

## DNA Reimbursement Program Extended

by Gale Lugo

The VHL Family Alliance (VHLFA) has extended the tissue donation program for another six months, through June 30, 2009. If you file a copy of your DNA mutation report with the VHL Tissue Bank at NDRI, the VHLFA will reimburse you \$100 toward the cost of DNA testing. You do not need to be a member of the VHL Family Alliance to donate tissue.

This tissue is being gathered to help promote research on VHL. Numbers count -- the more tissue is available, the more interest in VHL is likely. Here is our chance to be proactive.

The VHL mutation will no longer be passed in my family, at least the family I am in touch with. The only ones left with VHL are myself and my aunt who is 71 years old. Even though I don't have any biological children, nor expect to have any, I plan on donating any and all tissue, both during my lifetime and after I die. After all, I will no longer need them. And I try to recycle whenever I can.

At least the next generation of people with VHL can hopefully get more help, more answers, and maybe even a cure in their lifetime with VHL.

If you register with NDRI (US & Canadian residents only), there are a number of papers to fill out. Davlyn Tang at 800-222-6374 x 242, has been extremely helpful with all my questions in filling out the paperwork. I'm also available to go over the forms with you since I have done it already. I have all the papers filled out in my possession since I faxed Davlyn the forms. If I can be of help, send me an email [us-fl@vhl.org](mailto:us-fl@vhl.org).

You just have to call Davlyn in the Rare Disease Program and tell her you would like to register for the VHL program. She will send you all the necessary information.

Once you are registered, you the actual tissue donation is easy -- just give NDRI the name of the surgeon and the date and place of the surgery.

I am passionate about this program because I really think this is the break we really need to help find answers and to spread the word about VHL.

Won't you consider a valuable donation that can help our future generations?

### **To Researchers and Physicians . . . Von Hippel-Lindau Syndrome Tissue Available for Research**

Research requires 1) researchers, 2) human tissue for study, and 3) a well-described project to answer key questions. Each is needed for research progress.

In 2007 the VHL Family Alliance joined the Rare Disease Initiative of the National Disease Research Interchange (NDRI), to create an collection of tissue to advance VHL research. More than 400 specimens are carefully preserved and available for research projects.

#### **Register with NDRI for Research Projects**

All researchers with a project requiring human tissue should register with NDRI. There is no cost to register. This first step is essential to the growth of the NDRI tissue bank -- to assure that needed tissue is preserved, collected, and stored according to the requirements of your project.

#### **What's in the tissue bank collection?**

Fresh procurement from surgical donors including brain/cerebellum, eyes, adrenal gland, kidney, kidney cortex, kidney medulla, liver, lung, lymph node, optic nerve, pancreas, spine, spleen, and stomach tumors. Some samples are fixed with formaldehyde in paraffin blocks, other are snap frozen blocks or slides. Medical data is available regarding the donor on most tissue samples, including the specific DNA analysis. *continued page 2*

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Gale Lugo

NDRI is more than a catalog of tissue samples; it's also a "matching service" - matching up the tissues to the research projects. If a project has special sample preservation requirements, NDRI will do their best to meet these requirements. Write to [bank@vhl.org](mailto:bank@vhl.org) for online access to the catalog and other details.

**Obtaining specimens is easy and inexpensive**

After completion of the sample acquisition forms, withdrawing samples from the collection is relatively easy. There is a small fee for processing and shipping the samples. The VHL Family Alliance and NDRI cover the costs of collecting and storing the specimens, as well as collecting medical data and genotype information from the donor. U.S. National Institutes of Health also provides support.

**Studies funded by VHLFA**

Research proposals submitted to VHLFA are favored when utilizing the NDRI collection of VHL tissues.

**About NDRI**

NDRI is experienced with tissue collection for research on rare diseases. NDRI was founded to collect tissue to facilitate research on Juvenile Diabetes. Twenty-five years later, they have documented family histories of 2550 individuals and 500 families affected by diabetes.

