

Stereotactic Radiosurgery or Gamma Knife

In April 2005 the VHL Family Alliance opened a survey for people with VHL who have had Stereotactic Radiosurgery (SRS). SRS is the generic name for a treatment that is sometimes called by the name of the machine, like Gamma Knife or Cyberknife. Fifty-seven people responded to our survey, sharing their experiences. 46 (81%) of these respondents had a total of 63 planned treatments with SRS. 11 (19%) considered it, but chose not to have the procedure.

How did you first become aware of SRS? 35 people (61%) reported that the option was first raised by their neurosurgeon. Another five people learned about it through VHLFA.

Which of the advertised characteristics attracted you to this procedure? Here people could check more than one response, so the fractions add up to more than 100%. 46 (81%) wanted to avoid open brain surgery, and 35 (61%) wanted to avoid the complications of open surgery. About one-third were attracted by the claim that it was easy ("like a trip to the dentist") and that you could go right back to work. In five instances, the patient was told this was his or her only option, as the tumor was not approachable by open surgery.

What research did you do? People could check multiple answers. 47 (82%) spoke with a neurosurgeon, 28 (49%) spoke with a radiation oncologist, 23 (40%) read the VHL Handbook, and 11 (19%) read the articles on the VHL website. 18 (32%) got second opinions to confirm the plan. Only 10 (18%) spoke with another person with VHL who had had the procedure.

What helped the most in making the decision to proceed? 24 (57%) cited trust in their neurosurgeon. 17 (40%) said they just really did not want to go through surgery, and they felt there was "no apparent downside." Five considered it their only option.

Of the 11 people (19% of those responding) who chose not to go with SRS, one is still in the decision-making process. The other ten did thoughtful research with their surgical teams, and concluded that open surgery would be a better alternative in their particular circumstances. Their open surgeries were successful.

Half the treatments occurred before 2002. 16 people out of 46 (35%) have had only one planned treatment, which might have been delivered in more than one session. 7 (15%) have had two treatments, 8 (17%) have had three treatments, and 12 (26%) have had four or more treatments, for a total of 54 treatments reported.

Of these 54 treatments, in 24 cases (52%), the treatment was administered in one session. In 2 cases, the treatment was spread over three sessions, and in 7 (12%) cases it was spread over four or more sessions. 26 (46%) were done with a Gamma Knife machine, 13 (23%) with a Linear Accelerator. Two Cyberknife treatments were reported, one Proton beam, one Intensity-Modulated Radiation Therapy (IMRT), and the 13 remaining (23%) were unsure what machine was used.

21 treatments (37%) occurred before the year 2000; 12 (26%) between 2001 and 2002, and 21 (37%) occurred since 2003. We do see an rise in the number of times SRS is being used, and a significant rise in interest. This change is likely due to the larger number of machine manufacturers and instruments today. Prior to 2000, all treatments were either by the Gamma Knife or Lineac machines.

We asked people how well they felt before and after the procedure, and over the course of the following year. Nearly everyone complained about the attachment of the frame or helmet to the skull, and wished there were a way to avoid them. Several of the newer machines do not require a frame.

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Frame or not, there was usually some discomfort on the day after the procedure.

Of the 54 treatments reported, 27 (50%) of the patients felt pretty much the same throughout the course of the post-treatment year. Nearly all of these were treated with some medication for swelling and/or pain, which the medications were usually able to control.

Six people (11%) said they felt quite sick at three months post-procedure. The tumor was growing, or the swelling was hard to control. Two of these required open surgery. Four gradually got better after the first three months without additional intervention.

Nine (17%) did not feel their worst until six months after the procedure. Five of these went on to require surgical removal of the tumor. One woman died from uncontrolled swelling and complications. One person complained of memory problems for two years following the procedure, but reported that this has normalized after two years. Three began improving after the six months mark, but it was a very difficult 18 months.

Was the treatment successful? In only 20 cases (37%) the tumor(s) shrank. Three (6%) grew. Six (11%) required surgery, and in seven cases, it's a bit early to say but the patients are doing well.

In 17 (31%) cases the tumor stayed the same size. While it is good that the tumors did not grow, we do not yet have sufficient long-term data to know whether the tumor has been permanently disabled, or whether it is only in a quiet period.

Would you recommend this treatment to others? The answers aligned perfectly with the outcomes: 68% (with good outcomes) said yes, and (19%) said no.

I first went through the summarized data, and then went back and read each person's survey form to get a clearer picture of his or her own experience. As I read through them I began to realize that I could pretty much predict the outcome based on the amount of research a person had done. If someone reported having read everything available on the internet, talked with a neurosurgeon and a radiation oncologist, and one or more people who had had the procedure, and made a thoughtful evaluation of the situation with this broad medical team, then you could pretty much rest assured that they were going to have a good outcome, with or without SRS.

But if someone reported having listened only to one doctor's opinion, and having taken it on faith with no further evaluation, then you could sense danger ahead. This was especially true if the SRS option was first suggested by a trusted neurosurgeon. That neurosurgeon may not have done all the careful consideration, but may just be letting you

know there are options besides surgery. As one respondent said, "I followed the recommendation without doing my own homework. If I had it to do over again, I would have read more about the procedure before embarking on it."

Because of the reports of bad outcomes, we asked ourselves if we should recommend against stereotactic radiosurgery for VHL. But in fairness, while there are some bad outcomes, there are lots of good outcomes as well. As with any new technology, it has its stunning successes, and its limitations. We have to understand where the limits are in order to use this new tool to its best advantage. It can be a very valuable tool. It can be exactly the right thing to do -- or not. There is no simple formula; each case has to be considered on its own.

