VHL Family Forum

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Study of rare disease helps unravel key question of human biology

by Rob Levy, Dana Farber Cancer Institute, Boston, Massachusetts

One of the oldest puzzles in biology is being solved by research into one of the world's rarest diseases. The disorder is known as von Hippel-Lindau (VHL) disease and occurs when blood vessels grow uncontrollably and form tight knots that can damage surrounding tissue. Caused by an error in a single gene, the disease is known to affect one in 35,000 people worldwide, or just over 6,000, total, in the United States.

Investigators led by William Kaelin, M.D., of Adult Oncology at the Dana Farber Cancer Institute (DFCI) are using their understanding of VHL disease to answer a question that has intrigued biologists for generations: How do animal cells sense the presence of oxygen – a major source of their energy – and how do they respond to rises and falls in oxygen levels in the blood?

The question is of more than theoretical interest. Understanding how cells detect oxygen in their neighborhood, and how they switch to alternate fuels when oxygen supplies are low, may one day lead to new therapies for conditions in which tissue is deprived of enough oxygen. It may also shed new light on cells' ability to attract additional blood vessels – an important avenue of cancer research.

"Our work is an example of how research into rare hereditary disorders can provide important insights into the normal functioning of genes and cells," Kaelin says. "It offers a window into a broad array of cell processes."

Following a lead

Kaelin first learned about VHL disease as a medical student. He began studying it in hopes that the unusual features of the disease might provide insights into how cells control the growth of blood vessels and utilize oxygen.

Though it is far from complete, the emerging picture of cells' "dialogue" with oxygen is already complex, involving the creation and destruction of proteins, the switching on and off of genes, and use of protein parts as signaling devices. The purpose of this activity is to keep cells attuned to the amount of oxygen in their vicinity, so they can burn it when it is plentiful and use other energy sources when it is not.

Biologists have long known that when oxygen levels drop, cells respond by switching on a gene called HIF. HIF activates other genes that help cells compensate for the loss of oxygen. Some of these genes enable cells to burn glucose (a sugar) in place of oxygen. Others trigger the growth of new blood vessels (a process called angiogenesis) that bring a greater flow of oxygen to cells.

Several years ago, Kaelin's lab and others found that when the protein for VHL disease is normal – as in more than 99 percent of the population – it is part of the cell's machinery for turning HIF on and off. "We showed that when the VHL protein [called pVHL] is defective, HIF is poorly controlled, preventing the cell from adapting to changes in oxygen levels," Kaelin remarks.

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Last year, several labs including Kaelin's demonstrated how one aspect of that machinery works. It turns out that pVHL helps destroy the HIF protein when oxygen levels rise. The result is that cells burn less sugar, cut back on their building of blood vessels, and begin burning more oxygen.

Still, there were gaps in scientists' understanding of how the system operates. A key one: what is the precise link between oxygen and pVHL? How does pVHL "know" whether oxygen levels are increasing, decreasing, or holding steady?

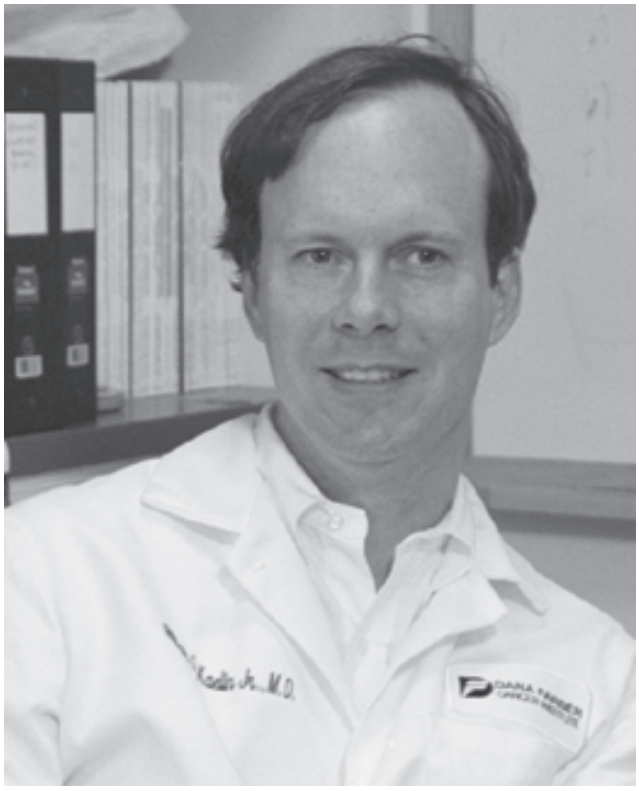
In a study in the April 20, 2001, issue of *Science*, Kaelin and his colleagues provide an answer.

The focus of the study is a small residue on the surface of the HIF protein. The residue is composed of an amino acid called proline. When oxygen is present, the proline residue becomes covered with hydrogen-oxygen pairs known as hydroxyl groups, the researchers report. The hydroxyl groups are the "Oxygen is Here!" sign that pVHL looks for.

"The hydroxyl groups play a key role in cells' ability to sense oxygen in their environment," Kaelin explains. "If they signal that oxygen is present, pVHL begins destroying the HIF protein, and the cell shifts from burning sugar to burning oxygen."

Broader applications

Intricate as this system is – and research is under way to draw out even more details – understanding it will help scientists develop new treatments for a variety of conditions.



William G. Kaelin, Jr., M.D., Ph.D., Associate Professor of Medicine, Harvard University, Dana Farber Cancer Research Institute, Boston, Massachusetts.

For example, many people suffer from conditions in which their muscles or other tissue don't receive enough blood as a result of clogged blood vessels. It may be possible, Kaelin's research suggests, to stimulate the growth of new blood vessels to these areas by preventing pVHL from destroying the HIF protein.

"Our work is also shedding light on the system that governs angiogenesis," Kaelin observes. A promising area of cancer research involves attempts to short-circuit angiogenesis so that tumors are starved of blood.

"This research illustrates just how much world has changed since the VHL syndrome was first identified more than 100 years ago," Kaelin says. "A convergence of technologies including gene cloning, techniques to analyze gene function, and the Internet, has made it possible to understand the basic mechanics of the disease and brought closer the day when we can develop new treatments for it."

For VHL patients and their families, support is vital medicine

When Joyce Graff began reading up on von Hippel-Lindau (VHL) disease – which claimed her husband's life in 1977 and afflicts her son, Damon – she felt like a one-member support group. Through 30 years of coping with her husband and son's condition, she had never met anyone with the disease or a family member of a VHL patient. Few doctors were familiar with the disorder and fewer still had expertise in treating it.

"I remember sitting one day in the Harvard Medical School library reading a research article on VHL, and I sat back and thought, 'I'm doing what a doctor would have to do to learn about VHL, and no doctor is going to be able to spend as much time reading up on it as I have,'" recalls Graff, of Brookline.

