



VHL Family Forum



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A Test for Genetic Privacy

Concerns voiced over firms' ability to access, abuse employees' data
by Jerry Ackerman, The Boston Globe, Sunday, February 25, 2001

Track maintenance worker Gary Avary had already undergone the surgery prescribed for his wrist pain and was back at work when his employer, the Burlington Northern Santa Fe railroad, ordered him to get a blood test.

The railroad said the test was to see if he had genetic deficiency -- one that might show his problem, carpal tunnel syndrome, was hereditary.

Trouble was, Avary claims he didn't know this until later.

And the fuss that followed his discovery has stirred up fresh concern that, along with its promises of better health, the fast-moving world of genetic research has potential for abuse in the workplace.

Reports have been rare of individual rights being violated by unauthorized use of personal genetic data. Following a flurry of worry in the 1980s sparked by a growing understanding of what genetic research could reveal, 37 U.S. states, including Massachusetts, now restrict or bar using such information in employment or insurance decisions.

But now the issue is a federal matter. Alarmed by the union representing Avary and other track workers, the US Equal Employment Opportunity Commission (EEOC) went to court in mid-February 2001 to file its first ever genetic-testing antidiscrimination lawsuit against the Burlington Northern Santa Fe Railway.

"As science and technology advance, we must be vigilant and ensure that these new developments are not used in a manner that violates workers' rights," EEOC chairwoman Ida Castro said in a statement.

The EEOC action came as the federally sponsored Human Genome Project and a parallel private sector effort announced a milestone in genetic research -- the mapping of all the 30,000 genes in the human body.

That data set the stage for research into the causes and effects of many maladies that are not now well-understood.

Judy Malone, an employment law specialist with the Boston law firm of Palmer & Dodge, thinks that as the genomic Pandora's Box opens further, employers will find it hard to resist the impulse to match individual genetic traits with job requirements.

"There are some [abilities] that probably do have a genetic component. An employer could make the argument that, 'It would be nice to know ...' There are a lot of things that would be nice to know, and there are laws against it," she said.

Andy Pickett, a lawyer at Jackson Lewis Schnitzler & Krupman in Boston and cochairman of the Boston Bar Association's labor and employment law section, added: "I think everyone is uncomfortable with the situation and the Orwellian images that it can conjure up."¹

The Burlington Northern Santa Fe railroad acknowledges that as many as 20 employees were asked to give blood samples for genetic analysis. It has since suspended the tests and agreed, under a temporary court order, not to use the data gained so far. The EEOC is continuing its investigation.

The union, the Brotherhood of Maintenance of Way Employees, also wants the railroad to explain how it

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planned to use the information. Railroad spokesman Richard Russack said some scientists think there may be a link between carpal tunnel syndrome and a specific chromosomal deficiency. He said the company health plan already covered medical costs to repair carpal tunnel damage. The genetic information was being sought to learn if some workers had a predisposition for such injuries.

But he added the railroad's medical staff hadn't decided what to do next before the court order came down. "I can't say what would have happened. We never got that far," he said.

The EEOC's action has put public officials and employers on alert.

Senate Democratic leader Tom Daschle leapt on the news to announce the filing of a bill, cosponsored by 150 House and Senate members, that would bar discrimination nationally in employment or insurance on the basis of genetic information.

Massachusetts became the latest state with such legislation when its law took effect in late November 2000. State Representative Jay Kaufman, the primary sponsor of the state's law, said it was prompted more by worry than actual abuses. "It didn't take much imagination to consider what might lie ahead," he said.

Dorca Gomez, chairman of the Massachusetts Commission Against Discrimination, which is charged under the new law with dealing with worker complaints, has been attending seminars sponsored by insurance organizations, law firms, and the Kennedy School of Government to learn more about the subject.

She said any complaints will be treated with caution.

"This is brand new territory," Gomez said. "There is a balance you have to strike between employers and employees."

Surprisingly, few court or public policy disputes over genetic privacy have been recorded in the 48 years since the double helix of DNA was first described publicly.

One dispute was over the US military's refusal until after 1980 to let African-Americans train as pilots if genetic tests showed a trait for sickle-cell anemia. The ban ended only after a class action suit delivered evidence that debunked the government's claim that pilots with this trait were likely to pass out when deprived of oxygen -- a possibility at high altitudes.

In 1999, a federal Appeals Court in California ruled that Lawrence Livermore Laboratory, a national research facility, violated the civil rights of thousands of female employees by conducting tests for syphilis, pregnancy, and the sickle-cell trait, without proper disclosure.

In a survey released last October, the American Management Association said just seven out of 2,100

employers reported doing genetic testing with the consent of employees. About 350, however, said they conduct tests related to workplace hazards, which can include genetic tests.

Dorothy Wertz, a social science researcher at the University of Massachusetts Medical School's Shriver Center in Waltham, says surveys she has conducted also suggest relatively few violations of genetic privacy connected with employment.

About 3 percent of 476 patients at 15 genetics clinics surveyed in 1995 reported being refused employment or insurance because of an inherited disease or disability, she said.

Follow-up inquiries, however, found some of those refusals were clearly job-related, Wertz said, including one person turned down for a firefighter job because of chronic bronchitis and another denied an editing job because she had cataracts.

"If someone can't do the job, the employer is justified in letting them go," Wertz said.

But Dr. Paul Billings, a founder of GeneSage, Inc., a San Francisco genetics services company, thinks the cases that do make news, such as the Burlington Northern Santa Fe railroad's, represent only the tip of a larger problem.

"No employer would admit doing such things," Billings said, "but the fact that we can detect any of it means that it is, in fact, going on."

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1. A reference to the "utopian" society described in George Orwell's *1984* (London, 1949), in which people are bred to have the level of intelligence appropriate to the tasks society needs them to perform, from leaders to street-sweepers.

For additional information on this important topic, see Mark A. Hall and Stephen S. Rich, "Laws Restricting Health Insurers' Use of Genetic Information: Impact on Genetic Discrimination." *American Journal of Human Genetics*, 66:293-307, 2000.

What legislation has been passed in your state?

Go to <http://www.nhgri.nih.gov>

Click on Public & Policy Affairs; then click on Policy & Legislature activities.

This listing includes legislation regarding employment and health insurance discrimination.

