



VHL Family Forum



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Teamwork for Health

Kansas City, April 15-17, 1994

-- Lois Erickson, *International Meeting Co-Chair*

We have declared this a year of breakthroughs in managing VHL.

With contributions from affected individuals and families, physicians, researchers, progress is being made every month. We look to all disciplines for ideas on how to manage von Hippel-Lindau disease. What can you contribute? Your expertise in a given medical area, your experiences in coordinating care and sharing information among health professionals. Your experiences and ideas with diet, massage, immunology, vitamins — literally anything which might contribute to improving diagnosis, treatment, and quality of life for people with von Hippel-Lindau disease. And of course, your moral and financial support.

You will hear about some of these breakthroughs in Kansas City.

Dr. Hartmut Neumann from Germany will share some of the many insights he has gained in the 20 years his team has been working with more than 100 people with VHL in Germany.

Speakers from University of Iowa, University of Kansas, and Mayo Clinic will share some of the special insights they have gained through teamwork — teams of medical professionals working together with the families to manage their long-term health.

Dr. Haring Nauta and Dr. John Adler will talk about improvements in treatment of brain and spinal lesions, including work to reduce the dosage of radiation and improve the accuracy of stereotactic radiosurgery.

Hetty DeVroom brings us news of some of the exciting research going on at the National Institutes of Health, including a paper being delivered at the Neurosurgery meeting the previous week on the effect of hormones on the growth of VHL tumors.

In the newsletter families continue to share their stories so that we can learn from their experiences. What is quite clear from what we have learned in this first year together is that the key ingredients in

managing our health are an early diagnosis, a conscious program of check-ups, and just the right amount of careful treatment. It takes teamwork -- among the patient, the family, and the members of the health care team -- clear communication, understanding, and sharing of the latest news.

Together we can do it. Please join us in Kansas for the kick-off. This is the year we begin making VHL stand for *Very Happy Life!*

Who's Coming?

As this issue is going to press, it is still early in the registration process. At this point we know that we will have participants from California, Georgia, Hawaii, Illinois, Iowa, Kansas, Maryland, Massachusetts, Michigan, Minnesota, Missouri, New York, Oklahoma, Texas, Washington, Wisconsin, Germany and Australia! Jennifer K. is starting up an affiliate of the VHL Family Alliance in Australia.

Fred Johnson will join Craig Warnick and David Torres on the program Sunday morning. Fred is a VHL spouse who is an Information Systems Trainer for the General Board of Global Ministries at the United Methodist Church. His wife Altheada is the startup chair of our New York Chapter.

We hope you'll be with us in Kansas to share your own knowledge, and meet everyone. It won't be the same without you!

-- Lois Erickson and Cindy Dearing, *Co-Chairs, the Kansas/Missouri Chapter, and the University of Kansas Medical Center.*

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Join us April 15-17 in Kansas City!

University of Kansas Co-Hosts VHL Conference

-- Debra Collins, M.S., University of Kansas Medical Center,
3901 Rainbow Blvd, Kansas City, KS 66160-7318

The University of Kansas Medical Center has had a long-standing interest in von Hippel-Lindau disease. The clinical team includes geneticists, genetic counselors, radiologists, neurologists, ophthalmologists, nephrologists, and other medical specialists as needed.

R. Neil Schimke, M.D., an internist, is board certified in both genetics and endocrinology. Debra Collins, M.S., is a board certified genetic counselor. Together, they follow over 50 individuals from several families who have or are at risk for having the gene, and therefore the symptoms of von Hippel-Lindau disease.

Over the past fifteen years, the Medical Center team has developed pre-symptomatic testing protocols and participated in research projects to help identify the gene for von Hippel-Lindau.

In 1979, Errol Levine, M.D., a radiologist working closely with the geneticists, published the first studies to establish the value of abdominal computed tomography (CT) scans in identifying abdominal cysts for VHL in family members at risk for VHL who do not have any symptoms. As a result, Dr. Levine and the Medical Center team established that CT scans are a valuable diagnostic tool for early identification of abdominal cysts or tumors requiring surgical intervention.

The geneticists have traveled to families' homes to obtain blood samples for research, arranged the shipment of surgical tissue samples to researchers, reviewed radiology and surgical reports from other institutions, and waited with families during a loved one's surgery to review screening tests needed by family members.

Much of the Medical Center team's work involves encouragement and support for families, as well as the arrangement of diagnostic tests and follow-up. The geneticists have formed close working relationships with many members of local families and have provided consultation and support for numerous families throughout the United States over the last fifteen years.¹

Dr. Schimke and Ms. Collins frequently contact other geneticists and researchers to exchange knowledge and new information on VHL to assure that all patients receive the best medical care available. Their patients have had the range of brain, eye, and spinal tumors. However, the most rewarding aspects of their work have been the patients who were identified early with renal cell carcinoma and pheochromocytoma, resulting in the successful surgical "cure" of these

The University of Kansas JayHawks, in Medical School call themselves the JayDocs. The JayDocs welcome you to Kansas City for the VHL Conference.

potentially lethal effects of the VHL gene.

1.. In addition to the many who have been helped by K.U., Susan and Craig Warnick in Maryland and Joyce and Damon Graff in Massachusetts are grateful for the expert and compassionate support they received from Dr. Schimke, Ms. Collins, Dr. Levine, and their team. □

My VHL Calendar

by Patti K., California

Here is a poem that I have created

To keep track of my VHL follow-ups that are so critically dated.