One of the particular cruelties of rare diseases is the isolation experienced by many patients and their families. "I felt like no one else could understand what I was going through," Graff says. "I wound up repressing a great deal of pain."

Today, though Damon, now 30, continues to battle the disease, Graff doesn't feel alone. In 1993, she and the mothers of two other VHL patients – one in Maryland, one in Michigan – founded the VHL Family Alliance. Now encompassing 10,000 members in 67 countries, the association serves as a crucial link for VHL families.

To let people know about the organization's existence, Graff and her co-founders wrote to every physician who had published an article on VHL disease in the previous 20 years and asked them to let their patients know about the organization. They started a

Joyce Graff, Brookline, Massachusetts

newsletter and asked doctors to distribute it to patients. "Little by little, we formed a very strong group."

The biggest boost to membership, as might be expected, was the advent of the Internet. The alliance's Web site – one of the first established by a disease-related organization – went live in 1994.

Today, the organization maintains a toll-free number for information and support (1-800-767-4VHL). "The average first call from a family lasts between 45 minutes and an hour," she says. "People are often reluctant to make that first call – they may never have reached out this way before – but once they call and discover they're talking with someone who has VHL, it's magic."

Because they are so widely dispersed, alliance members tend to stay in touch by e-mail, Internet chats, and phone calls. The organization sponsors an annual meeting in the United States and, every two years, holds a symposium for physicians and researchers studying the disease. "The symposium gives doctors a chance to share their findings and network with each other," Graff remarks. The alliance also raises money to support scientists in the field of VHL research, including Dana-Farber's William Kaelin, M.D. (See related story, page 1.)

Because VHL can affect different organs, treatment can involve physicians from a variety of specialties. "We convey to patients and families that treatments are available, but it's a complex disorder, and finding the right doctors is hard work," Graff says. "When people call asking, 'Where is there a specialist for VHL?' we tell them, 'You're going to get to train one.'"

Graff emphasizes that with the proper treatment, VHL disease can usually be managed. The alliance has identified a set of clinical-care centers around the country that have experience treating the disorder. "The key is to stay on top of it and pay attention to symptoms," she says. "We tell people that, even though no cure exists, there's a lot they can do avoid the worst consequences of the disease. Through the efforts of people like Dr. Kaelin, more treatments are becoming available to manage this condition and keep it at bay."

Graff currently serves as the Alliance's Chairman of the Board and Editor of the organization's newsletter. "The group is a vital link for people affected by this disease," she remarks. "To have a support group of people who understand what you're going through has been – for me and many others – an incredibly healing experience."

Pansies for Hope
Hope sees the invisible,
feels the intangible and
achieves the impossible.

Help achieve the impossible!

Give to advance research on VHL! see page 15

Sleep well!

If you have trouble sleeping, try relaxing for an hour or so before getting into bed. Read, listen to music, take a warm bath (not a hot bath or shower). Don't take work to bed with you. Avoid strenuous exercise within a couple of hours of bedtime. Cut out caffeine and cigarettes (both are stimulants). Alcohol my help you fall asleep, but the sleep will probably be fragmented, light, and unsettled, and you're likely to wake up suddenly. Or try to relax each muscle group, progressing slowly from your toes to your head. Get up at the same time every morning, no matter how poorly you've slept, and try to get through the day without a nap.

Tip #57 from *Wellness Made Easy: 101 Tips for Better Health*, from the University of California, Berkely Wellness Letter, 1990.

NCI Vaccine Study

In the March issue we published the following call for volunteers for a study at the U.S. National Cancer Institute:

"Looking for volunteers to try an experimental immunological therapy. Protocol ID 98-C-0139. The study will administer a vaccine concocted from the patient's own cells, to determine whether the VHL tumor suppressor protein can be immunologically targeted by vaccination. The study proposes to treat patients with sporadic RCC who carry VHL mutations in their tumors with corresponding mutant VHL peptide vaccination. If, in the opinion of the principal or associate investigators, it is not in the best medical interest of the patient to enter this study, the patient will not be eligible."

Patients with known familial VHL are ***not eligible*** for the vaccine study. In fact it would be ***dangerous*** for people with VHL, as they could be harmed by participating. However, if you know other people who have Renal Cell Carcinoma, please feel free to refer them to this study -- a possible new therapy for cancer that has grown out of the research on VHL. This is only one example of how research on this disease is helping to unlock the secrets of cancer.

The purpose of the vaccine clinical trial is to generate an immune response against tumor cells and save the normal cells of the body. Therefore, the immune system must be able to recognize certain characteristics that exist in the cancer cells but not in the normal cells. One way that tumor cells can differ from other cells is in the presence of a *sporadic mutation* of the VHL gene, occurring at random during one's lifetime. This mutation occurs in approximately 50% of renal cell cancer patients in the general population. Sporadic mutated VHL genes produce mutated proteins that are unique to the cancer cells, thus providing a "target" for the immune system.

If someone has a *germline mutation* of the VHL gene, or has inherited an alteration in the VHL gene in every cell, then the mutation is present in all cells and could cause the immune system to generate an attack on all cells, which would be a life-threatening situation.

For additional information, people with sporadic RCC who do not have VHL should please contact Deborah Pearson as shown below.

Open to VHL patients: In addition, there is a screening study (NCI-89-C-0086) which is specifically designed for patients who are known to have VHL. Volunteers who are accepted into the study will receive a comprehensive work-up, genetic counseling, and blood sampling. There is no treatment component for the screening study and it takes about 4 days to complete the testing and work up. If you are interested in it, you or your physician can call the Urologic Oncology Branch at 301-496-6353 to see if you may be eligible to participate. You will learn a great deal about your condition which you can use to help your local team learn more about VHL in general and your health maintenance in particular.

For more information on the screening study go to http://cnetdb.nci.nih.gov/trialsrch.shtml and enter the study number NCI-89-C-0086, or contact Deborah Pearson.

Deborah Pearson, Director of Outreach and Patient Recruitment, National Cancer Institute, Division of Clinical Sciences, Building 10, Room 12N214, Bethesda, Maryland 20892. Tel: +1.301.435.7854; Fax: +1.301.594.7951; E-mail: pearsond@mail.nih.gov

Your Donations Make a Difference!

by Fran Mott, Michigan

VHLFA is supported almost entirely (95%) by individual contributions from people just like you. We appreciate your help at any time. Here are a few ideas:

Are you a Federal employee? The Combined Federal Campaign (or CFC) is the annual fund-raising drive conducted by Federal Employees in their workplace each fall, a kind of United Way for federal workers. Each year, Federal Employees and military personnel raise millions of dollars through the CFC that benefits thousands of non-profit charities. The employee would select from a variety of charities during their annual benefits enrollment in the fall, and have money deducted from their paychecks.