In less than two years, the VHL community has responded generously to our call for research tissues. To date, 35 patients have contributed tissue, and another 21 have completed paperwork in anticipation of future surgeries. Once the tissue is processed for storage, a single tumor can provide several samples for research. The existing tissues have provided more than 400 samples thus far...

We are working with NDRI to promote this resource to researchers so the tissues are used in research protocols. There is a customized service, whereby NDRI can design custom systems to deliver

protocol specific human biomaterials to meet the specialized needs of individual scientists.

Funded in part by the National Institutes of Health (NIH), NDRI provides biomaterials to more than 250 of the nation's academic-based research centers including Harvard Medical School, Massachusetts Institute of Technology, Mt. Sinai School of Medicine, Stanford University, and Thomas Jefferson University. NDRI also provides tissues to government agencies and NIH grantees, the U.S. Food & Drug Administration, the U.S. Department of Agriculture, The Centers for Disease Control, and to the nation's top pharmaceutical, biotechnology and Research & Development programs.

**Frequently Asked Questions:**

*What hospitals does NDRI work with?*

NDRI has a network throughout the country and can arrange to retrieve tissue from almost all hospitals where a patient is having surgery. If contacted at least a few days before the surgery, there is usually enough time to make all the arrangements. The NDRI phone is answered 24 hours daily, 877-221-6374

*On the permission form at the hospital, I said they could use my tissue for research. How is this different?*

The tissue removed from surgical procedures are usually examined by a pathologist, who produces a written report, then the tissue is stored in a local refrigerator for some months before disposal. If a local physician writes a paper about a single case, usually this "case study" is a report of only one case - which is interesting - but we hope to promote research leading to publications on a larger number of cases.

By pooling VHL samples at NDRI, many samples are available to all researchers with approved projects - including local physicians. We want to provide access to local doctors, and also provide access to many more samples to add breadth to a research study.

**NDRI -**  
<http://ndriresource.org>  
 Advancing the procurement, preservation and distribution of human cells, tissues and organs for research and transplant.

**Patients – Call for Tissue! – Think Bank! - write to [bank@vhl.org](mailto:bank@vhl.org) or call 877-221-6374**

Having your eye enucleated? We have a team now seeking eyeball donations to research.

Surgically removed tumor tissue and cysts, with whatever healthy margin your surgeon needs to take for your health, would be very helpful to research.

Biopsy materials, both fluid and tissue, all of that is extremely helpful to research.

When someone passes away, NDRI can organize in your area "rapid recovery" of the tissues you are willing to donate, so that the body is ready on time for the funeral, even for an open casket viewing.

# Laughing Matters

by Anita Kalathara

"HoHo HaHaHa." Thus begins a conversation with Sandra Boris-Berkowitz about laughing yoga. In her interview on the Powerful Patient with Joyce Graff, Sandy discusses her evolution from care-giving educator to full-time laughing yoga leader.

Sandy taught deaf and blind children for 28 years. After her mother was diagnosed with Alzheimer's, she began working as a caregiver educator, coaching caregivers for senior citizens. As her mother's condition worsened, she learned first-hand the importance of taking care of the caregiver, and adding joy and humor back into her own life.

While researching humor, she found a family doctor in India who uses laughter as a healing method. Laughter yoga is based on a simple truth that all children know: laughter makes you feel better. Children laugh about 400 times a day; adults laugh only about 15 times a day.

Dr. Madan Kataria got together with a group of people and told jokes. After a week, they began to run out of jokes. Some people complained about different aspects of the jokes -- too sexist, too racist, or simply not funny so Dr. Kataria removed the jokes. According to Dr. Kataria, "We started laughter as an exercise, and combine it with yoga breathing. When you laugh in a group it turns into real laughter until it becomes unstoppable, from your deep within. Anyone can laugh: no jokes, no humor, no comedy skills." From the small group he started in 1995 there are now more than 6,000 laughter clubs in 60 countries.