In **January** it's really no pain

I just have to begin the yearly VHL monitoring process all over again.

In **February** an MRI of the brain should make sure
That that nasty little brain tumor is shrinking and pure

In **March** the only issue at mind
Is that annual female checkup from chest to behind

In **April** it's off to Kansas we go
For the First VHL Conference and to meet others we don't know.

In **May** if I'm lucky the results might be here
Of the DNA testing that has been going on for almost one year.

In **June** a 200-mile trip we will take
To a special hospital where a renal angiogram they will make.

In **July** the month is all mine
I think I'll go swimming to work those kinks out of my spine.

In **August** it's time to check on that brain lesion once more
Another MRI will make sure that no more gamma knife is in store.

In **September** the start of another school year is here
Oh! those little second graders are really so dear.

In **October** the time for a physical exam has come quick
Including the lab-work and yet another "little stick."

In **November** the whole morning is taken
For a complete spinal MRI they'll be making.

In **December** one would think you could breathe
But I have to have an abdominal Cat Scan and Retinal exam, if you please.

The year is all over and all I can say
Is hopefully no more surgeries and more time to play.

This is the calendar of a VHL patient who had three surgeries
within 7 months and teaches second grade in California.

Finding People with VHL in Slovakia

by Otakar Mašek, M.D., Ilava, Slovakia

In less than twenty years we have made a dramatic difference in the outlook of three VHL families in Slovakia.

In 1977 a 47-year-old man was successfully treated for Renal Cell Carcinoma in both kidneys in our general hospital in Ilava, Slovakia. Later, when he had symptoms of pressure in the brain, it was thought that the cancer in the kidney had spread to his brain. It was only after his death that the pathologist determined that it was not cancer, but a VHL brain tumor and cyst.

After studying the medical literature on VHL, I screened the rest of the family using the diagnostic methods available in our country. Signs of VHL disease — mainly in the central nervous system and the kidneys — were found in another four members of this family.

In 1985 I used ultrasound to diagnose VHL in the kidneys of a woman from another family. In screening the rest of her family I found another two affected people who did not yet have symptoms. At present, out of 60 living members of these two families there are five who are affected with VHL. Six members of these two families died of VHL before the disease was identified.

A third VHL family in Slovakia is being followed by Dr. Streicher in Bojnice. There are 28 living members in this family, eight of whom have VHL. I don't know any other VHL families who are being regularly followed. I have been following the two families under my care for 15 and 8 years respectively.

Our hospital is small. Nonetheless, within a distance of 80 kilometers (about 35 miles), we have the facilities — ultrasound, CT, ophthalmoscope with fluoresceine angiography — necessary to diagnose and monitor VHL.

In 1991 I made contact with Dr. Hiltrud Brauch of the Molecular Pathology Laboratory of Technical University in Munich, Germany. She did a complete DNA analysis of the members of the first family, and about half the members of the second family. At present we are gathering blood samples from the rest of the second family, and from the family under Dr. Streicher's care.

All the investigations and therapy are free of charge in Slovakia. The cost is paid by the National Health Insurance Company.

The two families under my care have no pheochromocytomas [adrenal tumors]. During the past fifteen years there has been kidney involvement, but no metastasis. Therefore we use renal sparing techniques

Dr. Hartmut Neumann to speak

While he is in the United States, Dr. Neumann will be speaking at the following locations:

April 14	Boston, MA	Brigham & Women's Hosp.
April 15	Boston, MA	Lahey Clinic Grand Rounds
April 16	Kansas City	VHL Conference
April 19	Bethesda, MD	National Institutes of Health
April 20	Baltimore, MD	Johns Hopkins Hospital

and do not like to remove kidneys. Three people had hemangiomas of the brain removed. All of them are in good health.

According to Dr. Neumann, the incidence of VHL in Germany is 1 in 39,000; Dr. Maher calculates one in 35,000 in the U.K. In Slovakia there are about 5 million people, so we would expect about 120 people affected with VHL. In the three families we monitor there are 80 living members, or about 40 potential carriers of the VHL gene. That means that there are at least another 80 people we have not yet found.

We have therefore decided, with Dr. Neumann's help, to do more publicity among physicians in Slovakia and the Czech Republic, to increase awareness of VHL. □

“

Because of deep love, one is courageous.

— Lao Tse

”

Slovakia is the eastern half of the former Czechoslovakia, between Poland in the north and Hungary to the south. Over the past few years the Czech and Slovak republics have achieved a “Velvet Divorce,” final this January, separating peacefully into two nations.

Czechoslovakia was one of the most highly developed countries of Eastern Europe, with a good system of basic health care. The Czech Republic is heavily industrialized, while Slovakia is more rural with scattered pockets of oil refineries and heavy industry, especially near its capital, Bratislava. With the privatization of industry, and the phasing down of the Soviet military-industrial complex, the plants in Slovakia which make tanks are looking for new peacetime products.

Slovakia has a spectacular rolling landscape studded with wooded hills, rising steeply to the Carpathian Mountains. The budding tourist industry boasts fine winter sports.

Our thanks to Dr. Ksenia Khenchuk, Head of the Humphrey Program for Eastern European Studies, Boston University.

Sherri D., Tennessee, is working hard at her physical therapy following spinal surgery. Her drawings show her faith, her strength of spirit, and her optimism. "The Lord has been good to me, letting me get through lots of things." Sherri sends you this spring bouquet. □

Roberto G's Story

by Hartmut Neumann, M.D., Freiburg, Germany

The Freiburg University Clinics are one of the centers in Europe with experience and focus on clinical care for people with VHL. I have seen approximately 100 patients, descendants of more than thirty families.

