



VHL Family Forum



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The Art of Conscious Living

Using the Wisdom of Your Body and Mind to face stress, pain, and illness

by Jon Kabat-Zinn, Ph.D.

Over the course of fourteen years, more than six thousand people have attended the stress reduction program at the University of Massachusetts Medical Center. In doing so, they have embarked on a lifelong journey in an effort to regain control of their health and to attain at least some peace of mind. They come referred by their doctors for a wide range of medical problems ranging from headaches, high blood pressure, and back pain to heart disease, cancer, and AIDS. They are young and old and in-between. What they learn in the stress reduction clinic is the *how* of taking care of themselves, not as a replacement for their medical treatment but as a vitally important complement to it.

The stress clinic is not a rescue service in which people are passive recipients of support and therapeutic advice. Rather it is a vehicle for active learning, in which people can build on the strengths that they already have and come to do something for themselves to improve their own health and well-being.

In this learning process we assume from the start that as long as you are breathing, there is more right with you than there is wrong, no matter how ill or how hopeless you may feel. It will take conscious effort on your part to move in a direction of healing and inner peace, learning to work with the very stress and pain that is causing you to suffer.

The stress in our lives is now so great and so insidious that more and more people are making the deliberate decision to understand it better and to bring it under personal control. They realize the futility of waiting for someone else to make things better for them. Such a personal commitment is all the more important if you are suffering from a chronic illness or disability that imposes additional stress in your life on top of the usual pressures of living.

The problem of stress does not admit to simple-minded solutions or quick fixes. At root, stress is a natural part of living from which there is no more escape than from the human condition itself. Yet some people try to avoid stress by walling themselves off from life experience; others attempt to anesthetize themselves one way or another to escape it. Of course, it is only sensible to avoid undergoing unnecessary pain and hardship. Certainly we all need to distance ourselves from our troubles now and again.

“Facing our problems is usually the only way to get past them.”

But if escape and avoidance become our habitual ways of dealing with our problems, the problems just multiply. They don't magically go away. What does go away, or get covered over when we tune out our problems or run away from them, is our power to grow and to change and to heal. When it comes right down to it, facing our problems is usually the only way to get past them.

There is an art to facing difficulties in ways that lead to effective solutions and to inner peace and harmony. When we are able to mobilize our inner resources to face our problems artfully, we find we are usually able to orient ourselves in such a way that we can use the pressure of the problem itself to propel us

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through it, just as a sailor can position a sail to make the best use of the pressure of the wind to propel the boat. You can't sail straight into the wind, and if you only know how to sail with the wind at your back, you will only go where the wind blows you. But if you know how to use the wind energy and are patient, you can sometimes get where you

want to go. You can still be in control.

If you hope to make use of the force of your own problems to propel you in this way, you will have to be tuned in, just as the sailor is tuned in to the feel of the boat, the water, the wind, and his or her course. You will have to learn how to handle yourself under all kinds of stressful conditions, not just when the weather is sunny and the wind blowing exactly the way you want it to.

We all accept that no one controls the weather. Good sailors learn to read it carefully and respect its power. They will avoid storms if possible, but when caught in one, they know when to take down the sails, batten down the hatches, drop anchor, and ride things out, controlling what is controllable and letting go of the rest. Training, practice, and a lot of first-hand experience in all sorts of weather are required to develop such skills so that they work for you when you need them. Developing skill in facing and effectively handling the various "weather conditions" in your life is what we mean by the art of conscious living.

The issue of control is central to coping with problems and with stress. There are many forces at work in the world that are totally beyond our control and others that we sometimes think are beyond our control but really aren't. To a great extent, our ability to influence our circumstances depends on how we see things. Our beliefs about ourselves and about our own capabilities as well as how we see the world and the forces at play in it all affect what we will find possible. How we see things affects how much energy we have for doing things and our choices about where to channel what energy we do have.

For instance, at those times when you are feeling overwhelmed by the pressures in your life and you see your own efforts as ineffectual, in all likelihood you will wind up feeling depressed and helpless. Nothing will seem controllable or even worth trying to control. On the other hand, at those times when you are seeing the world as threatening but only potentially overwhelming, then feelings of insecurity rather than depression may predominate, causing you to worry incessantly about all the things you think threaten or

might threaten your sense of control. These could be real or imagined; it hardly matters in terms of the stress you will feel and the effect it will have on your life.

Feeling threatened can easily lead to feelings of anger and hostility and from there to outright aggressive behavior, driven by deep instincts to protect your position and maintain your sense of things being under control. When things do feel "under control," we might feel content for a moment. But when they go out of control again, or even *seem* to be getting out of control, our deepest insecurities can erupt. At such times we might even act in ways that are self-destructive and hurtful to others. And we will feel anything but content.

If you have a chronic illness like VHL, or a disability that prevents you from doing what you used to be able to do, whole areas of control may go up in smoke. And if your condition causes you physical

“ If you know how to use the wind energy and are patient, you can sometimes get where you want to go. You can still be in control. ”

pain that has not responded well to medical treatment, the distress you might be feeling can be compounded by emotional turmoil caused by knowing that your condition seems to be beyond even your doctor's control.

What is more, our worries about control are hardly limited to major life problems. Some of our biggest stresses actually come from our reactions to the smallest, most insignificant events when they threaten our sense of control in one way or another, from the car breaking down just when you have someplace important to go, to your children not listening to you for the tenth time in as many minutes, to the lines being "too long" at the supermarket checkout or at the bank.

It is not easy to find a word or phrase that really captures the broad range of experiences in life that cause us distress and pain and that promote in us an underlying sense of fear, insecurity, and loss of control. If we were to make a list, it would certainly include our own vulnerability and mortality. It might also include our collective capacity for cruelty and violence, as well as the colossal levels of ignorance and greed, delusion and deception, that seem to drive us and the world much of the time.

What could we possibly call the sum total of our vulnerabilities and inadequacies, our limitations and weaknesses as people, the illnesses and injuries and disabilities we may have to live with, the personal defeats and failures we have felt or fear in the future, the injustices and exploitations we suffer or fear, the losses of people we love and of our own bodies sooner

or later? It would have to be a metaphor that would not be maudlin, something that would also convey the understanding that it is not a disaster to be alive just because we feel fear and we suffer; it would have to convey the understanding that there is joy as well as suffering, hope as well as despair, calm as well as agitation, love as well as hatred, health as well as illness.

In groping to describe the aspect of the human condition that the patients in the stress clinic and, in fact, most of us, at one time or another, need to come to terms with and in some way transcend, I keep coming back to one line from the movie of Nikos Kazantzakis's novel *Zorba the Greek*. Zorba's young companion turns to him at a certain point and inquires, "Zorba, have you ever been married?" to which Zorba replies (paraphrasing somewhat) "Am I not a man? Of course I've been married. Wife, house, kids, everything . . . *the full catastrophe!*"

It was not meant to be a lament, nor does it mean

“ You are the world expert on your life, your body, and your mind, or at least you are in the best position to become that expert if you observe carefully. ”

that being married or having children is a catastrophe. Zorba's response embodies a supreme appreciation for the richness of life and the inevitability of all its dilemmas, sorrows, tragedies, and ironies. His way is to "dance" in the gale of the full catastrophe, to celebrate life, to laugh with it and at himself, even in the face of personal failure and defeat. In doing so, he is never weighed down for long, never ultimately defeated either by the world or by his own considerable folly.

