be introduced to its future master. The new master comes to the Center for four weeks of



*In Belgium, there are narrow streets, unrecognizable sidewalks, and strange traffic patterns.*

residential training with the dog. The dog and its new master begin to venture into town together in order to become familiar with intensive traffic conditions and with the difficulties encountered in a big city.

But the dog is much more than simply a guide. It is also, and perhaps especially, an unrelenting friend, a gleam of tenderness, a comforting companion to the person who has to cope with the handicap of blindness.

Adeline worked for more than 20 years for the National Production Center. During that time she assisted in a successful campaign to create a Belgian stamp honoring guide dogs, issued in November 1998. This was the first time in Belgium that the value of the stamp (17 + 4) was marked on the stamp in Braille.

She also worked on the team to evaluate the design for the new Euro currency, ensuring that coins and bills can be identified readily by blind people. In the U.S., all bills are green and the same size. Blind people have to depend on the honesty of merchants making change, and fold and store the bills in different ways in order to tell a \$20 bill from a \$1 bill.

In the new Euro currency now in use in most European countries, each bill is a different color and size so that they can be easily identified. The coins are also different sizes, and the edges are milled in distinctive ways to make them easier to identify by touch.



Our thanks to Chris Hendrickx, Chairman of VHLFA Belgium, and to the Belgian Centre for Guide Dogs, Tongeren, Belgium, for their assistance in preparing this article. Belgium has two official languages: Flemish (which is very like Dutch) and French. Adaline and Chris live in the Flemish part of Belgium. Many Belgians speak multiple languages. Chris speaks Flemish, Dutch, German, French, and English.







## Clinical Trials

### Early Results

There are no published results yet from the clinical trials of the new angiogenesis inhibitors, but nonetheless early responses are encouraging.

One patient has had shrinkage of kidney tumors. One patient saw his brain tumors shrink nearly 50% in volume in three months.

The most exciting response has been the lessening of edema around some brain tumors. VHL tumors have a tendency to "recruit fluid" around them, causing the tissues to soak up fluid like a sponge. Since it's not a cyst, and you can't just drain off the fluid, the doctors really have no treatment for it. It causes increasing pressure and increasing symptoms even though the tumor remains the same size. One patient in the PTK trial had significant reduction in this edema, with an accompanying improvement in his symptoms.

Side effects reported remain quite tolerable -- some people experience fatigue, a little wooziness, and sometimes some nausea which can be controlled with medication.

This is the only clinical trial specifically designed to test the effectiveness of a new drug with VHL. Over the past four years, PTK has been tested with nearly 1000 patients in trials for various types of cancer. It is doing very well with kidney cancer, and is now in Phase III testing in colorectal cancer. It is being combined with additional agents in early Phase I and II studies. The fact that it works on both the VEGF and PDGF pathways is making it much more effective than earlier drugs, and the hope is that by adding agents that work on a third or fourth associated pathway, the combination will be even more effective.

### To Inquire:

Contact Dr. Patrick Wen, +1 (617) 632 2166, or ask a local oncologist about access to trials involving Novartis PTK-787, Bayer 43-9006, or other inhibitors of VEGF, PDGF, and HIF-1-alpha. Currently the only trial specifically for VHL is in Boston with Dr. Wen. A second site at Duke University is expected to open by June 2004. Participants can begin in Boston and transfer to Duke when it opens.

### Taking Part in Clinical Trials: What Patients Need to Know

The U.S. National Cancer Institute (NCI) has prepared a booklet and website as part of its patient education program. The NCI sponsors, conducts, and oversees clinical trials and other cancer research in the United States, and provides research-based information to health professionals, patients, and the public.

This booklet is for patients, their families, and others who care about them. Each section answers questions many people have about clinical trials:

1. What are clinical trials?
2. What happens in a clinical trial?
3. Should I take part in a clinical trial?

It provides background information, explanations of terms, and lists questions to ask the doctor or nurse about any study you are considering. The resources section lists other sources of information about cancer and treatment studies.

The booklet can be obtained by calling 1-800-4-CANCER, or on the internet. The full brochure is posted on the internet at:

[http://oesi.nci.nih.gov/taking\\_part\\_treatment/](http://oesi.nci.nih.gov/taking_part_treatment/)

The full title of this brochure is "Taking Part in Clinical Trials: What Patients Need to Know."

**Regional Meetings --  
Coming Soon to a location  
near you!**

**Tampa, February 7  
Los Angeles, February 21  
Kochi, Japan, May 20-22  
New York, June 19**

**See page 13 for details**

# A Tribute to my Mom

By Emily S., New Jersey

My mom, Amelia A., died in October at the age of 81. But this is not about her death, it is about her life. She was a woman who became an inspiration to many people. She never backed down from the challenges of life. I always told her that if she could bottle her inner strength and sell it, she would be a millionaire.

She rarely spoke of her childhood. She was the youngest of eight children. Her mother died in her late 30's in 1929 when Amelia was 7 years old. Growing up in the Depression in a troop of eight children was not easy, but she never wanted to talk about the bad times.

Amelia married my father Vincent and had three daughters. We never had a lot of money, but my sisters and I always felt secure in my parents' home. As time went on, it became apparent that there was some health issue that ran in my mother's extended family. Two of her brothers died young, and then in less than two years my mother lost both her sisters. During this time my father also passed away. She was devastated. Her support system was gone. Her brothers were busy with their own families. She was lonely and unable to understand what was happening. But she relied on God and her daughters to get her through those very trying times.

As often happens, in times of stress, there is illness. Mother had a mastoid infection which required surgery. She had her share of various illnesses, some of which were likely VHL but many of which were not. Nonetheless, she had 70 years of relatively good health with surgeries every few years. She never gave up. She was sometimes angry with herself that she would not do as much as she used to, but she drew on her inner strength and carried on. She had a little wink, and made us feel that she still had the strength and courage to overcome anything in life.

In 1994 I was diagnosed with a small kidney cancer tumor in one kidney. The doctor recommended removing the kidney, and within three days it was done. She was always on the phone with me, encouraging and praying for me. Mom knew how to yell at me and get me mad so I wouldn't feel sorry for myself. Her strategy worked – you can't feel sorry for yourself if you're angry about something else. My sister and I learned through her example not to worry about ourselves because there are so many other people with medical problems. Who are we to complain?