This year the VHL Family Alliance is participating in their national campaign. If you work for the federal government or the post office, or if you know someone who does, please tell them to look for us (CFC #1098) in this fall's listing of eligible organizations. Thank you.

United Way. VHLFA is not a member of United Way, as they require that you have paid professional staff. However we are eligible for their "donor choice" program. You can write in VHL Family Alliance (with our address) as the recipient of the money you pledge to your local United Way. This way you can support your local United Way and VHLFA too!

Gifts of stock are a great way to support the work of the VHL Family Alliance. You can help the VHLFA and realize significant tax savings by making a gift of appreciated stock that has been held for more than one year. Donors of stock are entitled to claim a charitable deduction for the current market value of the stock and avoid capital gains tax on the increase in value. See your tax adviser for details.

Making tough choices, living with fear

By Susan Friedman, The Boston Globe, 4/15/2001

I was 33 when I was diagnosed with breast cancer. Like most cancer patients, I wondered ''Why me?'' I had been a vegetarian for most of my adult life. I didn't drink or smoke, I had no family history of the disease.

None of my doctors offered any explanation. No one told me that of the more than 180,000 women who are diagnosed with breast cancer each year, approximately 5 to 10 percent have a hereditary form of the disease. No one told me that as a women of Eastern European Jewish descent, I had a much greater chance - one in 40 - of carrying a mutated gene. No one told me that a blood test could determine whether or not I carried these genes.

I didn't learn these facts until I read about hereditary breast cancer in a magazine in 1997, a year after my diagnosis. That's how I discovered that mutations in the BRCA1 and BRCA2 genes are involved in 30 to 70 percent of all inherited cases of breast cancer. I also learned that those who carry the mutations also carry an increased risk of ovarian cancer.

I thought again of my paternal grandmother who had died young of what was described as kidney cancer. It occurred to me that it might have been ovarian cancer. I immediately called my doctors. I wanted the test.

First, I was told, I had to undergo genetic counseling. I didn't think I needed counseling; as a veterinarian I already had a medical background. But what I learned from the genetic counselor prepared me to make some of the most difficult decisions of my life.

I learned that there are no easy answers when it comes to gene testing for breast cancer. Testing positive for the BRCA gene mutations doesn't guarantee that you will get breast cancer. Instead, you are diagnosed with a risk.

The lifetime risk for breast cancer with a mutation can be as high as 80 percent, and the risk for ovarian cancer can be as high as 30 percent, but there may be mitigating factors that have not yet been identified by scientists.

And what would I do if I did have the mutation? The most effective way to reduce my risk was prophylactic surgery to remove my healthy breast and ovaries -- a drastic option that doesn't totally eliminate the risk. There are medications like Tamoxifen that might reduce the risk by as much as 50 percent, but these carry side effects and the data are unclear with respect to carriers of a BRCA mutation.

High-risk surveillance is also an option, but early detection hadn't caught my cancer before it had spread to my lymph nodes.

There were also nonmedical concerns. Science has given us genetic testing, but there are few accompanying laws to protect against genetic discrimination by employers or insurance companies. To guarantee my privacy and to be sure that I had no history of genetic screening in my medical records, I paid for the test without informing my health insurance provider.

The social implications of gene testing were even more disturbing. Would I be shunned for my genetic flaw? Would my young son be targeted as a carrier?

Despite all of these issues, I decided to have the test, and I discovered that I did carry one of the heritable mutations. As the first in my family to be tested, I felt obliged to tell my relatives. I hadn't spoken to some of these relatives since childhood. It's not news that will necessarily bring a family together.

Then came the agonizing decisions. Having just finished treatment for breast cancer, which included four surgeries, four months of chemotherapy, and six weeks of radiation, I now learned I was at risk of further cancer. I was young, I had a happy marriage and a 3-year-old son. I was desperate to lower my risk as much as possible. I decided to have prophylactic surgery.

My husband was supportive of my choices. I knew that I had made the right decision when precancerous cells were found in my healthy breast.

In the two years since my surgeries, I have met other women going through the hereditary cancer risk experience. Many of these women are being given inaccurate information by untrained health-care providers, and are being told that they don't need genetic counseling before making these life-altering decisions.

The choices available for those living with the risk of cancer are gut-wrenching -- living with fear, relying on imprecise surveillance methods, taking medications with side effects, sacrificing healthy organs.

There are no right or wrong decisions in this highly personal and difficult journey, but the fact that the options are so imperfect and the consequences so drastic underscore the need for more research and education in the field of cancer genetics.

Susan Friedman is the founder of FORCE: Facing Our Risk of Cancer Empowered, a nonprofit organization for women at risk of hereditary breast and ovarian cancer.

Enfermedad de VHL

On June 24 in Santiago, Chile, a press conference was held to present the book, "La Enfermedad de von Hippel-Lindau," a publication sponsored by the Chilean Medical Association and the VHL Family Alliance, published and distributed by Recalcine Pharmaceuticals. The Chairman of the Chilean Medical Association presented the book, and then Dr. Ramirez spoke about his experiences in helping Pierre Jacomet arrive at a diagnosis. Pierre had been told he had MEN (multiple endocrine neoplasia, another hereditary condition that can lead to pheochromocytomas), but Dr. Ramirez questioned that diagnosis and kept pursuing the question, finally arriving at VHL. Getting sufficient information on VHL was one major part of the problem.

While there is now a number of excellent articles about VHL in English, German, and French, there has been very little in Spanish other than a few articles describing one doctor's experiences with one patient, similar to the early articles seen in English in the 1960's and 70's. This new book provides a comprehensive view of the condition in Spanish language, for physicians in Spanish-speaking countries worldwide.

Pierre Jacomet of Chile headed the effort to create this book. He drew material from the *VHL Handbook* (translated into Spanish by Dr. Myriam Gorospe), from Dr. Hartmut Neumann's treatise on the preventive-medicine approach to VHL, and from his own experiences with pheochromocytomas. "The most important issue we want to communicate," said Pierre, "to the press and to the doctors throughout the Spanish-speaking world, is that we are already in touch with almost 10,000 people diagnosed with VHL in 67 countries, and that there are many more who are still undiagnosed. We need to find all of them, help them through their fears and doubts, help them obtain a diagnosis, and alert the medical community about how to identify and treat this elusive multi-symptomatic disease."

We are very excited to have this very important work in Spanish language. Recalcine is distributing the book to physicians throughout Central and South America, and the VHL Family Alliance will be distributing it also in the United States and Spain, and on the internet. We are hopeful that this will make an enormous difference in the lives of people with VHL and their families throughout the Spanish-speaking countries.

We are extremely grateful to Alejandro Weinstein, CEO of Recalcine, for bringing to fruition this invaluable contribution toward improving diagnosis, treatment, and quality of life for people with von Hippel-Lindau disease. Watch for coverage in the news, especially in the magazine *Que Pasa,* and in newspapers associated with *El Mercurio*, which is the oldest and most prestigious newspaper in South America.

