



# VHL Family Forum



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## Exploring the Faith Factor

by Dr. Herbert Benson, M.D., Mind/Body Medical Institute, Beth Israel-Deaconess Hospital, Boston

Dr. Benson began working with people with high blood pressure, helping them through biofeedback to lower their own blood pressures without medication. What he discovered was that people could not only lower their blood pressure, they could reverse heart disease and generally increase their levels of health and well-being through a relaxation technique he calls the Relaxation Response. Once the mind reaches a state of deep relaxation, the body is able to relax and repair some of its important self-protective elements. The field of understanding the intimate connections between the mind and the body, which Dr. Benson pioneered, is gaining importance in understanding how we can optimize the body's natural defenses and deal with life's twists, turns, and challenges.

The causes of VHL tumors are quite physical. One copy of the VHL gene does not build the right protein. But what causes the second copy to be deactivated? What can we do to keep it healthy? Does the body have natural defenses to repair it when it is threatened? Dr. Steven Lott of M.D. Anderson once likened the change in the gene to a spelling mistake. "So what we need," I replied jokingly, "is a spell-checker." Actually, he said, we have a spell-checker mechanism in our bodies, to go around and verify that the DNA in each cell is in order. If not, it will fix it, or order the mutant cell to self-destruct. However if our stamina is low, the spell-checker mechanism doesn't work as well.

While we do not yet have full understanding of this process, we do know that keeping our bodies and minds strong is important to preparing them to deal with and fight against all stresses, disease, infections, and other threats to our well-being. The Relaxation Response, laughter, and focusing on remembering times of wellness can have a beneficial effect on enhancing our stamina.

-- Joyce Graff, Editor

When the film *Lawrence of Arabia*, the desert classic starring Peter O'Toole, came out a number of years ago, there were reports that concession stands were inundated at intermissions with demands for drinks -- despite the fact that many of the theaters were air-conditioned or in cool climates. A veritable

epidemic of thirst hit many moviegoers as they became immersed in the hot, sandy story they were viewing on the screen.

The moral of this incident is that the influential and even life-changing forces we encounter are often not those things that are externally real. In the case of Lawrence, of course, people weren't really deprived of water, but they identified with those waterless conditions so thoroughly that their bodies became "convinced" they were on the Arabian dunes. The result: an overwhelming sense of thirst.

Medical and scientific research is demonstrating ever more clearly that the things we can touch, taste, and measure may frequently have to take a backseat to what we perceive or believe to be real. It's how we interpret reality or how our body "sees" the concrete world around us, that is important. To put this another way, our personal power and potential for well-being are shaped by the negative or positive ways we think. The first-century Roman philosopher Epictetus recognized this fact in this statement attributed to him: "Man is disturbed not by things, but by his opinion of things." In a similar vein, *Proverbs* 23:7 says of the person with an "evil eye," "...as he thinketh in his heart, so is he." *Continued, page 2*

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This principle of the importance of a person's personal beliefs has been one of the focal points of my own research during the years since the publication of *The Relaxation Response* in 1975 and *The Mind/Body Effect* in 1979. I've concluded after scientific observations conducted in the United States, the Indian Himalayas, and elsewhere that it's difficult to place definite limits on the physical and mental powers of those who hold profound beliefs.

My research has convinced me that there are many additional possibilities for the Relaxation Response -- especially as it operates with a person's deepest religious or philosophical convictions -- which were not apparent when my first two books were published. In my experience, those who discover the exciting and powerful forces of the mind do so by eliciting the Relaxation Response in conjunction with their personal belief system.

The term *Relaxation Response*, for those who may be unfamiliar with the concept, refers to the inborn capacity of the body to enter a special state characterized by lowered heart rate, decreased rate of breathing, lowered blood pressure, slower brain waves, and an overall reduction of speed of metabolism. In addition, the changes produced by this Response counteract the harmful effects and uncomfortable feelings of stress.

In this relatively peaceful condition, the individual's mental patterns change so that he or she breaks free of what I call "worry cycles." These are unproductive grooves or circuits that cause the mind to "play" over and over again, almost involuntarily, the same anxieties or uncreative, health-impairing thoughts.

A simple technique I use to bring out, or elicit, the Relaxation Response consists of four steps: (1) finding a quiet environment; (2) consciously relaxing the

body's muscles; (3) focusing for ten to twenty minutes on a mental device, such as the word *one* or a brief prayer; and (4) assuming a passive attitude toward intrusive thoughts.

A number of years ago, I thought that this approach was all that was required to elicit benefits from the Relaxation Response. And it's true that the basic procedure is as valid as it ever was for helping individuals reduce stress, lower blood pressure, and otherwise enhance their physical and mental well-being. But now I've come to understand that the effects of this simple technique, combined with a person's deepest personal beliefs, can create other internal environments that can help the individual reach enhanced states of health and well-being.

This combination of a Relaxation-Response technique with the individual's belief system is what I call the Faith Factor. It's by no means an entirely original concept; rather it's a new kind of "package" that contains two powerful but familiar spiritual vehicles: (1) prayer or meditation; and (2) a deeply held set of philosophical or religious convictions. My function in exploring and describing this Faith Factor is to serve as a bridge between two disciplines: traditional faith and meditative practices, and scientific observation.

I am not interested in promoting one religious or philosophical system over another. Nor do I intend to comment in any way on the truth or falsity of any religious system. Rather, I'm most concerned with the scientifically observable phenomena and forces that accompany faith. Also, I plan to concentrate on the techniques and attitudes that can be used by those of any faith to tap those forces.

Not only did my research -- and that of my colleagues -- reveal that 25% of people feel more

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### **Attending religious services linked to better health.**

Researchers are discovering that going to church or synagogue may be as good for the body as it is for the soul. Harold Koenig, M.D., M.H.Sc., and colleagues at Duke University Medical Center in Durham, North Carolina, report in the October 1997 issue of the *International Journal of Psychiatry in Medicine* their study of more than 1,700 older adults in North Carolina revealed an association between religious observance and enhanced immune function that was consistent among multiple analyses.