A year later the same doctor removed my mother's only kidney for the same reason. This time, seeing the toll dialysis was taking on my



Amelia A., December 2002

mother, I resisted his suggestion to remove my second kidney. I did some research on the internet, and contacted the VHL Family Alliance. I went to a geneticist with my family history, and had a DNA test to confirm a diagnosis of VHL. The pieces of the puzzle began to fall into place. Many of the health challenges of nearly 20 people in three generations of our family were finally identified as VHL. One of Mom's brothers with VHL lived to be 84.

When I first got that diagnosis, I thought other members of my family would be thrilled to finally have the name of the enemy – and the keys to managing our health. But still many people didn't want to know, declined to go for DNA testing, or avoided checking on very real symptoms which to me were clearly VHL. Some had the attitude, "If I die, I die." But having seen the devastating effects of untreated VHL in our family, I realized that the outcome was more likely a life-changing disability that would affect not just the person in denial but also the entire family. Dialysis, digestive problems, blindness, paralysis are all possibilities with VHL. But the earlier you find issues and get appropriate treatment, the less likely that a disability will occur. You learn to live with it and manage it and appreciate every day, and "don't sweat the small stuff."

When her grandchildren were affected with VHL, Mom always took time to encourage them and give them hope. She knew they were worried, and she would say, "What's the matter? I have VHL too, and look how old I am!" She attended their football games, and ate lunch with her granddaughter watching "The Price is Right." Of course she worried and prayed constantly for them too.

Mother and grandmother, we will all treasure her and she will continue to inspire us for the rest of our lives. She has helped to mold the people we are today, and her spirit will always live on in the hearts and minds of generations to come.

## Ask the Experts

**Question:** We are seeing a lot of information in the news about new treatments for pancreatic cancer. Is any of this information relevant to VHL? Besides, what is the cellular distinction (if any) between VHL-related pancreatic cancer and the sporadic pancreatic cancer in the general population? When we read things about prevention and cure of pancreatic cancer, how much of that is relevant to VHL? If someone with VHL has metastatic cancer from the pancreas, are these proposed therapies for pancreatic cancer likely to help? -- *Confused*

**Answer:** Most if not all of this information pertains to adenocarcinoma of the pancreas. Adenocarcinoma of the pancreas is not seen in association with VHL at any higher rate than the general population. VHL does not give an increased risk for adenocarcinoma as far as we have seen.

The type of pancreatic tumors that VHL patients get are neuroendocrine tumors of the pancreas. These arise from different types of cells than adenocarcinomas and are far less aggressive. Neuroendocrine tumors of the pancreas can occur in patients without VHL as well, although they are very uncommon. The neuroendocrine tumors in patients with VHL tend to be very slow growing and only rarely (about 18% of patients with these tumors) do they spread to other organs like the liver. When they do spread, they can cause problems which is why we follow them very closely and remove them if they are growing or have reached a certain size.

Most, if not all of the information pertaining to adenocarcinoma of the pancreas is irrelevant for a patient with VHL neuroendocrine tumors of the pancreas.

— *Steven K. Libutti, M.D., Senior Investigator, Surgery Branch, Center for Cancer Research, National Cancer Institute, Bethesda, Maryland, USA*

## Regional Meeting Notes

At the Regional Meeting in Boston, Dr. John Libertino of the Lahey Clinic talked about the value of 3-dimensional imaging in diagnosis and in planning surgery. Being able to rotate the image of a kidney tumor or brain tumor allows the surgeon to plan the surgery with much greater accuracy than ever before, and lowering risk of damaging nearby structures.



**Give generously to cure VHL  
through your  
United Way Campaign or  
Combined Federal Campaign  
Our CFC ID is 1098  
or write us in on your  
United Way Campaign**

# 10 Warning Signs of Caregiver Stress

— adapted from the *Alzheimer's Disease and Related Disorders Association*, [www.alz.org](http://www.alz.org)

When someone in the family is sick, roles change and family members take on the tasks that would normally have been performed by the person who is ill. This puts strain on family roles and relationships. It is important to talk about these changes, and work out agreements that allow the person who is ill to feel they are contributing, and the caregiver not to feel overly burdened.

In a survey of caregivers for Alzheimer's patients, more than 80 percent of caregivers report that they frequently experience high levels of stress, and nearly half say they suffer from depression. Many caregivers don't recognize their needs, fail to do anything about them, or simply don't know where to turn for help.

Too much stress can be damaging to caregivers and to the person for whom they are caring. Recognizing the signs and learning how to reduce stress can help.

1. **Denial** -- about the disease and its effect on the person who's been diagnosed. "It's not going to affect me."
2. **Anger** -- at the person who is ill or others: that no effective treatments or cures currently exist, and that people don't understand what's going on. "In he asks me that question one more time I'll scream!"
3. **Social withdrawal** -- from friends and activities that once brought pleasure. "I don't care about getting together with the neighbors any more."
4. **Anxiety** -- about facing another day and what the future holds. "What happens if he gets more severe symptoms?"
5. **Depression** -- begins to break your spirit and affects your ability to cope. "I don't care any more."
6. **Exhaustion** -- makes it nearly impossible to complete necessary daily tasks. "I'm too tired for this."

7. **Sleeplessness** -- caused by a never-ending list of concerns. "What if she falls and hurts herself?"

8. **Irritability** -- leads to moodiness and triggers negative responses and reactions. "Leave me alone!"

9. **Lack of concentration** -- makes it difficult to perform familiar tasks. "I was so busy, I forgot we had an appointment."

10. **Health problems** -- begin to take their toll, both mentally and physically. "I can't remember the last time I felt good."

If you are a caregiver who is experiencing several of these stress symptoms on a regular basis, consult a physician.