Please report any suspected incidents to:

Emily Soper, Program Support Coordinator
Genetic Alliance

4301 Connecticut Avenue, NW, Suite 404
Washington, DC 20008-2304

esoper@geneticalliance.org

Tel: 202.966.5557 ext. 200

Fax: 202.966.8533

Helpline only: 800.336.GENE

<http://www.geneticalliance.org>

A Pilot Study

of Genetic Privacy, Discrimination and Informed Decision Making

The purpose of this study is to identify and document incidents of genetic discrimination and privacy abuse. For the purposes of this questionnaire, we define genetic discrimination as being treated or favored differently based on the results of a genetic test, diagnosis of a genetic condition or family history information.

Have you or a family member:

Been diagnosed with a genetic condition? For the purposes of this study, a *genetic condition* is a current condition or future health concern that is passed down through a family member or caused by a change in a gene or chromosome. It can be discovered through genetic testing, by having symptoms of a condition that another family member has been diagnosed with, or being a carrier of a condition. A pre-symptomatic condition is a genetic condition that does not show now but may develop later.

Been identified with a genetic predisposition? A *predisposition* is the potential to develop a certain inheritable disease or condition.

Been informed about the risks and benefits of genetic testing which may lead to being identified with a genetic condition or predisposition? This forms the core of informed decision making.

Had problems in obtaining employment or being promoted due to a genetic condition or predisposition?

Had problems obtaining health, disability and/or life insurance, or had rates and/or scope of coverage varied because of a genetic condition or predisposition?

If you answered yes to one or more of the above questions, we would like you to complete the Genetic Discrimination Questionnaire and return it to us. The questionnaire can be found under "Privacy and Discrimination Pilot Study" on the Genetic Alliance website, or paper copies can be obtained by telephoning the Genetic Alliance at +1 (202) 966-5557.

Please Help

The questionnaire is available at <http://www.geneticalliance.org> or by calling Vicky Whitemore, PhD, Associate Director, Partnership for Genetics Services Pilot Program The Genetic Alliance +1 (202) 966-5557 x204

Looking for Lawyers

in All the Right Places

by Thomas D. Rodenberg, esq., VHLFA Director, Blue Springs, Missouri

It's a very common question: "Where can I find a lawyer to help me with a claim against my insurance company?"

Unfortunately, it is a question that may not have an easy answer. Most attorneys would expect to be paid by the hour to help you with a claim against your insurance company. Attorneys' hourly rates vary greatly. You could expect to pay from \$100 to \$300 per hour for an attorney. Many people will not be able to pay for services at those rates. They will need to find a lawyer who will help them at a reduced hourly rate or even for no charge, called "*pro bono*" services.

Where can you look for such a lawyer? The best place to look for such a lawyer is through your state or local bar associations. Every state has a state bar association and most counties and major cities have local bar associations. These associations are a great source for referrals to reduced rate or even *pro bono* attorneys. To find out how to contact these associations, the simplest way would be to call a local lawyer's office and ask for the telephone number of the state bar association and any local bar association. Then, call that association and let them know you are looking for an attorney to assist you for a reduced fee or on a *pro bono* basis. The association will be able to quickly direct you to the right person or let you know that no such services are available.

Another great way to look for lawyers through a bar association is on the Internet. Just type in "[your state name] bar association" in any search engine. For example, I typed in "Colorado Bar Association" under Yahoo¹. The search listed the home page for that association. The home page had a section called "In the Public Interest". Under that section, it listed "Legal Clinics" which usually involve speaking with lawyers at reduced fees or for no fees; a section titled "Free or Low-Fee Legal Assistance" which provided telephone numbers; and a section titled "Free or Low Cost Referrals" with numbers to call for referrals to such attorneys. You will find these associations to be a very good resource when looking for a lawyer.

The other key to looking for lawyers in all the right places -- *persistence*. It may take a few or even quite a few calls to find such an attorney.

Remember that attorneys have to make a living and providing reduced fee or *pro bono* services work against making a living. Just keep calling, and hopefully our legal system will find a way to provide you with needed services.

1. With a web browser, go to <http://www.yahoo.com>

Uncharted territory?

By Pierre Jacomet, Chile

The experiences in my own family with pheochromocytomas have led me to some conclusions that are only hinted at in the literature, but which I feel it is important for families and physicians to hear. We have all read the warnings in the *VHL Handbook* and in previous articles in the *VHL Family Forum* about the potential dangers of untreated pheos, and the need for testing. In families that are aware that they are at risk for pheos, and who are careful about screening, the worst repercussions of pheos will likely never occur. But there are family members who are "hiding out" from VHL, who do not want to get tested, or who may be unaware that they are at risk for VHL. It is for them that I am writing.

Of the 16 people in my family who have had pheos, only three have been diagnosed in time to prevent their deaths. The rest were diagnosed after their deaths, during the autopsy. They were not diagnosed because their symptoms were misunderstood. I did not understand how this could happen until I learned a great deal more about pheos. Let me explain.

Pheochromocytomas¹ (pheos for short) are relatively rare, usually benign tumors. Most arise from the adrenal medulla (90%) and the organs of Zuckerkandl (8%). They occur rarely in extra-adrenal sites (outside the adrenal glands) in the abdomen, chest (less than 2%) and neck (less than 0.1%). A number of pheos in or around the heart have been reported; these are usually located in the left atrial region. In the general population, pheos occur at all ages with a peak of incidence in the third and fourth decades. In adults, the tumor occurs with equal frequency in both sexes, whereas 60% of the affected children are male. Multiple tumors (adrenal and extra-adrenal) are more common in children (35% of the cases) than in adults (8%). Approximately 10% are familial and more than 70% are bilateral. Less than 10% are malignant. These are more often outside the adrenal glands and actively secreting a hormone called dopamine.

Pheos are not exclusively associated with VHL. Some otherwise healthy family groups may present with them as an isolated occurrence. Other families present with them in association with Multiple Endocrine Neoplasia (MEN types II and III), and von Recklinghausen disease (Neurofibromatosis). But a number of VHL families do develop pheos, adrenal or extra-adrenal. Most pheos secrete a number of hormones: epinephrine, norepinephrine, dopamine, VMA (vanilylmandelic acid), and metanephrines. Rarely they have been found to contain other hormones.² The diverse symptoms produced by release of these drugs can *confuse the diagnosis*.