A number of previous studies have indicated that people who attend religious services at least once a week frequently are in better physical health than those who do not. What has been unclear until now is whether only the most healthy can get to church regularly, or whether frequent church attendance prevents their health from declining or at least slows the decline.

In the first study to examine the relationship between religious attendance and the immune system, Duke researchers have followed the religious behavior since 1986 of a randomly selected group called the Establishment of

Populations for Epidemiologic Studies of the Elderly. They interviewed 1727 participants at home and tested their blood for nine substances that indicate activity of the immune system and inflammatory response.

The investigators found those who attended religious services frequently were only half as likely to have elevated levels of interleukin-6 (IL-6), which acts on a wide variety of cells, regulates the immune response and is involved in a variety of diseases, injuries and infections.

They said the relationship was not related to depression or negative life events. Similar associations were found for four of eight other substances tested to assess the immune system and inflammation.

This finding provides some support for the hypothesis that older adults who frequently attend religious services have healthier immune systems, and supports the work of Dr. Herbert Benson and others that when a stress management program includes an element of belief, it can be even more powerful. Prayer, meditation, the support of a caring community of friends, and taking time to slow down has a healthy effect not only on the mind but on the body as well.

spiritual as the result of the Relaxation Response, but it showed that those same people have fewer medical symptoms than do those who reported no increase in spirituality. It became clear that a person's religious convictions or life philosophy enhanced the average effects of the Relaxation Response in three ways: (1) People who chose an appropriate focus, that which drew upon their deepest philosophic or religious convictions, were more apt to adhere to the Relaxation Response routine, looking forward to it and enjoying it; (2) affirmative beliefs of any kind brought forth remembered wellness, reviving top-down, nerve-cell-firing patterns in the brain that were associated with wellness; (3) when present, faith in an eternal or life-transcending force seemed to make the fullest use of remembered wellness because it is a supremely soothing belief, disconnecting unhealthy logic and worries.

I already knew that the Relaxation Response could "disconnect" everyday thoughts and worries, calming people's bodies and minds more quickly and to a degree otherwise unachievable. It appeared that beliefs added to the response transported the mind/body even more dramatically, quieting worries and fears significantly better than the Relaxation Response alone. And I speculated that religious faith was more influential than other affirmative beliefs.

These are some of the principles and practical lessons I've drawn from my long medical quest for lasting truths. I hope they prove helpful to you:

***Let faith, the ultimate belief, heal you.***

According to medical research, faith in God is good for us, and this benefit is not exclusive to one denomination or theology. You can believe in God, in a quiet, introspective way or declare your convictions out loud to the world -- either way, you'll still reap the physiologic rewards.

For many reasons, religious activity and churchgoing are also healthy. Religious groups encourage all kinds of health-affirming activities -- fellowship and socializing perhaps first among them, but also prayer, volunteerism, familiar rituals and music. Prayer, in particular, appears to be therapeutic, the specifics of which science will continue to explore.

***Trust your instincts more often.*** People describe the process of finding out what is important to them, of tapping into their beliefs, in very different ways, sometimes calling it "soul-searching," "mulling it over," "listening to one's heart," "going inside of one's self," "praying," or "sleeping on it." Some people act on instincts or common sense; others find a truth or intuition emerges slowly. But most people know when something "feels right." Most people have a kind of internal radar that occasionally calls out to them.

The next time you're faced with a major decision, medical or otherwise, ask yourself, "What feels like

Kari N., age 13, Rienzi, Mississippi, won First Place in the North Mississippi District Science Fair for her exhibit on von Hippel-Lindau.

the right thing to do?" or "What would I do if the choice were entirely up to me?" I'm not suggesting that you make decisions based on this factor alone, but at least let belief be a player. Honor your convictions and perceptions enough to make them a part of a hearty intellectual argument.

Let your instincts guide you. Follow them up with research. Put your health in good, trustworthy hands. Let your health have time to correct itself. Invest remembered wellness and a reasonable application of self-care, medications and surgery for maximum health returns.

***Practice and apply self-care regularly.***

Work with your doctor, and with the unconventional practitioners if you so choose, to learn self-care habits. I consider self-care anything an individual can do, independent of doctors or healers, to enhance his or her health. This includes mind/body reactions such as remembered wellness, the Relaxation Response and the Faith Factor. It also embraces good nutrition, exercise and other means of stress management.

I use the term "self-care" because it puts the burden on you, it shifts the emphasis from your role as passive patient to active participant -- a shift that medicine has not always encouraged. However, I caution against becoming self-absorbed in self-care. Don't become fixated on your health or on the avoidance of aging, illness or death. Make your daily Relaxation Response session, your jog or your salad at lunch a "no-brainer" -- something you do without analysis. Simply delight in the event itself.

It's almost always valuable to seek the assistance of your physician to determine the difference between a condition that will benefit from self-care exclusively and one that requires drugs or procedures to treat.

**Dr. Benson's Relaxation routine:**

1. Find a quiet environment
2. Consciously relax the body's muscles
3. Focus for 10-20 minutes on the word "one" or a brief prayer
4. Assume a passing attitude toward intrusive thoughts (don't worry about them, keep focused on your word or phrase)

Learning about your body is an evolutionary process. You'll work toward a more independent attitude. Become acquainted with the warning signs of heart attacks, strokes, cancer and other life-threatening diseases. Over time, you'll develop a sense of what symptoms are important -- those that are extreme or don't go away.

**Beware of people with all the answers.**

Be careful of any physician, nontraditional healer, spiritual guide, mind/body guru, or any adviser who claims to have all the answers or wants others to think so. Besides love and sex, writers and lecturers today take up few topics with as much evangelistic zeal as health and spirituality. It is no small task shielding these very personal matters from unhealthy speculation and overanalysis, but start tuning out overly confident or all-knowing mentors and guides. Value your emotions and intuitions the same way your brain does; don't let someone manipulate your wiring for his or her gain.