Following publication of my first article in an international journal,¹ I had a telephone call from a woman in Italy, Luisa G., who had read that article, and was looking for help for her brother, Roberto. They came to Freiburg to meet with me.

Roberto is now 39 years old. He was 22 when he had his first symptoms of VHL. Roberto had a history of several weeks with headaches and ataxia [difficulty in walking straight] before his first operation for cerebellar hemangioblastoma in 1976. In 1983 he experienced the same symptoms, and a similar tumor on the other side. Again the same symptoms in 1989, caused this time by a huge cyst. During surgery to remove the cyst, however, no tumor was found. Roberto and Luisa brought an MRI done after the surgery. Their question was whether the cyst shown on this MRI was left over from his first surgery, or was caused by another tumor not yet removed.

Although they came with one clear question, I knew that there were other questions to be answered as well. As documented in the series of articles I published in 1992, in the Journals of Neurosurgery, Neurology, and Psychiatry, I knew that we should look beyond the brain for possible VHL issues.

I began by asking about the family: parents and three siblings alive and healthy. I recommended a full medical evaluation for Roberto, beginning with ophthalmoscopy, which disclosed a small retinal

angioma on the left eye, which was treated with laser photocoagulation. This confirmed the diagnosis of von Hippel-Lindau disease.

Roberto had had a motorbike accident in 1969 which traumatized his testicles. He was told that the left testicle had atrophied [degenerated] as a result of this accident, and that he had a cyst on the right. In 1981 he was found to have a zero sperm count. He and his wife adopted a baby girl in 1984.

On his second day in Freiburg an abdominal CT disclosed a 6 cm right renal mass and several cystic masses in the left kidney up to 2 cm. In the pancreas there were a few small cysts. Physical examination and later ultrasound of the scrotum revealed cysts in both epididymes, but no atrophic testicles. His infertility was caused by his epididymal cysts.²

Consultation with the neurosurgeon revealed three solid lesions in the brain and two cysts. Luisa asked what to do. She was especially interested in gamma knife treatment, done by Dr. Linquist in Stockholm or Dr. Steiner who had introduced that method and had moved to Charlottesville, North Carolina, USA. This was the first time we had heard about this method, and we were surprised to learn of it from a non-physician! The family had previously consulted with a colleague of theirs in Vicenza, Italy, for electron accelerator radiation, who at that time had no experience working with brain tumors. We recommended waiting, since there were no neurological complaints.

Confronted with this new situation, Roberto and Luisa decided to go home for six weeks, before returning for additional angiography and kidney surgery. The angiography confirmed one right kidney tumor. In the left kidney there were irregular vascular structures, but no tumors.

Surgery was planned to remove the kidney tumors

and spare the kidneys. However during surgery additional lesions were found on the upper right kidney, resulting in total nephrectomy [removal of the right kidney]. A total of four small and one large tumors was found. We were disappointed that we had not seen these tumors on the CT before.

In June 1990 the family invited me to accompany them to Stockholm to consult with Dr. Linquist and his gamma knife team. I was very impressed with the accuracy of the planning of the procedure, and how exactly every one of the 201 cobalt60 radiators was focused in the radiation helmet. We discussed the risk of bleeding and swelling of nearby tissues, which seemed to be low. At that time only very few hemangioblastomas had been treated.³ He could not at that time give any assurance of quick positive results. The cyst was already quite large. They set a date of mid-July for treatment, but during the next month the headaches and ataxia increased, forcing another solution to the problem.

Roberto and Luisa contacted Dr. Claude Lapras, a neurosurgeon in Lyon, who removed three hemangioblastomas and created a drainage path for the cyst.

Roberto recovered completely, is working, and undergoes regular abdominal CT and MRI of the head, which have shown no new lesions and no growth of the known existing lesions.

In 1990 all Roberto's parents and siblings (ages 65, 62, 40, 33, and 30) were screened by ophthalmoscopy, abdominal ultrasound, 24-hour urine assay, and physical neurological examination. The parents and the father's blind sister (age 66) were also screened using CT of the abdomen and brain. All we found was one renal cyst in the father, which is not necessarily related to VHL. All of them remain healthy in 1994.

Until Roberto's diagnosis in 1990, none of the Italian doctors he had consulted knew enough about VHL to do a complete screening and make a coordinated treatment plan. All his treatments were planned only to solve a particular problem at a particular time, without taking into account the more general situation and possible future recurrences. The family feels that there is still little knowledge about VHL in Italy, as most doctors still consider it quite rare and not worth an investment in learning. As readers of the *VHL Family Forum* know, knowledge about VHL is not widespread in any country. I could certainly relate similar examples in Germany.

Doctors learn from every patient, even when they already know a lot about a disease. I certainly learned from my experiences with this family. I was surprised how well informed they were. They taught me about gamma knife and linear accelerator treatments.

I was disappointed that we found more tumors in Roberto's kidneys than we had seen on the CT, resulting in the loss of one kidney. This convinced me not only that we should use intravenous contrast

medium, but that the timing of the injection and the imaging should be calculated to give optimal detail on the pictures of the normal and abnormal kidney structures. Furthermore, we are still wrestling with the question of how long we can leave tiny renal tumors where they are without risk to the patient.