Anybody who knows the book can imagine that living with Zorba must in itself have been quite the "full catastrophe" for his wife and children. As is so often the case, the public hero that others admire can leave quite a trail of private hurt in his wake. Yet ever since I first heard it, I have felt that the phrase "the full catastrophe" captures something positive about the human spirit's ability to come to grips with what is most difficult in life and to find within it room to grow in strength and wisdom. For me, facing the full catastrophe means finding and coming to terms with what is most human in ourselves. There is not one person on the planet who does not have his or her own version of the full catastrophe.

Catastrophe here does not mean disaster. Rather it means the poignant enormity of our life experience. It includes the crises and disaster but also all the little things that go wrong and that add up. The phrase reminds us that life is always in flux, that everything we think is permanent is actually only temporary and constantly changing. This includes our ideas, our opinions, our relationships, our jobs, our possessions,

our creations, our bodies, everything.

In the Stress Reduction Clinic we learn and practice the art of embracing the full catastrophe. We do this so that rather than destroying us or robbing us of our power and our hope, the storms of life will strengthen us as they teach us about living, growing, and healing in a world of flux and change and sometimes great pain. This art involves learning to see ourselves and the world in new ways, learning to work in new ways with our bodies and our thoughts and feelings and perceptions, and learning to laugh at things a little more, including ourselves, as we practice finding and maintaining our balance as best we can.

As you embark on your own journey of self-development and discovery of your inner resources for healing and for working with the full catastrophe, what you learn will come primarily from inside you, from your own experience as your life unfolds from moment to moment rather than from some external authority or teacher or belief system. Our philosophy is that you are the world expert on your life, your body, and your mind, or at least you are in the best position to become that expert if you observe carefully. Part of the adventure is to use yourself as a laboratory to find out who you are and what you are capable of doing. As Yogi Berra once said, "You can observe a lot by just watching."

Dr. Kabat-Zinn is Director of the Stress Reduction Clinic at the University of Massachusetts Medical Center, Worcester, Massachusetts. His work was recently featured in the PBS Television series *Healing and the Mind* with Bill Moyers. This article is an excerpt, reprinted with permission of the author, from Dr. Kabat-Zinn's book, *Full Catastrophe Living* (Delta Books, New York, 1990, \$12.00 US, \$15 Canada), a self-teaching guide based on his course at the Stress Reduction Clinic. A growing number of medical centers include such programs as a complement to medical treatment. If you prefer a class, ask your medical team to refer you to a program in your area. □

It's Nice to Know

"I had no idea there was such interest and so many are affected with VHL. My experiences were confined to myself, my mom, aunt, and one of my two sisters, all with VHL. The information contained in the *Forum* told me more than I ever knew. It's nice to know researchers are so interested in VHL. All I can say is 'thank you'." -- Theresa B., Tennessee

Don't Go Alone

"My family has become convinced that one should never go alone to a doctor's appointment. If the news is difficult to hear, the brain shuts off at a certain point and just won't accept any more information. It helps if there are two people there, preferably with the unaffected person taking notes. If you have to go alone, take a tape recorder. You'll be amazed when you listen to the tape the next day." -- Darlene Y., Massachusetts

The Brain/Body Connection

by Adam H., New York

Over the last several years I have done a great deal of work learning about improving the brain/body connection, using exercise and diet to make the most of my walking, balance, coordination, and speech.

I am thirty-six years old and have von Hippel-Lindau disease. I have had brain surgery six times since 1975, and I can still walk, talk, drive and even jog. I do all the listening and learning and experimenting I can. I figure if I close my body and mind to any option, I'm only hurting myself. Let me share with you what I have learned. You might find something useful here for yourself.

Everyone's health situation is different. A diet/exercise routine that's helpful for one person may be of no value to another. That's because we're all different in lots of ways, from tumor location to age to the toxicity of our daily environments, and all this stuff really does have an effect, so you've got to experiment with stuff like exercise and diet.

Do a lot of physical activity. It's boring and it seems stupid, but I've seen what happens to me when I have had to curtail my activities, so I know that exercise is really valuable. In deciding what to include in your activities, experiment.¹ Invent your own exercises that are based on the activities that are hard for you. Also, do some pre-invented stuff that seems to be beneficial to you. Do things that seem beneficial to your whole body -- like jogging -- as well as exercises that seem to work only on a specific part -- like push-ups.

As for the quantity of time per day that you spend doing this stuff, I've found that there's a point of diminishing returns. In other words, everything that you do up to that point is very beneficial, but if you exceed that point and continue to exercise, while you won't hurt yourself in any way, the benefits will lessen until you're kind of wasting your time. For me this point is at three to four hours of exercise per day. I have a feeling, though, that the optimal time per day that you want to devote to physical activities is something that varies a lot from person to person. So if you want to find out what it is for you, guess what you need to do? You have to experiment.

Varying the quantity and quality of the foods I eat have shown me that the stomach definitely has some influence over the way a person makes use of the old brain-body connection. By avoiding junk foods, or doing an herbal toxin-cleansing fast² for up to a week, the improvement afterward can be amazing. It's up to you to determine whether the possible long-term balance/coordination improvement is worth such a

radical change in your diet.

The weather seems to have an effect on my ability to move around. Warm and cold don't seem to matter in and of themselves, but sudden temperature changes definitely influence my abilities negatively. If you're smart (which I am not) you'll plan your daily activities with the weather in mind.

Always be aware of ground conditions. Wet, hilly, rocky -- things like that can have an influence on the way that you move around. To optimize your capacities you have to always be aware of conditions where you are and where you're going. You have to look ahead and be ready for what's coming. Hopefully, increased awareness of what the environment is like and how these conditions will affect you will help you, as it does me.

Except for increased awareness, I have not found any absolutes for making the best use of the environment. What works for one person under certain conditions may not work for someone else. So guess what you have to do? That's right -- always experiment.

Recently I began taking shark cartilage³ as an experiment to see if it would keep tumors from forming. I found to my surprise that I could move around better. Walking, balance, coordination -- they all improved. Several people noticed the change and commented. It is still early to say whether the benefits are lasting, but I'm very encouraged. I would love to share experiences with other people who are experimenting with shark cartilage.

Okay, that's what I've learned. What have you learned? If you have any tips for navigating through this world, please tell us about them. Why shouldn't others benefit from your experience?