## Ways to reduce caregiver stress:

- Know what resources are available in your community
- Become educated about VHL and ways to manage it
- Get help from family, friends, and the VHL Family Alliance, [www.vhl.org](http://www.vhl.org), 1-800-767-4VHL
- Take care of yourself by watching your diet, exercising, and getting plenty of rest
- Manage your level of stress by consulting a physician and using relaxation techniques
- Accept changes as they occur
- Engage in legal and financial planning
- Be realistic about what you can do
- Give yourself credit for what you have accomplished; don't feel guilty if you lose patience or can't do everything on your own

## Newsletter schedule changing.

The *VHL Family Forum* is changing to a new publication schedule in 2004. From four issues a year, we have grown to five including the Annual Report issue.

In 2004 we will publish three regular newsletter issues and the Annual Report issue, for a total of four.

Your ideas and requests for articles are always welcome!



# Eugen von Hippel

As we enter 2004, we enter the centennial year of one of the landmark papers in the history of von Hippel-Lindau disease. The first step in solving a problem is to have a good description of the problem.

Eugen von Hippel wrote in 1904 "about a very rare disease of the retina" and in 1911 added "the anatomical basis" of that disease, which he named angiomas of the retina. He studied one extended family, with several generations exhibiting numerous lesions typical of those of von Hippel-Lindau Disease (VHL).

Dr. von Hippel was honored in his lifetime as a physician, clinician, teacher and researcher. He spent his entire life in service to others.

Eugen von Hippel was the son of another exceptional ophthalmologist, Arthur von Hippel (1841-1917), professor of ophthalmology, founder and head of the University Eye Clinic in Göttingen, later succeeded in that post by his son Eugen. Eugen studied at the best schools — Giessen, Freiburg, Berlin, Heidelberg, and Göttingen — and received his doctorate in medicine in 1890.

As a young physician he first worked in pathology under Dr. Arnold at Heidelberg. During this time he studied cadavers with severe infections, which influenced the course of his later research. In 1892 he began to specialize in ophthalmology and became assistant to Dr. Leber. He studied and lectured in ophthalmology and won a prize for his research.

He became fascinated with disorders in formation of the eye, including hydrophthalmus (a form of glaucoma), corectopia (abnormal situation of the pupil), corneal defects, congenital cataracts of various types, and angiomas of the retina, which has become known as von Hippel's disease. He not only took great pains to describe these malformations in exquisite detail, but also sought to determine just how they came about, and how they might be tied to damage during embryonic development. His paper on angiomas of the retina was published in 1895.

From 1909 to 1914 he taught at Halle and published his research in a series of publications dealing with the diagnostic signs and clinical results of these disorders. Later he taught at Göttingen, and produced a series of studies on sympathetic ophthalmia, tuberculosis of the eye, and choroid membrane sarcoma, and on diseases of the optic nerve. He contributed to a number of textbooks, notably on diseases of the optic nerve, pathological anatomy of the cornea, and malformations of the eye.



In his tribute to Dr. von Hippel, Dr. Baurmann of Karlsruhe admires him for his astounding breadth and richness of creativity. He took an active role in the work of his students, helping them think and talk through the problems they were tackling. He demanded the best efforts of everyone, physicians, nurses, and all other employees of the clinic. He instilled in everyone the spirit of respect for accomplishment in everything they did. This resulted in a very unusual harmony and positive mutual cooperation which benefited the work of the clinic in very favorable ways. His students went out into practice "equipped not only with a broad knowledge of clinical medicine, but above all with the ability to think critically and scientifically, and all had learned in that clinic how to gain self-confidence."

Prepared with the kind assistance of Dr. Hartmut P. H. Neumann.



# Clinical Care Center in Philadelphia

*Hospital of the University of Pennsylvania*

A new VHL clinical care center has recently been established at the Hospital of the University of Pennsylvania (HUP). While VHL patients have been seen for many years at HUP, the formation of the clinical care center organizes and clearly identifies physicians involved in and experienced with the care of VHL patients.

Initial contact for the patients is through the Division of Medical Genetics in the Department of Medicine. Dr. Katherine Nathanson with the genetic

counselors in the Division, meet with patients and provide genetic counseling, genetic testing and oversight of VHL clinical care. While the Division is based at HUP, Dr. Nathanson is credentialed at the Children's Hospital of Philadelphia (CHOP) and sees children with VHL and works with the appropriate physicians at CHOP. Genetic testing for VHL for both adults and children is available locally at CHOP; the VHL team at HUP works closely with the testing laboratory.

Scheduling of appointments is done with an emphasis on consolidating appointments as much as possible. The physicians within the VHL clinical center are in regular contact with each other about short and long term medical management plans for each patient.

Within the VHL Clinical Center of HUP the physicians provide a variety of expertise important to the medical care of patients with VHL. The surgical expertise includes minimal invasive surgery for RCC (Keith Van Arsdalen, Urology), adrenal sparing surgery for pheochromocytoma (Douglas Fraker, Surgery) and neurosurgery (Eric Zager, Neurosurgery). The team also includes experts in hypertension and pheochromocytoma management (Raymond Townsend, Medicine), neuro-oncology (Myrna Rosenfeld, Neurology) and retinal diseases (Michael Tolentino, Ophthalmology). HUP has state of the art imaging techniques with significant expertise in CT imaging of the kidneys, neuroradiology, interventional radiology and nuclear medicine studies.

Together, the VHL team within the clinical care center at HUP provides state of the art medical care for patients with VHL.

Hospital of the University of Pennsylvania, Philadelphia, PA. Barbara Bernhardt or Lynn Godmilow, Genetic Counselor,  
Tel: +1 (215) 662-4740; Fax: +1 (215) 614-0298;  
E-mail: [godmilow@mail.med.upenn.edu](mailto:godmilow@mail.med.upenn.edu) Their website is <http://www.uphs.upenn.edu/penngen/>

## Uncle Eugen

*by Eric von Hippel, MIT Sloan School of Management*

As a young boy my father, Arthur von Hippel, and his family were always taken care of by "Uncle Eugen" von Hippel in medical matters related to the eye. Dad (now 105 years old) was young and not aware at the time of the research Uncle Eugen was



doing, but he does clearly remember a particular visit to his lab. Dad had managed to get some glass in his eye from playing ball with his glasses on.

Dad had to wait around for Uncle Eugen to get to the lab, and began to look around for something useful to do. There was a cage of monkeys at the lab for experimental work, and Dad decided that opening the cage door to pet them was just the right activity to fill the time. Once the door was open, the monkeys all rushed out and began to rampage around the lab. Uncle Eugen came in to observe all his precious instruments being scattered, and Dad and the monkeys madly running around.