Mind/body medicine should remind us of the precious nature of our minds, and of the importance of critiquing the messages we allow to become actualized in our brains and bodies.

**Remember that the "nocebo" is equally powerful.** Unfortunately, remembered wellness has a flip side. It can have negative side effects, called the *nocebo* (as opposed to *placebo*.) Our agitated minds may inappropriately trigger the fight-or-flight response in the body. Similarly, automatic negative thoughts, bad moods and compulsive worrying eventually take up physical residence in our bodies. People who dwell on worst-case scenarios, who exaggerate risks, or who project doubt and undue worry keep the nocebo effect busy in their physiologies. They signal their brains to send help when no physical sickness is present, persuading the body to get sick when there is no biological reason sickness should occur.

Remember that immortality is impossible. While it's healthy to listen to your heart, it's also harmful to deny or duck the truth. No one lives forever. No matter how well-versed you become in mind/body medicine, no matter how far medical progress may be able to set back the clock, death is, like illness and pain, an unfortunate but natural fact of life.

I must sound as if I'm talking in circles, first telling you not to let a diagnosis define you, then warning

you not to fall prey to denial. Nonetheless, some lecturers and New Age entrepreneurs imply that all disease is curable and that we can avoid death and aging if we only believe. These salespeople do great harm to people by fostering guilt, and they damage the field of mind/body medicine, which is legitimately trying to establish its findings and change the way Western medicine is practiced. No evidence exists that death can be denied its eventual toll.

Indeed, fear of death can bring out the worst in people, but the realization that death is an inevitable, natural occurrence can also propel healthy, impassioned living.

Living well, exercising and eating appropriately, seeing doctors when you need to but not over-relying on the medical system -- these are all proven buffers against disease and illness.

**Believe in something good.** Even though we do not necessarily need all the pills and procedures that conventional medicine and unconventional medicine give us, these medicinal symbols retain an aura of effectiveness and often appease our desire for action. While we must learn to use medicine more appropriately for the conditions it can help, and to wean ourselves from excessive spending on unnecessary therapies, we'll often need some catalysts for belief, even if belief is really the healer.

So remember the vigor from the time you felt healthiest in your life. Remember the blessing your mother said to you before you left for school, the smell of incense at church, or the tranquility you felt picking up stones from the beach on Cape Cod. Remember the time the penicillin vanquished your ear infection, or the time the surgeon removed the splinter from deep in your foot and your pain immediately ceased. Remember how full-throated you sang in the choir or how long you stayed on the dance floor of a nightclub. Remember the doctor who really cared about you or the chaplain who prayed with you in the hospital. Remember the way you felt when you made love to your husband or wife, and the way you felt when your daughter or son was born.

Then let go, and believe. You've read all about your physiology, you've surrounded yourself with good caregivers who help you take a moderate, balanced approach to your health and health care. Now it's time to enjoy your endowment, this wiring for faith that makes the power of remembered wellness so enduring.

Believe in something good if you can. Or even better, believe in something better than anything you can fathom. Because for us mortals, this is very profound medicine.

Excerpts from Herbert Benson, M.D., *Beyond the Relaxation Response* (1984, Times Books, NY) and *Timeless Healing* (1996, Simon & Schuster, NY). Reprinted with the kind permission of the author and the publishers. See also <http://www.med.harvard.edu/programs/mindbody/> for available books and audio tapes. □

## Ask the Experts

**Question:** I have been having vertigo and tinnitus problems since early 1994. I had the ear area scanned with one of my regular MRIs about that time and no tumors were found. I was diagnosed with Menière's disease and have been treated for such since that time with some positive results.

I read with great interest your two articles on ELST in the September 1996 issue. I sent copies to both of my physicians. They reviewed my prior scans with a neuroradiologist and still saw nothing, but they recommended a CT scan of the temporal bone area. An ELST the size of a quarter was found. The tumor was successfully removed in February, without any hearing loss or balance problems. The remaining tinnitus faded as the swelling went down.

The one thing my doctors disagreed with in the article was the statement that "they are often best left in place." My doctors felt that these tumors must be removed because of the dangers they pose if they hemorrhage.

Thank you again for your great work in keeping VHL patients informed. I would never have known of these tumors and their association with VHL without your work. I should have better hearing and balance in the future because of this article. — *Marty M., Illinois*

**Answer:** Although the existing medical literature suggests that endolymphatic tumors frequently enlarge rapidly and often produce life-threatening circumstances, our experience with many patients with von Hippel-Lindau syndrome and ELST suggests that this is not accurate.

Our review of these patients indicates that the tendency of these tumors is toward progressive hearing loss, since degree of hearing loss seems to be related to the duration of symptoms. However, it is somewhat unusual for these tumors to reach a life threatening size and it seems even more unusual for them to suddenly hemorrhage. Of the many patients I have seen, I know of no patients with hemorrhage.

The natural history of these tumors is not completely established, but they certainly grow slower and tend to reach a much smaller size than the medical literature now suggests.

It is now possible to remove these tumors and preserve hearing. I have similar patients who have received surgery at the NIH. Several tumors have been removed with no degradation in hearing, and in a few cases hearing has improved after surgery. In fact, surgery of the endolymphatic sac is commonly performed for Menière's disease and usually does not produce a hearing loss. However, the consistency with which these tumors can be removed with preservation of hearing has not been established.

Early results are hopeful, and we encourage patients and physicians to consult with Dr. Daniel Choo or myself on possible surgical approaches to ELST.