Action to prevent "genetic underclass"

by Zosia Kmietowicz, London

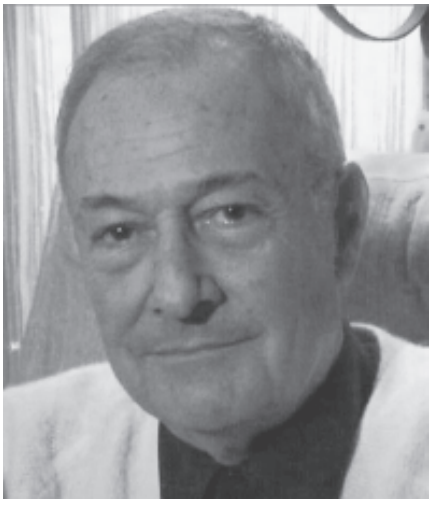
A ban on the use of genetic tests by insurance companies for at least the next two years is needed to prevent the creation of a "genetic underclass" of people unable to obtain insurance, a cross party committee of Members of Parliament (MPs) has concluded.

The British House of Commons Science and Technology Committee says more research is needed to establish the impact of allowing insurance companies to use genetic test results when calculating premiums. If they are allowed to do so, some people may be deterred from finding out whether they are at risk of developing a disease and miss out on early treatment. Others may become uninsurable because of their genetic make up.

The Genetics and Insurance Committee, set up in 1999 by the U.K. Department of Health to evaluate the scientific and actuarial relevance of genetic tests by the insurance industry, has approved only one genetic test (for Huntington's chorea) for use in calculating premiums, yet many insurance companies also ask for test results for early onset Alzheimer's disease and hereditary breast and ovarian cancer, even though there is doubt as to how relevant or reliable these are.

Insurers believe, along with the Association of British Insurers, that not including test results in their calculations would be too costly. However, some companies do not ask for test results or only take account of negative test results.

Genetics and Insurance[---]5th Report Commons Science and Technology Committee (HC174) is available at www.publications.parliament.uk/pa/cm/cmsctech.htm



Pierre Jacomet, Chile

Genetic Testing Derailed at BNSF

In a major victory for workers' rights in the United States, the Burlington Northern Santa Fe Railway Company (BNSF) has settled a lawsuit filed by the Brotherhood of Maintenance of Way Employes (BMWE) in February 2001 to stop the coercive genetic testing of its employees by BNSF.

The BMWE filed suit on February 9 against BNSF and Athena Diagnostics in Sioux City, Iowa (Western Division of the U.S. District Court for the Northern District of Iowa) and was soon joined by the Brotherhood of Locomotive Engineers (BLE), seeking "to remedy the illegal, compulsory regime of genetic testing of injured employees" by the BNSF.

On February 12 Judge Mark C. Bennett, by consent of the parties, issued a temporary restraining order and BNSF agreed to halt its coercive genetic testing program which BNSF said it had begun in March 2000. "This order should be a real relief for those who believe individuals still have some rights of privacy in the United States," said Harry Zanville, lead counsel for the BMWE, at that time.

Reaching a settlement April 6, BNSF agreed to terminate all genetic testing of employees represented by BMWE and BLE. The railroad also agreed to destroy all blood samples and records of testing previously done (when authorized by the affected individuals), confirming the status of the destruction to the BMWE and BLE, and agreed not to discipline any employee for failure to comply with requests for medical information in connection with previously conducted tests.

BNSF, acknowledging the necessity for national legislation limiting the use of genetic screening in employment decisions, agreed to "commence written and oral expression of this position to key officials of Congress and the Executive Branch" within 30 days of execution of the agreement. The significance of this provision of the settlement agreement is readily apparent as the U.S. Congress is being asked to enact a comprehensive, national prohibition against genetic testing.

BNSF was the railroad Senator Edward Kennedy was talking about when he said, "genetic testing is a real and frightening problem, and it is happening right now, by one of the largest railroads in the country" as he reintroduced the Genetic Nondiscrimination in Health Insurance Employment Act the week of February 19. Bills were defeated in the previous session of Congress in part because opponents argued it wasn't happening.

"The results of this unprecedented lawsuit are of immense benefit to not only BMWE and BLE members, but for all workers," said BMWE President Mac A. Fleming. "This victory demonstrates that corporate control of workers' private lives can not only be halted but can be completely eliminated."

"This is a major victory for workers' rights and personal privacy for all working men and women who should not have to fear mandatory genetic testing," said Ed Dubroski, BLE International President. "Not only did all of labor support our cause, but we also drew strong support from a broad cross section of America, including the medical community, civil rights groups and Americans from every walk of life."

"This was a critical case and we successfully drew a line in the sand to protect the essence of privacy rights," said Zanville. "However, the BNSF should be applauded for its decision to do the right thing after this serious misconduct was discovered."

The Brotherhood of Maintenance of Way Employes represents 45,000 rail workers that build and maintain the track, bridges and building on the railroads in the United States and Canada. For further information visit www.bmwe.org. The Brotherhood of Locomotive Engineers, North America's oldest labor organization, has 58,000 members in the U.S. and Canada. The BLE is the certified bargaining representative for, among others, locomotive engineers on U.S. Class 1 and Canadian railroads, Canadian rail traffic controllers and, through its American Train Dispatchers Department, U.S. train dispatchers. For further information visit www.ble.org.

An interview by Mike Wallace with BMWE member Gary Avary and his wife Janice, the Nebraska nurse credited with making the genetic testing discovery, was shown in a segment of the television magazine *60 Minutes*, which aired in April 2001.

Jay Platt was a featured speaker at ***National Cancer Survivors' Day***, June 3, 2001. He was interviewed on CNN Sunday Morning. Jay, a retired Marine who has VHL, walked the Appalachian Trail in 1999 with one eye and a brain tumor.

"I've learned there's something to be gained in all that we go through, especially the tough times," Jay said. "I think that having cancer has made me a better person. The Appalachian Trail became for me a metaphor for life. There are hills and valleys, just as there are ups and downs in life. You may be scaling a steep and difficult hill today, but over the crest of the hill there could be a beautiful valley, an easy walk down. A 'never quit' attitude is what keeps you going when almost every fiber of your being wants to give up, or when others say 'it' can't be done."

Long Wait for MRIs in Canada

by Tania Durand, Ottawa, Canada

In Canada there is a 7-9 month wait for MRI's. What does this mean to Canadian VHL patients? I know what it means to me. It means that if I need a routine MRI check-up to follow the tumors or masses I already have, I need to make my next MRI appointment the same week I get the results from my present MRI scan. This is the only way that I have a chance to be close to the top of the six month waiting list in Ottawa, Ontario, for an MRI. If you've put your annual screening off for any length of time and think that you can go into your doctors office and have an MRI in a relatively short amount of time, you may be in for a rude awakening. The only way I've managed to keep up my annual screening that has more than once alerted me to major problems is to keep on top of the MRI process at every turn.