The next half hour was spent catching monkeys. Dad recalls that Uncle Eugen was "rather displeased and out of breath" at the end of this, but that he also seemed to think it funny. He also recalls that he was not punished - which seemed to him reasonable.

After all, he *had* helped his uncle catch the monkeys!

Dr. Eric von Hippel is a Professor at the MIT Sloan School of Management, specializing in research and teaching related to innovation.

International Medical Symposium

May 20-23, 2004

**Kochi, Japan**

See the call for papers on page 16  
or <http://www.vhl.org/conf2004>

# Dr. Lewis joins our Medical Advisory Board

Richard Alan Lewis, M.D., M.S., was born in Boston, Massachusetts, the elder son of two physicians. His younger brother, Harry, is Gordon MacKay Professor of Computer Sciences at Harvard University and currently Dean of Harvard College.

Dr. Lewis was graduated magna cum laude from the Roxbury Latin School (the oldest continually operated independent school in North America) in 1961, and from Harvard College A.B. cum laude (Biology) in 1965. He received his medical degree from the University of Michigan in 1969 and a Master of Science in Ophthalmology from the University's Rackham Graduate School in 1974. After serving as an Intern in the Department of Medicine at the University of Michigan Medical Center, he was then a Pre-Residency Fellow in Retinal Disease and a Resident in the Department of Ophthalmology at the University of Michigan Hospitals, where his inspirational mentor in ophthalmic genetics was Harold F. Falls M.D.. An additional year of Fellowship in Macular Diseases was split between the Albert Einstein School of Medicine and the Montefiore Hospital (George Wise M.D.) in the Bronx, New York, and the Bascom Palmer Eye Institute (J. Donald M. Gass M.D.), the University of Miami, Miami, Florida.

He then returned to the faculty of the University of Michigan Medical Center for five years and was recruited to Baylor College of Medicine in 1979, where he is now Professor of Ophthalmology, Pediatrics, Medicine, and Molecular and Human Genetics and Faculty Associate at the Huffington Center on Aging. Throughout his tenure, he has been the Medical Director of Ophthalmic Diagnostic Services for the Department of Ophthalmology and a member of the Medical Staffs of the Methodist Hospital, Texas Children's Hospital, St. Luke's Episcopal Hospital, the Harris County Hospital District, and the Veteran's Administration Hospital.

Although his primary clinical practice covers retinal disease, including ocular complications of diabetes, hypertension, and the ocular manifestations of other major systemic illnesses such as AIDS, his research interests have focused on genetics and hereditary eye disease like VHL, particularly those that cause visual disabilities in infants and children.

His collaborations in the Department of Molecular and Human Genetics at Baylor have led successfully to the mapping and identification of more genes for hereditary eye disease than any other clinical ophthalmologist in the United States.

His curriculum vitae includes more than 350 entries in peer-reviewed journals and textbooks and five named lectureships throughout the United States.

Page 10



Dr. Lewis is married to Patricia N. Lewis, Ph.D., M.B.A., currently the Executive Director of the A I M Foundation, Houston, Texas. They have two children, Richard N. Lewis, a Chemical Engineering graduate of Princeton University and currently Vice President of the Capital Group, an investment firm in Los Angeles, California, and Catherine P. Lewis, also a Chemical Engineering graduate of Princeton University and currently employed at the Exxon-Mobil Research and Engineering Company in Fairfax, Virginia.

With all the VHL problems I have experienced, I ask many questions. But one I've never asked is: "Why me?" We will always have unanswered and unanswerable questions. Faith is God's gift that enables us to live with the questions, in the very midst of them. -- *Michael L., North Carolina*

"I agree, Michael. I have never been able to say "Why Me?" when I look around and see all the suffering in the world. Everyone has suffering and the lucky ones learn what is important in life from their suffering. VHL has taught me to be grateful for each day and not worry about insignificant things. I also Thank God every time I go to the bathroom since some doctors wanted both my kidneys removed. Thankfully I have one remaining kidney. How many people realize the importance of their health instead of taking it for granted?" -- *Emily S., New Jersey*

We announce with regret the resignation of Peggy Marshall. We thank Peggy for her service and wish her luck in future endeavors.

## Ask the Family: Dandelions and Cancer

**Question:** What if they say you have a cyst in your kidney? My doctor says they can turn into tumors and that the tumors are cancer, so the easiest thing to do is to remove both kidneys. How can I wait if it's cancer? – Pam S., Georgia

**Answer:** In VHL it is normal to have multiple cysts and tumors on both kidneys. If we operated for every little cyst and tumor, we would all run out of kidney in a very short period of time. So we had to come up with a better way of dealing with cysts and tumors in the kidney.

A cyst doesn't "turn into" a tumor. But in the lining of the cyst there is often a seedling of a tumor. Picture a seed in a balloon. The cyst is the balloon, a sac filled with liquid. That balloon is not cancer, but it can be big. It may cause some compression problems, but in general, the cyst is a non-event. As the tumor grows to fill up the cyst, it used to seem to "turn into" a tumor.

With improvements in imaging, and greater experience with surgically removed cysts and tumors, we now understand that they don't "turn into" tumors, but the tumor may grow to fill the cyst. This is why you may hear them talk about a "dense" cyst (looks darker), or a "multi-loculated cyst" (multiple cysts back-to-back, looking like it has two chambers). What is of interest to us in planning surgical strategies is the size of the hard tumor within the cyst, not the cyst itself.

Let's say for example, that you have a 4 cm cyst with a 1/2 cm. tumor inside. All you need be concerned about is the 1/2 cm. tumor, which is too small to think about surgery. You work with your medical team to watch tumors and check on their growth rates. New techniques like Radio Frequency Ablation can be used to stunt their growth. But as they approach a size of 3 cm, then it's time to talk about surgically removing the tumors.

Watching these tumors grow is a somewhat foreign concept for those of us who are used to dealing with questions of "cancer" versus "not cancer." Perhaps dandelions will help you understand why we don't worry so much about cancer cells in the lining of the cyst, but we do get quite concerned about cancer cells in a 3 cm. tumor. For anyone in a country that doesn't have dandelions, picture some other small wild flower that spreads its seeds on the wind.