It is a known fact that no disease entity can cause more diverse manifestations than pheo. Some of these manifestations are associated with an increase in catecholamine levels. Exclusion of most of these conditions can be done by combining clinical and biochemical tests. The addition of plasma metanephrine assay gives us one more tool, but it is

“Based on the experience in our family ... patients with pheochromocytomas can present symptoms akin to neurotic or psychotic states.”

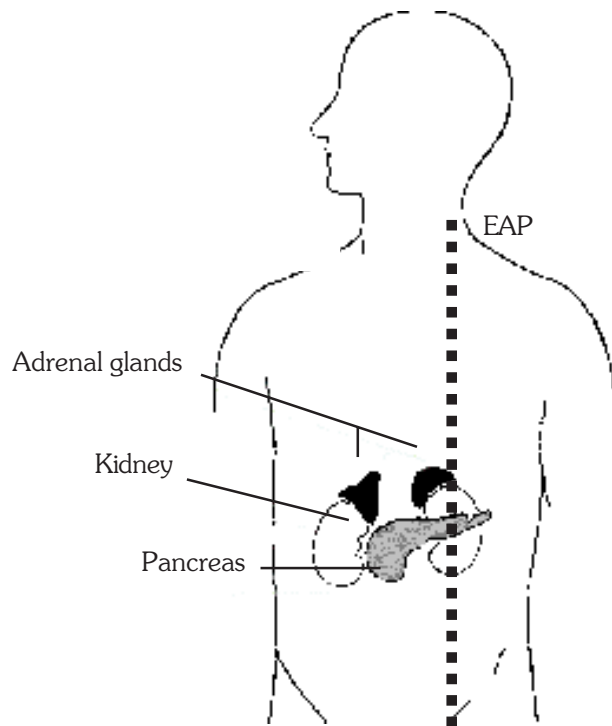
still a complex process of confirming the existence of the pheo and then locating where it is hiding in the body. CT and MIBG can be used to locate the pheo.

As there is *no prevention* for pheo, all patients with severe or episodic high blood pressure and associated symptoms should be screened, especially if they do not respond to treatment. Other indications for screening include:

- All hypertensive children
- All individuals with VHL, MEN II, or MEN III and their first-degree relatives even if they have normal blood pressure and no particularly suspicious symptoms. Cases of low blood pressure and pheos have been reported in our family. It is especially important to test people with VHL prior to any surgery, or before or during pregnancy, or before labor and delivery.
- Individuals having episodes of high blood pressure during labor, exercise, anesthesia or radiological procedures.

Medical texts and articles stress the need to distinguish pheo symptoms from those of other conditions, a process called differential diagnosis. Among others, the following conditions can present similar symptoms. Pheochromocytomas might be misdiagnosed as any of these conditions:

1. Anxiety, tension states, psychoneurosis, psychosis, or *erectile dysfunction in males*
2. Hypoglycemia
3. Menopause
4. Vasodilating headaches, ophthalmic migraines and cluster headaches
5. *Suspected drug abuse*: amphetamines, cocaine, LSD, phenylpropanolamine, caffeine
6. *Known drug effects*: interaction of monoamine oxidase inhibitors with certain food and beverages (beer, wine, cheese), clonidine withdrawal symptoms, atropine administration, nasal decongestants, tricyclic antidepressants⁴
7. *Lesions of the nervous system*: trauma, tumor, stroke, focal arterial insufficiency, autonomic hyperreflexia, diencephalic seizure and syndrome



The vertical dotted line marked EAP shows where extra-adrenal pheos may lie, along a line from the groin to the neck on either the right or left side of the body.

8. *Dysfunctions of the central and peripheral nervous system:* cardiogenic hypertensive reflex in angina pectoris; exaggerated response to hypovolemia or infection, paroxysmal tachycardia, familial dysautonomia.

In our family, all too often the pheo presented psychotic symptoms. The patient was then sent to a psychiatrist or psychoanalyst and treated with no success, the cause of his or her condition being physical. This is dangerous and sometimes fatal, as pheos can be highly lethal tumors.

In order for a person to evolve through life it requires a certain stability, a sense of self. Pheos, with their abundant secretion of unexpected drugs, *alter the balance*. In so doing, they alter mental functions, producing attacks of panic, anguish, anxiety, rage, and sometimes, erectile dysfunction in males.

In our family group, pheos have been responsible for a number of deaths at ages that vary from 14 to 54. Most of them happened in males aged 30. They invariably presented the same symptoms: anxiety, anguish, rage, drug use, alcoholism, poor decision making capabilities and extended periods of sexual impotence. All were treated unsuccessfully with psychotherapeutic methods before dying. Their pheos were detected *post mortem*. This state of affairs is serious because it neglects a physical, organic cause of

a supposed neurosis. In our family group only three pheos have been detected and removed. The patients, although labeled neurotics prior to surgery, after a period of adjustment were able to lead normal lives. Two of them were alcoholics before surgery. Pheo removal *ended* the alcohol abuse without need of special therapies for that particular symptom.

Based on my experience, I feel that there can be a *direct relationship* between pheos and psychiatric conditions. This is not to say that all psychiatric patients have pheos, nor that all people with pheos display psychotic behaviors. Rather, I suggest that patients with pheos can present symptoms akin to neurotic or psychotic states. This may sound exaggerated. But we all know that drugs we take (alcohol, cocaine, and so forth) do alter consciousness. Why should it be different with chemicals produced in error by our own bodies?

This seems to be uncharted territory. Because there often is not a great deal of communication between a patient's physicians and psychologists, the relationship may go undetected. In my opinion, this state of affairs is dangerous. VHL families need to be vigilant and remember to test for pheos when any of these misleading symptoms appear in the family.