We have seen good and poor outcomes from each of the machines. The machine is not the critical factor; the treatment plan and the experience of the operator are much more important. Be sure that somewhere in the planning you add the experience of a physician who has treated hemangioblastomas and understands how these soft tissue tumors will respond. The more experienced physicians qualify tumors carefully to avoid problems.

We were glad to see that the survey results confirm the current information in the VHL Handbook. If you have not yet read the newsletter articles describing patient experiences with SRS, make that an important part of your research. <http://vhl.org/stereo> Remember that 68% had good outcomes; 19% did not. Another ten people had good outcomes with open surgery, which is also success. Be sure you achieve a successful outcome, and help us shrink the 19%.

The lessons from this survey are summarized well by the respondents:

1. Do your homework. The people who had the best responses reported having spoken with both a neurosurgeon and a radiation oncologist, reading the Handbook, and reading the comments of other people with VHL who had had the procedure.

2. Tumors should be small. Larger tumors, or ones with an associated cyst, were more likely to respond badly. "I now think it was a mistake to treat five brain tumors in one day, especially when two of the tumors were large."

3. Take it easy for months after the procedure. This really is surgery. Give your body lots of time to heal. "I was feeling so good that I went tubing in the snow. After bouncing around I got light headed, passed out, and was air-lifted to a hospital. After a day I went home. My doctor said that after a surgery you are supposed to take it easy. It just didn't feel like a surgery."

4. Manage the swelling. One patient was told that "Edema is a rare occurrence." For people with

VHL, this is not a rare occurrence, it is a very common experience. You and your doctor need to know before the treatment how you are going to treat the swelling that will occur after the procedure. Your team needs to calculate to what extent a tumor of this size is likely to swell, how the swelling will be managed, and anticipate the problem.

5. It's a treatment; it's not a "cure". "I misun-

derstood that this procedure would prevent future hemangioblastomas, so I stopped getting MRIs. My tumor grew back and needed to be removed surgically."

6. In sum: As one respondent put it, "Do your research. SRS won't work on every tumor. The tumor cannot be too large or have a cyst. If it works, it's a true blessing."

Ask the Family: Affected Children

Question: I have a daughter who will soon be five years old. This afternoon I received her test results, and she tested positive for VHL..

Is there anybody with children of the same age? I have the VHL Handbook, but I'm having a hard time dealing with this information emotionally. It's a great shock for me at the moment. I hope I get over it soon. I know how hard it can be to live with VHL, and now that I know my daughter has it, it seems even more difficult. — *Nathalie D., Europe*

Response: I can imagine what you must be feeling right now. My father has VHL, and so do I. My son was tested two weeks after birth and I learned in a phone call a few weeks later that he had tested positive for VHL.

All I can say is: Hang in there. The initial shock will wear off! Arm yourself with knowledge, as you are seeking to do. My son is almost 9 now and thank God, has yet to show any signs of VHL problems. Remember, testing positive for the VHL gene is not a guarantee of problems, it just means you need to be more diligent with watch for a problem so it can be managed early.

My son sees a retina specialist yearly, to check for hemangiomas, has a blood test yearly to check for catecholamines (a screening for pheochromocytoma). He also has a yearly abdominal

ultrasound. For now, my doctors in Boston at the VHL clinic say this is sufficient. In a few years we will do the first MRI. I print out copies of the Handbook from <http://www.vhl.org/handbook>, keep a copy for myself, and give one to each of my child's doctors. The screening advice is there and it's a great place to start. I will also add, if your doctors don't feel the screening is needed (something I have run into with doctors not familiar with VHL) - then take your handbook, and consult another doctor.

I would also recommend consulting a genetic counselor about talking to your child regarding VHL and the screenings you are putting your child through. For my son at age 9, we haven't had the talk about VHL (by my choice, that will come later). For now, I have decided on a more age-appropriate explanation about why we have the screenings,

I tell him there is a family history, and that we are "making sure nothing is wrong, but being able to take care of it when and if something does happen".) I feel it's important to be honest, but not overwhelming with information.

I hope that helps. Feel free to write to the online support group (vhlfa@yahoogroups.com), or to the VHL Family Alliance (info@vhl.org), or call 1-800-767-4845 or 1-617-277-5667. — *Maria L., Maine*

Recycle for VHL!

Free mailing envelopes are available in which you can recycle empty ink cartridges and old cell phones instead of throwing them away. VHLFA will receive a commission for every ink cartridge and cell phone received.

There are over 200 million empty ink cartridges and old cell phones being thrown away annually. Nearly every cartridge except Epson has a value to a recycler. Thirteen brand names of telephones have recycle value. Old laptop and handheld computers, including PDAs and Palmtops, can also be recycled.

You might have a recycle drive at your school or workplace, or put a supply of mailers at a post office or local store.

Call Brian Lesser at Cartridges for Kids (800-420-0235) to get additional prepaid bags or shipping labels.

Due to postal and customs regulations, this program operates only in the United States.



Cancer survivors gather for support

About 1,000 attend Lambeau Field event

By Rowena Vergara, vergara@greenbaypressgazette.com.

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Cancer survivor Kathy Sladky of Green Bay lost vision in her left eye, walks with limited mobility and, as a result of surgery, has a metal plate in the back of her head. If that "soft spot" is bumped, she would see stars.

But none of that stops her from walking, driving, and living by her own terms.

"I look at life a lot differently," said the 39-year-old woman who has dealt with von Hippel-Lindau disease, a rare form of cancer that causes abnormal growths of tumors throughout the body.

At age 20, in 1985, she was diagnosed with cancer after a neurologist discovered a tumor "the size of a golf ball." (See *Is VHL Cancer?* below)

"I had almost died from it," she said.

It was the first of seven surgeries Sladky would endure over the next 20 years.

Sladky was one of nearly 1,000 attendees at a cancer survivors celebration event Tuesday, June 7, at Lambeau Field in Green Bay — a day sponsored by St. Vincent Hospital in partnership with the Green Bay Packers.