When dandelions sprout in the spring, they start out green — greener than my grass, so I rather appreciate them. Then they grow pleasant little yellow flowers that I rather like, so I enjoy them as a happy sign of spring. But then one day the yellow flowers turn white, and little seeds begin to blow in the wind and go off to seed my lawn and my

neighbor's lawn — not a very neighborly thing to do.

So the trick to enjoying dandelions is to pick them while they're yellow.

Similarly, the trick to managing kidney tumors is to "pick them while they're yellow," before the cells mature to the point where they know how to go off and plant themselves in other parts of your body (metastasize). We are working to avoid metastatic cancer. It's not the young cancer cells that are the problem, it's the spread — the metastasis — that's the problem.

You can take a yellow dandelion and crumple it all up and spread it all over the lawn, and it won't result in any new dandelions. The cells don't know how to seed the lawn. And yet it's still a dandelion. You can examine the DNA of a green dandelion, and it's still a dandelion, but it doesn't know how to seed the lawn. Think of your cyst as a green dandelion.

Those cells in the lining of that cyst are cancer cells, but they don't yet know how to metastasize. We may develop a lot of cysts and tumors in both kidneys during our lifetimes. If we take out every cyst and tumor — or if we remove the entire kidney the first time we see a cyst or tumor — we will quickly run out of kidney. The Good Lord gave us some extra kidney to deal with (it only takes 25% of one kidney to do the job), but nonetheless there's a limit.

So the goal of all these strategies of watching and maintaining the kidney is the stay on your own kidney power through your lifetime, **and** avoid metastatic cancer. That's why we watch and manage them until the risk is high that they will turn white, and then we "pick them while they're yellow" and essentially turn back the clock and give you another 8-10 years before you get to that point again.

You say that your doctor suggests that it is "easier" to remove the whole kidney and get rid of the threat of cancer. "Easier" for whom? Perhaps easier for the doctor, since a nephrectomy is a simpler surgery than a partial nephrectomy. But it is by no means easier for the patient, who now has to deal with dialysis and is a patient for the rest of his or her life. The better Quality of Life decision is to apply this strategy of watchful waiting and responsible management of VHL tumors, and stay on your own kidney power.

-- Joyce Graff, Executive Director, VHLFA



# Please Join us at a Regional meeting

*Make..*

for information and directions, see [www.vhl.org/meetings](http://www.vhl.org/meetings)

## Annual Meeting New York/LaGuardia June 19, 2004

The **Annual Membership meeting** of the VHL Family Alliance will be held Saturday, June 19, 2004, 9 am - 5 pm, in conjunction with a Northeast Regional Meeting.

It will be held at Crowne Plaza/LaGuardia Airport, 104-04 Ditmars Blvd., East Elmhurst, NY 11369. Hotel space is available at that hotel for only \$99/night. Be sure to say you are coming for the VHL meeting 718-457-6300

**Presenters** will include Dr. Gladys Glenn and Dr. Emily Chew from the U.S. National Institutes of Health. Dr. Glenn will speak on VHL Screening and treatment. Dr. Chew will talk about eye issues. Dr. Wendy Chung, Clinical Care Center coordinator at Columbia-Presbyterian Medical Center, will present information on DNA testing. All will be available to answer your questions.

The Program will include **VHL Connections** - an opportunity for us just plain folks to share experiences and stories.

Conference Registration is \$25 per person in advance or \$30 at the door, includes lunch.

CEUs will be available for genetic counselors.

## Northwest Region Everett, Washington January/February 2004

The Northwest Region is planning an informal get-together in the early months of 2004, Dutch treat at Denny's, with an eye to planning a Regional Meeting later in the year. For additional information on date and time, please contact Diana B., +1 (425) 252 3193, [dibeal2111@yahoo.com](mailto:dibeal2111@yahoo.com) or Alice C. at [AMCoday@msn.com](mailto:AMCoday@msn.com)

## Western Region Los Angeles, California

**9-4:30, February 21, 2004**

A Western Regional Meeting will be held Saturday, February 21, in the Conference room of the Zilkha Neurogenetic Institute, Keck School of Medicine, on the campus of the University of Southern California (USC), 1501 San Pablo Street, Los Angeles.

Dr. Steve Giannotta of the USC Department of Neurosurgery will talk about "Treatment Options for Hemangioblastoma" and Dr. Rich Selby of the USC Hepatobiliary and Pancreas Surgery Division, will talk about "VHL Tumors in the Liver and Pancreas, and Explanation of the Whipple Operation." After lunch there will be a round table discussion of issues relating to von Hippel-Lindau disease for patients and their families.

Registration \$25 in advance or \$30 at the door, includes lunch. For more information, please contact Dawn Cerf, VHLFA Regional Chair, (805) 541-5658, [dawncerf@charter.net](mailto:dawncerf@charter.net)

**Medical Symposium  
Kochi, Japan  
May 20-23, 2004  
See page 16 for details  
Papers still being accepted**



## *..Connections*

### **South/Southeast Tampa, Florida**

**Saturday, February 7, 2004**

A Southeast Regional Meeting is being planned for Saturday February 7 in Tampa, where it "rains sunshine" -- a nice sunny place to meet! The meeting will be held 10am-5 pm in the Tampa area.

Dr. Gary Wood, a clinical psychologist who has VHL himself, will be with us to talk about Psychological Aspects of VHL

Bob Keesler will share his thoughts on how Together -- We Can Make a Difference!

Joyce Graff and Patricia Rasmussen from the Board of Directors will also be attending the meeting.

The meeting place will be announced by post-card to people within driving distance. Registration \$25 in advance or \$30 at the door, includes lunch. For further information, please contact the meeting chairperson, Gale Lugo, in Maitland, at 407-628-1504, [curiosa90@aol.com](mailto:curiosa90@aol.com)

### **Southwest Region Dallas, Texas**

**March/April 2004**

A Southwest Regional Meeting is being planned for Dallas in March or April of 2004. Watch for further details, or feel free to call. If you would like to assist in the planning and organization of this meeting, or to suggest topics, please contact Michele Sanchez ([vhltx\\_ms@yahoo.com](mailto:vhltx_ms@yahoo.com), 281-403-0109) or Fin Winford ([fin@utdallas.edu](mailto:fin@utdallas.edu), 972-264-6886)

## **In Appreciation**

This issue of the *VHL Family Forum* is dedicated to Peggy and Don Marshall of Corinth, Mississippi, in appreciation of their ten years of outstanding volunteer service to the VHL Family Alliance and eight years on the Board of Directors.