For Sandy, laughter gave her something she could share with her mother. Even in the later stage of Alzheimer's, "It was hard for me because my Mom was no longer the mother I had known. She would repeat the same questions, which didn't leave much room for conversation," says Sandy. She began using these laughing techniques with her mother and saw a noticeable difference, "It brought my old mother out. And watching and listening to her laugh, I realized that my mother was in there



Sandra Boris-Berkowitz, M.Ed., LRC, is a Laughter Yoga Leader certified by the Dr. Kataria School of Laughter Yoga. She is also a teacher and a licensed rehabilitation counselor still, just different." After finding so much joy in using Laughter Yoga herself, Sandy decided to open her own business of teaching Laughter Yoga, in which she combines the methods of Dr. Kataria and her own added techniques.

Laughing has real benefits. It provides support for your immune system, helps you breathe, reduces stress and your risk of cardiovascular disease. According to Sandy, "It just takes one person to laugh and the others will follow." For all the disbelievers, it is a known scientific fact that your body can't tell if you're laughing for a real reason or not. This means that anyone can try. And as Sandy says, "Fake it until you make it." Sandy's recommend dosage of laughter is three times a day. "Think of it as a vitamin."

If you would like to hear Sandy's contagious laughter or join her in a session of Laughing Matters, listen to her interview on the Powerful Patient show at <http://www.powerfulpatient.org> -- and/or --

**Join Sandy at the Massachusetts Meeting  
February 1, 2009, 2 pm, at the  
Watertown Library in Watertown, Mass.  
Please call 1-800-767-4845 ext. 4 for details**

## Nominations for VHLFA Board of Directors

As a dynamic organization, the VHL Family Alliance (VHLFA) is seeking nominations for the Board of Directors. This highly effective body seeks to find dedicated and motivated nominees who can commit time and energy to promote the mission of the Alliance: improving diagnosis, treatment, and quality of life for individuals and families affected by Von Hippel-Lindau disease.

We are seeking nominees with strong organizational and business skills, a passion for the cause, a desire to help shape the future of the VHLFA through promoting outreach, research, education and fundraising, and an ability to commit to monthly teleconferences and 1 or 2 in-person meetings annually. There are additional communication and opportunities for involvement on committees of the Board and other engagements.

Please feel free to contact the Nominating Committee with questions at [nominations@vhl.org](mailto:nominations@vhl.org). We look forward to having a great group of candidates from our membership, friends, families, supporters and anyone else who has a passion for VHL.

# Calm in Stressful Times

From Harvard Health Publications, Harvard Medical School, Boston, Massachusetts

There's a free guide to remaining calm during stressful times, from Harvard Medical School. Lately, every day seems to bring a new cause for worry -- the mortgage crisis, the struggling economy, rising unemployment. And on top of all that, the holiday season (a recurring source of stress). This constant barrage of disturbing news and emotional hurdles can have a big impact on health.

Although you won't find the word "stress" anywhere on the list of the ten leading causes of death in America, many highly-regarded studies link chronic stress to ailments such as heart disease, stroke, and a weakened immune system.

"Stress doesn't just make you feel tense and edgy, it can actually impair your health," says Dr. Michael Miller, editor in chief of the Harvard Mental Health Letter. "Thankfully, there's plenty we can do on our own to reduce stress in our lives." The Harvard Medical School *Portable Guide to Stress Relief*, a free guide offered by Harvard Health Publications, provides helpful tips on how to start.

Of course, sometimes just thinking about embarking on such a program can feel overwhelming. Don't freeze in your tracks. Instead, follow Dr. Miller's suggestion to start small.

One stress-management technique that may work for you is a form of deep breathing known as the relaxation response. Another useful approach, known as cognitive restructuring, aims to change patterns of negative thinking. Not only will these strategies help you feel calmer, they may also reduce your blood pressure.