From individuals who have been cancer-free to those still undergoing treatment, hundreds gathered in honor of National Cancer Survivors' Day, an annual event celebrated in more than 750 cities throughout the United States and Canada.

In the state, lung cancer is the leading cause of cancer deaths in males and females, according to the American Cancer Society. Prostate cancer is the most frequently diagnosed cancer among Wisconsin men, and breast cancer continues to be the leading cause of cancer diagnosed in Wisconsin women. More than 75 percent of all cancers are diagnosed in people 55 and older.

For many cancer survivors, the love and continuous support from family members have helped them beat the odds.

Curtis Johnson finds motivation in his granddaughter Abby, his daughter Sara, and his dog, he said.

"She (Abby) had a lot to do with his getting better. Now that he's not going through treatments, he's starting to get his strength back," said daughter Sara Gerharz.

Sladky has turned to her faith in God for guidance. "I've been accepting things the way they are. This is what God dealt me and I'll do the best I can and accept it," she said.

Earl Steinbrecher credits his wife, Beth, for keeping an eye out for him for the past 20 years

Kathy Sladky,
Wisconsin



through his instances of melanoma cancer and prostate cancer.

"Any time one hears cancer, it's devastating. But, you have to be strong and stand by your spouse," Beth Steinbrecher said.

Many survivors said the idea of cancer never occurred to them until they personally acquired it.

Sometimes, it comes without warning, said Greg Cooley, a radiation oncologist at St. Vincent Hospital.

"Most times you don't have symptoms from these cancers until they're more advanced. It's important to catch these when they're asymptomatic," Cooley said.

For Georgia Burr, who wore a shirt that read, "Dear Cancer, I win you lose," one doctor's visit has made all the difference. With two operations and radiation for seven weeks, she has been "cancer free for three years now."

"Don't put off your mammogram or physical. I was going to put it off, but I might have been too late," she said.

Editor's Note: Is VHL Cancer?

Von Hippel-Lindau is known as a familial cancer syndrome. The simple definition of cancer is "cell growth out of control." Using that definition, all the tumors of VHL are cancer.

Some doctors do not consider a tumor to be "cancer" unless it has at least the potential to metastasize, or spread to other tissues. Using this definition, the VHL tumors of the eye, brain, and spinal cord tumors are not cancer, but VHL tumors of the kidney and pancreas are cancer because the larger tumors can metastasize. On rare occasions, the adrenal tumors (pheochromocytomas) have been seen to metastasize as well. People who have a

diagnosis of VHL have a screening protocol that is essentially an “early warning” system that allows them to be watchful, and hopefully diagnose any kidney or pancreatic tumors at early stages so that they can be monitored and dealt with before they spread.

Some of the other tumors of VHL have cells that, under the microscope, are cancer cells, and are sometimes diagnosed as cancer even though they do not spread. The endolymphatic sac tumor (ELST), for example, sometimes comes back with a pathology report of “low grade adenocarcinoma with low metastatic potential.” From studying these tumors over many years, we have learned that they almost never spread to other tissues. Nonetheless, an ELST

can be “locally invasive” meaning that it can tunnel into nearby bone and tissue, so it needs to be controlled to preserve hearing and balance. (See Alex’s story, page 8.)

Cystadenomas of the epididymis have sometimes been misdiagnosed as more dangerous tumors, but we now know from watching their “natural history” that they do not metastasize. If your doctors seem to be more concerned about the metastatic potential of a tumor of VHL than the Handbook would seem to indicate, please be sure to get a second opinion before any proposed surgery, radiation, or chemotherapy. Their advice may be exactly correct, or it might be more than necessary.

Radiation Causes Cancer, but rarely

A pair of new studies published in July 2005 indicates that even low doses of radiation — such as those delivered during medical imaging studies — are likely to increase a person’s risk of developing cancer.

Exposure to everyday sources of radiation, mostly medical x-rays, raises the risk of cancer but not by much, according to the National Research Council.

People should think twice about having unnecessary high-dose x-rays such as the full-body CT scans being offered by some clinics, the panel advised, but otherwise should be reassured by the findings.

Most sources of radiation are natural — gamma rays from space, and radon from the ground, air, and water. “These sources account for about 82% of human exposure,” the report reads. The 18% of human-made radiation comes mostly from medical radiation but also tobacco, televisions, and smoke detectors.

The National Research Council is part of the National Academy of Sciences, an independent organization set up by Congress to guide government on matters of health and science.

The second study, published in the *British Medical Journal*, examined nuclear industry workers in 15 countries who had been exposed to low doses of radiation over an extended period of time, finding that these workers had a slightly higher risk of cancer death.

“We have shown that even low doses of radiation cause cancer,” said Dr. Elisabeth Cardis, head of the radiation group at the International Agency for Research on Cancer (IARC) in Lyon, France.

In its commentary, PBS News reported that a full-body scan is equivalent to 100 times a mammogram. If you had a full-body scan annually beginning in middle age, you would have a 1/50 (2%) chance of dying of cancer. That’s about the same as your risk of dying in an automobile accident. David Ropeik of the Harvard Center for Risk Analysis says that he is actually reassured by the report. “Yes, radiation does cause cancer, but doesn’t cause very much compared to a lot of other things that can. And I’m reassured to find that in the most updated findings here.”

References: National Research Council, “Health Risks from Exposure to Low Levels of Ionizing Radiation: BEIR VII Phase 2,” and Frijheid et al, “Risk of cancer after low doses of ionising radiation: retrospective cohort study in 15 countries.” *BMJ*. 2005 Jul 9;331(7508):77. Epub 2005 Jun 29. Additional information from PBS News, from Reuters Health, and from the X-ray Digital Community (AuntMinnie.com) was used in the preparation of this article. Full text is available at www.pubmed.com, PMID 15987704.