— *Dr. Edward H. Oldfield, Chief, Surgical Unit, Natl. Inst of Neurological Disorders & Stroke, Bethesda, Md*  
*Dr. Choo Tel: 301-496-5368; Fax: 301-402-0409 or*  
*Dr. Oldfield Tel: 301-496-2921; Fax: 301-402-0380.*

## Teen Conference Call

A number of young people have requested a forum for teens, where young people can voice their concerns and support one another. You people between the ages of 13-17 are invited to join us on a telephone conference call:

- Sunday, January 25, 1998, 4 pm EST
- Sunday, February 22, 1998, 4 pm EST
- Sunday, March 29, 1998, 4 pm EST

These calls are open to all teens whose family is affected in any way by VHL -- whether they themselves have VHL, or a parent, brother, sister, or other relative has VHL.

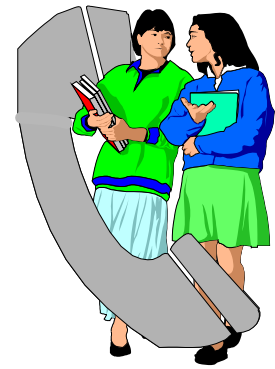
Dial 1-800-890-6812. You will hear a tone, like a second dial tone. Dial the conference code, 1-47233, and you will be connected to the group. (If your long distance carrier is Buyers United, you will need to enter code 4-47233 instead.)

There will be a group of teens on the line. Please choose a place with a quiet background so that everyone can hear. Please do not use two extensions in the same house at the same time, as this can cause interference on the line. It's a little like meeting in a dark cave: you can't see the faces, but you can hear one another just fine.

The meeting will be facilitated by Peggy Marshall, Co-Chair of the VHL Family Alliance, a professional child care provider, mother and grandmother. Peggy has had VHL herself since she was 12 years old. Her daughter Tammy was diagnosed at age 15, and her granddaughter Kari was diagnosed at age 9.

Parents are asked not to attend, as this is to be a private space for teens. If you have questions, call 1-800-767-4VHL. If you would like to call in from outside the U.S., please call 617-232-5946 to make a reservation so that we can arrange a line for you to call.

We are still seeking sponsors -- funding, or weekend use of corporate telephone switching equipment -- to keep this service going. If you can help, please call Peggy at 1-800-767-4VHL.



"When one door of happiness closes, another opens, but often we look so long at the closed door that we do not see the one that has been opened for us." — *Helen Keller*

# Advocacy and You

-- Don Marshall, Mississippi

**If not me...Who? If not now ....When?** Your vote counts. Your opinion counts. You can make a difference. We are all advocates at one time or another. Each of us is a lobbyist, guaranteed by the First Amendment "to petition the Government for a redress of grievances." As individuals we have the right to address our legislators to support issues that affect our lives. Not only is this a right but it is a responsibility to let our legislators know how we feel. Every day of every Congressional Session, be it Federal, State or Local, issues that affect us are being determined and decided. Are we going to sit back and see the results of these decisions after they become law or are we going to be a pro-active part of the decision making process?

An understanding of how to lobby and advocate your needs to your representatives should begin with a basic understanding of how the United States government works. Federal and State Congresses are composed of two governing bodies. The Federal Congress is comprised of the Senate (two Senators from each State), and the House of Representatives (435 Members determined by population of each State). Individual State Congresses have a similar makeup. Each Legislator is elected by the constituency of the area they serve. Legislatures have the power to make laws. Both bodies (Senate and House of Representatives) must agree on a proposal (a bill) before it can be sent to the President for his signature. The President can veto the bill and send it back to the House and Senate. The veto can be overridden if both the House and Senate approve the bill by a two-thirds margin.

A bill can be introduced in either the Senate or House. A Senate Bill is identified by the Letter S. (i.e., S. 89) and a House Bill by the letters H.R. (i.e., H.R. 306). Legislation introduced by the members of Congress can come from many sources. Talking with constituents, media, congressional aides and staff, advocates and lobbyists, interest groups, and the Executive Branch (White House or various agencies), can originate an idea that may become a legislative proposal.

Legislation is grouped into three main categories: authorizing, appropriations, and entitlement. Authorizing bills usually set a ceiling on the maximum amount of funds that can be spent by a program for a period of three to five years but do not establish the funds to operate the program. The National Institutes of Health, Orphan Drug Tax Credit, and FDA "reform" are authorizing bills. Appropriation bills allocate funding for specific federal programs, such as providing funding for research into rare diseases. Medicare and Medicaid programs are examples of entitlement programs. These

are measures that guarantee a certain level of benefits to persons who meet eligibility requirements set by law.

Before a bill is introduced you can make an impact by contacting your Legislators to express concerns that matter to you. During the process while a bill is in hearings both in subcommittees and committees, your voice can still be heard. Each Legislator has a dedicated staff that can have significant influence over the course and content of legislation.

Over the next few issues of the *VHL Family Forum* we will look at the next Congressional Session, the bills that effect us, and how to be an effective advocate for our needs and interests. We will look at how to address an issue, who to contact, and how to have the greatest impact on the decision making process.

## Patient's Bill of Rights

by Deborah Zabarenko, Reuters, with comments by Don Marshall

President Bill Clinton endorsed a health care "bill of rights" for American consumers on Thursday, November 20, defending it against opponents who view the plan as the first step toward government-run medicine. "There are still those who oppose it, and that is their right," Clinton said at a White House ceremony in which he formally accepted the plan. "But this is a case where the national interest must prevail over the narrow interest, where the family's interest must prevail over the fear of change."

Vice President Al Gore was more blunt in his remarks at the same forum: "If any special interests want to make this a war, it's one that we're proud to fight on behalf of America's families." Families with VHL will be helped by this bill.

The health reform plan, modest in scope when compared with the Clinton administration's failed effort to reform health care in 1993-94, would, among other things:

- Guarantee consumers' right to be informed about health care plans in plain language. *Health Maintenance Organizations (HMOs) often deny us the right to the presymptomatic testing we need to manage our health using clauses in the "fine print."*

- Require health care plans to pay for emergency room visits if a "prudent layperson" would reasonably feel at risk of permanent injury without immediate care. *For example, if a person with a history of heart disease went to the hospital for chest pain, and it turned out to be something less urgent, the HMO would still be required to pay the bill.*

- Allow patients to appeal any denials of coverage to a review board. *This review board must be independent of the insurance carrier. As long as*

**U.S. Voters - Make your voices heard!**

A phone call or a one-page handwritten or typed letter to your legislators would make a difference! A personal story about why you care can make a particularly strong impact. Let them know this issue is important to their constituents.