1. See: Denise A. Morris and James R. Sowers, "Pheochromocytoma: An Update" in *Manual of Endocrinology and Metabolism*, Norman Lavin, ed., Little Brown & Co. New York.
2. Hormones reported associated with pheos include vasoactive intestinal peptide, serotonin, ACTH, somatostatin, opioid peptides, alpha-MSH, calcitonin (particularly in MEN II and III), parathyroid-like hormone, and neuropeptide Y (a potent vasoconstrictor).
3. Bahemuka, M. "Correspondence: Pheochromocytoma with schizophreniform psychosis." *British Journal of Psychiatry* 142(1983)422-429.
4. "Tricyclic antidepressants (which block neuronal uptake of norepinephrine) represent another drug category with effects that can either mimic pheochromocytoma or can provoke an attack in patients with a pheo -- in addition these drugs complicate differential diagnosis since in addition to blood pressure disturbances they can cause false-positive biochemical test results. They are more commonly used than MAO inhibitors. In particular, there are a lot of VHL patients who are on these drugs." -- Graeme Eisenhofer, Ph.D., NIH.

References:

- Manger & Gifford, "Pheochromocytoma", Blackwell-Science, 1996
- Owen et al, "Increased dopamine-receptor sensitivity in schizophrenia" *Lancet* (1978) ii, 223-5
- Schildkraut, J.J. "The catecholamine hypothesis of affective disorders: a review of supporting evidence." *American Journal of Psychiatry*, 122(1965)509-22.

Studies at NCI seeking patients

There are two studies going on at the U.S. National Cancer Institute in Bethesda, Maryland. Patients may apply for enrollment in the study.

Genetic Study of Patients With Inherited Urologic Malignancies

Looking for participants who have VHL cysts and/or tumors in the kidney. Protocol ID: NCI-89-C-0086. The study will identify the particular genetic mutation in the patient, and correlate this genotype with the particular disease expression, presenting age, clinical manifestations, rate of tumor growth, and rate of recurrence.

This is not a treatment protocol, but is a study of the "natural history" of tumors, watching how they grow over time. People who enroll in this study would receive genetic counseling, a complete physical examination, and an expert opinion at the NCI at no charge to them other than their initial travel to and from the NCI. NCI will collect blood and tissue samples. Another benefit for patients is knowing they are contributing to fighting cancer that indeed may affect their future generations. If patients are accepted into the study, future travel to NCI are paid for by NCI, with follow-up visits every 3 months to 3 years, depending on the specific condition. The patient may incur some hotel charges beyond a daily stipend that is given to them. A total of 2,300 patients will be seen as part of this study.

Vaccine Therapy with Tumor Specific Mutated VHL Peptides in Adult Cancer Patients with Renal Cell Carcinoma

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.

For additional information or to apply for inclusion in either of these studies, please contact Deborah Pearson, Director of Outreach and Patient Recruitment, National Cancer Institute, Division of Clinical Sciences, Building 10, Room 12N214, Bethesda, Maryland 20892. Telephone: +1.301.435.7854; Pager: 1.888.516.3804; Fax: +1.301.594.7951; E-mail: pearsond@mail.nih.gov

Ask the Experts

Question: My doctor recently mentioned to me that I have a high red blood cell count, and that it might indicate tumor activity. I never heard of this. Is this true?" — *Concerned*

Answers:

(1) A high red blood cell (RBC) count is called Polycythemia. It may be indicative of a number of conditions. It is important that a Hematologist determines why the red cell count is high. Depending on the level, treatment may require phlebotomy* to decrease the "thickness" of the blood and allow it to flow normally to vital organs.

In VHL, the old literature speaks of elevated Erythropoietin (EPO) when hemangioblastomas are present or growing. I have seen just one patient with VHL who had high erythropoietin and increased RBCs that normalized after a symptomatic brain hemangioblastoma was removed. I have also seen an individual with VHL who gets periodic phlebotomies, and did not have significant hemangioblastomas. These are the only two I have seen within the many hundreds I've seen with VHL in the United States.

Although it is rare in VHL, when it occurs, it is real, and worth pursuing in case this is the presenting sign of VHL or increasing tumors in someone already known to have VHL.

— *Gladys M. Glenn, M.D., Ph.D., National Cancer Institute, Bethesda, Maryland*

*phlebotomy - taking off some blood, essentially donating a pint of blood.

(2) Polycythemia is defined by an hematocrit (i.e. volume of RBC) higher than 47% in women and 54% in men. In the medical literature, a secondary polycythemia occurs in about 20% of cerebellar hemangioblastomas but I only know thirty-seven VHL patients with a true polycythemia among 520 French patients with CNS hemangioblastoma (about 7% of cases). Polycythemia is normalized after surgical removal of the tumor and we now know that it is related to production of EPO by the hemangioblastoma. EPO, like VEGF, is regulated by pVHL, and the inactivation of the VHL gene is responsible for its overexpression by hemangioblastoma.

On a clinical point of view, the first VHL patient I met in 1990 had already been operated 3 times for cerebellar hemangioblastoma. Polycythemia responsible for breathlessness and facial blushing was the only sign of a new tumor requiring neurosurgery. It is well known that pheochromocytoma and renal cell carcinoma can also result in polycythemia, but I have seen that in only one VHL patient. Thus, it is important to know that occurrence of polycythemia in a VHL patient can be the first sign of growing cerebellar hemangioblastoma and to perform a CNS MRI in this situation.

-- *Stéphane Richard, M.D., Ph.D., French VHL Study Group, Paris*

Ask the Family

Question: In 1982, I developed a brain stem tumor that produced strange and severe dizziness when I turned my head too suddenly or tilted my head back too far. Never before or since have I had a tumor develop so quickly, causing such severe symptoms. Just as suddenly, in a matter of weeks, the symptoms stopped, and I have had no brain stem problems since. However, I am not sure what happened to the tumor--whether it disappeared, just became dormant, or something else. -- *Michael L., North Carolina*

Answers:

(1) I also had a brainstem tumor that caused strange and severe dizziness when I turned my head in certain positions or tilted my head back. The tumor has since been removed but I was initially misdiagnosed with "benign positional vertigo". That was definitely a problem because the correct diagnosis was delayed for almost two years, and in the meantime, that tumor kept growing and caused more trouble. In my opinion, anyone with VHL should always get an MRI whenever they have similar symptoms and should never be satisfied with "benign positional vertigo" as a cause for such symptoms. -- *R.K., California*