For the past ten years Don was our Publications Chairman, ordering materials and sending out packets of information to new members, and Peggy chaired the Hotline and the Chapters Committee. Peggy served as Chairman of the Alliance for two years. We are very grateful for all their many contributions of time, talent, and effort, and wish them all the best.

"We learned we are part of a large caring and sharing family that can support each other through the most trying of times." (Don Marshall, 1996)

Altheada Johnson is our new Hotline Chairman, and Publications are being handled out of the Brookline office. We are still seeking a new chairman for the Chapters Committee.

In this issue we specially remember Janet Irvin and Cheryl Risser, who passed away recently. Their lives are celebrated here by their family and friends, who will miss them very much.

#### **Our Thanks for Donations from . . .**

Elizabeth Augustine  
Jeremy Babcock  
Mrs. A. M. Baker  
John & Marilyn Barcus  
Susan Bocchieri  
Steve Bradley  
Alexis & Thomas Buddig  
Combined Federal Campaign  
Clark Falcon  
Theresa & Steven Fruecht  
James A. Goethe  
W. W. Grainger  
Mark & Deborah Hogan  
Lee & Toni Horwitz  
Innovative Processing  
Joyce Johnson  
Mrs. & Mrs. J. H. E. Johnston  
George & Carole Martz  
Donna Nichols  
Barbara Reeder  
Dennis & Shirley Simpson  
Teresa & John Soltes  
Mrs. John Somerville  
Paul & Marilyn White  
designated donations from various United Ways

#### **In Honor of . . .**

Martin Amato, by Norine & Martin Amato  
John Barbee, by Harry & June Wilcox  
Good reports of Ericka Barcus, by Ellen & Frank Barcus  
80th Birthday of Ellen Barcus, by Ellen & Frank Barcus  
81st Birthday of Frank Barcus, by Ellen & Frank Barcus  
Pierre Bonneau, by Pia & Winthrop Munro

*cont'd page 14*

## VHL Family Forum

cont'd from page 13

Susan Burgoon by Barbara J. Smith  
Audrey Clifton, by Valencia Claycomb  
Alice Coday, by Stephanie Armacost  
Dr. Sidney & Dorothy Cohn, by Harry & June Wilcox  
Joyce Graff, by the Urology Nursing Society  
Carolyn Hays, by Harry & June Wilcox  
Virginia Hufford on her birthday, by Sadie Hampson, her sister Nancy Shank  
Becky & Jean Lima, by Tony & Darva Berkompas  
Robert Lydon's birthday, by Mary Swanston  
Kelly & Ross Mackesey, by Carolyn Benson  
Don & Peggy Marshall, by Anonymous  
Sally Overman, by Harry & June Wilcox  
Philip & Mitchel Roche, by Tamara Phillips  
The Roche Family and in celebration of Kelly's wedding, by Deborah & Barry Brewer, Irene Burell, P. Dennis Connelly, George & Mary Hodan, Geraldine Keller, Paul Kinard, Dorothy and Lyman Meyer, John & Linda Meyer, Betty & Lawrence Minton, Perry & Dennis Rossi, Deborah Trone, Barbara Ziegler  
Rev. & Mrs. John Sewell, by Harry & June Wilcox  
Evabeth Thomas, by Dolores Debenedictus  
Re. Robert Van Dorn, Jr., by Harry & June Wilcox  
Harry & June Wilcox, by Virginia Worthington  
Virginia Worthington, by Harry & June Wilcox

## In Memory of . . .

Amelia Amalfitano, by Anne Marie Bishopp, Virginia & Thomas Gorman, Owens Group Foundation, Gladys Stevens, Laura Stevens, Sheryl Vassallo  
Mike Armstrong, by Jenny & Brent Mathison  
Frank Binder, by Carolyn Binder, Michael & Lois Massanari  
Christine Bonacci, by Karen & Thomas Bonacci, Eileen McGaughey  
Darlyn Borg, by Dand & Monica Andjus  
Anthony Centunzi, by James & Jacqueline Dougherty  
Michael DeCoste, by Thomas McHugh  
Natalie Duckworth, by John Duckworth  
Krystal Dunn, by Patricia & Clifton Davis, Cheryl & John Funk, Shirley & Larry Huff, Kimberly & Russell James, Gloria & Lon McPherson, Christina Melhorn, Barbara & Brian Tuthill, Janet Weinberg  
Thelma Emigh, by Evabeth Thomas  
Mark Freesmeier, by Mary Louise Freesmeier, Joe Mikecin, Lenore & Frank Miles  
Betsy Jane Fuller, by her sister-in-law, Diana Mancia  
Joseph T. Gershey, by Helen, Robert & Thomas Gershey  
Frank Warren Graff, by George & Michele Kelly  
Mercedes Guevara, by Evabeth Thomas  
Charles M. Hall, Sr., by Carolyn Kay & John Calkins, Diana Hall, Betty Lewis, Martha B. Miley  
Donald Harrington, by William & Lynn Hayden, James Wilieko  
Harold Hefner, by Dana & Monica Andjus  
Janet Irvin, by Louis & Theadora Bax, Mary Jo Biondi, Mary Rita Bishea, Mary Bowman, Veronica Costello, Patricia & Robert Hovey, Joyce Johns, Patricia & John Lasar, Carolyn Lejeune, Mary Ann Lusk, Michael P. Lusk, Tom & Nancy Lusk, Richard & Belinda Lusk, Jr., Mary L. McCabe, Maureen McMahon, Mr. & Mrs. Thomas Moody, Tom & Valarie Moody, Colleen Navolio, Margaret O'Keefe, Beth & Donald O'Neil, Therese