We also learned that infertility can be related to VHL cysts in the epididymus. Roberto had undergone repeated and costly fertility tests without receiving clear information about the cysts, nor the VHL diagnosis.

Roberto may also be a "new mutation," the first in his family to have VHL. In Freiburg we have a patient in a similar family, and a few more cases of apparently isolated VHL. While their children are at 50% risk of having VHL, we will have to wait for DNA tests to confirm whether the parents are in fact free of VHL, or carry the gene quietly, with no clear expression of VHL. VHL does not "skip a generation," but it may appear that way, being very mild in a parent and more serious in a child.

Since his surgery in 1990, Roberto has remained free of recurrence for three years. From experiences with this and other patients I wonder if tumor growth declines in older people with VHL. I don't have a convincing answer yet, but it is an interesting question. As people with VHL are living longer and longer, we will learn more about its long-term course.

1. *Journal of Neurosurgery*, 1989.

2. Epididymal cysts do not always affect fertility, but can block the vas deferens.

3. See *VHL Family Forum* 1:3 (1993), 10-12 for an update on use of stereotactic radiosurgery on hemangioblastomas. □

What We Learned from our Experience

by Luisa G., Italy

As VHL is a disease with various recurrences and at this time can only be treated surgically, every surgery has to be planned very carefully and possibly performed by the most qualified surgeon you can find, especially where the brain is concerned.

We learned not to trust the doctors 100%, but to always get a second or third opinion until we are satisfied with the plan. Each of us is our own best advocate.

Families should never be afraid of the truth. It is only through knowledge that we can handle each situation in the best possible way. □

Families Share Diet and Exercise Tips

by Altheada J., Damon G., Peggy G., G.P., Darlene S., Mark B., Patti K., Ronald S., and Scott C. edited by Joyce G.

A group of families with von Hippel-Lindau disease has been sharing diet and exercise tips during the past year.

Since people with VHL are a relatively small population, no scientific studies exist yet to guide us in these areas. The information we have assembled contains lessons learned from related disorders, some interesting theories, and some good old "common sense." We will appreciate your own ideas and feedback on these topics.

Please note that these hints are to be added to your normal medical check-ups, and are not a substitute for the regular screening suggested in the *VHL Handbook*¹ and recommended by your medical team.

VHL is in a group of diseases called "hereditary cancers" because some VHL tumors are malignant. While most VHL tumors are not malignant and do not metastasize, or spread to other tissues, the process of tumor formation is the same general process that other tumors go through. Therefore, techniques which "prevent cancer," -- inhibit tumor formation, prevent changes in genes, and reduce stress -- can be applied to VHL.

While this list was compiled with VHL patients in mind, you will find that there is good information here for all family members -- indeed, for everyone.

There are thousands of books and articles on nutrition and cancer prevention. Your local library, hospital, or the local office of the American Cancer Society are good resources on this topic.²

Nutritionists now recommend keeping the amount of protein per day within the recommendations of the Food Guide Pyramid. Select foods from the pyramid in variety, moderation, and balance. If you choose a vegetable source, be sure to balance it so as to get a complete protein. See a good vegetarian cookbook, such as *Diet for a Small Planet*,³ which discusses complete and incomplete proteins.

VHL families who have studied this topic on their own or with nutrition counselors have provided the following tips.

- **Quit Smoking.** Smoking is the biggest cancer risk of all -- the main cause of lung cancer and 30% of all cancers. It has been specifically isolated as a cause of kidney cancer. Since people with VHL are already at risk for kidney cancer, it significantly increases that risk. For people with VHL the particular risk factor is the nicotine. For this reason it is best to avoid other nicotine sources such as chewing tobacco and the patch. Try Smoke Enders or other similar support programs instead.

- **Avoid chemical additives in foods.** We do not know what impact food additives may have, but as a general rule, if you can't pronounce it, don't eat it.

- **Consider avoiding growth hormone.**

Growth hormones are fed to cattle and chickens in the United States to increase food production. Through the use of growth hormones, chickens go from egg to meat market in six weeks. We do not understand the impact on humans of eating this much additional growth hormone.

The FDA and many physicians feel that since Growth Hormone is a protein, it is broken down in the stomach and is not of concern. Other people believe that it may increase the rate of growth of tumors.

If you would like to avoid eating Growth Hormone, ask your butcher whether their beef or chicken was grown using injected Growth Hormone.

- **Eat your vegetables,** especially soybeans and cruciferous vegetables like broccoli, Brussel sprouts, cabbage, cauliflower, Chinese cabbage, kale, mustard, rutabaga, and turnips. Beta-carotene and other substances in vegetables counteract environmental effects which can modify genes and cause tumors to form. Scientists are also finding that a substance in these vegetables, named *genistein*, blocks an event called angiogenesis, the growth of new blood vessels.⁴ Hemangiomas are formed from such blood vessels. By inhibiting capillary growth, genistein just may keep new tumors from growing beyond harmless dimensions.

- For those with kidney tumors, **be gentle with your kidneys.** While VHL tumors are generally not functional problems of the kidney, but are structural defects, applying some of what we have learned about reducing stress on the kidneys may be helpful. Keep the protein intake within the guidelines of the Food Guide Pyramid. Limit the amount of caffeinated and alcoholic beverages you drink, both of which increase the load on the kidneys. It is not necessary to eliminate them, just use them in moderation.⁵

- Keep an eye on your **stress vitamins.** Periods of stress consume greater amounts of vitamins, especially C, E, and the B complex. When stress is high, increase your intake of foods rich in these vitamins, especially around the time of those check-ups, before and after treatments, and during times of decision-making. It is particularly important that B vitamins be taken **from dietary sources** rather than pills, since they need to be taken in balance with one another. Taking artificial doses of one can cause a deficiency in another. Good dietary sources of the B complex are liver, brewer's yeast,⁶ and wheat germ.