The free guide from Harvard Health Publications, culled from the pages of the special health report, *Stress Management: Approaches for Preventing and Reducing Stress*, provides detailed suggestions for soothing anxiety and worry. Whether you have one minute or half an hour, The Harvard Medical School *Portable Guide to Stress Relief* will teach you ways to manage the strains of your day. It describes ten common stressors and how to defuse their impact, and offers information on how to use meditation to lower stress levels. You will also find step-by-step instructions for "mini-relaxation" routines, organized according to how much free time you have available.

To begin, try these sample mini-relaxations:

## *De-stressing when you've got 1 minute*

Place your hand just beneath your navel so you can feel the gentle rise and fall of your belly as you breathe. Breathe in slowly. Pause for a count of three. Breathe out. Pause for a count of three. Continue to Page 4



breathe deeply for one minute, pausing for a count of three after each inhalation and exhalation.

Or alternatively, while sitting comfortably, take a few slow deep breaths and quietly repeat to yourself "I am" as you breathe in and "at peace" as you breathe out. Repeat slowly two or three times. Then feel your entire body relax into the support of the chair.

## *When you've got 2 minutes*

Count down slowly from 10 to zero. With each number, take one complete breath, inhaling and exhaling. For example, breathe in deeply saying "Ten" to yourself. Breathe out slowly. On your next breath, say "nine" and so on. If you feel lightheaded, count down more slowly to space your breaths further apart. When you reach zero, you should feel more relaxed. If not, go through the exercise again.

Also in this guide:

- Using a gratitude journal to turn your focus away from negative thoughts and feelings
- Learning to straighten out cognitive distortions
- Helping your children — or yourself — reduce stress with a "worry box."

The Harvard Medical School *Portable Guide to Stress Relief* is available to download for free from Harvard Health Publications, the publishing division of Harvard Medical School, at to <http://www.health.harvard.edu/stress-relief>



## Balanced

Richard Mickley from California recently displayed his sculpture entitled "Balanced" in the 19th annual INSIGHTS exhibition of the San Francisco

Lighthouse for the Blind and Vision Impaired. Held in the San Francisco City Hall, this nine week event was a juried art show for blind and vision impaired artists that included works by 44 artists from around the world.

# Pancreas and Digestion

Reporting a new article by Damerla Venugopal, MD, Vladimir Gotlieb, MD, Heidi Larson, RD, and M. Wasif Saif, MD., Yale University, New Haven, Connecticut.

**Editor's note:** More than half of people with VHL will have one or more cysts or tumors of the pancreas. Most frequently these are cysts, which in themselves are considered harmless. Hard tumors of the pancreas need to be monitored closely, as described in the VHL Handbook and in more recent research from Dr. Steven Libutti in the U.S. and Dr. Pascal Hammel in France.

Those "harmless" cysts in the pancreas, however, can often cause issues simply by blocking the pancreatic duct, preventing enzymes from reaching the gut, and causing disruption of normal digestion. This new article in the Journal of Supportive Oncology (see Note 1) provides a strategy for helping get the digestion back on track by prescribing some pills to provide more pancreatic enzymes.

When the amount of pancreatic enzymes being delivered to the digestive tract is insufficient to do the job, there may be vague abdominal discomfort, pain, abdominal distention, excessive foul-smelling flatus (wind), belching, diarrhea, steatorrhea (excess fat in the stool), and weight loss. This is a condition called pancreatic exocrine insufficiency. It is common in people with pancreatic tumors, most commonly after surgery. However, most people with pancreatic cysts and tumors will have a blocked or partially blocked pancreatic duct and are also likely to have some need of Enzyme Substitution Therapy (EST).

These distressing symptoms have a negative impact on both the physical and psychological health of patients. It is important to maintain a healthy weight in order to maintain stamina for life and for treatment of any other issues.

Even though EST is simple and inexpensive, doctors are not always aware to check these levels and prescribe the pills. Recognizing the importance of this issue, the latest version of the National Comprehensive Cancer Network guidelines (<http://www.nccn.org/pancreaticcancer>) lists pancreatic enzyme replacement as one of the key factors in the supportive care of patients with pancreatic tumors. The article reviews the rationale, indications, diet, and future directions relevant to EST.