Grants to Individuals

At this website on the internet there is a list of opportunities for grants to individuals who may be visually impaired, or have hearing loss or other physical impairments.

<http://www.lib.msu.edu/harris23/grants/3disable.htm>

New Chairman for Kansas and Missouri

Barbara S., Kansas

VHL has been connected to my family since before I was born. The term was introduced to my family for the first time in 1959.

My Aunt Rae Donna lost the sight in her right eye one afternoon while at work at Hallmark Cards in Kansas City, Missouri.

She was sent for an eye examination at the University of Kansas (KU) Medical Center where several Ophthalmologists checked her. One of them threw out the name "Von Hippel" as a possibility for the cause. Because she was pregnant at the time with my cousin Rhonda, the consensus was that as soon as my Aunt delivered the baby she might regain the sight in her eye. — Wrong!

In those days eye doctors still thought that "Von Hippel's disease" affected only the eye, and "Lindau's disease" affected the central nervous system. They didn't realize it was all one syndrome. No one made the medical connection between Rae Donna's eye problem and her brother Robert, my father. Robert experienced a series of brain tumors, and kidney cancer that metastasized to his lungs, claiming his life in 1977.

Years later, my cousin Rhonda graduated from the University of Missouri at Columbia in 1980, and took a job with the University. On a routine eye examination, doctors discovered that she too had hemangiomas in one of her eyes.

An alert doctor there, Dr. Carl Ide, treated the eye with laser surgery and recommended she have further tests with endocrinologist Dr. David Gardner. Various tests showed no other medical problems. In talking to Rhonda, Dr. Gardner inquired if any other family members had any similar problems. Rhonda told him her mother (Rae Donna) had high blood pressure and many headaches. Dr. Gardner suggested that Rhonda tell her Mother to contact her family doctor about having a test to see if she might have a pheochromocytoma.

The test showed abnormal readings, suggesting that she might have this tumor of the adrenal glands. Rae Donna went to the University of Missouri to see Dr. Gardner. Von Hippel-Lindau was diagnosed, and geneticist Dr. Sandra Davenport became involved.

Dr. Davenport traced our family tree, and realized that VHL was the cause of my Father's demise. My aunt was told that in 1980 that there were only 64 cases of confirmed von Hippel-Lindau cases on record. In those days

VHL was very hard to diagnose, and information about confirmed cases were not kept in an organized manner. Many families were told incorrect stories like that. Now we know that VHL affects one person in 32,000, in every ethnic group, worldwide.



Most of my knowledge and support for my own medical problems came from my aunt, uncle and cousin. Many in our family line chose to ignore the warnings about the possibility of "Von Hippel". Little was understood then about how to manage the disease.

After being diagnosed with my own case of VHL in my eyes in 1979, I spent a week in the hospital trying to recover from what happens IF you let the eye angiomas go untreated. I had a severely detached retina and needed additional surgeries to bring the disease in my eye under control. The maximum vision they were able to restore in my eye was 40%; now it is zero. This is a good example of what can and does happen if the disease is left untreated. Other than the multiple surgeries of both eyes, I have mostly remained unaffected—something I attribute to my persistence to stay on top of the disease, and also to the choices I have made to eat healthy and exercise in life.

My sister was not so fortunate. Vicky's procedures ranged from having her pancreas removed in a Whipple procedure done when she was first diagnosed with the disease in the late 1980's, multiple brain surgeries, and finally succumbing to this disease in the Fall of 2004. I know how hard this has been on all my family but mostly, my Mother.

Because of this, I have personally taken the position that it is my responsibility to fight, to manage my own health, to do whatever I can to help further the research on Von Hippel-Lindau disease, and to help others to live well with VHL while we all work for a cure. This is why I have elected to become the VHLFA chapter chair for Missouri and Kansas.

Please feel free to e-mail me or call me with your requests. My email address is us-ks@vhl.org or us-mo@vhl.org, or call the office for my telephone number. I am at your service.

Brooke Elizabeth McLaurin: Miss North Carolina 2005

After months of debilitating headaches and bouts of vomiting, on March 7, 2003, I underwent a routine brain MRI to determine their cause. I had no idea that once the MRI was completed I would be rushed to the emergency room at Cape Fear Valley Medical Center in a wheelchair, admitted to the Neurosurgical Step-Down Unit, and scheduled for brain surgery first thing the next morning. I will never forget that night, as I lay alone in my room, terrified of what was to come. At the age of 21, I have to admit all I wanted was my mother by my side, but as a patient in ICU that is against policy.

I was diagnosed with a brain tumor known as a hemangioblastoma. It was the size of a 9 mm bullet and was surrounded by a cyst the size of a large egg. The tumor was located in the cerebellum. This is the second largest part of the brain and is located at the back of the head. The functions of the cerebellum are to produce smooth, coordinated movements of the skeletal muscles, maintain equilibrium, and sustain normal posture. I was warned about the chances of my having to learn to walk and talk again.

After an eight hour surgery to remove the tumor and during many weeks of recovery at home, I grew more and more curious about my illness. Upon researching hemangioblastomas, I discovered a disease called Von Hippel Lindau. This is a genetically transmitted disease that can be fatal. I learned that blood vessels in our bodies grow like trees, but for patients diagnosed with Von Hippel-Lindau (VHL) blood vessels grow like "knots". These knots of capillaries can grow in various parts of the body, forming tumors and cysts known as hemangioblastomas and angiomas. According to the VHL Family Alliance's VHL Handbook, 1 out of 32,000 people has VHL, and more than 14,000 people in 88 different countries are affected daily. In 1993, the VHL gene was discovered. The primary responsibility of this gene is to suppress tumor production in the body. When a breakdown of this gene occurs, tumors form. The VHL Handbook also explains that approximately 85% of kidney cancers are linked back to the VHL gene mutation.