To find the names and addresses of your representatives,  
Senate: call 202-224-3121 or see <http://www.senate.gov/senator/>

House: call 202-225-3121 or see <http://www.house.gov/writerep/>  
A call or letter is more effective than an e-mail message.

*the review board has financial interest in the insurance carrier, decisions will not be in the best interest of the patient!!*

· Give patients direct access to specialists. *HMO's have been raising barriers to access to specialists, and penalizing staff doctors for recommending specialists. People with rare disorders like VHL need specialists to manage their health.*

· Require health plans to give information about their physicians, including how many times they have performed certain procedures, whether they have been sued for malpractice and how they are paid. *How many times have we been sent to a physician that has not ever dealt with a VHL patient when there are medical professionals close by but outside of our PPO/HMO that can and do provide care for VHL patients?*

The plan is aimed at middle-class consumers who already have health care coverage, and Clinton promoted it in that light.

"Today, Americans receive consumer protection when they purchase cars, use credit cards, buy toys for their children," he said. "All this commission is recommending is that we extend that kind of protection when a person visits a doctor, checks into a hospital or buys a new health plan."

He also said it was likely to "stabilize" and "harmonize" U.S. society in general if consumers had more confidence in the cost, quality and accessibility of health care.

The American Medical Association, which represents U.S. physicians, said the rights guaranteed by the plan would preserve "the sacred bond between patient and physician, and will help restore the public's confidence in the entire health care system." *The insurance industry has been building a wall between the consumer and the physician, sometimes overruling the decisions of the physician.*

But Rep. Bill Thomas, a California Republican who chairs a health care panel of the House Ways and Means Committee, said the plan was at odds with the original Bill of Rights, contained in the U.S. Constitution: "Today's proposal extends the reach of federal power directly into people's doctor/patient relation-

ships." *If we believe that we need these consumer rights, we need to state that clearly to our representatives.*

Hours after Clinton's announcement, Senators Joe Lieberman, a Connecticut Democrat, and John Chafee, a Rhode Island Republican, announced they would form a bipartisan task force to focus on health care, notably consumer information and cutting red tape. *Send copies of your letters to these Reps. and encourage them in their activities.*

John Sweeney, president of the giant AFL-CIO labor federation, gave the plan qualified support, calling it a "common sense set of answers" to health care problems, while saying that more might be done to serve workers' needs.

Gail Shearer, a health care analyst with Consumers Union, which lobbies Congress on behalf of consumers, praised the administration plan. "This is not about the government running health care," Shearer said in a telephone interview. "This is about making private companies accountable to somebody other than their shareholders ... it would mean that an HMO would no longer be the judge and jury when it came to treatment decisions."

Some 67 million Americans now participate in HMOs, and millions more have other forms of managed care. Shearer noted, however, that the plan is not yet law, and that in any event it does nothing for the more than 41 million Americans who have no health care coverage. Tens of millions more are under-insured or lack coverage for part of each year.

## Wacky VHL Humor

*from Tania D., Ontario, Canada*

Something that happened last week at work made me feel good. My two bosses were speaking rapidly with their hands a flying and I started to laugh because they looked so comical. The owner of the company looked at me and asked me why I was laughing, and my spontaneous reply was "because I still have the ability to". They know what I'm going through and that statement made them smile and made me realized that the reason that people who are going through such traumatic times have to keep their sense of humor.

Here's a humorous idea: Tattoo zippers on your scars and freak the surgeons out when they examine you.

I have seven brain tumors, all little ones that I hope stay that way. I've named them all after the seven dwarfs, and imagine myself as Snow White, cleaning them all out of the house. I just wish all my tumors were named Sleepy and don't wake up for a long, long time.

— L L L (Live, laugh, love)

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## Sleepless in Seattle!!

– Alice M. Coday, *Seattle meeting co-chair*

The 5th Annual VHL Patient/Provider Conference co-sponsored by the University of Washington Medical Center will be held June 5-7, 1998 in Seattle, Washington. Meetings will be held at the Embassy Suites Hotel in Bellevue from noon Friday through noon Sunday.

This year's conference will have a new and exciting twist that will no doubt have you sleepless with excitement after listening to leading researchers and the latest developments in diagnosis and treatment of VHL. Most important, it will be an opportunity to get practical information and support from others who are dealing with this challenging disease. It won't be the same without you . . . so let's meet in Seattle!! An opportunity to see Seattle, the number one city in the USA!!

## Symposium in Paris

The biennial Medical Symposium on VHL will be held September in Paris, hosted by Dr. Stéphane Richard and VHL France, Mireille Proux, Présidente. The meetings will be held in English, with some French translation.

The meetings will take place in the Luxembourg Palace, built in the 1620's for Marie de Médicis, the widow of King Henry IV of France and grandmother of Louis XIV. The palace complex sits in the beautiful Luxembourg gardens.

The medical meetings will be held Wednesday-Friday, and the language will be quite scientific. A formal dinner is planned for Thursday evening. Families are especially invited Friday afternoon, when there will be a special session designed as an exchange of information among families and health care professionals.

A touring program is being organized for companions of the attendees. Registration fees will be announced in March. This 17th-century structure is not wheelchair accessible. Please let us know if accommodations for wheelchairs is needed. For information about the area, see <http://www.paris.org/Monuments/Luxembourg>

## Local Meetings

**Belgium**, by Chris Hendrickx

We had a meeting November 10 to discuss incorporating under Belgian law. It's so exciting to see it becoming a formal organization! Even though there is a Dutch support group an hour north in Holland for the Flemish-speaking people and a French group for the French-speaking people two hours south in Paris, nonetheless it is important to have a Belgian group that understands the medical system and culture of Belgium.