Pancreatic enzymes are essential for proper digestion and absorption of nutrients. The key enzymes are amylase, lipase, trypsin, and chymotrypsin. The pancreas secretes these enzymes in a rhythm coordinated with the cycles of the gastric system. Following the emptying of the stomach, the pancreas gets to work secreting

enzymes to process the food. The exocrine secretion rate rises by three to six times within an hour, and is back to the base rate about 3-4 hours after eating.

The quantity and duration of secretion is coordinated with the caloric value of food eaten, the free fatty acid content, the presence of certain amino acids, the solidity of a meal, and the readiness of the food for absorption by the body. After a standard meal, the output of lipase rises by 3 to 6 times, and the output of amylase and trypsin rises by 10 to 20 times. To prevent rapid degradation of lipase, the acid balance in the duodenum has to be within the right range, and the amount of bicarbonate secreted into the duodenum is critical for fat digestion. (See Note 2)

Nutritional care of patients with pancreatic cysts and tumors presents numerous challenges, as patients often suffer from a myriad of gastrointestinal (GI)

symptoms, and people who have had pancreatic surgery have additional considerations. The goals of nutrition in such patients are to prevent or correct malnutrition; prevent wasting of muscle, bone, and lean body mass; and reduce nutrition-related side effects.

Fats are a concentrated source of calories, providing more than double the calories per gram provided by carbohydrate and fat. The digestion of long-chain fatty acids occurs in the small intestine and requires both bile and lipase. A diet containing 30%-35% of calories from fat is normally the starting recommendation.

Before restricting fats, the doctor should investigate other potential causes of diarrhea, such as lactose intolerance, bacterial overgrowth, bile acid insufficiency, and infection with *Clostridium difficile*. In cases of fat restriction, short-chain and medium-chain triglycerides (MCTs) can be used as a calorie source and do not require the aid of bile acids and lipase to be shuttled to the liver. MCT oils (such as coconut oil) can be purchased over the counter in many pharmacies and supermarkets. They can be used as a fat replacement in cold foods but should not be used in cooking due to a low boiling point.

Carbohydrate digestion begins in the mouth with saliva, and is further broken down in the small intestine with the help of pancreatic

**Table 1**

**Signs and Symptoms of Malabsorption**

- Vague abdominal discomfort or pain
- Abdominal bloating or distention
- Excessive gas
- Belching
- Diarrhea, fatty, or floating stools
- Weight loss

juices. Incomplete carbohydrate digestion due to insufficient amylase can result in diarrhea from undigested starches reaching the colon. Patients who have had a non-pylorus-preserving pancreaticoduodenectomy (as in a Whipple procedure) should avoid simple sugars, which can cause dumping syndrome and can make diarrhea worse. Recommendations for carbohydrate intake range from 45%–60% of calories depending how well the pancreatic enzymes are balanced.

Protease is required for protein digestion. Poor protein digestion and absorption can lead to production of toxic substances in the intestine and an increased risk of intestinal infections. Protein needs in patients with pancreatic tumors are not well known. Initially, protein can constitute 15%–20% of caloric intake. A 24-hour urea nitrogen test may be helpful to determine nitrogen balance and to offer a better estimation of protein needs.

Alcohol inhibits gastric lipase secretion, and therefore should be avoided.

If pancreatic imbalance goes on for a long time, making it hard for the body to absorb the nutrients in the food, it can result in vitamin and mineral deficiencies. Absorption of Vitamins A, D, E, and K depends on absorption of fats. Vitamin B<sub>12</sub> deficiency may also be present, because protease is required for cleavage of vitamin B<sub>12</sub> from protein. Iron deficiency can occur when proton pump inhibitors (antacids) are prescribed. (See Note 3) Post Whipple patients have an increased propensity toward calcium, zinc, and iron deficiencies. (See Note 4) When a patient presents with anemia, testing for serum B<sub>12</sub>, red blood cell folate, and iron can help identify the cause of anemia. No current data exist on vitamin supplementation in pancreas patients.