More than 7,000 people are waiting seven months and longer for all but emergency or urgent MRIs at the Ottawa Hospital. Across Ontario, the waiting list for an MRI is growing by almost 12,000 patients a year. Cancer patients are waiting months for a follow up MRI to see if their disease has responded to treatment. It's said that Ontario needs at least 80 more scanners to meet the current demand.

Those of us who are keenly affected by this problem need to raise the visibility of the issue and get government to put the capital money into the budget to fix the problem. In London, Ontario, for example, the Multiple Sclerosis (MS) clinic wrote for and recieved grant money to operate their existing MRI machine around the clock, making MS screens only a 1 month wait instead of a year. They did it by working with the local television station and newspaper to publicize the plight of the people involved, and by writing grants applications to get private money to supplement what the government is able to do. Toronto Raptors basketball star Vince Carter jumped the MRI queue by paying for his MRI. Some people with access only to Canadian Health Care have been waiting for 14 months and still don't even have an appointment.

Let's take action in our local communities to raise the importance of addressing this issue and devising plans of action to do it. Government money is not a bottomless pit, it needs to be supplemented by private funding by pharmaceuticals and imaging companies. The real work is getting real people's stories to be picked up by the newspapers and television journalists to get the real change (more MRIs and less waiting).

Meanwhile, I suggest that if you're putting off your screening *don't put off making the appointment* -- it may be a long wait, that could potentially cause you harm.

Tania Durand, Chairman, Canadian VHL Family Alliance

References: Articles from the *Ottawa Citizen*, January-February 2001: "MRI Backlog grows 12,000 a year", by Sharon Kirkey; "Rock to Ontario: Fix MRI crisis, MRI Cancer patients wait months", by Sharon Kirkey; "Athlete jumps MRI queue", by April Lindgren.

The Canadian VHL Family Alliance is an official Canadian Charity. Donations go to support local programming and pay for newsletters delivered to Canada. Volunteers are needed to extend services within Canada. Canadians may call 1-800-767-4845, or write to canada@vhl.org.

Call to British patients

by Dan Whitmore, Wales, U.K.

VHL in Britain is a hidden disease. That's the view I've come to after over a decade knowing I have the condition.

In the twelve years since I was diagnosed I have met only three other people with the same condition. During the same period, outside my team of medical professionals, I have only come across one doctor who knew what VHL was.

Yet statistically there are estimated to be 1200 of us out there, many undiagnosed, and many others feeling isolated by a confusing illness that most doctors can't even spell.

I don't know what the situation is like for people with VHL in other countries but for me it's been a confusing journey. I am treated at four different hospitals, spread all over the country. One for brain and spine, one for kidneys, another for eyes, and yet another for genetic counselling. None of these hospitals seems aware of what the others are doing and consequently tests are repeated unnecessarily and I spend up to two weeks of every year travelling between appointments for check-ups.

The situation for people with kidney problems is an entirely different story here. Treatment is well coordinated and through three national support groups there is information and advice available at every turn. As VHL led to my kidneys being removed followed by dialysis I find this very useful but it makes me realise what the VHL community here is missing.

It was not until two years ago when I bought a computer and hooked up to the internet that I discovered the VHL Family Alliance. It was through the VHL website that I first learned fully about the disease. I printed information from the site for my General Practitioner who couldn't find it listed in his medical book when I first saw him. He is now very well-informed on the subject!

There was, until some time ago, an organised UK branch of the VHL Family Alliance. Unfortunately, because of assorted health problems of people involved, the group is currently dormant. Mark East, from Leeds in the north of England, did an excellent job providing phone support to people.

Sadly, Mark died shortly before Christmas 2000. I never met Mark but I used to talk to him on the phone where I found him friendly and supportive. I'm sure there are many others he helped with his friendship and sound advice. He will be sorely missed.

Dan Whitmore, Wales

During my most recent visit to the Genetics clinic at St. Marys Hospital in Manchester I spoke to my doctor about an idea I had been considering for some time. I wanted to contact all British VHL patients to ask them if they would like to form some kind of network here for patients. My doctor agreed that, in co-ordination with other hospitals around the UK, they would be prepared to send a letter to all VHL patients on their books.

This is just the first step. I don't know exactly VHL patients in Britain want. As I see it we need several things. We need to communicate with each other so that we can share information and support each other; We need to raise the profile of VHL both to the public and to the medical profession; And we need to raise funds to support research.

This is a stumbling first step. If you are British and have VHL, or if a member of your family has VHL, I would be very pleased to hear what you think about the idea of a more organised VHL group here. You can contact by e-mail - dan@newswales.co.uk - or by phone - +44 (0)1547 550684.

In addition to Dan's direct contact information listed here, the VHL Family Alliance in the U.K can be contacted via our telephone number in London +44 (0)20-7681-1796, where phone messages and faxes are accepted, or by writing to info@vhl.org. Messages will be forwarded to Dan or another appropriate volunteer for action.

Meet the Directors

The Board of Directors is the panel of volunteer leaders who shape the agenda of the Alliance and see that its programs are carried out. The slate of nominees for to the Board for 2001-2004, to be presented to the membership for election at the Palo Alto meeting, includes Kathy Braden, Indiana (for re-election); Altheada Johnson, New York (returning to the Board); Tom Lusk, Illinois; Patricia Rasmussen, Minnesota; and Tim Nielsen, California. We will be introducing them to you in the next few issues.

Sheila Tepper

Sheila joined the Board in July 2000 as Director of Fund-Raising and Development. Sheila has a family member with VHL.

Sheila brings with her a wealth of experience in raising funds for the Arts in the Los Angeles area where she lives. She is currently active on the Boards of Trustees of the Museum of California Design, and of the Los Angeles County High School for the Performing Arts, similar to the one in New York, and "the best one west of the Mississippi", and has been a leader in organizations including the California Chamber Symphony Society, the Los Angeles Contemporary Exhibitions, and the Friends of the Joffrey Ballet.

Sheila has a lifelong commitment to the Arts and humanities. For the past 15 years she served as Executive Producer of the radio program "Backstage California," a weekly radio program of in-depth interviews between artists of all disciplines, scholars, critics, and others exploring issues in the arts and humanities. The show is broadcast on many radio stations throughout California. She is a member of Art Table, a national organization for professional women in the visual arts.

