

VHLFA: Looking to the Future

by Camron King, Strategic Planning Chair, Board of Directors

Organizations that don't change tend to fade away. As supporters working toward a cure for VHL, we want our Alliance to thrive and continue to grow; to have the ability to positively impact the lives of those affected; and to one day, find a cure!

To make this happen, a hardworking committee of volunteers has begun a strategic planning process developing a roadmap, goals, and objectives for the Alliance. We are taking a comprehensive look at VHLFA programs and services, the people we serve, and how we can work better and smarter going forward. Look for more information and opportunities to weigh in on the future of the Alliance. In the meantime, please send your thoughts to info@vhl.org.

One of the ways the Alliance serves the VHL community is as a vital resource for information and contacts. The VHLFA website, www.vhl.org, is a primary vehicle. The Website Committee has been working to update the website and prepare a streamlined, user-friendly repository of information for you in the months to come.

These two committees are just two examples of the ways in which we can all contribute to the VHL Family Alliance. The Alliance cannot exist or provide the much-needed programs and services without your help! Fundraising is an easy way to have a huge impact. We, collectively, can move the needle by asking friends and family to make a small contribution. Just think, if each of the 6,000 people who receive this newsletter asked ten people to each donate \$10, each person would raise \$100 for a grand total of \$600,000! We would have funds available for research that would rival large, well-known organizations.

This is what it takes: small steps to make great strides for the future of the VHL Family Alliance! Get involved today! *Help Uncover the Cure!*



Camron King

Increase in Life Expectancy

A recent study published in the Journal of Medical Genetics* has documented good news for people living with VHL. The average life expectancy of someone with VHL has gone up nearly 17 years! The VHL Family Alliance has played a significant role in this positive outcome. Screening and treatment guidelines, patient education and empowerment, patient support, a sense of community, and Clinical Care Centers are just a few examples at the surface of the Alliance's role.

Advances in the clinical world are also major contributors to longer life. Sequencing the VHL gene; genetic testing; improved diagnostics and treatment; limiting whole organ excision and preserving healthy and active tissue are some of the changes contributing to longer life expectancy.

Ultimately, it is research that is the key to the increase longevity. The more than \$1.3 million of research funded through the VHL Family Alliance has had a major impact, directly and indirectly! Imagine the outcome of another \$1.3 million! For example, a patient registry is sorely needed. Amongst other information, the registry can answer the ever-provocative question of what role do environmental factors play in manifesting this genetic alteration.

The power of being together, taking care of your health, being watchful, and keeping your spirit strong cannot be underestimated. Continuing with the Alliance's commitment to funding high quality research can also not be undervalued.

***Note:** Wilding et al., "Life expectancy in hereditary cancer predisposing diseases: an observational study" from St. Mary's Hospital, Manchester, England. *J Med Genet.* 2012 Feb 23. PMID 22362873.

Inside this issue!

VHLF: Looking to the Future
Increase in Life Expectancy
ASK THE EXPERTS -
CT and Pancreas Tracking
Clinical Trials Information
Tummy Troubles (Pancreatic Insufficiency)

Adding a Dietician to my Team
New CCC, Tampa
Eva Lou Rodenberg
Mom's Day Run
The Risk to Blossom -
Concert by Jennifer Behnke
29er Softball Tournament
Living with a Rare Disease

**May is VHL
Awareness Month!**

Tell your story: bit.ly/IASqlh

ASK THE EXPERTS:

CT preferred for pancreas tracking

QUESTION 1: I am still a little confused why CT scans are needed for diagnosis and tracking of pancreatic neuroendocrine tumors (PNETs). I would prefer if possible to use MRI for these annual scans in order to reduce my lifetime exposure to radiation. Why would CT be preferred?

– Tina G., Oregon

Response: With respect to CT, there are a couple of reasons why I believe it is a superior study to MRI for evaluating PNETs in general, and in VHL specifically.