Trace element deficiencies have been documented in patients with chronic pancreatitis and may occur in people with pancreatic cysts and tumors. In our experience, patients often limit food variety, so we believe it is good to prescribe a multivitamin with minerals. If symptoms of malabsorption persist, it can help to take a form of fat-soluble vitamins that can be mixed with water (“watermiscible” vitamins). Vitamin B<sub>12</sub> is indicated for those found to have a deficiency; the sublingual (under-the-tongue) variety avoids some other balancing issues. Additional micronutrient supplementation can be provided as indicated by blood testing.

**Indications for Enzyme Substitution Therapy**

In our experience, oleic acid breath test, assessment of stool elastase, and estimation of fecal fat content are the main methods of estimating the degree of fat malabsorption. We advocate EST to all patients with pancreatic cancer, and would therefore

assume it would be helpful also to people with VHL. EST has been shown to help patients with a greater than 15% loss of fat in feces, but its application in patients with less than a 15% loss is debatable. However, Dominguez-Munoz demonstrated a role of EST in patients with pancreas issues who do not have digestive symptoms and who have less than a 15% loss of fat in feces, as these patients are likely to have low levels of vitamins A, D, E, and K; ferritin; and prealbumin. (See Note 5)

The article cites a number of studies showing the effectiveness of EST.

**Practice Guidelines for Physicians**

The main principle of EST is simulation of the normal complement of pancreatic enzymes by taking supplements during or just after meals. EST can often relieve many of the symptoms associated with pancreatic enzyme deficiency, and can allow patients to increase food intake and to improve their nutritional status. Patients should be instructed on the signs and symptoms of malabsorption (Table 1) as well as the rationale for starting EST. Table 2 offers patient information that can be provided when patients start EST.

Replacement pancreatic enzymes are available in different formulations and dosages, at varying costs. EST preparations are dosed by lipase content but also contain amylase and protease. Enzymes can be dosed by fat intake or by weight.

In our practice, we prefer calculating the dosage by fat intake. Our usual starting dose is 50,000 IU per meal; we escalate the dose depending on how

<p><b>Table 2</b>  <b>Useful Information for Patients on EST</b></p> <ul style="list-style-type: none"> <li>- Take enzymes at all meals and snacks. Grazing should be avoided, as it may result in persistence of symptoms.</li> <li>- Enzymes should be taken whole with liquid. Contact of enzymes with the mouth and tongue can result in irritation and sores in the mouth.</li> <li>- If you cannot swallow the enzymes whole, you can mix them with a nondairy food that can be swallowed immediately such as applesauce. Antacids that contain calcium or magnesium can interfere with the effectiveness of the enzymes.</li> <li>- Taking half of your enzyme dose at the beginning of a meal and the other half toward the end of the meal may improve symptoms.</li> <li>- Your doctor may have given you a prescription for an acid-reducing medication such as ranitidine or famotidine. The prescription is to improve enzyme activity and should be taken as recommended.</li> <li>- Enzymes are started at a lower dose and increased if your symptoms do not resolve.</li> <li>- If bloating remains a problem, changing to a different formulation may help.</li> </ul> <p>Abbreviation: EST = enzyme substitution therapy</p>
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well it relieves symptoms, and by monitoring for appropriate weight gain. A patient-generated diary documenting food intake, EST compliance, and the incidence of diarrhea can help identify a need for changes to the dosages.

If steatorrhea persists despite enzyme changes, a lower fat diet may be warranted. The amount of pancreatic enzymes required will vary with the amount of food eaten and may need to be increased with larger meals (eg, two with a meal and one with a snack).

The effectiveness of EST depends on how well the patient manages these calculations and the timing of food and pills.