Editors notes:

1. Check with your medical team to see if there are any exercises you should avoid because of specific injuries or recent treatments. The physical therapy department can assist you in designing your exercise program.
2. Be sure to check with your doctor before embarking on a highly restrictive diet. Be careful to get enough fluids and basic cell nutrients so that you do not lose muscle mass.
3. We do not have enough data on shark cartilage at this time to recommend for it or against it. As with all supplements, it is *not a substitute for*, but a possible addition to, regular medical checkups. The book *Sharks Don't Get Cancer* by I. William Lane (Avery Pub. Group, Garden City Park, NY, 1992) has generated a lot of interest in the press, and several members are interested in experimenting with it. If you are interested in joining a shark cartilage interest group, or if as a medical professional you would like to assist this group in capturing their learning in the most useful way, please contact the Alliance. □

Be Optimistic!

by Ken and Hazel M., Cambridgeshire, England

Ken and I met at an Air Force hospital where we were both working, near the town in England where our families have lived for generations. When I was pregnant with our first child, Ken began having all the symptoms of sympathetic pregnancy. We teased about his "morning sickness", until it became much too intense to be a joke. He had a brain tumor removed about the time our daughter Anne was born. Because of the stories of other tumors in his family, I asked the doctors if it could be hereditary, but was assured it was not.

With a sick husband and a tiny baby at home, I worried that I wouldn't be able to cope, but Ken quickly bounced back from the surgery and we managed just fine. We settled into a happy and comfortable life. We welcomed our daughter Jayne two years later.

A few years later Ken began experiencing pain in his back. Doctors told him he had a slipped disk, and he was undergoing treatments at the hospital clinic to stretch his spine and heal the slipped disk. He went for treatments regularly for some six years, and was

“ Laughter has been the most important ingredient in our marriage. ”

not getting better. It was our general practitioner who finally suggested that perhaps it was not a disk after all, but some kind of tumor. Tests revealed a spinal tumor which needed surgery. The stretching treatments had aggravated the tumor, which was now so involved with the spinal cord that they feared it would rupture. Surgery was very involved. While it saved his life, it left him with paralysis from the tumor down.

With this tumor, we received a diagnosis of VHL. We were told it was hereditary, and the doctors began to look elsewhere in his family to see if there were other affected relatives. Five of Ken's seven brothers and several of their children and grandchildren have VHL. His father and grandfather also had tumors. After at least four generations, the condition was finally given a name and we can now see the connections among the symptoms.

Ken worked hard with his physical therapy and began to walk again. One time when I went to pick him up from the rehabilitation treatments, seeing him, silver-haired and walking with only one crutch, I laughed that he reminded me of Long John Silver. The next time I came I brought him a stuffed parrot to perch on his shoulder. Laughter has been the most important ingredient in our marriage.

Ken began having symptoms which felt to him like a urinary tract infection. The doctor who was treating

him was convinced it was a spinal tumor and declined to do tests for an infection. By the time they did the tests, the infection was well established, and the medication he had been taking had caused a stomach ulcer. The surgery for the ulcer reduced his mobility, and it was back to rehab to learn to walk again. Our daughter Jayne, then age 12, who was always closest to her father, became very depressed. We believed that she was missing her special games and outings with her father.

Ken was very discouraged, and would often ask me "Why do you stay with me?" Our daughters were seeing the marriages of many of their friends' parents breaking up, and were getting worried, both about their father's health and about the prospect of our home breaking up.

We went to family therapy for a time, to help us all deal with our fears and emotions about Ken's health and his disability. Through that counseling we learned that Jayne was blaming herself for her father's paralysis! Some years before she had left a roller skate in the back garden, and Ken had slipped and fallen on it. Jayne was sure that it was this accident which had caused Ken's disability. As much as we tried to reassure her that it had nothing to do with her, she had convinced herself that it was so. Little by little we are working to help her let go of this self-punishment.

I decided to take action to reassure my husband and daughters. I arranged with the vicar of our local parish church for a renewal of our wedding vows. This is not normally done in the Anglican Church, but the vicar was very sweet, helped to write a special service, and arranged for coffee and a little celebration to follow. On 30 August 1986, with a group of our special friends, we renewed our vows — for better or for worse, in sickness and in health. Our daughters put tin cans and a "Just Married" banner on our car, and saved their own money to buy us a lovely gift.

Knowing now that Ken's was dealing with von Hippel-Lindau disease, and that our daughters were at

In Honor Of . . .

In celebration of birthdays, anniversaries, or other special occasions, why not consider sending an "In Your Honor" card?

The VHL Family Alliance will send a special card to your honoree in your name. The amount of your gift is not revealed unless you ask us to do so.

A supply of cards may be purchased in advance for a minimum donation of \$5 per card.

Recognition of your "In Honor Of" donation will be printed in the next issue of the newsletter.

See page 15 for ordering information.

50% risk of having it, we became very watchful for signs of the disease. We took them for eye appointments every six months. Each time one of them had a headache, I would play games with them, based upon the neurological tests I had seen the doctors do for Ken in the clinic — walk a straight line, heel to toe; touch your finger to your nose. While it may not have been very scientific, it helped me to calm myself down when I saw that they could pass these tests, and that the headaches went away like normal headaches.

Jayne is very like me, Anne is very like Ken. I guess I had convinced myself that Jayne couldn't possibly have VHL. After all, Jayne had inherited my asthma, which I felt terribly guilty about. So when they found a VHL lesion in Jayne's retina we were doubly shocked. Fortunately it was easily treated, and seems to be her only involvement. But for Ken and me, and of course for our girls, this began a second voyage with VHL.

At age 18, Anne had a brain tumor removed, and only months later surgery to remove a large tumor from her pancreas. Ken had a particularly hard time seeing Anne in the hospital after surgery — all the emotion any father would feel seeing his child in pain, along with a certain guilt because she got this disease from him. Just as I didn't want to give Jayne my asthma, so Ken certainly did not want to give them VHL. Neither of us had any choice in the matter. But here we are, and we're going to make the best of it.

It is hard work coping with Ken's disability — hard for him, and hard for me. But I have learned to do his exercises and care at home. I am a member of Carers National,¹ an association of people who care for handicapped people at home. We receive a magazine with lots of information about services and legislation of interest to handicapped people.

Ken and I laugh a lot. We have a weird sense of humor. Sometimes people look at us as though we are not taking life seriously enough. But if you can't laugh at yourself, who can you laugh at? Everybody has a different way of coping, ours is laughter.

I watched my family go through each of their operations and come to terms with their illness in their own way. At times I felt as though I was going out of my mind with worry and that my heart would break. It was hard to be cheerful all the time! I just had to be there for them.

Ken is working hard to make sure that the doctors learn as much as possible through his own case, in order to make our daughters' medical care that much better in the future. We only want them to be happy and to live life to the full.

Our family is very active now in publicizing VHL in England, through Action Research,² a charitable organization which has helped to fund the genetics research of Dr. Eamonn Maher at Cambridge University. Anne recently participated in a bike-a-thon for

cancer and VHL. She rode 27 1/2 miles and collected over £200. People are very moved that, having had brain surgery last year, Anne is working, riding in the bike-a-thon, and living a normal life thanks to the medical advances that have been made since her father's time. We are hopeful that through continued research and information sharing our children will never experience the kinds of serious problems we have seen in our own lives and in older generations.