Under normal circumstances, if you eat a balanced

diet including a green salad, a glass of juice, and at least 4-5 servings of fruits and vegetables a day, you should not need to take extra vitamins. Under stress, add another few servings of fruits, and add wheat germ and/or brewer's yeast to casseroles and breads. Choose and orange rather than coffee and donut.

- A number of people report mild to moderate hearing loss or ringing in the ears. First, check to make sure this is not an early sign of a brain tumor. When this has been ruled out, try adding Vitamin E to your diet — an extra 500 mg. per day for 2-3 weeks — and see if this makes a difference. Make sure too that you are getting enough vitamin B's. In one study of people who work in high-decibel workplaces, nearly half the men with tinnitus [ringing in the ears] and hearing loss were deficient in vitamin B12.⁷ Good sources of dietary B12 include lean meat, poultry, fish, shellfish, and dairy foods. Several B vitamins play a role in keeping all nerves healthy, not just those that aid hearing.

- **Use alcohol in moderation.** Estrogen is suspected of promoting tumor growth, especially in breast cancer. One study links alcohol consumption with a rise in estrogen levels. "The evidence for a subtle dose-response relationship [between alcohol and estrogen] appears to be getting stronger."⁸ While this study pertains to breast cancer, not VHL, it may have some relevance.⁹

Exercise Tips

Except for periods following surgery or eye procedures (laser or cryotherapy), **get lots of moderate exercise**, to keep your cardiovascular health strong. Following any medical procedure, check with your doctor regarding resuming exercise.

It is particularly important to be conscious of making small reductions in exertive activities for 2-3 days following eye procedures. Even though you probably feel no injury at all, remember that there is a small wound, a tiny cauterization, which is a temporary weakness in the wall of some of the capillaries in your eye. It makes sense not to pump too much pressure through that weakened vascular area for a couple of days, until it heals. Most normal activities are fine; just don't plan to move furniture or heavy boxes for a couple of days, and perhaps go walking instead of jogging for a day or two to reduce the amount of impact. Follow your doctor's recommendations about limiting aspirin and other blood-thinning medications as well.

Avoid activities which cause impact to the head, like boxing, as there is evidence that impact to the head can cause retinal detachment, and may be implicated in triggering or accelerating the growth of VHL brain tumors.

We know that moderate amounts of exercise are good for everyone — walking, swimming, yoga and

- Fats, oils, & sweets

- Milk, Yogurt & cheese

3-4 servings/day children

- Meat, beans, eggs, nuts

2-3 servings per day

- Fruits & vegetables

5-9 servings per day

- Breads & cereals

6-11 servings per day

The Food Guide Pyramid

U.S. National Institutes of Health

low impact aerobics are especially good. Tennis, jogging, and higher impact aerobics are probably okay depending on your own medical condition, but should be checked with your medical team, especially if there is concern about retinal detachment.

Some families have reported an observation that excessively strenuous exercise may encourage the growth of tumors — not cause them, but perhaps increase their growth rate. This is only a family observation, not proven nor medically verified. Excessive aerobic exercise which pumps your heart rate above the recommended maximum for your age, power weight lifting which causes your veins to stand out on your head, or operating a jack-hammer, may not be a good idea.. The theory is that if a hemangioma is a structure made up of blood vessels, then putting that structure under excessive pressure may be encouraging it to grow. We would appreciate hearing from you as to whether you observe any correlations along this line in your own families. In the future, formal studies may prove or disprove this theory.

We are learning all the time! Please give us your feedback on these ideas, and send in ideas of your own.

Thanks to Dr. Rosita Arvigo, the late Adelle Davis, Dr. Gladys Glenn, Dr. James Lamiell, Cary Rothenburger, Dr. Gregory Shropshire, and Dr. Kuen Shi Tsay for their information and coaching on this topic.

1. Available from the VHL Family Alliance. One copy free to members. Additional copies \$1.50 to members. 2. Some excellent pamphlets on "Diet, Nutrition and Cancer Prevention" are available free by calling 1-800-4CANCER or 301-496-8664. 3. Frances Moore Lappé, *Diet for a Small Planet*, Ballantine Books, New York, 1971,1992. 4. See page 8. 5. *Patient Handbook*, PKR Foundation, Kansas City. 6. You will find brewer's yeast in a health food store. Many of the richer vitamin supplement powders have a base of brewer's yeast. 7. *Prevention*, September 1993. 8. Matthew Longnecker, UCLA School of Public Health, editorial accompanying the study Marsha Reichman, *Journal of the National Cancer Institute* 85:692, 722, 1993. 9. If you are contemplating beginning a course of estrogen therapy -- birth control pills or hormone replacement -- you might ask your doctor to consult with Dr. Gladys Glenn at NIH before proceeding. There is a study under way there to evaluate the role of estrogen in VHL. Results will be reported at our meeting in Kansas City in April. □

Scientists Unraveling Why Vegetables Retard Cancer

by Natalie Angier, *The New York Times*

The more researchers understand about the ingredients found in fruits, vegetables, beans and herbs, the more impressed they are with the power of those compounds to retard the bodily breakdown that results in cancer and other chronic diseases.