### **Summary**

In the opinion of the authors, EST has a unique role in the management of pancreatic insufficiency and should be considered for most patients with pancreatic cysts and tumors to provide supportive care. Newer, "enteric" pills, coated to protect the stomach lining, are usually tolerated better than older preparations which are not enteric coated as only 1% of these preparations actually reach the duodenum, as shown by Dimagno et al. (See Note 2) The use of antacid medications with EST may make the enzymes more effective. Control of symptoms such as fat malabsorption and diarrhea may have a major impact on an individual's quality of life.

### **Notes:**

1. The full article, Venugopal Damerla, MD, Vladimir Gotlieb, MD, Heidi Larson, RD, and M. Wasif Saif, MD. "Pancreatic Enzyme Supplementation in Pancreatic Cancer" J Support Oncol 2008;6:393-396, is available on the internet at <http://www.supportiveoncology.net/journal/articles/0608393.pdf>
2. DiMagno EP, Malagelada JR, Go VL. The relationships between pancreatic ductal obstruction and pancreatic secretion in man. Mayo Clin Proc 1979;54:157-162. [431121]
3. Examples of proton pump inhibitors. Read the active ingredients on the label. Brand names vary by country.
  - Omeprazole (some brands: Losec, Prilosec, Zegerid, ocid)
  - Lansoprazole (brands: Prevacid, Zoton, Inhibitol)
  - Esomeprazole (brands: Nexium)
  - Pantoprazole (brands: Protonix, Somac, Pantoloc, Pantozol, Zurcal, Pan)
  - Rabeprazole (brands: Rabecid, Aciphex, Pariet, Rabeloc)
4. Anderson JJB. Minerals. In: Mahan LK, Escott- Stump S, eds. Krauses's Food Nutrition and Diet Therapy. 11th ed. Philadelphia: WB Saunders; 2003:120-163.
5. Dominguez-Munoz JE. Management of maldigestion in chronic pancreatitis: a practical protocol. In: Dominguez-Munoz JE, ed. Clinical Pancreatology for Practicing Gastroenterologists and Surgeons. London: Blackwell Publishing; 2005:288-295.

## **New Media For You**

We are working with a number of new technologies in an effort to serve you better. We will appreciate your feedback

### **Radio - Podcasts**

The Powerful Patient has been very successful, reading more than 20,000 people each week throughout 2008. We are moving to a shorter format in 2009, to make the programs easier to use as Podcasts. There is a podcast menu on the Powerful Patient website. We are in the process of listing with iTunes and other podcasting sources, so we should be showing up there by the end of January.

### **Facebook - MySpace**

We now have more than 1000 members in our VHL group on Facebook! This is "social networking" - helping to raise visibility among your friends. You can join the group there, and can create your own "cause" page to gather donations for VHL. Several people have already created "cause" pages. It is also possible to link your Firstgiving page into Facebook.

### **Inspire**

Where Facebook is a place for the general public, Inspire is a place for people who are more directly affected by VHL to discuss the deeper issues around VHL itself, both medically and emotionally. It's a wonderful place to ask questions, find support, and know you are among folks who know what you are going through.

### **YouTube**

With the new YouTube contest, our presence on YouTube will be growing this spring, working toward having a strong presence in time for International VHL Day on May 9. See contest rules on page 9, and help us raise awareness and build momentum.

### **Webinars**

We began a series of Webinars (seminars on the web) which give us the ability to have the slides for you to watch as you listen to the audio. There are recordings available on the website that you can watch. This is the list as of January - watch for more!

VHL 101

Pre-implantation Genetic Diagnosis (PGD)

Report from Copenhagen

Report from Kidney Cancer Symposium

### **Coming up! - participate in the live session**

Jan 29 - Pregnancy and Family Planning, with Jessica Everett, Genetic Counselor, U of M

watch <http://vhl.org/meetings> for more

### **Feedback**

Please fill out the survey at [vhl.org](http://vhl.org) - Thank you!

# Benefits of Eating Fruit and Vegetables

*Naturally occurring apigenin facilitates the death of cancer cells*

Now a study by the Biochemists at University of California at Riverside biochemists reports that eating apigenin – a naturally occurring dietary agent found in vegetables and fruit – improves cancer cells’ response to chemotherapy, and helps keep cancer cells from proliferating.