I look back on this traumatic time in my life with strength, faith, and optimism: strength to carry-on, despite any situation; faith in the Lord that blessed me with a full recovery; and optimism that one can overcome any obstacle in life through faith and determination.

As Miss North Carolina, I plan to travel across this great state educating fellow citizens about brain tumors and Von Hippel Lindau Disease. I am



determined that these efforts will give hope to survivors of VHL and "Untie the Knot".

Community Service Project: Brain Tumor Research and Awareness: Understanding Von Hippel-Lindau Disease

Goals as Miss North Carolina: Educate officials and citizens about the threat of brain tumors and VHL in hope to show the prevalence that these diseases have in our society. Partnering with the VHL Family Alliance and brain tumor foundations and associations from across the state and nation to eradicate brain tumors and provide a tremendous increase in funding for the search for a cure.

Ambition: After obtaining an MBA with scholarships provided by the Miss America Organization, become a successful entrepreneur. Owning and operating a full service personal image and wellness studio with the mission of improving an individual's image and confidence by promoting their uniqueness; while contributing to the economic growth of the state of North Carolina.

Brooke's Achievements: In her year as Miss Fayetteville, Brooke sponsored a golf tournament. With the earnings from that tournament she made donations to the Brain Tumor center at Duke and the VHL Family Alliance, and sponsored a Continuing Medical Education seminar on VHL for physicians in the Fayetteville Area, taught by Dr. Gladys Glenn of the National Cancer Institute.

We in the VHL Family Alliance wish her well in her reign as Miss North Carolina, and are delighted to be working with her to meet her goals!

See <http://www.missnc.org>

Another Great Birthday!

Karen A., New Jersey, with Sally Swift

In March of 2000, when our son Alex was four years old, a large endolymphatic sac tumor invaded his brain and right ear. It was determined to be VHL, an anomaly for the doctors because they had never dealt with VHL in such a young child. No pediatric surgeon in New Jersey had ever removed that kind of VHL tumor. A neurologist experienced in adult VHL operated together with a pediatric neurosurgeon. After 14 hours of surgery, we heard those magic words, "clean margins". But the price was large. If someone in your family has VHL, you know what I mean.

You know what VHL can do to a patient and his family. Alex is profoundly deaf in his right ear, missing one carotid artery, with partial facial paralysis, compromised balance (inner and middle ear also removed). He has to have MRIs and other tests on a regular basis. We all had to be tested as VHL carriers, including our now seven-year-old daughter Amy. Every childhood illness and injury has to be examined and treated with extra caution and care. We try not to think about what we almost lost, and what we all might have to face in the future.

On the bright side, Alex celebrated his ninth birthday in June, he's fairly comfortable with his hearing aids, he plays Little League, basketball, swims, is an excellent student and seems to be growing up like any normal, happy, healthy boy. We all take a vitamin supplement to help us manage stress and keep our energy up.

All our immediate family's DNA tests for VHL were negative. Alex is the first in our family ever to have VHL. That makes us feel even more strongly that VHL research is critical, as are the funds to support it.

So I am determined to raise funds for The VHL Family Alliance in any way possible. They do important work that not only will help my family and yours, but could affect anyone we know — a neighbor, a teacher, a clergyman or mail carrier. We are very much aware that the number of new families with VHL is growing. So this is where I choose to put my focus. And I'm writing to urge you to do the same.

We all can do our part, not only to raise funds, but to bring VHL awareness to each of our communities. Everyone has heard of Muscular Dystrophy, but how many know that the number of VHL cases closely rivals those of MD? How many of your friends and neighbors have even heard of VHL? The money is important, but the name is, too. When you are considering fund-raising, remember that Name Recognition is half the battle.

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*Alex at nine
New Jersey*



Don't have the time, you say? I work full-time running two businesses and as a substitute teacher. With two children under ten years old, a house, a husband and a dog, free time does not come easily to me. But I've found that fundraising can be easy, and not time consuming. I want to share with you some successful fundraising efforts I've undertaken. If each of us tries just one of these ideas for The VHL Alliance, together we can accomplish a lot!

My very first fundraising endeavor was with The Pampered Chef Organization, www.pamperedchef.com. I hosted a party in my home for VHL and raised nearly \$500. It was a lot of fun and a great way to meet new people and get the word out on VHL.

In my school, every other Friday throughout the school year, the teachers "dress down" and wear casual clothes. To earn that privilege they give about \$80 each to charity for the year. Last year my co-workers split their donations between VHL and another worthy charity. This was a wonderful way to inform the community about VHL and get them involved.

Recently I was ordering some book covers online from a company called BookSox at booksox.com, I came across a page designed specifically for donations. After speaking with Joyce, we signed up The VHL Family Alliance, which will now receive \$1 from every BookSox cover purchased online. The buyer simply puts the VHL number, 02445-100, in the space provided (or chooses VHL from the list) and VHL gets the donation. The one dollar is donated by this very generous company from the purchase price; it's NOT an extra dollar charged to the customer. This is huge. I am always on the lookout for other companies willing to do the same thing.

Here is a list of some other ideas you can put into action in your community:

Sell VHL wristbands (see page 9) like the ones you've seen for Lance Armstrong's LiveStrong campaign and for other charities. Children love to

do this, and are never too young to learn about the importance of charitable giving.

Network in your school, neighborhood and community to find local business sponsors who will support a VHL Walk-A-Thon or Read-A-Thon.

Ask a local nursery to sell you flowers at a reduced price, then resell them for fundraising profit at your school, church or synagogue, local swim club, Little League games, supermarkets — you can think of lots of other places. Lemonade Stands work well in those places too.

Bake Sales and Car Washes are always a fundraising hit.