Nutritionists and epidemiologists long have observed that people who eat a plant-rich diet suffer lower rates of cancer than do meat loyalists.

Now scientists are beginning to figure out why. Beyond the well-known benefits of vitamins and fiber, plant foods are plush with chemicals that have no nutritional value and are not necessary for immediate survival yet may impede cancer at a variety of stages.

Most of the experiments performed so far have been done on animals or isolated cells, and no specific ingredient from fruits or vegetables has been proved in long-term human trials to prevent or retard cancer. But biologists are encouraged that many laboratory results are in harmony with the empirical studies of long-lived populations.

And just when researchers thought they had a reasonable grasp of the basic anti-cancer compounds that might be found in a healthy diet, they discover a novel pathway through which ingredients in plants may help foil disease.

In the current issue of *The Proceedings of the National Academy of Sciences*,¹ scientists from Children's University Hospital in Heidelberg, Germany, report that they have isolated a compound called genistein from the urine of people who eat a traditional Japanese diet, heavy on soybeans and vegetables. Through test-tube experiments with a synthetic version of the chemical, Dr. Lothar Schweigerer, his student Theodore Fotsis and their colleagues, have discovered that genistein blocks an event called angiogenesis, the growth of new blood vessels.

That talent could have significant implications for both the presentation and treatment of many types of solid tumors, including malignancies of the breast, prostate and brain. Scientists had previously determined that if a tumor was to expand beyond a millimeter or two in size, or four-hundredths to eight-hundredths of an inch, it first must foster the growth of new capillaries around it. Once it is fully vascularized, the malignancy then receives the oxygen and nourishment it needs to keep swelling, eventually invading the blood and lymph system and seeding fatal metastatic colonies elsewhere in the body.²

By inhibiting capillary growth, genistein just may keep nascent tumors from growing beyond harmless

dimensions.

Genistein is found in high concentrations in soybeans and to a somewhat lesser degree in cruciferous vegetables like cabbage. In those on a traditional Japanese diet, the scientists found, the urine level of the compound is at least 30 times that of Westerners.

Schweigerer also speculated that such a diet could explain why, when Japanese men leave their country for several years to work in the United States or Europe, their rate of invasive prostate cancer rises sharply. He proposed that any tiny prostate tumors that had been kept in check by a daily intake of, say, miso soup, would finally be free to grow once the Japanese men had assumed a more Western, genistein-poor culinary style. But he stressed that this was merely a theory, unsupported by data.

Nevertheless, if genistein proves its mettle through testing in animals, the compound may be useful, not only as a dietary measure to prevent cancer, but in a concentrated form to treat tumors already in progress.

"This is a fascinating report," said Dr. Judah Folkman of Harvard Medical School, who has worked out many of the details of how tumors become vascularized as they grow. "It's a novel finding. Nobody has ever suggested before that you could find in the urine certain dietary factors that inhibit the proliferation of blood vessels, and I think this work will get wide attention."

Folkman and others view blocking angiogenesis as an ideal sort of therapy, one that would attack the malignancy while leaving normal tissue intact. Apart from the sinister demands of tumors, new blood vessels grow in the adult body only after fairly rare events like extreme injury, heart attack, or the implantation of an embryo in the uterus, and thus any compound that blocked angiogenesis would have a few side effects.

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1. T. Fotsis et al., "Genistein, a Dietary-Derived Inhibitor of In Vitro Angiogenesis," *Proceedings of the National Academy of Sciences*, 90:7, 1 April 1993, 2690-2694.

2. The angiomas of VHL are knots of excess capillaries, which might be seen as the vascularization described above, without the malignant tumor. □

Fax Needed

A good used phone/fax machine
for our Public Relations Committee chairperson
in California

(or a donation of \$400 to purchase a new one).

Patti will be happy to give your
used fax machine a good home!

Our New Soybean Diet

by Darlene S., California

I am forty-eight years old, and live with my husband in California. We have one married son, two dogs and two birds.

For almost thirty years my husband and I have been eating a diet of rice, with no concern as to what type of foods went with it. We did eat soybean products, mainly tofu, on occasion, only because my husband, being of part Asian descent, was raised on this type of food. But lately we have become much more serious about soybeans.

In 1966 I had my left kidney removed due to kidney cancer. In 1986 they said that my pancreas was not functioning properly and prescribed pills to replace the missing pancreatic enzymes. I don't digest food properly without the pills.

In 1987 I was diagnosed with VHL, with multiple tumors and cysts on various organs, including my right kidney, pancreas, liver, brain and eye. I began to notice pain and difficulty after eating certain foods, especially meat or protein. I also noticed if the amount of food was not in moderation it would affect my abdomen (pain) and my only remaining kidney. I was forced to concentrate on my diet and limit amounts of food, not only to feel better but to preserve my life.¹

About six months ago, my husband noticed an article in the *Los Angeles Times*, reprinted from the *New York Times*, about the benefits of a soybean diet and the effect of *genistein*² on tumor growth. It sounded very much like my particular problem of abnormal blood vessel development causing hemangioblastomas. These were the type of tumors I had removed from various parts of my body over the years. At this point we decided to seriously concentrate on this particular diet. We began eating, on a daily basis, moderate amounts of food that would mainly consist of tofu, tempe, soup (mostly miso) along with more cruciferous vegetables (usually cut up in the soup) with a little pasta, less fat, high fiber foods, and more fruit. Not only did we lose over 30 pounds in no time, but we discovered an overall feeling of wellness.