**Denmark**, by Richard Harbud

The Danish affiliate has begun a homepage for Scandinavia at <http://home5.inet.tele.dk/harbud/vhl/>. There is a description in Danish of the work of the local group there, and contact people who speak Danish, Norwegian, and Swedish. Many thanks to Richard and Vibeke Harbud for making this happen.

**Illinois**, by Ellen & Bob Lydon

Dr. Daniel Dalton, urologist of Northwestern University spoke with a group of twelve members in Chicago, an excellent first meeting. They are planning another get-together in March, this time on a weekend day.

**Indiana**, by Kathy & Andy Braden

The first Indiana meeting was very well organized and attended. 32 people came from as far away as Illinois and Mississippi. Cindy Hunter, M.S., a genetic counselor from the University of Indiana, spoke about DNA testing issues for VHL families.

**Louisiana**, by Peggy & Don Marshall

We had 28 folks in attendance. Dr. Jim Gnarra of the Louisiana State University Medical Center gave a presentation on the history of finding the VHL gene, his own research into VEGF, and the three areas of

research his lab is focusing on.

**Massachusetts**, by Laurel Newson

Fourteen people from the Massachusetts chapter met in September with Dr. Karol Krzystolik from Poland. We had an excellent discussion about DNA testing, and the right to know or not know the results. A "Team VHL" contingent participated in the annual Dana Farber Jimmy Fund marathon and walk helping to raise money for Dr. Kaelin's research.

Dr. Richard Klausner, Dr. Eamonn Maher and Dr. Hartmut Neumann spoke at Dana Farber Cancer Research Center in November as part of the 50th anniversary of Dana Farber.

**Minnesota**, by Lois Erickson

We had our first Minnesota VHL meeting August 23. There were thirteen people present, and a number who were unable to attend. There were quite a few new members hungry for information and excited about the Alliance, as we were in 1993.

Everyone seems really "tuned in" to the internet! I will have to go to someone's house and go through the VHL section, <http://www.vhl.org>

**New Zealand**, by Val & Jon Johnson

The New Zealand group is growing, with new contacts coming both from doctors in New Zealand and Australia, and over the internet. They are in the process of arranging meetings with the Northern Regional Genetic Service at Auckland Hospital to establish a screening protocol for families with affected members.

**Pennsylvania**, by Maria Shipton

The State of Pennsylvania will have two chapters, using the telephone area codes to distinguish them. The Eastern division held a small first fund-raiser in August. Additional activities will be planned for the new year.

Team VHL at the Women's Mini-Marathon in Cork, October 1997

## British Group has new leaders

The re-formed U.K. group is off to a strong start! Co-Chairs Mark East and Beverley Stone will share leadership of the group and are looking for additional chairpersons for various committees, to extend the reach of their work.

Mark East is a Ph.D. candidate in genetics at the University of Leeds in England. Mark and his mother both have VHL. His new bride Michelle is a nurse in a bone marrow transplant unit. Mark and Michelle will focus on interactions with the medical community, building the visibility of VHL in the medical community in England, and helping to strengthen the chain of information about VHL for physicians in the U.K.

Beverley Stone, a lifelong friend of the late Gillian Houlders, will focus on fundraising and public relations. She organized a parachute jump as a fundraiser, and plans to walk on airplane wings next spring -- *really!*

Dora Beeforth and her husband Andy are helping to answer telephone calls from other families with VHL in the U.K. Dora and her brother have VHL. Her late father, Victor Midgley, was the original founder of the British support group.

Professor Eamonn R. Maher of Birmingham continues as their primary advisor. They will be building a medical advisory board over the next year.

People in the U.K. and Republic of Ireland are invited to call or write to Beverley, Mark, and Michelle, and Dora and Andy to ask questions and offer assistance to grow and strengthen the new U.K. group. VHL Family Alliance, U.K., c/o Mark & Michelle East, 7 Conway Mount, Leeds, LS8 5HZ England. Tel/Fax: (London) +44 (0)171 681-1796 or Dora & Andy at +44 (0)1931 716031, E-mail: Mark in care of [info@vhl.org](mailto:info@vhl.org) or to Maura Hurley in the Republic of Ireland, [maurah@indigo.ie](mailto:maurah@indigo.ie)

## Irish Fun Run

by Maura Hurley, Ireland

Unfortunately, raising money for an organization is never an easy or likable job. It is probably one of the most distasteful jobs in an organization. However, without it a voluntary group can not survive. For those of us who have VHL and the many people who are affected by it, the VHL Family Alliance provides us with information and support and is pursuing research into this disease. To do these things a group needs money.

Here in Cork, on the south coast of Ireland, every year our regional newspaper holds a Ladies Mini-Marathon road race which is 5 miles long. This year approximately 3,000 women of all ages took part. The majority of them just walk or jog the 5 miles. However, every person who participates uses it as a means of raising funds for the organization of their choice, i.e. Rape Crisis Centre, AIDS Research, Multiple Sclerosis, Leukemia, etc. This year we had 31 participants completing the race for research into VHL and for the VHL Family Alliance.

We all sold sponsorships for the people completing the race, as did they themselves. Everybody said how willing people were to sponsor them and were glad to see research into this familial cancer. Unfortunately the majority of people have been affected by cancer, of one kind or other, through either a family member or a friend. The VHL gene not only affects people with von Hippel-Lindau disease, but is also involved in the majority of renal cancer in the general population. Understanding how this gene works will also help researchers understand how faults in other similar genes contribute to certain types of cancer.

On the day of the race itself everybody had a marvelous time. We all met beforehand, took photographs and generally enjoyed the atmosphere and excitement generated by the people participating in the marathon. The weather was ideal on the day, it was cool and dry. At the finish everyone received a lovely bronze medal for completing the race. A couple of the girls said it was the first time they had ever received a medal for anything! We all then went to a pub for sandwiches and refreshments. For some of us, the day was more like a full marathon than a mini-marathon, as that night we ended up going to a disco at a local hotel and some of us had our VHL tee shirts still on us.