1. CT is a superior anatomic study to MRI. Relationships of the tumor to other structures are more easily discerned and therefore it helps in operative planning.

2. An early arterial phase CT scan is the most sensitive and specific study for diagnosing PNETs in the pancreas and it can also be used to evaluate the liver (although I admit, an MRI can be more sensitive for the liver).

3. MRI is much more subject to motion artifact and inter-scan variability depending on the specific machine used and the algorithm for image reconstruction used. This makes it difficult to get precise measurements from scan to scan. Since changes in the size of the lesion can often dictate need for management, accurate measurements are of critical importance.

It is for these reasons that it is my strong opinion that a three phase contrast (early arterial, portal, delayed) CT scan be the scan of choice for evaluating and diagnosing PNETs. If a patient cannot receive contrast, an MRI is a reasonable second choice.

– Steven K. Libutti, M.D., Albert Einstein College of Medicine and Montefiore Medical Center, Bronx, NY

Clinical Trials Information

Where can a patient find out about clinical trials?

– Edith G., Poland

See one of these websites:

<http://www.clinicaltrials.gov>

<https://yourtreatmentchoices.com>

<http://www.centerwatch.com/>

The new site, clinicalresearchtrials.nih.gov, is a resource to specifically help patients and their families learn about the clinical trials process and encourage them to become participate in studies. It is part of a comprehensive clinical trials awareness activity by the US-National Institutes of Health.

Trials in which you might be interested:

- Pazopanib, an angiogenesis inhibitor taken as a pill and approved for advanced renal cell carcinoma: Contact Dr. Eric Jonasch, at M.D. Anderson Cancer Center, Houston, TX; phone: 713-792-2830.
- DNA testing for unclear diagnosis: Contact Eleanor Rattenberry at the University of Birmingham in the UK; email: Eleanor.rattenberry@bwhct.nhs.uk

I recently spent a week at NIH being tested for a possible ELST. It was great to see first-hand how it all works. It was a particular pleasure to feel that my symptoms were being carefully listened to. With most doctors, when you explain funny symptoms they look at you with a funny face. But here I felt heard, and they performed tests to see if I was telling them something important. I am very grateful for their help and guidance to me and to my team of doctors at home. – Susi M., Spain

Tummy Troubles?

by Tina D. Gruner, Registered Dietitian, Certified Diabetes Educator, Madras, OR

As one of the moderators of the Inspire discussion group for VHLFA, I have been hearing from a number of people with VHL that they are experiencing



Tina D. Gruner

problems with digestion—bloating, cramping, abdominal pain, diarrhea and fatty stools. These problems may be caused by simple pancreatic cysts, and will surely be worse following pancreatic surgery. A dietitian can help get the digestion back into balance. Let me explain.

What and where is the pancreas?

The pancreas is in the upper abdomen that lies behind the stomach and is located to the right and under the liver and gallbladder. It is about 5–7 inches long. The gallbladder and the liver connect to the pancreas by way of the common bile duct (see figure). The pancreas has a long tube that runs through it called the pancreatic duct. The pancreatic duct connects to the common bile duct and then carries the products made by these organs to the beginning of the small intestine (called the duodenum).

What does the pancreas do?

The pancreas regulates how the body's cells are fed 24 hours a day. The pancreas is responsible for:

- Producing digestive chemicals and enzymes to break food down into nutrients that can be absorbed through the walls of the small intestine and delivered to the cells.

- Producing hormones that regulate blood sugar.

These three digestive enzymes are:

- ▶ *proteases* to break down protein foods
- ▶ *amylase* to break down carbohydrates and sugars
- ▶ *lipase* to help us absorb fats

The other important job of the pancreas is to make hormones (insulin and glucagon) that help balance blood sugar and regulate the body's ability to feed every cell 24 hours a day.

- After a meal, the pancreas makes insulin, which allows the sugar to travel from the bloodstream into the cells where it can be burned for energy or stored as fat for future use.
- When the blood sugar starts to drop too low (between meals or during sleep), the pancreas makes a hormone called glucagon which tells the liver to release stored sugar, or to make sugar from fat and muscle cells.