Since diet has become a crucial factor in my life, it became essential to choose food wisely to avoid unnecessary pain and agony to my already fragile system. I also have diabetes.³ With these limited amounts of food, less fat and proteins, my blood sugar, which was previously a problem, is now controlled by the diet alone.

When I went back for my latest tests, the follow-ups from my last brain surgery in December 1992, I was told that that tumor had not returned, and that the others have not increased in size. The doctor com-

photo of Darlene and husband

mented that I must be doing something right! I really believe the soybean diet contributed to my continuing good health. Eating more fruit and high-fiber foods has also benefitted my husband, since he is a survivor of colon cancer.

We believe we have discovered something important and beneficial to our well-being and hope others will try the diet and hopefully reap the benefits as we did. Thank you for giving me this opportunity to share my diet experience with everyone.

I've been through many ups and downs over the years living with this disease. My life has changed a lot and I'm learning to cope with my limitations. I've been fortunate to have a loving and caring husband by my side to pick me up each time the chips are down.

I'm sitting here calming down from our latest 6.6 earthquake tremor. Talk about shaky! Our house took quite a beating, but we're alive and grateful.

1. The symptoms Darlene describes are not uncommon with certain kinds of pancreatic cysts, depending on size and location. The pressures exerted by the cysts can disrupt the normal flow of digestive enzymes produced by the pancreas, resulting in difficulty digesting food.

2. See reprint of this article on page 8.

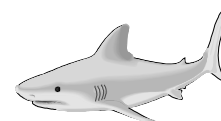
3. Diabetes, a disturbance in the body's normal mechanism for regulating blood sugar, is also a rare consequence of VHL cysts of the pancreas. As Darlene describes, it can usually be managed with diet. □

Shark Warning . . .

Editorial

We have spoken with several researchers working on cartilage in general, and it does look like there are some promising advances coming out of this work which we will report in later issues. However it is their feeling that ingesting cartilage will not be helpful. Very little of the chemical required to shrink the tumor will make it through the digestive tract to the tumor. When used as an effective therapy, this chemical is administered intravenously.

For both points of view, see I. William Lane, *Sharks Don't Get Cancer* (Avery Publ. Group, Garden City Park, NY, 1992) and T. Beardsley, "Sharks Do Get Cancer: Cartilage Cure Relies on Wishful Thinking," *Scientific American*, 269 Oct 1993, pp. 24ff. □



A chapter of the
VHL Family Alliance
 is being formed in
New York State

All interested parties please contact:

Altheada Johnson
 341 Adelphi Street
 Brooklyn, NY 11238
 or call (718) 622-2457

Family Gene Map

Dr. Berton Zbar and his colleagues at the Frederick Cancer Research Laboratories, National Cancer Institute, are making excellent progress in their mapping of the VHL gene.

They are identifying and studying in detail the particular mutation patterns along the gene which occur in individual families. They are hoping to be able to predict, based on this DNA information, which VHL manifestations may occur in an individual.

Now that the VHL gene has been identified, Dr. Zbar and others are working to map the full gene, reproduce in the lab the protein which this gene normally encodes, understand how the VHL gene mutations modify this protein, and what can be done to help.

Those families who have contributed blood and tissue samples to Dr. Zbar's research may be able to benefit now from what has been learned so far. Once they have identified the particular mutation area in your family's DNA, anyone in the family can be tested for VHL. With this information, the testing lab can go directly to this area of the gene and examine it, making it much easier and more cost-effective to do an accurate test for the gene.

"This information should be kept with the family Bible," says Dr. Zbar. "It can be used by everyone in the family to do the most efficient test for VHL."

The Frederick lab is not accepting new samples for their research. This offer is only available to those families whose samples are already on file. Write to:

Dr. Berton Zbar
 Frederick Cancer Research Institute
 Building 560, Room 12-71
 Frederick, MD 21702

Testing markers for these mutation areas are made available to DNA testing laboratories, where new blood samples can be examined. Families for whom the direct tests do not yet work can still use the Linkage Analysis method,² which requires samples from two clinically diagnosed family members.

1. See *VHLFF* 1:2, June 1993. 2. See *VHLFF* 1:1, March 1993.

They Found It!

-- Joyce G., Massachusetts

A year ago I shared with you that we had submitted my son's blood sample for DNA testing. He has VHL, his father died in 1977 and he has no living relatives with a clinical diagnosis of VHL.

The first answer was negative. Clinically we know he has VHL, but they couldn't see it in his DNA. We asked that they keep the sample on file and try again when new markers became available. It took a year, but they did find the mutation area!

What this means to us is that his father's sister can now be tested. After thirty years of wondering and being watchful, she can finally get a definitive answer whether or not she carries the faulty gene. With a "no" answer, she will finally know for sure that her daughters and grandchildren are not at risk for VHL.

Other family members whose mysterious symptoms might or might not be VHL can also be tested and get a definite answer. There are concerns about misuse of this information by insurance carriers.¹ But for us, what a relief after all these years of worry!

1. See *VHLFA*, June 1993. □

Volunteers Needed

The Alliance of Genetic Support Groups (AGSG) and Georgetown University Child Development Center have recently received an NIH grant to develop a Human Genome Education Model for consumers of genetic services and multidisciplinary health professionals. We are seeking members of genetic support groups like the VHL Family Alliance who would be willing to spend 25-30 minutes on the telephone responding to questions on ethical, legal and social issues related to the Human Genome Project. The survey can be administered in Spanish or English. To protect privacy and ensure confidentiality, no identifying information will be used.