She has also held key positions in shaping legislation and services for children and handicapped people. She is a founding member of the American Association of Disability Communicators, and attended four White House Conferences on Employment of the Handicapped, and served for many years on the Los Angeles City Council for the Handicapped. She founded and continues to lead in the Children's Hospitals Environmental and Educational Resources (CHEER), an organization which enrolls many artists, decorators, designers, entertainers, architects, and manufacturers to donate many thousands of dollars in in-kind services to create attractive, comfortable hospital environments for children. She has earned numerous awards, including a Citation of Merit from the Mayor of Los Angeles.

"I look forward," Sheila says, "to being part of the extraordinary team that helps those who have VHL and helps fund research for the cure."

Resources

Help for caregivers: June 11-17 is Carers Week in the U.K. www.carersweek.org

Carers National in the U.K. provides a support network for people caring for family members with illness or disability. 20-25 Glasshouse Yard, London EC1A 4JT , UK, Tel: +44 (0)20 7490 8818; Fax: +44 (0)20 7490 8824; http://www.carersuk.demon.co.uk/ There are groups in Northern England and Ireland as well.

Well Spouse Foundation, New York, focuses on support for spousal caregivers. Regional support groups, national conference, getaway weekends. 30 East 40th Street PH, New York, NY 10016; Tel: (212) 685-8815, (800) 838-0879; Fax: (212) 685-8676; http://www.wellspouse.org

Online forum CareShare: Audrey Guggenheim has recently started CareShare, an online forum for caregivers, at www.delphi.com/careshare . Her hope is that it will become a community "where anyone caring for a seriously ill person can share experiences, ask questions, support one another, and, even gripe. Caregiving is tough enough ... why go through it alone?" For further information, call 212-765-9596 or send e-mail to agsente@pipeline.com.

Children:

Band-Aides and Blackboards: Joan Fleitas, a nurse and nursing professor at Fairfield University in Connecticut, has constructed a website about kids growing up with medical problems. Its goal is to help people understand what it's like, from the perspective of the children and teens who are doing just that. Joan is passionate about her website "that highlights the narratives of children with serious medical problems. It is a peek into the world as they experience it and is designed to sensitize others to the pictures that they paint through their words." See http://www.faculty.fairfield.edu/fleitas/contents.html

Insurance Information:

"Protecting Your Health Insurance Coverage" is a 45 page booklet outlining five key steps that consumers can take to understand their Federal health coverage protections under HIPAA, produced by The Private Health Insurance Group (PHIG) at The U.S. Health Care Financing Administration (HCFA). You may order single hard copies by calling 1-800-633-4227. For 2-100 hard copies, fax your request to 1-410-786-4786, or download the booklet by clicking on "Publications" on the home page at http://hipaa.hcfa.gov

HIPAA OnLine responds directly to individual concerns about health coverage under the U.S. Health Insurance Portability and Accountability Act of 1996 (HIPAA), answering questions about: pre-existing conditions, special enrollment, certificates of creditable

coverage, or how to cope with the denial or loss of health coverage, a welcome new tool has arrived. A confidential, free, easy-to-use, 24-hour-a-day, Internet-based tool, HIPAA OnLine helps answer consumer questions rapidly and accurately on the Federal health coverage protections provided by HIPAA, and how their health coverage is affected by life events such as: job changes, marriage, divorce, birth, adoption or death. The website works by guiding users through a series of questions that often lead to local resources for more information. HIPAA OnLine is on the Internet, at http://hipaa.hcfa.gov by clicking on the HIPAA OnLine logo. It is also available on CD. To request a CD, click on the Help icon on the HIPAA OnLine Web page or send an e-mail to hipaacd@saic.com (quantities are limited).

Ask the Experts

Question: I have some elective abdominal surgery coming up, and the anesthesiologist is recommending an epidural. Doesn't that involve sticking a needle into my spinal cord? Should I be concerned about possible VHL tumors in the way? -- *Tania D., Ottawa, Canada*

Answer: With epidural anesthesia the catheter is entirely outside the dura (the strong, fibrous covering of the spinal cord) and outside the cerebrospinal fluid (CSF) that is contained by the dura. However, occasionally during placement of the catheter for epidural anesthesia the needle enters the dura and the CSF space. It would be quite a rare occurrence for it to go deep enough to reach the spinal cord or a tumor in the spinal cord. Therefore epidural anesthesia is not contraindicated in patients with VHL, it just needs to be selected and planned with knowledge of the current state of the central nervous system involvement with VHL. That is also so for any major surgical procedure. In addition to the potential spinal involvement with large hemangioblastomas, the cerebellar tumors can cause pressure-related changes that can be abruptly exacerbated by withdrawing CSF from the spinal area. -- *Edward H. Oldfield, M.D., Chief, Surgery Branch, National Institute of Neurological Disorders and Stroke, Bethesda, Maryland*

Question: My partner often mentions the significance of hiccups as an indication of VHL. Her MRI's and CAT scans have all been negative, but she does hiccup more than the average person. I don't think I hiccup more than 2 or 3 times a year, but she does pretty regularly. It makes me very nervous. Are hiccups really an indication of VHL problems? -- *Concerned, New York*

Answer #1: This might be something that relatives talked about in her family. Brain tumors can sometimes occur near the hiccup center in the brain and can cause hiccups. There is one family in particular that swears that increased hiccupping is their first sign of a brain tumor. So if she has heard this in her family, it could be contributing to her anxiety.

However there are lots of things (including anxiety) that can set off hiccups. One swallow of a carbonated beverage will do it for me. I know that as a young woman I got hiccups quite regularly and very intensely. I still get them intensely, but less often and I have learned ways to control them. I do not have VHL, it's just the way I am.

So ***can*** hiccups be related to VHL? -- *Yes.* Are they a sure sign of VHL? -- *No.*

If her scans are clear, then they are most likely garden-variety hiccups.

Things that work for me:

1) Hold your breath and take 10 sips of water swallowing each one in turn before you take another breath. It's the sip-swallow action and buildup of carbon dioxide that helps.

2) Swallow a whole teaspoonful of sugar, all grainy, without chewing it. -- really!

3) At the first sign of hiccups, gently press against your breastbone. Find the spot that gives you the most relief, and press as firmly as required. With this method I can usually stop them before they get established, so this is my preferred method. My spot is low, right between my breasts.

I am also forwarding your question to Dr. Oldfield for an expert medical reply.

-- *Joyce Wilcox Graff, Editor, VHL Family Forum*

Answer #2: We have cared for a couple of patients at the NIH in whom hiccoughs were the initial sign of a brainstem hemangioblastoma. From our studies it is clear that there is a particular site in the brainstem from which almost all brainstem hemangioblastomas arise and that site is in an area posteriorly just below the fourth ventricle in an area known as the "area postrema". Involvement of that region can be associated with hiccoughs. Therefore, if the hiccoughs clearly persist much longer than one might expect they normally should, it might be a good idea to get an MRI scan.