How can cysts disrupt the balance?

While cysts are benign (they do not become cancerous), they may block one or more of the tiny tubules in the pancreas that deliver insulin, glucagon, or pancreatic enzymes to the gut. It's somewhat like stepping on the garden hose. Even though the pancreas is still making these hormones and enzymes, they are unable to get to where they need to go to aid digestion.

Diabetes is the condition that occurs when the pancreas does not make enough insulin to keep blood sugar within the normal range or when the delivery of insulin to the gut is blocked. This can be treated with pills that can help the pancreas make more insulin, or pills that tell the liver to make less sugar, or injections of insulin to replace what is not getting produced or delivered. An endocrinologist and a certified diabetes educator (dietitian or nurse) can help with the management of diabetes and help develop a personalized plan for meals and exercise.

Tumors near the common bile duct can also block the gallbladder from delivering bile. Blockages near the liver can affect liver function. Be sure to discuss any pain or yellowing of skin or eyes with a doctor.

Pancreatic insufficiency is when the pancreas is not making the digestive enzymes, or when their delivery to the gut is blocked. Removal of all or part of the pancreas clearly reduces the ability of the pancreas to make and deliver these enzymes. When the food is not broken down, the nutrients cannot be delivered to the cells. The food simply goes right on through and out the other end without being digested and absorbed. In other words, the cells are still starving. This condition is called "malabsorption." One major sign of malabsorption is loss of weight. It is critically

important to your health to get your digestion back in balance. This is more than an annoyance; it is one of the keys to your health and the strength of your immune system.

Symptoms of malabsorption include: diarrhea, bloating, cramping, abdominal pain, fatty stools (appear frothy and oily on the top of the toilet bowl water, with a strong odor), and possible deficiencies of fat-soluble vitamins (A, D, K and E). A registered dietitian who works with clients with cystic fibrosis, pancreatic cancer, or pancreatic insufficiency should be able to help with this problem.

How can the system be rebalanced?

Digestive enzymes can be taken by mouth to get the digestion back in balance. The dietitian or nutritionist will interview you about what you eat, when you eat, how you feel, and what comes out the other end. Based on this information, a combination of enzymes (lipase, amylase, and protease) will be recommended. Different brands have different percentages of these enzymes.

It is best to take enzymes which are dispensed as prescriptions, as their composition is more carefully regulated. It is possible to find digestive enzymes over the counter, but most people find that they do not work as well. The bottom line, though, is what works best for each individual.

As with insulin, enzymes have to be taken when you eat and in balance with what you are eating. This is not a medication to "fix" a problem, it's a preventive — replacing the natural enzymes that your body is not able to produce,

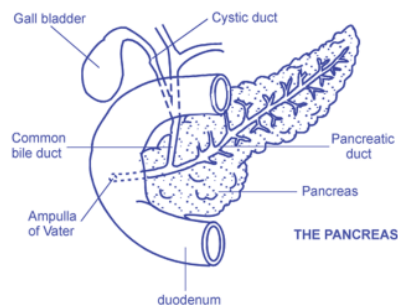
making it possible for you to digest your food. You don't take them by the clock, you take them in coordination with whatever and whenever you eat.

A dietitian or nutritionist works out the recommended dosages for each person. The basic rule is that if you are still experiencing symptoms, you need more. If you get constipated, you are taking too much.

The enzymes are needed in the small intestine. When you take them by mouth, they have to travel through the stomach, where the acid environment can break them down. Your doctor may prescribe a proton pump inhibitor (or other antacid) that will lower the acid in the stomach and allow the enzymes to get through to the small intestine.

General meal plan recommendations

Fats are the hardest type of food to digest. People who have pancreatic insufficiency usually do best on a low-fat diet, even if when they are taking a prescription oral enzyme.