The £4,747 we raised (nearly \$7000) was donated to the VHL Family Alliance and VHL research in England and America. Every donation helps to continue the important work being carried out by this group and the vital research work which is needed to get to the stage where we can manage VHL and one day find a cure for it.

# VHL in Poland

by Altheada Johnson, New York

The NY Chapter of the VHLFA had its 4th annual meeting on Sunday September 21, 1997. Ten people attended including Dr. Karol (say 'Karl') Krzystolik all the way from Poland. He is the type of doctor every patient would love to have, concerned, knowledgeable and very compassionate. He lost a daughter to spina bifida, and is very aware of the questions VHL patients and families must address.

He and another researcher are working on finding VHL families in Poland. His co-worker does the actual DNA testing and he does the clinical work including some counseling and referral to necessary specialist. As you can imagine he is overwhelmed and other research interests have been postponed. Dr. Krzystolik would like his research to concentrate on what can defend or keep the unaltered VHL gene healthy.

Dr. Krzystolik had very interesting thoughts on alternative medicine. He feels that vitamins like vitamins A & E and microelements or minerals like selenium could play a roll in cancer treatment. There has, of course, to be more research. He thinks we should not treat ourselves as sick persons, VHL is not a disease but a predisposition because not every person with the mutation will get every manifestation of the disease and some may not get any. Dr. Krzystolik feels that big stress causes decreased immune function—so use stress management techniques such as relaxation or humor. Avoid x-rays as much as possible—having VHL requires that we all get CT scans and women must get mammography for breast cancer screening but not every dental visit, for example, requires x-rays.

Lastly, Dr. Krzystolik said that he steers his VHL patients to one or two doctors in a particular specialty, this way you make an expert. There are not that many of us and a doctor seeing no or perhaps just one or two patients with VHL would never get the experience he needs.

Dr. Krzystolik had some very interesting questions for us too. He is faced with a very difficult situation. A husband, due to past experiences, has become distrustful of doctors. He has VHL and also has several children. His wife does not know that the children have a 50% chance of also having VHL. Dr. Krzystolik asked how he should handle this? He must honor the patient's right to confidentiality but is concerned that the wife does not know about the potential medical concerns of her children. He also asked our opinions on other questions like: At what age should a child be told about their diagnosis? Should all the children in a family, those found negative as well as those found positive for the VHL

Dr. Karol Krzystolik (left) at the New York chapter meeting, September 1997.

mutation, be screened just so everyone is treated equally? Should parents be told which children have tested positive for the VHL mutation? Will knowing make a parent treat their children differently?

This was a very interesting meeting. It reminded us of just how small the world is. VHL families on the other side of the world face the same basic problems we do.

## When's the Next Meeting?

### ...Please Join Us!

**Nashville**, February 10, 1998

**Memphis** in February/March, 1998

**Atlanta** Town Hall meeting for brain tumor patients and families January, 1-4 pm. Call American Brain Tumor Association, 800-886-2282 for details.

#### Teen Conference Calls:

- Sunday, January 25, 1998, 4 pm EST
- Sunday, February 22, 1998, 4 pm EST
- Sunday, March 29, 1998, 4 pm EST

**San Francisco**, March 27-29, 1998, Conference of the National Brain Tumor Foundation, Tel: 1-800-934-CURE or +1 415 284-0208, or see <http://www.braintumor.org>

VHLFA Patient/Provider Conference,

**Seattle**, Washington, June 5-7, 1998. Embassy Suites, Bellevue

Third International Symposium on VHL,

**Paris**, France, September 16-18, 1998. Le Sénat, Jardins de Luxembourg convention ctr

VHLFA Patient/Provider Conference,

**Atlanta**, Georgia, spring 1999.

Need more details? please contact the hotline at +1 800 767-4845 or [info@vhl.org](mailto:info@vhl.org).

I'm enclosing a donation. I admire so much the work the VHL Family Alliance does. It makes us aware that with proper monitoring we can live as long as most people, rather than dropping off like flies as our predecessors did. It makes us get on with life instead of being submerged in VHL fears. Thanks a million. -- Greta R., Nepal

# Meet the Directors

## ***Renee Rosado, Fund-Raising.***

Renée is a development engineer working for a software vendor in California. She was raised in California and loves to travel, especially to the islands of Hawaii. She likes long distance bike riding, golf, cooking and entertaining. Her hobbies also include researching the family tree, photography, working with stained glass and other arts and crafts.

"I was blessed in life by learning about love, relationships and commitment by being married to a wonderful man for 20 years." Her late husband, Dennis Rosado, passed away in September 1989 of complications from surgery for a VHL brain tumor. Renée has remained very close to Dennis' family, and committed to helping to improve diagnosis and management of VHL.

Renée chairs the Fund-raising Committee, working to find grant funding for VHLFA programs. She will be glad for your suggestions and assistance.

## ***Madge Hall, Public Relations.***

Madge brings a diverse background to the VHL Family, having worked in the insurance field in Oklahoma City and Houston; Office Manager for a Fortune 500 corporation in Houston; Officer and Public Relations for a Chemical Company in Houston, as well as in Education and the Oil Industry in Oklahoma City. She is now "retired" and works on a part-time basis, and is looking forward to devoting more time to the VHLFA. A newly elected member of the Board of Directors, she chairs the Public Relations effort. She is also Chairman of the Oklahoma Chapter. She asks that you be generous with your suggestions to assist her in doing the best job possible, which will be helpful to all of our VHL family.