(2) I too was being treated for benign positional vertigo. Until I had a very bad fall one day (hit my head against the corner of the bedroom wall), and they decided to do some more tests. I had an MRA, where they found something that they thought might have been an aneurysm. Followed by an MRI only a week later, where they found the beginning of a tumor, later identified as VHL. This diagnosis was a great shock to me and my family, as this was unheard of in my family before. So I definitely would recommend an MRI being done to rule out anything else. -- *Barbara M., Australia*

Question: I have a problem lying flat. It makes my eyes roll and my stomach feels like I'm riding over the crest of a roll-coaster. This also happens if I put my head back when standing, like looking up at a plane or drinking from a can. Does anyone experience this and has anyone managed to work a way round it? I had brain surgery to remove some cysts 14 months ago and my neurologist told me that I might eventually stop having these symptoms but I should accept that this is now me. Advice please? Oh, apart from this I'm 95% recovered from my surgery, so we live to fight another day! Remember, life's too short and it costs nothing too smile! — *Cheers, Lee P., United Kingdom*

Note: Be sure to check any such symptoms first with your doctor, as Lee did, to make sure there is no problem that needs attention.

Answers:

(1) I also have the same problem in lying flat and tilting my head back to look up. So, I always use a

pillow and don't tilt my head up very much. It was the same for my father as well as a friend of mine who had neurosurgery (not VHL surgery) in the same area. It might improve in severity as the years go by, but you can learn to adjust to it. -- *R.K., California*

(2) My sister elevates her bed. That is the only way that she can stay in the bed, and she always has two pillows. She has equilibrium problems as well. I hope that your problems will ease for you. -- *God speed, Linda D., Alabama*

(3) I have found that if I clasp my hand around the back of my head, this helps to keep my head and neck steady, and I can look up at a bird or plane flying by with much less pain and dizziness. (Not for too long, though!) Hope that helps you both a bit. -- *Barbara M., Australia*

(4) This problem was most severe for me 23 years ago after my 1st brain operation. Even tilting my head back slightly caused a strange and almost unbearable dizziness. Now, after several more brain operations, it is much less severe. Often I can lie completely flat; if I get the dizzy feeling, it almost always passes after a few seconds. -- *Michael L., North Carolina*

Excerpts from our online discussion at vhlf@yahoogroups.com. Used with permission of the contributors.

Human Research Protections Course

A new continuing education program on the protection of human participants in research is now available online at <http://cme.nci.nih.gov>.

Developed by the National Cancer Institute (NCI) for the National Institutes of Health (NIH), the web-based course offers continuing medical education (CME) credit for physicians and contact hours for nurses and other members of research teams. The new program also responds to the mandate requiring education on human subjects protection for all investigators who apply for or receive NIH funds for research involving people.

Titled *Human Participant Protections Education for Research Teams*, the course incorporates interactive modules, case studies, and exercises. Topics covered include ethics, federal regulations, informed consent, and institutional review boards.

The program offers up to two hours of category 1 credit of the Physicians Recognition Award of the American Medical Association. Cine-Med., a continuing medical education provider, is accredited by the Accreditation Council for Continuing Medical Education (ACCME) to sponsor the credits. Application for nursing contact hours is in progress.

This announcement also appears on the NCI Web site at: <http://www.nci.nih.gov/aboutnci/index.html>.

Physical Activity and Immune Function

James S. Huddleston, M.S., P.T., Mind/Body Medical Institute, Beth Israel Deaconess Medical Center, Boston, Massachusetts. <http://www.mindbody.harvard.edu/>

Exercise and health go hand in hand. People who exercise on a regular basis, or who are physically active throughout the day, tend to get sick less often and live longer. There is a long list of health benefits associated with physical activity, everything from lowering high blood pressure, to losing extra weight, to improving sleep and mood, to maintaining function and independence as we age. And there is evidence that regular exercise might also positively affect immune function.

Renewed interest in the relationship between physical activity and immune function has grown out of the HIV epidemic. Several studies have demonstrated that persons with impaired immune systems can exercise safely without risk to their health, and in fact, can enhance their emotional well-being as well. In these studies, exercise also seemed to increase numbers of certain immune cells that help to bolster immune activity.

It appears that regular exercisers don't get sick as often as less active people. Evidence indicates that a J-curve relationship exists between the intensity of exercise and the risk of upper respiratory tract infection (URTI) (colds and flues). Moderate exercise (brisk walking) may decrease the risk of URTI below that of a sedentary person, but high-intensity exercise (running and/or training for marathons and ultra-marathons) may raise the risk above average.

Immune system changes that apparently are related to the intensity of exercise have been identified. Moderate endurance exercise, such as brisk walking, stimulates positive changes in the function and numbers of various immune system cells, such as natural killer cells (NK) one of the body's first lines of defenses against viruses. It is also associated with prolonged improvement in the killing capacity of neutrophils, one of the most efficient phagocytes (cells that kill foreign microorganisms and initiate the immune response). These changes may be related to the release of hormones such as endorphins and enkephalins that help to regulate immune function.

On the other hand, high intensity exercise may have a negative impact on immune function. Immune marker changes that suggest the increased risk for high intensity exercise include, lower measures of immunoglobulins (antibodies) like those found and measured in saliva, depressed NK cell activity and decreased neutrophil phagocytic activity. These negative effects may also be related to the release of stress related hormones such as cortisol and ACTH which have immunosuppressive characteristics.

High intensity exercise is also associated with muscle cell damage and inflammation. The immune system is involved with tissue repair. It is theorized that while the immune cells are busy with the repair process, host protection may suffer. There appears to be a window of opportunity for infection during recovery from high-intensity exercise. Consequently, rest, good nutrition and hydration are recommended

“ Moderate endurance exercise, such as brisk walking, stimulates positive changes in ... the body's first lines of defense ... On the other hand, high intensity exercise may have a negative impact on immune function. ”

after bouts of vigorous exercise to allow the body to recover, and moderate exercise may be the better choice for enhancing health and well-being.

Growing interest in complementary medicine and the self-help movement has also spurred interest in the benefits of exercise in cancer treatment. Epidemiological studies have reported a reduced incidence of cancer in physically active groups. The research suggests that physical activity has a protective affect against the risk of developing some cancers, most notably cancers of the colon, breast, prostate and reproductive system. NK cells and microphages (another phagocyte) are involved in the first line defense against the development and spread of tumors. Exercise seems to enhance the efficiency of both these cell types, helping the body fight against tumor growth. Current hormone and exercise research is providing hopeful insight into other possible biological markers and how physical activity may affect tumor development and regression.