Survey participants must be at least 18 years old, and have someone in the family with a genetic disorder that was diagnosed more than one year ago, or have a risk of a genetic disorder in the family.

Call or write for additional information. People who leave their names and addresses will be sent additional information about the project and a Consent Form to return if they decide to volunteer.

Summaries of survey results will be provided to participants upon request and will also be made available to policy makers. Participation may provide greater visibility for your organization and the genetic disorder it represents. Thank you for helping with this important project.

Joan O. Weiss, MSW, LCSW, Executive Director
 Alliance of Genetic Support Groups
 35 Wisconsin Circle, Suite 440
 Chevy Chase, MD 20815
 1-800-336-GENE, 301-653-5553
 Fax: 301-654-0171 □

To the Editor:

I have just received the copies of the *VHL Handbook* and I want to congratulate you and the membership for putting together a first class production.

I know this will be of great benefit to the many members of the families with this problem as well as many people in the medical community.

I wanted you to know that I think it is an excellent pamphlet and keep up the good work.

-- Robert B. Welch, M.D., Associate Professor of Ophthalmology, Johns Hopkins University School of Medicine, and Chairman Emeritus, Department of Ophthalmology, Greater Baltimore Medical Center, Baltimore, Maryland

To the Editor:

I am disappointed to find no mention of optometrists in your *VHL Handbook*, except for the delightful illustrations by Vincent Giovannucci, O.D.

Optometrists in all fifty states and the District of Columbia can dilate patients' pupils and conduct a thorough fundus examination. Optometrists are now being extensively trained in the detection and management of eye diseases.

The importance of a dilated eye exam, whether performed by an optometrist or ophthalmologist, is to detect eye disease. If VHL lesions are found, the patient should be referred to a retinal specialist for the appropriate laser or cryotherapy treatments.

Patients at risk for VHL must be responsible for managing their own eye care. A refraction for a new glass prescription is not a sufficient evaluation for the presence of retinal angiomas. Patients at risk for VHL must share this medical information with their eye care practitioners. Patients should expect, and make sure they receive, a dilated pupil exam that includes a careful inspection of the back of the eye (fundus) for retinal angiomas.

-- John L. Baker, O.D., Associate Professor, Illinois College of Optometry, Chicago.

To the Editor:

Thank you for the *VHL Handbook*. I liked everything!! I wish this had been available when my husband was sick. I had to do my own research on the disease plus the medical staff could tell me very little themselves about VHL. I have gathered quite a bit of information myself from different sources.

It was very frustrating for me because there was literally nothing available. There were no support groups, no literature, no medical staff support. There was nothing, just fear, for sixteen years.

-- Donna M., New Hampshire

To the Alliance:

I am enclosing my donation, and my congratulations. The professionalism, the hope, the will and energy that have brought this about will ultimately defeat VHL.

-- Ron N., Massachusetts

Sacred Process

by Karen Koenig

There is something
Inside me
More substantial than
A kidney or an ovary.
Something which cannot be
Cut away or altered or
Overcome.

There is something linked
Not just to flesh and blood,
Though that now is so,
But connected also somehow
To eternity.

Something that will not always need
Oxygen or light,
Water or food.

Every time another part of me
Is removed or invaded,
This eternity-linked part
Shows itself to me
A little more surely,
A little more clearly.

It is all part of
The sacred process
Of my life.
All is well
Peace
All is well.



Karen Koenig is an artist and poet who has VHL. Dr. Morton F. Goldberg of the Wilmer Ophthalmological Institute and Johns Hopkins University writes, "When VHL rendered her incapable of painting her beautiful portraits, Karen Koenig had recurrent opportunities to fall into the well-known emotional patterns of denial, recrimination, grief, and despair. Instead, she chose love of life, love of God, and love of family; and created word paintings demonstrating her resilience, perseverance, and above all, her splendid optimism.

"Inherent in her poems is a joyful, natural, and unencumbered spirituality that is universal in its applicability. Despite her impaired vision, she has the capacity to see and perceive, as well as the will to enjoy.

"And with these buoyant and beautiful poems, succeed she did."

This selection is from her new book of poetry, *Sacred Process*, available from Kärelek Press, 800 West End Avenue, New York, NY 10025. \$15 postpaid U.S. and Canada. For addresses outside North America, please add another \$5 for postage. Karen's book will be for sale at a special conference price in Kansas City. □

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Volume 2, Number 1, March 1994

Newsletter of the VHL Family Alliance

Toll-free in the United States and Canada: 1-800-767-4VHL

Adviser: Debra L. Collins, M.S., Genetic Counselor, University of Kansas Medical Center 1-913-588-6043 (day)

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We have enclosed your holiday gift -- your own new VHL Handbook.

Please consider sending your gift to help us continue this work.

The VHL Family Alliance is dedicated to improving diagnosis, treatment, and quality of life for people with VHL. Please support our vital programs: information, hotline support, education, advocacy. Ask friends and family members to give donations instead of ties and handkerchiefs.

We are all volunteers. We have no paid staff. 100% of your donation goes directly to provide services. All contributions are tax deductible in accordance with IRS regulations.

This is **your** Alliance. We need **your** help. **Thank you!**

This page will be updated



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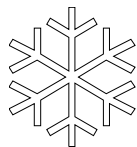
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