Vol 11, No. 5, December 2003

Rigali, John Ruddy, Joseph & Joann Shanahan  
Michael Johnson, by Allan Saugstad  
Margie Kneip, by Thomas McHugh  
Theresa Lundsted, by Mary Ahrens, Marilyn Hinderer, Craig Lundsted, Joanne Lundsted, Kimberly Miazek, Fran & Michael Mott, Carol Weisenreder, Nicki Williams  
Peggy Lutz, by Mary Ann Madison  
Mary Mahan, by Ruben Mahan  
Loriann Marquardt, by Lois & Don Erickson, Joyce Graff, Patricia & Earl Rasmussen  
Pam Mayville, by Ronald Mayville  
James McCulley, by Eunice McCulley  
Laverne Rice, by the Accidentals Bowling League, Wanda & Gary Millett  
Cheryl Risser, by Wanda Baer, Georgia & Bruce Barton, Arnetha Beard, Geoffrey Blythe, Stephanie & James Boone, Verne R. Brown, Alice Campbell, Barry Cargill, Mary Lou Canvar, Patti Christmas, Comerica Bank, Daniel Cramer, Evelyn & Marvin Delaplane, Craig Denooyer, George & Laurei Feezel, Trina Fentriss, David Fox, John & Vicki Gardner, Joyce & Steven Gerber, Mark Gitin, Carol Hearrell, Howard Holmes, Integrated Health Associates, Eric Jacobson, Elizabeth & Joseph Kreder, Ladies' Auxiliary VFW Post 9927, Linda Lakshminarayanan, Mark Langkos, A.C. Lilly, Jrs., and Agnes Lilly, Carmen Setta Ludy, Mary Mahony, Mano & Yvonne Mavroleon, Timothy McGillen, Metro Toyota-Jaguar, Sharon Miller, Fran & Michael Mott, Narda Microwave East, Chuck Norman, Northcoast LLC, Jane Pettit, George & Barbara Pomey, Debra & Thomas Power, Linda & Daniel Risser, Thomas & Eileen Risser, SBAM, Allison Scott, Ken Shayna, CPA; Catherine & Robert Sigler, Gail & Lewis Sprague, Margaret Sutherland, Constance Timm, Jane Usitalo, Dana Waldman, Washtenaw Junior Football, Washtenaw Development Council Ann Arbor, Susan & Douglas Weber, Virginia Weingate, Mary Westkoff, John Williams, Elba & Steven Williamson, Jill & Jeff Woodruff, Bridget Yakley, Jerry & Eloise Yates  
Gwen Field Sither, by Craig Maxey, Allen Bennett Whaley  
Joe Swanston, by Mary Swanston  
Melvin Weldon, by Johnny Weldon

## Medical Advisory Board

Lloyd M. Aiello, M.D., *Beetham Eye Inst Joslin Diabetes Center, Boston, Mass.*  
Debra L. Collins, M.S., *Division of Genetics Univ. of Kansas Med Center, Kansas City, KS*  
Yujen Edward Hsia, M.D., *Prof. Genetics, Retired, Honolulu, HI*  
Col. James M. Lamiell, M.D., *Clinical Invest. Reg U.A. AMEDD Cntr & School, Fort Sam Houston, TX*  
Richard A. Lewis, M.D., *Ophthalmology & Genetics Baylor College of Medicine, Houston, Texas*  
John A. Libertino, M.D., *Chief, Institute of Urology Lahey Clinic Medical Center, Burlington, MA*

Eamonn R. Maher, M.D., *Genetics University of Birmingham, England*  
Virginia V. Michels, M.D., *Medical Genetics Mayo Clinic, Rochester, Minnesota*  
Haring J. W. Nauta, M.D., *Chief of Neurosurgery Univ. Texas Medical Branch, Galveston, Texas*  
Hartmut P. H. Neumann, M.D., *Nephrology Albert-Ludwigs University, Freiburg, Germany*  
Andrew C. Novick, M.D., *Chair, Urology The Cleveland Clinic, Cleveland, Ohio*

Edward H. Oldfield, M.D., *Chief, Surgical Neurology Natl Inst of Neurological Disorders, Bethesda, Md*  
Stéphane Richard, M.D., *Neuro-Oncologie Hôpital Kremlin-Bicêtre, Paris, France*  
Armand Rodriguez, M.D., *Internal Medicine Lauderdale Medical Group, Florida*  
R. Neil Schimke, M.D., *Dir. of Genetics University of Kansas Med Center, Kansas City, Kansas*  
Robert B. Welch, M.D., *Chair Emer, Ophthalmology, Greater Baltimore Medical Center, Maryland*

## VHL Family Forum, Newsletter of the VHL Family Alliance

Volume 11, Number 5, December 2003, ISSN 1066-4130  
E-mail: [info@vhl.org](mailto:info@vhl.org); Tel: 1-617-277-5667; Fax: 1-617-734-8233  
Toll-free in the United States and Canada: 1-800-767-4VHL

Editor: Joyce Wilcox Graff, 1-617-277-5667 (day), 1-617-232-5946 (eve)  
Adviser: Debra L. Collins, M.S., U. Kansas Med. Center, 1-913-588-6043  
Internet website <http://www.vhl.org>  
171 Clinton Road, Brookline, Massachusetts 02445-5815 U.S.A.

©2003 by the VHL Family Alliance. All rights reserved. Photocopy of the entire issue is permitted. Reproduction for publication requires written permission in advance. Distributed to members of the VHL Family Alliance, supported by dues and fund-raising. Advertising is accepted. We welcome your comments, suggestions, ideas and submissions. Copyrighted works or their modifications must be accompanied by the copyright notice. Opinion(s) expressed by the authors are not necessarily those of VHLFA.