People often ask if it's okay to exercise if you have a cold or are not feeling well. Here are some suggestions:

- If you have a cold, not feeling well from the neck up, it's okay to continue exercising. Just decrease the intensity, keep it comfortable and monitor how you feel during and after exercise.

- If the symptoms extend over your whole body (fever, muscle aches, excess fatigue), stop exercise until feeling better, and resume exercise slowly, allowing about 2 weeks for resumption of usual exercise level to avoid relapse or complications.

How much exercise is necessary to appreciate healthy benefits? Generally, moderate exercise,

including both aerobic and resistance training is recommended:

- Aerobic: 30-60 minutes, 3-5 times per week, brisk (comfortable but challenging)
- Resistance training: 1-2 sets of 8-12 repetitions, 8-10 different exercises, 2-3 times per week, moderate effort

However, if this seems like an impossible task, then simply consider increasing physical activity throughout the day. Although everything counts, and something is better than nothing, try to accumulate 30 minutes of brisk activity throughout the day, in at least 10 minute segments. That works out to 3-4 hours per week and can include activities such as housework, yard work,

gardening, play with your children, climbing stairs, and walking for errands.

It seems reasonable to assume that exercise and physical activity are essential components of a health promoting lifestyle, both for generally healthy individuals as well as people with chronic illness. It has both protective as well as bolstering affects on the immune system. Exercise increases specific immune system markers and biologically provides a protective effect on the body. We all know that exercise is good for us and research continues to show us some possible reasons why.

Remember: before you embark on any exercise program you should discuss it with your medical professionals.

Drink Water!

Water aids in a variety of health problems, yet we often forget to drink the recommended 6 to 8 eight-ounce glasses of water each day. Some beverages, such as those with caffeine and alcohol, are dehydrating, so if you drink them, you need even more water to compensate.

Your body is one-half to four-fifths water, depending on how much body fat you have. Water makes up nearly 85 percent of your brain, about 80 percent of your blood and about 70 percent of your lean muscle. (Because there are a lot of tissues that have less water, the average is about 50 percent.) The body relies on water for temperature regulation.

The carbohydrates and proteins that our bodies use as food are metabolized and transported by water in the bloodstream. No less important is the ability of water to transport waste material out of our bodies.

Lack of water is the #1 trigger of daytime fatigue. A mere 2% drop in body water can trigger fuzzy short-term memory, trouble with basic math, and difficulty focusing on the computer screen or on a printed page.

Besides helping your body run smoothly, there's some evidence that water helps prevent certain diseases. People who have had kidney stones can prevent further stones from forming by drinking lots of fluid. And in one study, women who drank more than five glasses of water a day had a risk of colon cancer that was 45 percent less than others in the study who drank two or fewer glasses a day. In another study published in the *New England Journal of Medicine*, men who drank at least six glasses of water per day cut their risk of bladder cancer in half compared with men who drank less than one glass, regardless of how much of other liquids they consumed.

Athletic performance can drop by as much as 20-30% if you lose as little as 4% of your body's water during exercise. Concentration and endurance begin to waver, muscle cramps set in prematurely and other dehydration-induced injuries may follow. Sports medicine experts recommend drinking 18 ounces of

water at least 1-1/2 hours before exercise, and then 6-12 ounces of water every 15 minutes to make up for water lost through perspiration.

Sports drinks are useful when consumed after or during vigorous and prolonged exercise in high heat. But most experts agree that water works better than carbohydrates or sugared beverages for moderate exercise. For instance, if you drink 12 ounces of plain water, your body will absorb 8 ounces of it within 15 minutes. If you drink 12 ounces of a 10% sugar solution, less than 1 ounce will be absorbed in the same period. The typical soft drink is a 10 to 12% sugar solution.

Water suppresses the appetite naturally and helps the body metabolize stored fat. Studies have shown that a decrease in water intake will cause fat deposits to increase, while an increase in water intake can actually reduce fat deposits. In 37% of Americans, the thirst mechanism is so weak that it is often mistaken for hunger. One glass of water shut down midnight hunger pangs for almost 100% of the dieters studied in a University of Washington study.

So Drink Water!

Most drinking water in the United States is safe to drink, but it's always a good idea to check with your local water authorities and with the U.S. Geologic Survey. The US Environmental Protection Agency has detected trichloroethylene in 25 states during the last 10 years. About 100,000 pounds of the chemical has been released into water and land from steel pipe and tube manufacturing industries in Georgia, Illinois, Massachusetts, Michigan, Pennsylvania, Texas and West Virginia between 1987 and 1993, allowing possible leaching into groundwater.

Note: Naturally anything your doctor tells you about special intake restrictions or dietary guidelines should take precedence over any general advice you read in any publication! If your doctor has set limitations for intake of liquids due to kidney insufficiency, be sure to follow that advice first.

Sources: Fiji Natural Artesian Water, The Bottled Water Store <http://bottledwaterstore.com/waterfacts.htm>, US Geologic Survey, <http://www.ga.usgs.gov/edu/>; U.S. Environmental Protection Agency, <http://www.epa.gov>, The Bottled Water Website <http://www.bottledwaterweb.com/>

Meet the Directors

Peggy Marshall of Corinth, Mississippi, is Chairman of the VHL Family Alliance, our Chief Operating Officer. Members of our Board of Directors are listed on page 14. Last June four members were elected or re-elected to the Board. Joyce Graff was re-elected to the Board after a one-year hiatus and is now serving as Chairman of the Board. Others elected to the Board in June 2000 were Tom Rodenberg, Jay Platt, and Sheila Tepper. We will be introducing them in this and subsequent newsletters.

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. Nominations are now open for additions to this group to be elected in June 2001. How about you? Please see page 16 for details.

Jay Platt

Jay Platt joined the Board in July of 2000 as the Director of Public Education and Spokesperson of the Alliance. Jay, a former Marine Corps Gunnery Sergeant, was medically retired in 1998 due to complications from VHL.