This poster³ hangs in our kitchen, where I read it at least once a day:

Think Positive!

Greet the morning with a smile,
Ponder each new day awhile.
Don't let your mood be sad or grey,
Be sunny and enjoy the day.
The world is waiting just for you
To come and show what you can do.
So don't sit back or shy away.
This day is yours in every way.

Be Optimistic!

1. Carers National, 29 Chilworth Mews, Longon W2 3RG. In the US and Canada contact the Well Spouse Foundation, P.O. Box 801, New York, NY 10023.

2. Action Research, Vincent's House, North Parade, Horsham, W. Sussex, RH12 2DA England U.K.; in US: American Cancer Society, 1599 Clifton Rd, NE, Atlanta, GA 30329-4251; in Canada: Canadian Cancer Society, 77 Cloor St, W, Ste 1702, Toronto, Ontario, Canada.

3. Poem anonymous, poster copyright 1991, Sandecor, Germany. □

Resources

Diet, Nutrition & Cancer Prevention

suggested by G.P., Virginia

The National Institutes of Health publishes a 39-page booklet on *Diet, Nutrition, & Cancer Prevention: A Guide to Food Choices*. To obtain a free copy contact 1-800-4CANCER, or 301-496-8664, or write to the National Cancer Institute, 9000 Rockville Pike, Bethesda, MD 20892.

Participation in Genetic Research Studies

The Alliance of Genetic Support Groups has prepared a brochure *Informed Consent: Participation in Genetic Research Studies*. It describes the potential benefits and risks of participating in such a study, questions to ask, study results and confidentiality issues, and storage of genetic information. To obtain a free copy call 1-800-336-GENE, or 301-652-5553, or write to the Alliance of Genetic Support Groups, 35 Wisconsin Circle, Suite 440, Chevy Chase, MD 20815. □

Paying the Bills

by Lee-Anne B., Connecticut, and Joyce Graff

For many of us, the system for financing health care in the United States is not working. Health care costs are rising, benefits through our health insurance plans are shrinking, and a significant percentage of the population, perhaps as many as 37 million Americans, have no health insurance coverage at all. An additional 50 million Americans who may be lucky enough to have some health insurance find their coverage inadequate -- unable to meet their families' needs.

A person who has a genetic disorder stands a strong chance of being rejected for health insurance because his or her potential health care needs may make coverage unprofitable to an insurance company. Even in those instances where an individual has only a genetic predisposition to a disorder or has a disorder which is not disabling and does not require medical treatment, many companies turn down health insurance applications. If a policy is obtained, the person may discover that it doesn't cover any medical disorder already present before the purchase of the policy. Such medical disorders are known as *preexisting conditions*.

If a preexisting condition is not disclosed when asked on an application for coverage, the insurance company has the right to invalidate the policy when a claim is made. In most cases, the claimant's premium dollars will be refunded and the coverage stopped.

Most large group plans go into effect after employees have been at work for a specified length of time (usually six months) and they may not have limitations on preexisting conditions.

For family planning purposes, prenatal testing which has shown that a child will be born with a genetic disorder causes that disorder to be classified as a preexisting condition. That preexisting condition must be disclosed for health insurance purposes. Additionally, many policies consider pregnancy itself a preexisting condition when it has occurred before the policy was obtained. Thus, if you are considering having children, it might be wise to obtain health insurance or change insurance before becoming pregnant or at least before undergoing prenatal testing. Some insurance policies do not cover maternity services at all.

If you have insurance, it is probably wise to try to retain your present policy, or at least to keep it until you have had a chance to examine other possibilities thoroughly.

Before changing jobs, investigate thoroughly the coverage and preexisting conditions clause of the policies which your new employer offers.

The Consolidated Omnibus Budget Reconciliation

Act (COBRA) requires the employers of twenty or more employees to offer continuation of health care coverage for 18 months to terminated employees. People who are eligible for SSI Disability whether income eligible or not may receive COBRA coverage for as long as 29 months and some qualified dependents may be eligible for 36 months. Under this law, the person who is insured must pay the full insurance premium out of his own pocket. It is possible to convert a group plan to a less comprehensive individual policy if COBRA coverage runs out before you have found a new job. *Just don't let your coverage lapse.*

When a dependent child reaches the age of majority, a new insurance crisis may arise because he or she may no longer be covered by the parents' policy. Some policies permit you to convert coverage to an individual policy when a dependent child reaches the age of majority. The important thing is *not* to let your child's health insurance coverage lapse before obtaining new insurance in his or her own name. *Be sure to begin the process of seeking new coverage for this child at least three months before the time the policy would expire.*

For a more in-depth treatment of this subject, you will want to obtain one or more of the following, or ask your local library to obtain them for their collection.

Health Insurance Resource Guide. \$10. Prepared by the Alliance of Genetic Support Groups, 35 Wisconsin Circle, Suite 440, Chevy Chase, MD 20815. 1-800-336-GENE. Explains the different kinds of health care coverage available in the United States, and how the rules work. Also provides information on options available when insurance is denied.

Fighting Back Health Insurance Denials, by Robert Peterson, J.D., with David Tenenbaum, M.A.. \$14.95. Published by the Center for Public Representation, Inc., 121 South Pinckney Street, Madison, WI 53703. Phone 1-800-369-0338. Introduction to the world of health insurance, with tips for getting the best type of coverage and strategies for combatting claim denials. The book outlines the most common reasons claims are denied, arguments and evidence people can present to insurance companies, and what to do when all else fails.

Paying the Bills: Tips for Financing Health Care for Children with Special Needs. \$5. Prepared by New England SERVE under a grant from the Maternal and Child Health Bureau. New England SERVE, 101 Tremont Street, Suite 812, Boston, MA 02108. Phone 617-574-9493. A 56-page booklet with a good overview of the topic, and an excellent bibliography. Good information for everyone, not only for the needs of children. □

Ask the Experts . . .

Controlling Panic Attacks

Q: I have an extremely hard time with the MRIs. I am very claustrophobic. Each time I have had them I have been heavily sedated. I have nightmares about waking up inside the machine. Do you have any suggestions of how to calm myself during these tests since it appears that I will need them periodically for the rest of my life? -- *G.P., Virginia*

A: There is a wide-spread problem with patients feeling acutely claustrophobic during the MRI. Approximately 10% of MRI's are cancelled because of patient anxiety.

One research study presented during the annual meeting of the Society of Behavioral Medicine several years ago looked at the effectiveness of relaxation training prior to an MRI. The results indicated that patients who learned various relaxation techniques and practiced them during the MRI were significantly more likely to complete their MRI than patients who did not learn relaxation techniques.

Patients who are interested in using relaxation techniques during their MRI ideally should receive individual training from a trained health care professional. Most hospitals have personnel who can teach such techniques, often in the psychiatry, psychology, or social work departments. If someone cannot get access to personal training, they can purchase a copy of a relaxation audiotope and practice on their own. The most appropriate techniques include meditation and imagery; techniques such as progressive muscle relaxation or deep breathing involve movement, which may interfere with the accuracy of the MRI.