Or auction something off on eBay and donate all or part of the proceeds to VHL. There also is a list of ideas on the VHL website at www.vhl.org/help

Feel free to e-mail me for support and for more ideas on your fundraising endeavors at my New Jersey address, us-nj@vhl.org. I look forward to hearing from you. For Alex, for all VHL families and those who care about them and for everyone potentially at risk — Let's get this party started!



Vehicle Donation Program

Donate a car or truck for benefit of VHLFA through our new vehicle donation program through Vehicle Donations for Any Charity (V-DAC).

This service is totally free and includes convenient pick-up of your car, truck, or RV anywhere in the U.S. You can donate online at www.v-dac.com or call 866-332-1778 to make your donation.

You are eligible for an itemized **tax deduction** of your vehicle's Retail Fair Market Value.



Sell colorful stretchable book covers for

Back to School. BookSox will donate \$1 for each book cover we sell. Request as many colorful flyers as you need, with our account number pre-printed on them.

These flyers can be placed in supermarkets, at the gym or at your church or synagogue. Just ask permission, first. The opportunities are endless. Be creative!

To request flyers, call Carole Meisse at 1-800-930-2241 or write to carolem@booksox.com. Give her our organization number "02445-100", the number of flyers you need, and the address to mail them directly to you.

United Way? write us in! 2005 Federal CFC #9710

**Please print out one or more posters
from our website to hang in your office
for workplace charity campaigns.**

**Hope
Strength
VHL.ORG**



Wear your blue VHL wristband proudly!

Request one as your thank-you gift for a donation of \$5 or more. Or sell VHL wristbands at local events. Call the office at 800-767-4845 to make arrangements for bulk orders of wristbands. Or create an Online Personal Fundraiser Page (see page 10).

Join ClubMom

and earn \$1 for VHLFA.
Take time to write up
your story too, and
increase awareness of VHL.
www.vhl.org/help



How Can You Help?
Pick a Project - Help Raise Visibility
Help Raise Money for a Cure!
See www.vhl.org/help

What's Up at NIH?

The primary VHL research study at NIH is open to U.S. Citizens, for whom travel and treatment are free. Residents of other countries may apply, but would be responsible for their own travel if accepted. Call Lindsay Middleton at 301-402-7911.

There is also a protocol open with Dr. Steven Libutti, studying pancreatic tumors. Anyone with a hard tumor of the pancreas may apply. Call Dr. Libutti at +1-301-496-5049

Dr. Emily Chew at the National Eye Institute (NEI) is testing the use of angiogenesis inhibitors in the eye. To inquire, contact Dr. Emily Chew or her coordinator, Katherine Shimel at +1-301-402-2863

The Neurological Institute (NINDS) also has a protocol for long-term study of the "natural history" of brain and spinal tumors. How do they grow over time? You have to have one or more existing tumors of the brain or spinal cord. You can apply to this protocol by calling Hetty DeVroom or Renee Smith at +1-301-594-8111. They only have about 15 slots left. Existing NIH patients preferred, but others may also apply.

Gokey-Thomas Can't Stop Smiling about "Amazing" Day

by Scott Kindberg, *Post Journal*, Jamestown, New York, August 1, 2005. All rights reserved. Reprinted with permission.

Melissa Gokey-Thomas' right knee and quadriceps were killing her.

But with two miles left in the Fort USA Ironman Triathlon last week in Lake Placid, New York, she wasn't about to quit.

Her brother, Steve, wouldn't let her.

"He was yelling at me, 'You can do it,' and he jogged with me for a while," Melissa said.

And when Melissa, the Fluvanna, New York, native, reached the final loop of the run on the Olympic speedskating oval, she could see herself on the jumbo television screen and her father, Todd, waiting at the finish line.

That was all the inspiration she needed.

Todd, 62, has suffered for most of his life from von Hippel-Lindau disease, which is a genetic multi-system disorder characterized by the abnormal growth of tumors in certain parts of the body.

All of Melissa's training for the 2.4 mile swim, the 112-mile bike and the 26.2-mile run — at her home in Texas and in Chataqua County for seven weeks — was to honor her father and raise money for the Cancer Research Fund / VHL Alliance.

She succeeded on both counts, raising more than \$72,000 for VHL research, including \$8,000 from the Janus Challenge for raising the second-most money of any of the 2,000 competitors.

"Doing an Ironman is tough, but it's nothing like what he's had to face," Melissa said. "It's nothing compared to what I did. He's been doing it for years and I've just been working hard for six months. I was just so excited to get to the end."

Melissa completed the swim in 1 hours, 5 minutes, 22 seconds, the bike in 6:45:03 and the run in 5:23:17. Her total time of 13:28:34 was well ahead of her goal of 17 hours. More importantly, Todd was permitted to present Melissa with her finisher medal upon the completion of the Ironman.

"It was the most amazing day ever," Melissa said. "It was so much fun, it felt so good and I had fun with it."

Other than having sore calves and quadriceps, she was feeling fine.

"I'm looking forward to exercising again," she said, "but I definitely won't run for two weeks."



Melissa with her proud father, Todd Gokey, at the finish line in Lake Placid. Melissa raised a total of \$72,775.

Personal Fundraising Pages

see www.justgiving.com/vhl

Maybe you can't run a Triathlon, but you can definitely help in your own way, among your own friends and community. Here's one idea.

You can create an online Personal Fundraising Page for any occasion:

- Marathons, walkathons, bike rides, or any sporting event
- In memoriam of a loved one
- Personal occasions like weddings or anniversaries
- Any social event you'd like to make more meaningful

You will have a web page that you can e-mail to your friends, asking their support. Credit card donations come to the VHL Family Alliance. If donors prefer, they can give by phone at 800-767-4845, or mail a check to the office.