Following his retirement from the military, Jay went on to become one of fewer than 300 people to have hiked the entire 2,160 miles of the Appalachian Trail from Maine to Georgia. In doing so, he helped raise more than \$100,000 for the Alliance.

Jay is currently a professional speaker and writer. In addition to his many motivational speaking engagements, he has represented the Alliance at Conferences and Symposia, and at the National Cancer Survivors Day in Washington. He is the author of *A Time to Walk: Life Lessons Learned on the Appalachian Trail*. See the logs of his trail hike at <http://www.vhl.org/hike>, and his website at <http://www.jayplatt.com>.

Jay and his wife Paz live in Georgia.



Thomas D. Rodenberg

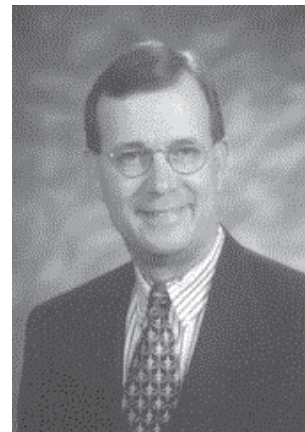
Thomas D. Rodenberg rejoined the VHL Board in 2000. He will serve as the chair of the insurance and legal committee. Tom is from Norborne, Missouri (pop. 848). He grew up on a farm in a family of 13 children. He has a diverse educational background. He received his bachelor's degree in religious studies (William Jewell College, Liberty, Missouri, 1979);

his master's degree in Semitic studies (Dallas Theological Seminary, Dallas, Texas, 1985); and a law degree (University of Missouri at Columbia, Missouri, 1989).

Since graduation from law school, he has practiced law in the areas of employment discrimination and civil rights, personal injury and general civil litigation. Because some of his siblings have VHL, he has been involved in many issues related to insurance coverage for persons with VHL. He has filed lawsuits on two separate occasions on behalf of persons affected with VHL seeking to recover money for insurance claims.

Tom currently practices law with the firm of Jeter Rains & Byrn, L.C., Blue Springs, Missouri. In addition to his legal practice, Tom serves as the Pastor-Teacher of Grace Community Church in Blue Springs. He was also recently elected to the Blue Springs Board of Education which serves 12,700 students with a budget of nearly \$90 million dollars.

Tom and his wife Kathy have four sons, James (12), Ben (10), Daniel (8) and Mark (7). Needless to say, Tom and his family lead very busy lives.



Chapter Leaders

Peggy Marshall will be holding a special meeting for Chapter Chairpersons, contact people, and others interested in being involved at the local level.

Friday morning, June 22, at the Sheraton Palo Alto, prior to the Conference. See page 12 for details.

Our most important work happens at the local level.

**Think Globally, Act Locally . . .
If not you, Who?
If not now, When?**

Pen-Friend age 13

Shanell is 13 years old and lives in Australia. She has recently learned she has VHL, and would like to correspond with another girl about her age who has VHL or another chronic illness. Interested pen-friends should write to info@vhl.org or by paper mail to 171 Clinton Road, Brookline, MA 02445.

Speaking Tips

by Jay Platt, VHLFA Director of Public Education

Quick. What fear ranks as number one in the minds of the majority of people? Some of the most common answers, in no particular order, are: snakes, spiders, heights, cancer, and death. But none of them is number one. The number one fear is (drum roll please): the fear of public speaking. That's right. Far above the fear of death and disease, comes the fear of standing in front of a crowd. Comedian Jerry Seinfeld says that this must mean that at a funeral most people would rather be the one in the casket, than the one giving the eulogy.

“

....the only thing we have to fear is fear itself... —FRANKLIN D. ROOSEVELT

”

I hope your fear isn't that great. But, if you do have this most common fear, at least now you know that you aren't alone. Thankfully, this is a fear that you can overcome with a little work. As a matter of fact, some of the world's greatest speakers and entertainers once felt like you. Celebrities such as TV weatherman Willard Scott and comedienne Lily Tomlin confess to a powerful nervousness before stepping before the cameras. And, probably the greatest actor of our time, the late Sir Laurence Olivier, developed an almost disabling case of stage fright at the age of 60!

Following is a list of various tips that you can use to help reduce your anxiety. Although you'll probably never fully rid yourself of all the "butterflies" in your stomach, you can get them to fly in formation.

“

Never rise until you have something to say; and when you've said it, cease.

—CALVIN COOLIDGE

”

Tips to reduce your anxiety:

1) Being nervous is natural. Being nervous means you care about giving a good presentation. Your nervousness produces adrenaline which helps you think faster, speak more fluently, and add the needed enthusiasm to get your message across.

2) Don't try to perfect. Much of the fear surrounding public speaking comes from the desire for perfection. Accept the fact that no one ever gets it perfect and neither will you. Besides most of your "mistakes" will never even be noticed by your audience unless you make a big deal of them.

3) Visualize success. Before your presentation, close your eyes and visualize yourself giving the talk of your

life. See the audience responding to you, hanging on your every word. This is the same method Olympic athletes use to perform at their peak. It works!

4) Know your topic. This should go without saying. You need to become an expert on your topic. The more knowledge you have on a particular subject, the more relaxed you will feel when discussing it.

5) Relax. Remember, it's not so bad. Have fun. A great way to stay relaxed even while speaking is through deep breathing.

6) Practice makes perfect. Alright, you caught me. Didn't I say earlier that you don't need to worry about being perfect? Well, yes I did. And you don't. But, that doesn't mean that you don't want to practice as if you're trying to be. No matter how many of the other tips you use, if don't practice (or rehearse) you won't be as effective as you could be.

7) Let the audience like you. They want to. Most audiences really want you to succeed. Why? Well, mostly because they know how they'd feel if they were up there speaking.

8) Make eye contact. Eye contact endears you to the audience. It makes each member feel special, as if you're talking to them. It also makes you feel better. Always begin your speech by looking for a few friendly faces. Bonus tip - If you add a smile, you're sure to get one in return.

9) Involve the audience. Ask questions, play games, etc. Not only does this keep your audience interest level high, it also allows you to relax.

10) Focus on your message. It's important to believe that what you have to say is important. It is! The audience needs to hear what you have to say. If you focus on that instead of how nervous you are, you're bound to do great.