Patients need to learn and practice the relaxation technique for a minimum of several days in order to be able to practice the relaxation on their own during their MRI. There are some MRI centers which have the capacity to play audiotapes in the MRI room, but since most do not, patients need to have the skills to do the relaxation on their own.

If people have experienced severe levels of anxiety and distress during their MRI and dread their next appointment, they might benefit from several sessions with a therapist who specializes in cognitive-behavioral therapy. During a process called systematic desensitization, patients can become gradually less afraid of a specific event.

-- *Alice D. Domar, Ph.D., Senior Scientist, Mind/Body Medical Institute, New England Deaconess Hospital Division of Behavioral Medicine, Boston, MA.*

**We can't wait to meet you
in Kansas City in April!**

About the Pancreas

Q: Can you please answer some questions about the pancreas? Are cysts in the pancreas removed or left alone? Can cysts and tumors be cancerous? Is it difficult to remove part of the pancreas, or does the whole organ have to come out? If the pancreas is removed, what are the ramifications?

-- *Patti and Wayne, California chapter.*

A: In VHL, pancreatic cysts are fairly common. For the most part, these do not interfere with pancreatic function, and should be left alone. Cancer of the pancreas is very rare in VHL.

Occasionally the cysts can cause obstruction of the duct system, such that pancreatic enzymes cannot be released into the intestine, which can sometimes cause *pancreatitis* [inflammation of the pancreas], sometimes of a recurring or chronic nature, but again, this is rare. It is very uncommon for pancreatic cysts to interfere with secretion of digestive enzymes such that the individual has difficulty absorbing nutrients from food. It is even more rare for them to be so extensive as to interfere with islet cell function, resulting in diabetes.

Your medical team will monitor any pancreatic tumors to make sure they are not being aggressive in their behavior, and will recommend surgery to remove the tumor if that becomes necessary. It is true that part of the pancreas can be removed if it is essential to do so. Most surgeons would be extraordinarily reluctant to remove the entire pancreas. If the pancreas is removed, or is destroyed, then the individual is highly dependent upon enzymes that must be taken with each meal, and would be a diabetic dependent upon insulin.

-- *R. Neil Schimke, M.D., Professor of Medicine and Pediatrics, Division Director, Endocrinology, Metabolism, and Genetics, University of Kansas Medical Center, Kansas City, Kansas.* □

Barn-Raising is Self-Help

Tina Farney's delightful illustrations of the old American tradition of barn-raising on pages 9, 13, and 16 of this issue depict what self-help is all about. No one person can raise a barn. Even an enterprising young couple can't do it alone. But if the community comes together and pools their individual skills and energies, the task is manageable, and even enjoyable. Each member of the community in turn benefits from this pooling of effort. What is concentrated on helping one person one time, becomes available to help the next person when it's needed.

No one person can manage VHL alone. Not even a strong and loving couple can manage by themselves. We need our community of friends around us. When we accept their help we are not only giving them the privilege of helping us, we are committing to them that we will do the same when they need us. □

Ask the Family . . .

Dear Family,

I have chosen not to disclose the diagnosis of VHL to my 11 year old daughter until we get the results of her DNA testing. She seems too young to carry such a burden. I have been able to explain my two surgeries to her in an honest way without labeling the cause as VHL. How have other members handled sharing a VHL diagnosis with such a young family member who could also be affected?

-- Patti K., California.

Dear Patti,

I guess my best advice would be simply to leave the door open for her to ask questions, and let her be your guide. Don't give her the impression that she should not ask questions about your operations, but don't tell her more than she wants to know.

It's a little like children's questions about sex. The classic example is the six-year-old who asks where the baby next door came from. The mother blushes and launches into an involved explanation about birds and bees. "OK," says the six-year-old, "but I thought they came from Cleveland."

As long as you leave the door open, the questions will come in small doses, as she is ready for the information. Be honest with her and with yourself. And don't be afraid to open yourself to the loving support of your friends. You will need that support, and you will be giving them the privilege of sharing it with you. -- Bobbie S., California

Dear Family,

How does one explain all this to a prospective mate? One girl told me that when she gets serious with a boyfriend she has her mother sit down with him and explain about their family tree. I'm terrified that if I do that my boyfriend will head for the hills.

-- Rachael M., Massachusetts

Dear Rachael,

In the winter of 1992 I met a wonderful guy named Leo. We started dating and it began to get quite serious. It was in the springtime that my mother and sister started asking me when I was going to tell Leo about my disease. My initial reaction was that it

had slipped my mind. I kept on saying that I would do it tomorrow, but tomorrow came and went. I tried giving hints, examples, and even the "what if" approach. Nothing worked. One day I finally broke down and explained everything.

His reply was even more surprising than I expected, "Well you'll just have to tell me the symptoms that occur so that if your brain tumors grow I'll know when something is wrong, and we'll be able to take care of it together."

Today he knows everything about VHL and is very supportive.

This is something you and your boyfriend have to work out between the two of you. It's not up to your mother to tell him, it's up to you. It's an issue of trust, honesty and commitment in your relationship.

I guess my sister was right when she told me that if someone doesn't like you because of a disease, then they weren't worth liking anyway. It's a good thing Leo is worth liking. -- Siobhan G., 20, Mich.

Dear Family,

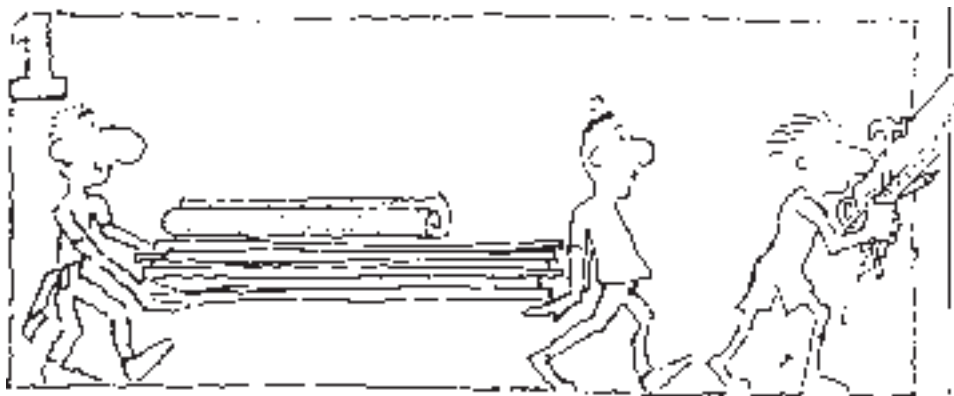
How do I talk to a person who has trouble dealing with my illness? -- Lisa W., Michigan

Dear Lisa,

The easiest way to handle a person like this is to sit them down and be honest and open with them. If they ignore the situation, it will not go away. Both of you will be better able to deal with it if it is out in the open and everyone is as comfortable as they can be. Sometimes people can't deal with it -- but at least you will have tried.