Madge first became aware of the VHL Family Alliance when her son's former pediatrician sent her

a copy of the *VHL Family Forum* just before the first conference, which was held in Kansas City. She will tell anyone who will listen, at least once, that was one of the happiest moments of her life; to learn she and her son were not dealing with VHL alone and that progress was being made in research of the disease. Like so many of us, even though she had been "dealing" with VHL for many years, because her husband also had VHL, most of those years were spent "in the dark," and uninformed. Thanks to the VHLFA, that's no longer the case!

# Ask the Family

Dear Family:

I'm in my mid-fifties. My brother, sister, and dad all died of VHL, but I've never had symptoms. Why would someone like me choose to have DNA testing? Isn't it true that once you're over 50 and have had no symptoms that it is safe to assume you don't have VHL?

– *Signed, Unaffected Sister*

Dear Sister,

I'm very grateful for DNA testing, and I have come to know that it's important to take advantage of this simple test at any age. If it were not for genetic testing, I would never have been diagnosed with VHL until it would have been too late and a lot of damage would have occurred to my body.

Seven of my family members have VHL, 3 have died from it. I was never affected, and I felt fine, so I didn't feel it was necessary to be tested. When I was 52 a visiting English doctor from the Children's Hospital in Los Angeles, suggested that everyone in my family be tested. We jumped at the chance.

Surprisingly, my results came back positive! I took the *VHL Handbook* to my doctor and asked for a VHL check-up. A routine MRI revealed that I had a pheochromocytoma, a tumor in my left adrenal gland, and that I needed immediate surgery. Following the MRI, I was given a blood test and the 24-hour urine test, both were negative. My blood pressure was low. Three tests all negative, indicating no presenting symptoms of the adrenal tumor. It was "hiding."

Had I not had the genetic testing and the MRI, I would not have known of the tumor until symptoms occurred, and then I might have had major problems like heart attack or stroke.

I encourage you, and anyone in doubt, to go for the testing. It's worth it! It saved my life.

God's blessings to you,

– *Evabeth T., California*

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...Joyce Graff, by Audrey Tobin

...Joyce Graff, by Harry & June Wilcox

...my daughter Altheada Johnson, by Lillian

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...Mr. & Mrs. Malcolm B. Parker on their

50th wedding anniversary, by H. & J. Wilcox

...Barbara Redding by LaRae Draper

...Korrina Sanchez, by E. & P. Sullivan

...Gay & Paul Verco by Patti & Ken Kohlen

...My VHL family, by Eileen Schumacher

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...Robert "Rondo" Anderson, by Amy

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\_\_\_\_\_

# Annual Report, 1996-97

Each year at this time we report to you where the money went. Our budget falls into three main categories: Education, Conferences, and Research. Expenses shown in this report are primarily for U.S., including publication expense for all English-speaking countries and worldwide distribution of English-language materials. Non-U.S. affiliates are self-supporting.

The second edition of the *VHL Handbook* was published this year. More than 6000 copies of this new Handbook have already been distributed, and orders are being received from hospitals and medical schools.

Two research grants were awarded, and a total of \$36,000 was paid out for research.

The Tissue Bank is operated under a grant from the National Institutes of Health by the University of Maryland, with no charge to our budget. Arrangements can be made for donation of tumor tissue by calling before surgery 1-800-847-1539.

This operating budget of \$38,143 serves more than 7000 people in 37 countries (see Figure 1) through the newsletter, the *Handbook*, the internet service, and a strong people-to-people network formed by volunteer families and physicians across the globe. This represents an increase of 27.5% in the number of people served since last year.

As shown in Figure 2, this year we spent \$38,143 for VHL Education, and \$36,000 for Research. The conference expense is the excess of expenses over revenue for the Bethesda and Hawaii meetings.

Our goal this season is to raise \$80,000 for the coming year: \$40,000 for research, and \$40,000 for education. The number and size of the research grants will depend upon your generosity. We can only spend what we have. We are all volunteers. We pay no staff; we do not rent office space. Our modest expenses go directly into programming and research.

Our most exciting new program for 1998 is the *Teen Conference Call*, beginning

monthly in January (see announcement, page 5). We are looking to our teenagers and their professional advisors to help shape this service to meet their needs. This program is being planned to support young people newly diagnosed with VHL through their sensitive teen years. An increasing percentage of these have never had a symptom -- they are mostly diagnosed through DNA testing and routine screening. Their needs are very different from those of people grappling with medical situations.

**We need your help!** We are already making a difference, bringing closer the day when there will be a better medical management for VHL and strategies for preventing tumors.

We realize that not everyone can contribute money, and we want to make sure that everyone has the information they need. If you can afford to give, please give a little extra for the person who can't. And if you can't afford to give at this time, perhaps you might suggest to a friend or relative that they contribute in your honor rather than buying you that holiday gift. Or have a garage sale or craft sale for benefit of VHLFA.

If every family could help contribute an average of at least \$100, we would more than meet this goal. *Be a Leader in promoting research --*

If not us, then *Who* will do it?

If not now, *When*?

**Best wishes for health and peace now and throughout the coming year.** -- Joyce Graff, Peggy Marshall, Kelly Heselton, and all the Directors

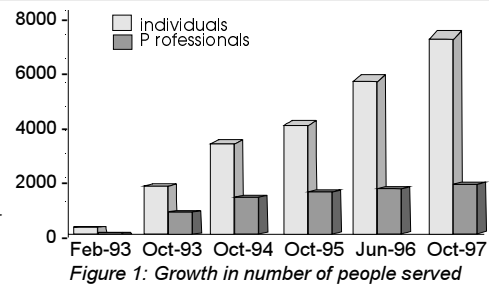


Figure 1: Growth in number of people served

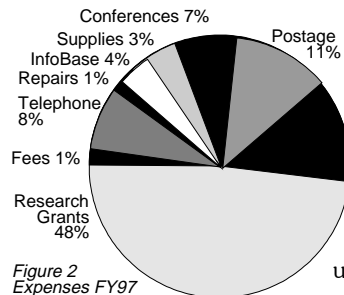


Figure 2: Expenses FY97

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