**Postmaster:** Please send address changes to VHL Family Forum, 171 Clinton Road, Brookline, MA 02445-5815.

**International Leadership**

Gerhard Alsmeier, +49-5931-929552

Chair, Verein für VHL Erkrankung b.F., Germany

Kathy Braden, +1 317 894-3909

Vice Chair of Board; Chair, Chapters Committee

David Forsell, +1 317 924-4852

International Liaison, Public Awareness

Joyce Wilcox Graff, +1 617 277-5667

Executive Director, Editor VHLFF

M. Luisa Guerra, Italy, +39 143 643220

Chair, Alleanza VHL

Vibeke Harbud, Denmark, +45 46 75 70 33

Chair, Foreningen af Von Hippel Lindau Patienter

Chris Hendrickx, Belgium, +32-3-658-0158

Chair, VHLFA Belgium

Pierre Jacomet, +56 32 824461

Chair, Chile &amp; Latin America

Joke Jansen, +31 172 539495

Chair, Belangenvereniging VHL, the Netherlands

Altheada Johnson, +1 718 622 2457

Secretary, Chair, Membership &amp; Hotline Committees

Valerie &amp; Jon Johnson, +64 9 534 8098

Chairs, VHLFA, New Zealand

Jennifer Kingston, Paul &amp; Gay Verco

VHLFA, Australia +61 2 9475-1441

Susan Lamb, +1 519 735-0236

Co-Chair, Canada

Tom Lusk, +1 630 789-8559

Chair, Finance Committee

Mattison C. Painter, Esq., +1 615 595-1437

Treasurer

Guy Allegre, +33 1 49 59 6728

VHL France, france@vhl.org

Patricia Rasmussen, +1 218 543-6245

Director of Clinical Care, vhlccc@vhl.org

Thomas Rodenberg, Esq., +1 816 224-3856

Vice Chair of Board, Chair, Insurance &amp; Legal Committee

Jill Shields, +1 519 268 1567

Co-Chair, Canada, canada@vhl.org

Maria Shipton, +1 724 349-0990

Chairman of the Board; Chair, Communications Comm.

Joseph Verdi, Ph.D., +1 207 885-8190

Chairman, Research Committee, vhlres@vhl.org

Karina Villar, M.D., Spain, +34 925490964

Chair, Alianza Española de Familias de VHL

Mary Weetman, +44 20 7681-1796

Chair, United Kingdom, uk@vhl.org

Bruce Weinberg, J.D., +1 (323) 854 6664

Professional Education Committee

**DONATION & MEMBERSHIP INFORMATION**

Name: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip/Postcode: \_\_\_\_\_

Country (if not USA): \_\_\_\_\_ Fax: \_\_\_\_\_

Phone (home): \_\_\_\_\_ Phone (work): \_\_\_\_\_

E-mail: \_\_\_\_\_ I prefer to get mailings ☐ via e-mail, ☐ on paper**Membership:**I am a ☐ Person with VHL ☐ VHL Family Member ☐ Supporting Friend ☐ Health Care Professional

My Occupation, or medical specialty, is \_\_\_\_\_

*All members receive the VHL Family Forum quarterly. Check here ☐ if audio version is needed*☐ New member ☐ Renewal (Dues \$25 per household, \$35 per professional) \$ \_\_\_\_\_☐ I cannot afford dues at this time, but please accept my donation (any amount) \$ \_\_\_\_\_☐ Please send me \_\_\_\_\_ brochures about VHL Research Fund to share with others**Donation:**

Tax deductible donation of . . . (amount) \$ \_\_\_\_\_

☐ In Honor of a person or event \_\_\_\_\_☐ In Memory of someone deceased \_\_\_\_\_☐ Please send a card to: \_\_\_\_\_**Registration:**

\_\_\_\_\_ people for the Regional Meeting in \_\_\_\_\_ @ \$25 each \$ \_\_\_\_\_

**Great Gifts!**\_\_\_\_\_ *Sacred Process*, by Karen Koenig -- inspirational poems about life & death with VHL @15.00 \$ \_\_\_\_\_\_\_\_\_\_ *A Time to Walk*, by Jay Platt -- Lessons learned along the Appalachian Trail @14.95 ea \$ \_\_\_\_\_\_\_\_\_\_ **NEW Comfortable grey golf polo shirt with VHL logo** @35.00 ea, specify size S, M, L, XL, XXL \$ \_\_\_\_\_☐ Please giftwrap my gift and send it to: (attach another sheet if needed)☐ Card should read: \_\_\_\_\_**Payment Method:**☐ Enclosed check, payable to the VHL Family Alliance **TOTAL: \$** \_\_\_\_\_☐ Master Card/Visa Card # \_\_\_\_\_

Expiration date: \_\_\_\_\_ Name as it appears on the card: \_\_\_\_\_

Signature \_\_\_\_\_

**Send this form to VHL Family Alliance, 171 Clinton Road, Brookline, MA 02445 USA****Canadians, please send donations to: Canadian VHL Family Alliance,****4227 Hamilton Road, Dorchester, Ontario, N0L 1G3 Canada**

# 6th International Symposium on von Hippel-Lindau “Recent Advances in VHL Disease & other Familial Kidney Tumor Syndromes”

May 20 ( Thursday ) - 23 ( Sunday ) , 2004

**Location:**

Kochi City Culture Plaza (CUL-PORT)  
Hotel Nikko Kochi, Kochi Japan

**President:**

Taro Shuin, Department of Urology, Kochi Medical School  
Web Site: <http://www.6thVHL2004.org>

Medical professionals who would like to present  
papers at the meeting should email abstracts to  
[vhlsympo@ics-inc.co.jp](mailto:vhlsympo@ics-inc.co.jp)

**For other details, please contact:**

- the Department of Urology, Kochi Medical School:  
Tel. +81-88-880-2402 or FAX +81-88-880-2404  
e-mail. [vhlsympo@ics-inc.co.jp](mailto:vhlsympo@ics-inc.co.jp)
  - Registration through ICS Inc., at  
Tel. +81-92-751-3244 or FAX +81-92-751-3250
  - Travel arrangements through JTB International Travel  
Phone: +81-3-5796-5445, Fax: +81-3-5495-0685  
E-mail: [vhl2004@itd.jtb.co.jp](mailto:vhl2004@itd.jtb.co.jp)  
Optional 2-day trip to Kyoto, English-speaking guide
- Japan business hours 7 pm - 4 am Eastern U.S. time  
or midnight - 9 am in England



Newsletter of the VHL Family Alliance  
171 Clinton Road  
Brookline, MA 02445-5815

ADDRESS SERVICE REQUESTED

NONPROFIT ORG.  
U S POSTAGE  
**PAID**  
Dulles, Va.  
Permit No. 056