All of my female friends had no trouble talking about my illness. On the other hand, some of the guys didn't want to discuss it. One night, not long after I was diagnosed, I went out to eat with some guy friends. Shortly after we ordered, silence fell over the table. You could have heard a pin drop. "Okay," I said. "I know why you're all so quiet. We have to talk about this. Everyone has to be comfortable because it's not going to go away." Some of them asked me questions about my illness and treatments. We talked awhile and began to relax. Things were better from then on. -- Brian D., age 22, Alabama, as quoted in *Candlelighters*, Winter 1993.

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Dealing with Brain Tumors

by Susan Warnick, R.N., Maryland

Craig, my husband of 13 years, has a particularly aggressive case of VHL. He has had ten cerebellar hemangioblastomas. All of his tumors progressed rapidly once diagnosed. We've been sweethearts since high school. I became a neurological nurse in part because of Craig -- to learn to be a good medical advocate for him, and to help find the best possible treatments.

The "routine" MRI was exactly like all of the others we had experienced over the years. There is the scheduling, the waiting for the appointment, the hour long scan, and then every VHL patient's favorite pastime -- awaiting the dreaded results.

As we played out all of the possible scenarios, we never imagined the words we would hear: "Craig has four new brain tumors." We had tried to prepare for one. We have become realistic about VHL over the years, but we always tried to remain cautiously optimistic. We had told ourselves we could once again deal with a tumor that could easily be surgically removed. Four, however, was not in our game plan.

Then the news went from bad to worse. The neurosurgeon explained that my husband's tumors were all located in inoperable areas of the brain, areas where it is extremely uncommon to develop a hemangioblastoma, even for patients with VHL. Three of the four tumors were supratentorial [in the cerebrum. VHL tumors are generally in the cerebellum or the brain stem.] His prognosis was slow neurologic decline and eventually he would die from the tumors. The doctor said that he could attempt to remove the tumors by surgical resection, but the surgery would definitely leave Craig with serious neurological damage. The doctor also informed us that stereotactic radiosurgery might be an option.

This news was not encouraging. Stereotactic radiosurgery had been recommended two years earlier in 1988. At that time I had spoken with several physicians across the country and found that stereotactic radiosurgery had been used to treat very few hemangioblastomas nationwide. What I learned in 1988 was that the success on hemangioblastoma was questionable, and in some cases the treatment might not have benefited the patients at all, but caused additional problems.

However, with an open mind and no other options, I launched again into massive research. Perhaps things had changed in two years. Thankfully, it seemed they had! I now learned there are a few major medical institutions that have used both linear accelerators and gamma knife stereotactic radiosur-

Craig in the halo frame during the setup process. gery for treatment of hemangioblastomas.

Their greatest success with stereotactic radiosurgery had been treatment of AVMs [vascular lesions]. Since hemangioblastomas are vascular tumors, I reasoned we had a good chance of success. Although the number of treated hemangioblastomas in 1990 were few, the outcomes reported to me were more encouraging. In some cases the tumors had actually decreased in size. In other cases they remained stable (with no increase in size). Most important, though, in most cases the symptoms produced by the tumors subsided.

Stereotactic radiosurgery is a little bit like laser surgery, done with radiation. First the doctors put a halo frame or helmet on the patient and fix it to the head. After this is complete, the patient has a CT, MRI, or angiogram with the helmet in place. Once the exact size and location of the tumor is determined, a computer is used by a team of neurosurgeons, radiation oncologists, and radiation physicists to determine the exact dose of radiation needed to treat the lesion.

Then the patient is taken to the linear accelerator or gamma knife unit. The helmet or halo is secured to the machine to keep the patient's head motionless. As many as 201 individual beams of radiation are aimed at the tumor site from different angles. The "surgery" occurs where the beams meet, directly at the target site. While the tissue each beam passes through receives only the one-beam dose, the tumor receives the total dosage from all directions.

The procedure may last from 10 minutes to one hour depending on the dose and location, or if more than one area is being treated in the same session. In Craig's case two tumors were treated in two separate sessions.

The patient usually spends the night in the hospital and is discharged the next day. This certainly was a welcome change to the very long hospital stays Craig had experienced on previous occasions!

There are still no published articles on stereotactic

radiosurgery for treatment of hemangioblastoma, though I understand that there should be one or two articles appearing soon. I spoke with many experts nationwide concerning stereotactic radiosurgery for treatment of hemangioblastoma.

Physicians with expertise in VHL still believe that, where possible, microsurgery to remove the tumor remains the best treatment option for hemangioblastoma.

It is important to consider the potential side effects of stereotactic radiosurgery. Patients may experience nausea or headaches the day after treatment. However these discomforts usually subside quickly. There is the possibility of brain edema [swelling] around the tumor site, even months after treatment. This can be treated with steroids.

Most seriously, there is the possibility of radiation damage to surrounding brain tissue. Every precaution is taken to avoid this, but the possibility does exist and is important to consider when making a decision. This complication did occur in Craig's case. One of his tumors was close to the optic tract, and he developed a loss of peripheral vision two years after treatment. Each time there is additional treatment in a given area, there is increased risk of damage.

Usually best results of stereotactic radiosurgery are with solid tumors 2.5 cm or smaller. Doctors commonly follow small, asymptomatic hemangioblastomas on MRI scans. Many patients have small tumors which do not change for years. As long as they remain small and do not cause problems, there may be no need for action.

It is important to remember that every case is different. You need to discuss your own treatment options, and the best treatment for your particular case, with physicians you trust.

Cysts are frequently associated with hemangioblastomas. The physicians I spoke with believe stereotactic radiosurgery is best suited for the solid tumors, and that the patient would be best served to treat the cyst prior to radiosurgery. In Craig's case, this was accomplished by aspirating fluid and injecting P32.

P32 was described to me by neurosurgeon Dr. Haring J. W. Nauta as "a radioactive material which decays quickly and penetrates tissue a very short distance. It acts on the cells in the lining of the cyst and doesn't get into the body."

This procedure worked well for Craig's particular kind of cyst. There are other ways of treating cysts -- again, talk with your physician about the best treatment plan for you.

Even with all of these considerations, the physicians I spoke with believe stereotactic radiosurgery has a place in the treatment of VHL hemangioblastomas, especially for those otherwise considered inoperable. They also agree that more experience is needed with hemangioblastomas before we will know all of the benefits. Dr. Tomasz Helenowski of the Chicago

Neurosurgical Center has had very promising early results. Dr. L. Dade Lunsford and Dr. George Alvaro at Presbyterian University Hospital in Pittsburgh have had similar good results in four of their eight patients, but four others have had recurrence of the lesions. All of the treatment centers I contacted reported similar results. It also appears that once the hemangioblastoma is significantly impaired, the associated cyst is also controlled.

The total number of hemangioblastomas treated with stereotactic radiosurgery remains statistically small. The physicians agree that more data needs to be collected before this treatment can be considered a cure for hemangioblastomas.