We should keep in mind that this has occurred in only a couple of patients among several hundred VHL patients that we have evaluated, indicating that everyday hiccoughs are the most likely explanation in most persons with VHL, just as in persons without VHL.

-- *Edward H. Oldfield, M.D., Chief, Surgery Branch, NINDS, Bethesda, Maryland*

The Truth About Public Speaking

by Jay Platt, Georgia

So you read last edition's article on overcoming speaking anxiety, but still aren't sure you want be a public speaker. You can't imagine yourself getting up in front a large group and sharing with them your experiences with VHL.

What you may not realize, however, is that there is more to public speaking than standing up in front of a group and putting on a lecture. As a matter of fact, in the words of Patricia Fripp, CSP, CPAE, one of the top professional speakers in the world, outside your home, *all* speaking is public speaking.

This is an important point because most of the time our opportunity to make an impact, or at least a strong first impression, doesn't come on stage in front of hundreds, but rather one on one.

While there are many variables involved, I'd like to narrow the process down to the least you need to know.

What do you say when someone ask you "the" question, "What is VHL?" Once you've been asked, it's too late to prepare your answer. That's why I believe it's vitally important that you have a script already rehearsed that you immediately follow when asked. That's right a script. Like an actor. Or politician.

Let's look at some possible answers. I'm not suggesting that these are the only ways to answer the following questions. Rather, they are ideas to stimulate your own answers. The key thing is to be prepared so you're not caught off guard, and can only reply with "Well, you know… Ah, Uhm, it's like, well…"

Example One: Questioner - "So, what is VHL?"

Your response - "VHL is short for von Hippel-Lindau syndrome. It's an underdiagnosed, hereditary condition which causes a variety of knot-like tumors to grow in various organs of the body. It was named after the two European doctors who first described it about a hundred years ago. Dr. von Hippel first discovered tumors in the eyes (specifically the retina), and later Dr. Lindau discovered these same people frequently also had tumor growth in other vital areas such as the Central Nervous System, the brain, the kidneys, pancreas, and the adrenal glands. The kidney and pancreas tumors can be malignant. Does that answer your question?"

Example Two: Questioner - "What is the VHL Family Alliance?"

Your response - "The VHL Family Alliance is a non-profit group dedicated to the diagnosis, treatment, and quality of life for those of those individuals and families affected by von Hippel-Lindau disease, or VHL for short. VHL is an underdiagnosed, hereditary condition which causes a variety of knot-like tumors to grow in various organs of the body. It was named after the two European doctors who first described it about a hundred years ago. Dr. von Hippel first discovered tumors in the eyes (specifically the retina), and later Dr. Lindau discovered these same people frequently also had tumor growth in other vital areas such as the Central Nervous System, the brain, the kidneys, pancreas, and the adrenal glands. The kidney and pancreas tumors can be malignant. Does that answer your question?"

Maria Shipton speaking on the steps of the Pennsylvania State House in Harrisburg during Jay's hike.

Example Three: Questioner - You've got von what?

Your response - "Ha, Ha! That's a very common response. <smile> Now you know why we use the initials! Von Hippel-Lindau syndrome, or VHL for short, is an underdiagnosed, hereditary condition which causes a variety of knot-like tumors to grow in various organs of the body. It was named after the two European doctors who first described it about a hundred years ago. Dr. von Hippel first discovered tumors in the eyes (specifically the retina), and later Dr. Lindau discovered these same people frequently also had tumor growth in other vital areas such as the Central Nervous System, the brain, the kidneys, pancreas, and the adrenal glands. The kidney and pancreas tumors can be malignant. Does that answer your question?"

So, there you have it. A few ideas to get you thinking. Word it your own way if you'd like, but please remember this. In the words of the television show Candid Camera, "When you least expect it, someone may come up to you and say "Tell me about VHL."

Jay Platt is Director of Public Education of the VHL Family Alliance. He can be reached at Jay@jayplatt.com. Jay was interviewed on CNN television Sunday, June 3, in connection with National Cancer Survivors Day. He is the author of *A Time to Walk* (see page 15).

Alabama Meeting

by Peggy Marshall, Mississippi

Our first meeting in Alabama was held at the University of Alabama Birmingham Medical Center. We had 12 attending and for some it was the first time to meet another person with VHL face to face.

It seems to surprise some people to see VHL affected individuals able to talk, walk and laugh. Jay Platt spoke and he certainly has a knack for making people smile.

The good news from this meeting is that we will be announcing very soon a new Chapter Chair for the Alabama Chapter.

Don and Peggy M. (Mississippi), Joseph C., and Liza P. (Alabama) in Birmingham.

The most important thing we do, the greatest gift we can give, is to let each other know that we are not alone.

Can you help in your own local community?

Please call or write to volunteer.
In the U.S.: Kathy Braden, Chapters Committee, (317) 894-3909, info@vhl.org
In other countries: Your country chairperson (if any), or Joyce Graff, +1 (617) 277-5667 or info@vhl.org

Jay Platt speaking to the group in Alabama.

This issue is dedicated to Bruce Reifman and Pat Henson, who passed away recently. Their lives are celebrated here by their family and friends, who will miss them very much.

Thank you for contributions from...

Anonymous, New Mexico
Lynn C. Andrews
Mary & Melvin Bennett
Sally Boss
Jean Marie Buscemi
Lori Davids
Mary Gwynne Dougherty
Lois Erickson
David & Shannon Forsell
Gartner Group, Stamford, Connecticut
Helen Geier
Curtis & Jackie Hallman
Dale Harrington
Harwick Chemical Manufacturing, Solon, OH
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Christine & Jerome Martin
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Poly One Corp, Cleveland, OH
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Aaron Riggs
Linda Robinson

Continued from page 14

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Bill & Judy Scheitler
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Jeanne Spence
Gladys Stevens
Joanna & Nick Terry
G. E. Thompson
Leslie & Bruce Trela
Jean Tygum
Dr. Eric von Hippel
Tim & Heidi Walter & family
Lisa & Michael Whitten
Beverly Yoder

In Honor of . . .

Sophie & Scott Borg, by Scott & Amy Borg
Sharry Brydon's birthday, by Mary Francis Duval
Susan Burgoon, by Barbara J. Smith
Damon Graff, by Joyce Graff
Chris Hendrickx, by Joyce Graff
Karen Johnson, by Helen Higgins, Mary Shefferly
Lisa Judelson, by Margorie & William Lancaster
Jane Ellen Kelting, by Emma Streed
Becky & Jean Lima, by Tony & Darva Berkompas, Jo Wheeler
Jean Lima, by Carol Doyle
Roy Marshall, by Tim & Martha Calnen
Tammy Nash, by Noble & Sandra Williams
Kathleen Neimann's birthday, by Julie Doyle
Korrina Sanchez, by BMS Management, Houston, TX; Kelly Cherry
Mary Kay Schimming, by Roby Beyler, Rosa Coffey, Laura Etter, Katherine & Robert Geier, David Gragg, D'Ann Hocking, Mary Kilton, Mary Lokken, Timothy McCauley, John & Marcia Minter, Mary Quinlan, Dale Rohde, Susan Ryan, Eldon & Joan Schimming
Sheila Tepper, by Betty Freeman
June & Harry Wilcox's 60th Wedding Anniversary, by Joyce & Damon Graff

In Memory of . . .