"After hearing about the justgiving.com/vhl web site, I created my own page, which was simple, and am surprised at the money being raised.

I only started out sending it to my family, and they have forwarded it to some of their friends, and I have raised over \$1000 already.

If everyone gives it a whirl, we can really get some money going into VHLFA and hopefully speed up the pace to finding a cure to VHL. Check it out for yourself!" -- Donna H., Florida

Start Your Personal Fundraiser
See www.justgiving.com/vhl
Other ideas at vhl.org/help

One Biomarker for Angiogenesis

During the first six months of 2005, researchers from the laboratory of Dr. John Heymach and Dr. Judah Folkman at Dana Farber Cancer Research Center in Boston analyzed blood samples from a number of clinical trials, including the PTK trial, trying to find a biomarker that would be useful in tracking the effect of anti-angiogenic therapy.

A biomarker is a chemical in the blood or urine that can be tested to indicate whether the treatment is improving the situation, or whether there is cause for concern. One example of a biomarker is the PSA test for prostate cancer in men. If the PSA levels are elevated, there is cause for concern, and additional tests are done to determine just what is going on.

In this case, the researchers are looking for a way to get a quick indication whether the amount of tumor is growing or receding, indicating whether the treatment is shrinking the tumor, or whether the tumor is still growing. Again, it's not the final answer, but it is an indication that can be gotten easily, without expensive scans.

In this study, they were looking at the levels of circulating endothelial cells in the blood stream. These are usually found in the lining of blood vessels. If they have been released into the blood stream they are of one of two types:

- CEPs, newly formed cells released from the bone marrow, on their way to becoming blood vessels (indicating that blood vessels are being formed); or
- CECs, mature cells released from the blood vessels, on their way to degradation, indicating that blood vessels are being destroyed.

A modest number of both are a normal part of the body's self-repair and renewal, but higher levels might indicate whether anti-angiogenic therapy is working.

In analyzing the pre-treatment blood samples, they noticed a very distinct difference between the blood samples from people with VHL, and other subjects in other trials. In most people, the normal levels of progenitor cells were very low, sometimes so low it was difficult to count them. In the 7 people with VHL who participated in the PTK study, the levels of progenitor cells was significantly higher.

They asked VHLFA to invite people with VHL in the Boston area to donate blood samples to give them a larger number of samples to analyze. Fifteen people generously donated their time and blood to this research. Because the samples needed to be processed fresh on the same day, volunteers had to come on the same day to the lab.

The team concluded that this is indeed a promising way of checking on the effectiveness of anti-

angiogenic therapy. CECs went way up following radio frequency ablation, indicating that the blood vessels in the tumor were dying. It may also be useful someday for detecting the presence of renal cell carcinoma -- alerting the doctor to the need for follow-up in the same way that a PSA test calls for follow-up for prostate cancer.

In reporting his results, Dr. Heymach thanked the VHL Family Alliance and these volunteers for their help in making this research possible.

References: Beaudry et al., Differential effects of vascular endothelial growth factor receptor-2 inhibitor ZD6474 on circulating endothelial progenitors and mature circulating endothelial cells: implications for use as a surrogate marker of antiangiogenic activity. *Clin Cancer Res.* 2005 May 1;11(9):3514-22. PMID: 15867254

Resources:

Project Mobility, 2930 Campton Hills Rd, St. Charles, IL 60175

Project Mobility is a non-profit organization created to help provide specially designed bicycles, as well as the training to use them, for various groups and events. These specialized bikes create a sense of freedom for those who are disabled. Bikes restore a sense of possibility and ability to those whom are often told by society that their life is about limitations and disability.

Hal Honeyman, founder of Project Mobility: Cycles for Life, Inc. has been involved with bicycles as a sport, business, and recreation for nearly thirty years. Hal's interest in "adaptive cycling" -- bicycles for people with disabilities -- was spurred when his own son Jacob was born with Cerebral Palsy. Hal wanted to find a way for Jacob to join the family when bicycle riding. After Jacob's needs were met, Hal found specialized bikes for other disabled children and began creating specialized bikes when other bikes were not available or did not exist for that particular disability.

For more information, see www.projectmobility.org or call Hal at (630) 762-9807

Mike Bentley maintains a listing of bicycle manufacturers and resellers of adaptive bicycles and tricycles at

<http://www.mikebentley.com/bike/handicap.htm>

Reserve the dates!
Symposium, Toronto, May 19-21, 2006
Salt Lake City, June 24, 2006

VHL in England

by Mary Weetman, Rochdale, England uk@vhl.org, with Carol Giblin, Manchester, England

The VHL Contact Group of the United Kingdom held a Day Conference in Manchester in April 2005. The Meeting was chaired by Mary Weetman, Co-Ordinator for the Group

The Meeting was attended by some forty six people comprising members, their families and carers together with professionals involved in this field of work. These had travelled to Manchester from all parts of the United Kingdom.

Mary drew attention to the Group's Website at www.vhlcg.co.uk which had been updated to include a 'voice over' facility to assist members who are visually impaired.

Joyce Graff spoke on "Hope, Strength, and Community." Joyce's strategy for coping with VHL may best be summarised thus: 'You manage VHL. Do not let VHL manage you'. She emphasised the importance of monitoring the progress of the condition and of seeking the appropriate treatment. She urged people not to be timid about asking for second opinions. She valued the importance of living with a half full glass approach to life; to be optimistic and, above all, **to keep strong**.

The second address was a paper delivered by Karin McGuire, a VHL Contact Group member, and was entitled 'My Life with VHL'. In her paper Karin described her personal and family experiences

in discovering the presence of the syndrome among relatives and, later, with herself. She recounted the experiences she had, both good and bad, at the hands of the medical profession and of the way she had come to terms with herself, her condition and how she copes. She emphasised that all who are affected by VHL, be they those concerned, or their families and friends, need to be strong and live alongside the condition rather than allow it to dominate their lives. This, she said, took time to achieve.