I can only say that in our own case, stereotactic radiosurgery was the best option, even with the complications. Craig's vision seems to be improving and may get back to where it was before the treatment. We have experienced VHL at its most cruel, and welcomed stereotactic radiosurgery as a treatment option. It provided us with hope when no hope was to be found.

I am happy to report that Craig's most recent scan (June 1993) is stable, which is very good news, and we are very grateful. He walks with only modest balance problems from prior episodes, speaks well, and drives. He will continue to pursue his Master's degree in pastoral counseling in the fall.

We would like to thank the entire medical team at Johns Hopkins Hospital for their compassion and concern during that difficult time. Special thanks go to Ben Carson, M.D.; Haring J.W. Nauta, M.D.; Moody D. Wharam, M.D.; Carol James, P.A., and Jennifer Bucholtz, R.N.

Many thanks to the physicians who have generously given me their time and helped immensely with the writing of this article, especially Dr. Tomasz Helenowski, Dr. George Alvaro, Dr. L. Dade Lunsford, Dr. Haring Nauta, Dr. Jay Loeffler and Dr. Moody Wharam. Special thanks to Dr. Lars Leksell who pioneered stereotactic radiosurgery at the Carolinska Institute in Stockholm, Sweden.

Please let us know if you have had this treatment and would be willing to share your experience with researchers trying to determine the effectiveness of stereotactic radiosurgery in treating VHL.

A List of Centers in the U.S. which perform stereotactic radiosurgery with gamma knife machines can be obtained from the American Brain Tumor Association, 2720 River Road, Des Plaines, IL 60018. Tel: 800-886-2282, Fax: 708-827-9918. The Alliance will help you locate a center near you which performs stereotactic radiosurgery with linear accelerator or gamma knife machines.

References: American Brain Tumor Association newsletter, *The Message Line*, Spring 1989, "Research Update: Stereotactic Gamma Knife Radiosurgery". Jennifer Bucholtz, RN, "Stereotactic Radiosurgery, Standard Teaching Plan," Johns Hopkins Hospital, 1992. Griff Harsh, MD, and David A. Larson, MD, "Gamma Knife Treats Brain Lesions," University of California San Francisco *Clinical Profile* 4:1 (1992). Jay S. Loeffler, M.D., Eben Alexander II, MD, "The Role of Stereotactic Radiosurgery in the management of Intracranial Tumors," *Oncology* 4:3 (March 1990), 21-38. L. Dade Lunsford, "Stereotactic Radiosurgery: At the Threshold or at the Crossroads," *Neurosurgery*, 32:5 (May 1993) 799-804. Haring J. W. Nauta, MD, Ph.D., M. Waspen Farra, MD, and Moody D. Wharam, MD, article in preparation for publication, "The Role of Stereotactic Radiosurgery in the Treatment of CNS Hemangioblastomas Associated with von

PAC-Man Surgery

by Patti K., California

It was a Monday, February 23, 1993. We drove the four hours to San Francisco -- not to go to a great restaurant or to see a show or even to see friends, but for brain surgery. The sense of unreality I felt in the car journey was to last the next two days. At times it was more intense. At others less so.

After preliminary medical screening I was taken to meet the radiation oncologist who would be part of a five-man team performing my surgery the following day. He showed me the Gamma Knife stereotactic radiosurgery machine. It was spherical in shape with a pac-man like opening on one side, and looked like it had just landed from Mars. My head would go in this opening, fitted with one of the helmets that lined the room. The choice of helmet would depend on what size hole the medical team decided would be used to shoot radiation beams through the 201 holes in the helmet to the tumor in my brain. The helmet would be attached to a metal ring screwed into my head so nothing could move. The procedure was programmed by a computer. Questions were raised by me about possible power outages -- we had been having very heavy thunderstorms in February. Jokes were made about getting the right angle.

At 6:30 the following morning I went to the pre-op room. An I.V. was started. I was given a mild tranquilizer. A neurosurgeon, part of the team, arrived to screw the aluminum frame onto my head. Unreality became less so, as I could feel the four screws going into my scalp. With this contraption on my head I was sent for a final brain MRI and CT scan. Hopefully nothing would move. The team then interpreted these films and determined the dosage of radiation and angles, while I waited in my hospital room.

After about two hours I was called down to go into the Gamma Knife machine. The doctors were huddled together in the small control room which reminded me of an air traffic control tower. The helmet was fitted -- luckily one with small holes -- and jokes were again made about getting the correct angle. I was lying face down and advanced mechanically into the machine. The doors closed. My head and neck were inside, my body outside. Everyone left the room for fear of exposure to radiation. I wondered about the rest of my body too.¹

Countdown was for 9 1/2 minutes. After 3 minutes the gamma knife nurse's voice told me I was doing great and only had 6 minutes to go. Again with 3 minutes left, then with 30 seconds left. I began my own mental countdown. 30-29-28....0. I was mechanically withdrawn and doctors entered the room. Everyone seemed very pleased and relieved, and I felt like opening champagne. My husband was outside and I was sent back up to my hospital room where I was

told I could have a late lunch!

I spent that night at the hospital and was released the following morning. I had only very minor post-operative symptoms. Mild nausea, mild headaches (which I nipped before they developed with Tylenol) and tiredness. A follow-up MRI was scheduled for six months later to determine if indeed they did get the right angle.

Was the surgery successful? Because this hemangioblastoma was so very small (4mm) and was not causing symptoms, doctors had said we could wait until symptoms developed, or try this as an effort to contain the growth of the lesion. Because the tumor was in a place where the danger to surrounding tissues was low, we went ahead with it. Six months later, the hemangioblastoma is the same size -- good news!

I feel lucky to have been able to benefit from this type of procedure. It was not invasive and sure beat invasive surgery, the neuro-intensive care unit, and a much longer hospital stay. It gives me peace of mind to know that this tumor has been dealt with, and is unlikely to grow and become a problem to me.

1. Dr. Wharam advises that the beam of radiation is so finely focused that the danger to tissues even one inch away is negligible. □

Grandma's Wisdom

"My Grandmother always said that Dad's brain tumor was caused by hitting his head in the hay loft."

"My Grandmother was horrified when I suggested that my father's brain tumor was caused by a genetic disease. 'Heavens, no!,' she said. 'It was caused by a high school football injury!'"

Actually, Grandma may well have been engaging in some reasonable deductive reasoning. While the VHL brain tumors in these cases were *not caused* by these injuries -- they were caused by defective genes -- the injury might have been the trigger which spurred its growth. There are a few reports in the medical literature in which head injury preceded symptomatic cerebellar hemangioblastoma development.

In two cases with which I am familiar, cerebellar hemangioblastomas were diagnosed within six months of head injuries sustained in automobile and industrial accidents. Both head injuries were significant, involving loss of consciousness. It is likely that small quiescent cerebellar hemangioblastomas were present before the head injuries. It is possible that head trauma caused the tumors to grow.

This is not something we can plan for or avoid, nor is it a reason to limit the activity of people with VHL. For example, a person with VHL could safely participate in almost all school sports, but boxing would not be a good idea because of repeated head trauma. Nonetheless it does help to justify Grandma's deductions.