Source: patient.co.uk

Continued on next page

Tummy Troubles?*Continued from Page 3*

Heart-healthy fats are good for us in small amounts, but too much may be more than your body can digest. A low fat diet is 40–50 grams of fat or less per day in the diet. One would need to take a higher dose of enzymes with a meal with a larger amount of fat in it.

One grocery tip is to buy all fat free or light foods or use very small amounts of the regular variety.

Red meat, processed meats, chicken and cheese can be very high in fat. Take the skin off chicken. Buy only lean cuts of beef and pork (lean cuts are the ones with fewer white streaks of fat in the raw product). Avoid fried foods and learn to bake, broil, and grill your protein foods.

One ounce of salami, regular cheese, pastrami or meat has 8 grams of fat. All animal sources of protein are higher in fat. Reduce the portion size to control the total amount of fat you are eating.

All dairy products can contain as much as 10 grams of fat per serving. Reduce portion size or choose nonfat or 1% fat alternatives. Nuts and avocados have a very high fat content. These fats are heart healthy fats and are not nutritionally bad for you, but you will need help in digesting them. Just remember to take extra enzymes when eating large amounts of these foods.

Fruits and most vegetables are fat free naturally, and their vitamins and fiber are essential to your health.

Eating out is tricky because it is harder to determine exactly how much fat is in the meal. One of our VHL patients who has lived without a pancreas for nearly 40 years worked as a travel agent and traveled internationally, eating local food. "I estimated how much Creon I would need and kept some Imodium in my suitcase for emergencies, but I learned to manage pretty well. Eating the local fare is part of the fun of traveling." (*Jackie H., PA*)

The dietitians with the most experience dealing with pancreatic insufficiency are those who work with people with cystic fibrosis (CF). VHL has no connection with CF but 75% of people with CF to have pancreatic insufficiency for a different reason. On the CFF.org website there is a list of Care Centers for CF. Call the CF Care Center nearest you and ask to speak with the dietitian who works with adults with CF.

Because fats are not being digested, the fat-soluble vitamins are not being absorbed. Ask the dietitian about water-soluble vitamin supplements.

The most important thing to know is that it is possible to get things back into balance and eat what you want and be comfortable. Take the time to find the right professional to help you. One step at a time. You can do it!

Reference:

<http://www.cff.org/LivingWithCF/CareCenterNetwork/>

Adding a Dietitian to my Team

by Fred R., MA

On top of all the other VHL issues I've had to deal with for the last year and a half, I have been having chronic soft stool with sometimes embarrassing loss of control. I lost about 60 lbs. Finally I started asking the VHLFA whether this might be connected somehow with VHL. They helped me see that those innocent cysts in my pancreas that the doctors said were "harmless" might in fact be at the root of this issue. I went to see a gastroenterologist who prescribed Creon, and I have been working with him to find the right dosage by trial and error. Progress—I finally stopped losing weight—but the bathroom issue persists.

Recently at the suggestion of the VHLFA, I tracked down a dietitian who works with people with cystic fibrosis. Not an easy quest, and it seemed pretty weird, but it was worth the effort! After ten minutes of conversation and vital statistics, the dietitian told me I am taking too little Creon. According to her calculations, for someone of my height and weight, I should not be taking the prescribed 5 pills with each meal, I should be taking 10–12! We talked about what to take when I snack and how to gather clues from what comes out in the end.

I like my gastroenterologist, but doctors are busy. He sincerely wants to help me, but it is clear now that, in addition to his expertise in sorting out what's a cyst and what's a tumor, I needed to add to my team a dietitian who has experience coaching people through the changes in diet and enzymes caused by my "harmless" cysts.

New CCC, Tampa

It is with great pleasure that we announce that the Moffitt Cancer Center has been named a clinical care center of the VHL Family Alliance, enabling us to promote our multidisciplinary treatment approach to hereditary kidney cancer throughout the state of Florida.