The final address was given by Professor Adrian Harris, Director of Cancer Research UK at the University of Oxford. His paper, 'New Approaches to Treatment for VHL' provided members with a clear scientific outline of the way in which the syndrome develops and of the scientific strategies which are being pursued in attempts to diminish or halt the onset of the condition. In the course of discussion the importance of funding for such projects emerged and of the value of volunteers prepared to participate in experiments.

Professor Harris' address well described the substantial research in the UK which is dedicated to work for VHL families. This all in need of funding, and participants for research purposes, backed up by a vocal lobby for the cause.

Tracey Fox-Stillwell raises funds for Dr. Maher's genetic research in Birmingham (see <http://Tantaraswish.co.uk>), but the VHL clinical research project in Oxford is not funded by these efforts.

Our thanks for donations from:

The complete thank-you list is carried in the print version of the newsletter only

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My Occupation, or medical specialty, is _____

All members receive the VHL Family Forum quarterly. Check here ☐ if audio version is needed☐ New member ☐ Renewal (Dues \$25 per household, \$35 per professional or outside U.S.) \$ _____**Yes! I want to help fund Research and Education, and find a cure!**

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

Please send me _____ VHL wristbands (minimum donation \$5 each)

Donating \$150 or more? Choose one of the gifts below (#1-7) free as our thank-you to you! I'd like item number _____

☐ In Honor of or ☐ In Memory of _____☐ Please send a card to: _____**Meeting Registration**

____ 2 people coming to the meeting in (city) _____ (see article page 16 for fee) \$ _____

Names for badges: _____

Extra Handbooks Needed:☐ The VHL Handbook (English) paperback format.

Please send _____ copies, at \$3 each for members; \$5 each for non-members \$ _____

Gifts of Music:☐ #1 Bach: Goldberg Variations, classical piano performance by Pierre Jacomet @\$15 each \$ _____☐ #2 Simply Standards, pop favorites sung by Shannon Forsell @\$15 each \$ _____☐ #3 Forever in His Care, songs of faith by Deb Hogan @\$15 each \$ _____☐ #4 Wayfaring Stranger, gospel music by Clenton Winford II @\$15 each \$ _____**Gift Books:**☐ #5 A Time to Walk, lessons learned on the Appalachian Trail, by Jay Platt @\$15 each \$ _____☐ #6 Sacred Process, the inspirational story in poetry of Karen Koenig @\$15 each \$ _____☐ #7 How Are You?, Manage your own Medical Journey, by Patricia Foote @\$15 each \$ _____

All prices include U.S. domestic postage. For mailing to destinations outside the U.S., please add \$5 \$ _____

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Signature _____

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4227 Hamilton Road, Dorchester, Ontario, N0L 1G3 Canada

Regional Support Meetings - Please Join Us!

San Francisco, California, October 1, 10-4

The California chapter will meet Saturday, October 1, 2005, 10:00 am - 4:00 pm, on the campus of the University of California at San Francisco, in Room 300 of the Health Sciences West building (HSW 300). There will be a presentation by Dr. Dean Chou of the department of Neurosurgery and UCSF Spine Center at 10:00 am.

There is a link to the map of the UCSF campus at www.vhl.org/meetings.

For more information, please contact Dawn Cerf, us-ca@vhl.org, 805-541-5658

Little Rock, Arkansas, November 19, 10-4

A regional meeting will be held in Little Rock, Arkansas, organized by Amy Gray Light.

Featured speakers will include Cynthia Lim, M.S., genetic counselor from the University of Arkansas Medical Center, Dr. David L. Reding of the Neurological Surgery Association, and Joyce Graff of the VHL Family Alliance, and time to share.

The meeting will be held at St. Margaret's Episcopal Church, 20900 Chenal Parkway, in west Little Rock. Their telephone number is 501-821-1311. For more information call 1-800-767-4845 X4.

VHL Handbook in Arabic!

The Arabic translation of the VHL Handbook is now complete, and is available for download from the internet. It was introduced at the first conference of the Arab American Nurses Association in Detroit.

The Handbook was translated into Arabic by Dr. El Moeiz Ahmed Saad of Bioscientia Institute, Ingelheim, Germany, & Amal Ahmed Saad and

Bethesda, Maryland, October 23, 10-4

A regional meeting will be held in Bethesda, Maryland, on Sunday, October 23, from 9:00 am to 4:00 pm

Featured speakers will include Tom Rath, author of best-seller "How Full is Your Bucket?"; Dr. Hartmut Neumann of Freiburg, Germany, one of the world's experts in pheochromocytoma; Dr. Emily Chew of the U.S. National Eye Institute, to talk about clinical trials for controlling eye tumors with drugs; Dr. Steven Libutti of the U.S. National Cancer Institute to talk about VHL in the pancreas, and Dr. John McDonough of the Kennedy Krieger Institute in Baltimore to talk about management of VHL in the spinal cord. And of course there will be time for all of us to share ideas and experiences.

The meeting will be held at the Bethesda Holiday Inn, 8120 Wisconsin Avenue, Bethesda, 877-888-3001. Registration is \$25, which includes lunch. For those who need hotel rooms, there are not many rooms left in the Holiday Inn itself, but there are additional modest-priced hotels in the area.

For more information, call 1-800-767-4845, ext 4

وادن ال ليبيه نوف تبتيك VHL

Omaima Ahmed Saad of Abu Dhabi, in the United Arab Emirates. This project was organized by Dr. Jochen Decker, and funded by Bioscientia Institute.

We are very grateful to this team of physicians and researchers for their assistance in making this important information available to patients and doctors throughout the Arabic-speaking world!



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