-- Dr. James M. Lamiell, Col., U.S. Army, Fort Sam Houston, Texas □

Alliance News

We have received our official 501(c)(3) status from the IRS, meaning that all donations to the Alliance are **tax deductible** on U.S. income taxes.

To participate in a **local meeting**, please call the 800 number for a time and place near you, or to offer your assistance in planning a local meeting.

To reach us **electronically** via MCI write to Joyce Graff, 3996438. On the internet write to joyce.graff@zko.mts.dec.com.

Plans for the **Annual Meeting** are taking shape. We will be meeting in Kansas City in April 1994. Please save up vacation time, frequent flyer miles, etc., so that you can join us in April!

We have planned some topics already and are lining up speakers. We would like you to help us plan the rest. What do you want to talk about? What do you want to hear? **This is your meeting** -- you get to help set the agenda.

VHL Family Alliance Annual Meeting April 15-17, 1994

Kansas City, Kansas

in the heart of the United States

Topics so far - *please let us know what you would like to add to the agenda. Proposals are welcome from family members and professionals.*

Living with VHL

Finding the Gene -- what it means to me

Advances in Treatments for the Eye

Advances in Treatments for CNS Lesions

Advances in Treatments for Kidney and Pancreas

Advances in Treatment of Adrenal Glands

Insurance Coverage, Legal Protection

Pros & Cons of Radiation for Diagnosis & Treatment

Having Babies -- Information, Options

Other Family Topics -- your choice

Time to Get Acquainted

We hope you and your loved ones are well.

-- Joyce, Peggy, Susan, Hazel, Lois, and Darlene

Mississippi Chapter

by Peggy M., Mississippi

I am happy to announce that the Mississippi Chapter of the VHL Family Alliance has been formed. After attending a support meeting in June and meeting with Joyce Graff, I knew that I wanted to be a part of the Alliance.

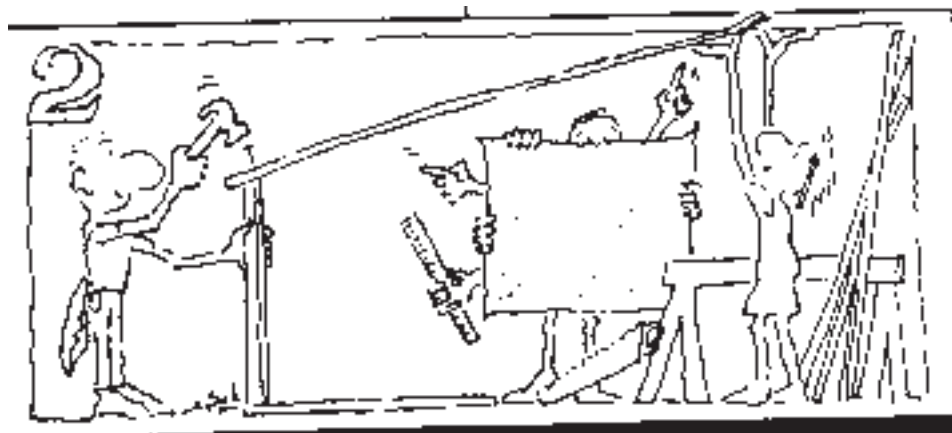
I have 35 years experience with VHL, having eye and brain tumors. I have one daughter affected since age 14, including involvement of the eye, brain, spinal cord, kidneys, and pancreas. The good news is it has not kept her down! Through it all she was determined to finish nursing school, and in December of 1992 she graduated and received her R.N., B.S.N. At age 31 her goal became a reality.

This was a particularly great accomplishment considering that she lost the use of her right arm and hand after her last brain surgery in 1991! She is currently working in the psychiatric division of our local hospital, with no major work limitations. She is a special woman who brings to nursing a very special empathy.

I have two sisters and one brother who are affected, and one unaffected sister. I also have two nephews that are affected. Over the years we have depended on each other for support and strength. We know the positive uplift of that support.

Four years ago through a local doctor in our small town I was given a name of a woman with VHL who wanted to meet me. Her father and several members of her family had been diagnosed with VHL. It was remarkable to meet someone else with similar problems. It has also taught me how valuable support groups like this can be. You no longer have to feel alone with a syndrome that only your family has experienced.

Through the Family Alliance we can communicate and support each other. I look forward to being associated with the Alliance and adding my support in any way I can. □



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☐ Professional (physician, nurse, etc.) specialty _____

☐ Other (please specify) _____

☐ I am interested in participating in a local support group

Preplanning information for the Annual Meeting (not a firm commitment)

I/we ☐ do ☐ do not plan to attend April 15-17 in Kansas City.

We will be _____ (number of) people

I would like to see a session at the Annual Meeting on the topic of

☐ Children and VHL -- stresses and strains on affected and unaffected children

☐ Families dealing with stress

☐ _____

☐ _____

☐ _____

Things I particularly liked in this issue of the newsletter:

☐ Art of Conscious Living

☐ Paying the Bills

☐ Brain/Body Connection

☐ Be Optimistic

☐ Dealing with Brain Tumors

☐ PAC-Man Surgery

☐ Resources

☐ Questions & Answers

☐ Other: _____

Things I would change: _____

Please share with us your own thoughts and experiences, comments and questions -- use as much paper as you wish.

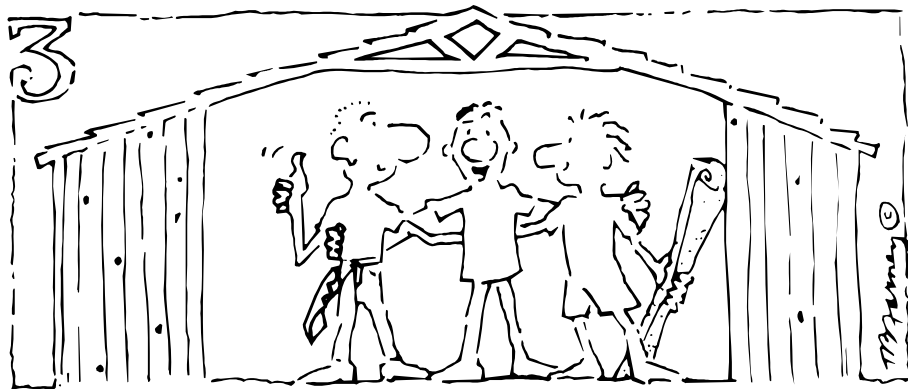
In Honor Of . . . donations (minimum \$5):

I am enclosing a donation ☐ In Memory Of ☐ In Honor Of

Honoree's Name _____

Please send card to (name and address) _____

Return to: VHL Family Alliance, 171 Clinton Road, Brookline, MA 02146



"Self-help is barn raising revisited." -- Len Borman, founder, Illinois Self-Help Center.

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VHL Family Forum

Newsletter of the VHL Family Alliance
171 Clinton Road
Brookline, MA 02146

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