The Moffitt Cancer Center is the only NCI designated cancer center in the state of Florida with presently 206 inpatient beds. The cancer center was originally founded by H. Lee Moffitt, a former state legislator and speaker of the Florida House of Representatives from 1982 to 1984 who had the vision to create a nationally and internationally recognized comprehensive cancer center over 25 years ago.

The Moffitt Cancer Center prides itself in offering the highest quality care to cancer patients and in doing so have developed a multidisciplinary approach to many cancer types. The hereditary kidney cancer clinic encompasses Moffitt physicians from over 10 medical/surgical specialties in addition to geneticist and genetic counselors. In addition, Moffitt has opened hereditary cancer clinics in other specialties including breast, colon, and gynecologic malignancies

all of which are being held in the same facility, the Lifetime Cancer Screening Clinic.

The Moffitt Cancer Clinic strongly believes that our nomination to join the clinical care centers of the VHL Family Alliance will enable us to further promote and expand our clinical mission.

We are listed on the VHLFA website, vhl.org/cc
Moffitt Cancer Center, Tampa, Kamala Kishore,
MS, Tel: +1 (813) 745-8119, E-mail: kamala.kishore@moffitt.org

Philippe E. Spiess, M.D., FACS and John Tourtelot, M.D., FACP, Co-Directors, Hereditary Kidney Cancer Clinic, Dept of Genitourinary Oncology and Endocrinology, Moffitt Cancer Clinic, Tampa, Florida.

Eva Lou Rodenberg

by Tom Rodenberg, MO, Member of the Board of Directors

My mom unexpectedly passed away yesterday, March 11, 2012. She had a massive heart attack early on Sunday and never regained consciousness. She was just shy of her 82nd birthday. She was ready to leave this earthly tent.



Eva Lou Rodenberg with five grandchildren and one great-grandchild

She bore 11 children of her own and raised the two children of her late brother. Of the 13 children she raised on the family farm, she saw 10 receive college degrees including 2 attorneys, 2 nurses, 2 educators, 2 highway patrolmen, 1 engineer, and 1 who earned a business degree.

Interestingly, as the last of her 11 surviving children who could make it reached her room, she took her last breath. She was quite a lady, if I do say so myself!

The good news for VHL people is that VHL did not rule or claim her life. She lived with VHL throughout her long life. In spite of VHL, she definitely lived a very happy life!

The New Handbook is Ready!

- Download (66 pages) which can be printed at home <http://vhl.org/handbook>
- Paperback, purchased from the VHLFA for \$10 + shipping at <http://vhl.org/vhlsales>, or at Amazon.com for \$14.99.
- Kindle version at Amazon.com



Mom's Day Run

Celebrate our Moms!

MAY 13, 2012, 8 AM – San Buena Ventura State Beach, California. For details, see vhl.org/meetings

Run/walk/skip or stroll along the beach on Mother's Day for a great cause!

Bring a friend, bring your Mom!!! 100% of the Registration Fee goes to VHL and LLS Cancer Research!! Together we can be amazing and make a difference!

The Risk to Blossom

Art song recital benefit for VHL Family Alliance

Jennifer Behnke, soprano

Eric Bunter, piano

Sunday, May 13, 2012, 7:00 PM

Christ and St. Stephen's Episcopal Church
120 West 69th Street, New York, NY

Performing Works by:

Richard Wagner, Claude Debussy,
Nikolai Medtner, Rayn Malone

Music on themes of inspiration, finding and embracing inner strength and the resulting desire to create beauty in the world.

Tickets at:

<https://www.brownpapertickets.com/event/238644>

29er Softball Tournament

June 16, 2012

by Stephanie Kaes, Canada



We are raising money for VHL with a fundraiser inspired by my brother Rick: for his love of ball, the game, the strategy, the friends and the beer; all a huge passion for a man who loved life, his wife, daughter, family, friends and, the game.

The 2nd Annual Tournament will host 144 players in a fun – but competitive softball tournament! Our goal this year is \$25,000. Please give generously. See you at the park! Details are posted at <http://www.rickbracey29er.com>

Join us June 3 at Softball City, Surrey, British Columbia, Canada.