For further tips on becoming a more effective speaker, contact Jay at: SpeakerTips@jayplatt.com.

Speak Out!

Tell your story and that of the VHL Family Alliance in your own community.

Volunteer to speak to groups of doctors, nurses, medical students, or philanthropic groups about VHLFA and the need for a cure.

Contact Jay for hints.
SpeakerTips@jayplatt.com

Health Management in von Hippel-Lindau

Eighth International Patient/Provider Conference on VHL

John R. Adler, M.D., Medical Chairman; David Irving, VHLFA, Conference Chair

It's time again to get together! 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.

The program includes new diagnostics for pheochromocytoma and DNA status, advances in diagnostic imaging, new surgical approaches, and complementary strategies for wellness and stress management. Just a few of the featured speakers: Dr. Graeme Eisenhofer of the National Institutes of Health will talk with us about his new low-cost test for pheos. Dr. Peter Jackson of Stanford will talk about the state of VHL research. Dr. Yasser El-Sayed of Stanford will talk about Pregnancy and VHL. Dr. Elson Haas of Preventive Medical Center of Marin will present his work on integrated medicine, stress management, and chronic illness. Dr. Ronald Bachman of Kaiser-Permanente Oakland Hospital will talk about the role of DNA testing. Additional presentations will discuss advances in diagnostic imaging, in treatment of brain and spinal tumors, in treatment of kidney and pancreatic tumors, and in kidney transplantation.

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.

“The VHL Conference was the first time I had ever been to a conference where researchers, doctors, health care professionals, and patients were all attending the same sessions and contributing — the synergy was remarkable. My compliments to all the organizers for your remarkable skill in keeping such a wide variety of people moving in the same direction.” — *Michael Brown, O.D., Veterans' Administration, Huntsville, Alabama* ☺

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

Meet us in Palo Alto!

22-24 June, 2001

Fairchild Auditorium, Stanford University

Palo Alto, California

Chaired by:

John R. Adler, Jr., M.D., Dept of Neurosurgery

David Irving, VHL Family Alliance

Physicians: Friday noon thru Sunday noon

Families: VHL101 begins Friday 9 a.m.

\$159 per person (\$139 before May 15)

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Reserve your hotel room today.

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.

Continuing Medical Education: This activity has been planned and implemented in accordance with the Essentials and Standards of the Accreditation Council for Continuing Medical Education through the joint sponsorship of the Stanford University School of Medicine at the VHL Family Alliance. The Stanford University School of Medicine is accredited by the ACCME to provide continuing medical education for physicians. Stanford University School of Medicine designates this continuing medical education activity for up to 13.75 hours in Category 1 credit toward the AMA Physicians' Recognition Award. Nurses and genetic counselors may receive a certificate of attendance which can be submitted to their licensing boards along with the agenda to obtain credits.

Brochures will be mailed out at the end of March, or see the online registration system at <http://www.vhl.org/conf2001>.

This issue is dedicated to Mark East and Maura Hurley, dedicated volunteers who passed away in November and January. Mark died of metastatic kidney disease. Maura passed away suddenly from complications following minor surgery. Maura was particularly active as an e-mail correspondent with people around the world, spreading her delightful sense of humor worldwide. We will miss them both a very great deal, and are grateful for their kindness in sharing themselves with us all.

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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**

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171 Clinton Road, Brookline, Massachusetts 02445-5815 U.S.A.



CONFERENCE REGISTRATION

DONATION & MEMBERSHIP INFORMATION

Please check one: I am a ☐ Person with VHL ☐ VHL Family Member ☐ Supporting Friend
☐ 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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City: _____ State: _____ Zip/Postcode: _____

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Membership:

- ☐ 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 Fund for Cancer Research to share with others

Donation:

- Tax deductible donation of . . . (amount) \$ _____
☐ In Honor of _____
☐ In Memory of _____
☐ Please send a card to: _____

Registration for Annual Meeting:

- ☐ # _____ people at \$139 per person (after May 15, rate is \$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 before May 15
 Call Sheraton Palo Alto, +1 (650) 328-2800 or 1-800-422-7895

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:** \$ _____
☐ 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,

709 River Road, P.O. Box 68, Braeside, Ontario, K0A 1G0 Canada

Help Lead VHLFA to 2004

Wanted: Spirited leaders and sound business heads to build an even stronger VHLFA in the next three years. That's right -- we need **you!**

Nominations are open for positions on the VHLFA Board of Directors and its Committees. This group of dedicated volunteers shapes the agenda for VHLFA activities and manages the organization. This is an exciting time for VHLFA. We are growing steadily and with strength, building our research fund, and attracting more exciting grant proposals.

Can you help with any of these important goals?

We are seeking people with financial or management experience from industry or healthcare who can share their expertise and guide our growth.

We want to expand the Clinical Care program to include more centers and strengthen this important "chain of information" about VHL around the world.

We need a person with scientific background to participate in the process of reviewing VHL grants. These are grants awarded every year to investigators who are entering the field of VHL research.

We want to increase service to the Spanish-speaking community in the U.S. and throughout the Americas.

We need someone who can help to write up grant applications, get them filed on time, and manage communications around this important activity.

Please send your nominations -- of yourself or someone else -- along with a statement of the skills this person would add to the VHL management team or one of the Committees.

Inquire about any of these volunteer positions, or send board nominations to:

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

See page 12 for details

VHL 101, June 22, 9 AM

Chapter Leaders Meeting June 22, 9 AM

Register by May 15 for discount rates!

Sheraton Palo Alto Hotel

625 El Camino Real

Palo Alto CA 94301

1-888-625-5144 (US) or +1 (650) 328-2800

Fax: +1 (650) 327-7362

info@vhl.org or 171 Clinton Road, Brookline, MA 02445. Call +1-617-277-5667.

Board nominations are due May 15. Elections will be held at the Annual Meeting, during the Palo Alto conference in June.

Volunteers Needed in U.K., Ireland

The VHLFA in England is a registered public charity. Additional help is needed to manage this organization in the U.K. Please volunteer your help. Write to editor@vhl.org or 171 Clinton Road, Brookline, MA 02445, or leave a telephone message or fax at +44 (0)20 7681-1796

VHL Family Forum

Newsletter of the VHL Family Alliance
171 Clinton Road
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