Rondo Anderson, by William & Marie Morillon
Dorine Bender, Barbara's mother, by Barbara & Richard Coughlin
Stella Carver, by Laverne Dittmer, Vicky & Stanley Palmer
Dixie, by Elsa Logan
Patty Feldman, by Elaine Mott
Gary Gleaves, by Ann Giffin
Bruce Gokey, by Todd Gokey
Frank Warren Graff, by Joyce & Damon Graff
Charles M. Hall, Sr., by Tondra & Michael Bolinger, Betty Lewis
Patricia S. Henson, by John Adamson, Janet Bryck, Ruth Chandler, Florence Eckert, Robin & Voss Graham, Janice Hemerle, Betty Henterly, Roger Hoover; Joe Johnson, Collierville, TN; Joseph Johnson, Bartlett, TN; Elizabeth Kakos; Jacob Kopp, Jackie Smith, Mary Spragins, Sidney Spragins
Jean Herrick, by Connie & Ian Bennett, Shirley & Ben Ruttan, Shirley Ruttan
Sam Hooker, by Virginia Hufford
Juliet Yuen Hsia, by Ted Hsia
Jane Jurgens, by Alan Cerf, Dawn & Doug Cerf; Southwest Research, San Antonio, Texas
Marjorie P. Martin, by Harold E. Martin
Florence Moszynski, by Maria Shipton
Jay Nichols, by Donna Nichols
Bruce Reifman, by Artie's Corner, Baldwin, NY; Board of Trustees of the Baldwin Public Library, NY; Martin Berg, Charles Smith Jewish Day School, Diane Charness; Chess Financial, Pepper Pike, OH; Susan Cole, Eric Cooper, Selma Daniels, Martha Dumonthier, Milton Engel, Carol Feder, Laura Fenves, Mariann Gorman, Dorothy Haughey, Frances Illowsky; Jaynesway Farms, Bartlett, IL; Dr. & Mrs. Jack Landau; Mark Laufman; Camille Lemongello, Tila Luschin, Terrence Messerman, Nancy Powell, Gary Resnick, patricia Ronston, Andrew Ruskin, Roberta Sears, Alvin Siegal, Rhoda Silver; Society of St. Vincent de Paul; Vinson & Elkins, attorneys, Washington, DC; Mary Particia von Stein, L. Constance Wallin
Denise Rouleau, by James & Sheila Lunny

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CONFERENCE REGISTRATION

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❑ Health Care Professional (physicians nurse, social worker, etc.)
Occupation, or medical specialty: _____ _____
All members receive the VHL Family Forum. Check here ❑ if audio version is needed

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Membership:

❑ New member ❑ Renewal (Dues $25 per household, $35 per professional) $ _____
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Donation:

Tax deductible donation of . . . *(amount)* $ _____
❑ In Honor of _____
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❑ Please send a card to: _____
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Registration for Annual Meeting:

❑ #___people at $159 per person $ _____
includes dinner Friday night, breakfast & lunch Saturday, breakfast Sunday, handouts
Names for badges: _____
CME certificate needed (doctors, nurses, genetic counselors): add $25 $ _____
All attendees must make their own hotel reservations
Space at the Sheraton is now at a premium; ask your travel agent for a nearby hotel.

Purchase merchandise: (proceeds help the VHLFA!)

❑ #___Copies of *A Time to Walk* by Jay Platt @ $15 each $ _____
❑ #___Copies of *How Are You?* by Patricia Foote @ $17 each $ _____
❑ #___Copies of *Sacred Process* by Karen Koenig @ $15 each $ _____
❑ #___Copies of the *VHL Video* @ $20 each, (specify __ US or __PAL format) $ _____
❑ #___VHL Teamwork Pin in ❑ silver ($17 each) or ❑ gold filled ($27 each) $ _____
❑ #___Copies of Pierre Jacomet's CD of Bach's Goldberg Variations @ $12 each $ _____
❑ #___Millennium Tee Shirt @ $15 each (Sizes: XL, XXL) $ _____
❑ #___Caring Tee Shirt @ $12 each (Sizes: M, L, XL, XXL) $ _____
❑ #___VHL Lap Blanket @ $40 each (brown & tan) $ _____

Payment Method:

❑ Enclosed check, payable to the VHL Family Alliance ***TOTAL:*** $ _____
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Signature _____

Send this form to VHL Family Alliance, 171 Clinton Road, Brookline, MA 02445 USA

Canadians, please send donations to Canadian VHL Family Alliance,
709 River Road, P.O. Box 68, Braeside, Ontario, K0A 1G0 Canada

Meet us in Palo Alto!

Eighth International Patient/Provider Conference on VHL

The meeting date is upon us. There are 123 people pre-registered, and we need ***you*** to make the experience complete! This year's annual meeting promises to be an outstanding educational experience for all, Special events are planned for Chapter Leaders, Beginners, and Physicians. Families are encouraged to invite their own health care professionals to attend this course, for which they can obtain continuing medical education credits from Stanford.

For Health Care Professionals: As we identify genes that predispose individuals to cancer, how can we use that information to improve medical outcomes? And how are families and individuals to live with this foreshadowing of their future? This course examines advances in diagnosis and management of von Hippel-Lindau, one of the most common but least understood of the familial cancers. For the past seven years we have held patient/provider conferences in the U.S. and Europe.

For Families: This is your chance to meet other people affected by VHL, and get lots of loving support from people who know exactly what you're going through. Come collect your share of hugs, as well as lots of current information on managing your health. The presenters have been asked to keep the language appropriate for a well-informed lay audience, so it should be just right for you!

For Beginners: Friday morning will begin with the course "VHL 101". This session will introduce the concepts and language that will be used in the conference, and is especially recommended for anyone who has not previously attended a VHL meeting. It's also a great place to get to know the other family members attending the meeting. In Minnesota, the class got rave reviews.

For Chapter Leaders: Chapter Chairpeople, Contact people, or those interested in taking a leadership role in their local areas are welcome at Peggy Marshall's meeting for Chapter Leaders, Friday morning.

Register online at http://www.vhl.org/conf2001 or by calling 617-277-5667.

Meet us in Palo Alto!

The Eighth Annual Conference on von Hippel-Lindau Disease
22-24 June, 2001

Fairchild Auditorium, Stanford University
Palo Alto, California

VHL 101, June 22, 9 AM
Chapter Leaders Meeting June 22, 9 AM

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