Living with a Rare Disease

by Mary Anne B., MA, prepared for Rare Disease Day (February 29).

My husband and I are both career teachers. We are a happy family with six beautiful daughters. We had no idea that we were affected with a rare disease until January of 2005.

I was away on a mission in Haiti when I got a phone call from my husband, Jim. He sounded very upset and told me that test results showed he had several tumors growing in various parts of his body: in his eyes, brain, kidneys, pancreas, and along his spinal cord.

I was devastated, and flew home the next day. When I met Jim at the airport, I remember asking him to promise me that he would fight this thing.

Soon we read the official diagnosis of "VHL." I called my sister who had been a nurse at Massachusetts General Hospital (MGH) for 41 years. She told me she had never heard of this disease.

Years earlier when one of my daughters at age 9 was admitted to MGH with a blood pressure of 245/193, we first heard the diagnosis of "pheochromocytoma" or "pheo," a tumor of the adrenal gland. She had gotten the same tumor that her father had at the same age. Later, at ages 15 and 18, she was readmitted with more pheos. Another daughter was treated for a pheo when she was a teenager. Their doctor reassured us that once they were out of their teen years, the pheos would cease—just as my husband's had. Each year our girls were given 24-hour urine tests for detection of tumors. My husband was left untested.

I remember calling this same doctor who had treated both my husband and our girls. I asked him what this disease—this VHL—was. He promptly replied that it was a "progressive" disease, and quickly got off the phone. It appears that both my husband and my daughters who had been treated for many years for pheos at two leading hospitals in Boston—the MGH and Children's—were not properly diagnosed. The pheos had been treated, but the bigger picture of VHL was not recognized. Dots had not been connected.

Diagnosis is the first great challenge for anyone with a rare disease. If such a diagnosis could be missed at these fine hospitals in Boston, it is probably missed

even more often elsewhere. This is tragic because if we had known what to watch out for and been treated earlier, my family members might have had different results today.

We then went for testing of our six daughters for this disease. Three of the six girls have genetically-inherited VHL. Since 2005, they have had removal of adrenal glands, one had a gigantic stomach reconstruction called a "whipple," one has been watched closely for tumors on her optic nerves, and my husband has lost 1-1/2 kidneys and his pancreas, and has had eye surgery as well. He is at risk for cancer.

Managing this disease is not easy and keeping up with screenings and procedures for four family members is a big job. Much of this could have been prevented if we had had a diagnosis earlier.

I am not asking for your pity, I am asking for your partnership in raising awareness of VHL and all rare diseases. Rare does not mean

non-existent.

Any family can suddenly be affected with a rare disease. When it affects you, it is not rare.

Research on rare diseases is teaching us a great deal about the more common diseases. The VHL gene in particular has taught us all a great deal about how cancer works in everyone.

Please help us tell our legislators everywhere that we need to study rare diseases, support drug development for rare diseases, and learn all we can about the mechanisms of these diseases so that we can not only relieve the pain and suffering of the millions of families directly affected, but we can also learn strategies for curing more common diseases as well.

One person in ten is dealing with some form of rare disease. To those of you reading this article, I want you to know that you are not alone. If we work together and with our friends and representatives, we can find the cures we need.



The Babineau family

Please check <http://vhl.org/meetings> for updates and directions or call the office, 800-767-4845, ext 4—and check for regional events throughout the year

Changed your Address?

Help the VHL Family Alliance provide you with the most up-to-date information!

Please help us ensure that you are receiving our mailings and emails by updating your contact information on our update form at Survey Monkey: <http://svy.mk/HFvY85>

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SATURDAY, NOVEMBER 17, 2012
Boston, Massachusetts

2012 Annual VHL National Meeting and Dinner

honoring

JOYCE GRAFF and DR. WILLIAM KAEIN

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<http://vhl.org/meetings/meet2012/bostonmeeting2012.php>

You can also see details of both events on this page