Xuan Liu, a professor of biochemistry, and Xin Cai, a postdoctoral researcher working in her lab, found that apigenin localizes tumor suppressor p53, a protein, in the cell nucleus – a necessary step for killing the cell that results in some tumor cells responding to chemotherapy.

The study, published in the *Proceedings of the National Academy of Sciences*, provides a novel approach to conquer tumor resistance to chemotherapy, and suggests an avenue for developing safe chemotherapy via naturally occurring agents.

Normally, cells have low levels of p53 diffused in their cytoplasm and nucleus. When DNA in the nucleus is damaged, p53 moves to the nucleus where it activates genes that stop cell growth and cause cell death. In this way, p53 ensures that cells with damaged DNA are killed. This is an essential process in the body’s immune system, “spell-checking” the DNA in our cells and making sure that cells that are beginning to change and become cancers are killed off. The body then makes new cells.

“In therapy you want to kill cancer cells,” explained Cai, the first author of the research paper. “But to stop cell growth and to kill the cell, p53 first

needs to be moved to the cell’s nucleus to function. Apigenin is very effective in localizing p53 this way.”

Apigenin is mainly found in fruit (including apples, cherries, grapes), vegetables (including parsley, artichoke, basil, celery), nuts and plant-

**“Our study advocates the inclusion of vegetables and fruit in our daily diet to help prevent cancer.”**

derived beverages (including tea and wine). It has been shown by researchers to have inhibit the growth of a number of cancer cell lines.

“Our study advocates the inclusion of vegetables and fruit in our daily diet to help prevent cancer,” said Liu, the research paper’s coauthor.

The National Institutes of Health supported the five-year study.

Next in their research Liu and Cai plan to design therapies for cancer by finding compounds that are like, but perform better than, apigenin.

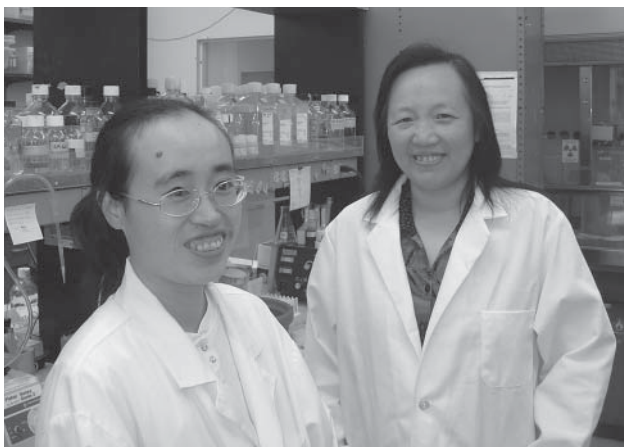
## New Book by Tom Rath

In *Strengths Based Leadership*, a follow-up to the bestselling *StrengthsFinder 2.0*, Tom Rath and Barry Conchie compiled the latest research on leadership. Their findings are filled with practical ideas on becoming a top-notch leader, developing the best team, and understanding the needs of your followers. Congratulations to Tom! Tom Rath is a member of the VHLFA Board of Directors.

## Cover the Uninsured Week, March 22-28!

For the past six years, the Robert Wood Johnson has worked together with a number of medical and religious groups to highlight the need for our nation’s leaders to make reforming our health care system a top priority in order to provide a solution for all Americans, especially the 46 million - including 9 million children - living without health insurance.

As a new Congress and administration take office in January, it is important that they put reforming our nation’s health care system at the top of their agenda. The VHL Family Alliance will be participating in Cover the Uninsured Week 2009 at the national level – you can help in your own community



Left to right: Xin Cai, a postdoctoral researcher, and Xuan Liu, a professor of biochemistry, at University of California at Riverside, California.

# Show Us Your Stuff!! Win a Prize!!



## Hey, Kids! Original Drawing and Photo Contest

Hey Kids and Parents!

We are looking for photos and drawings to add to the VHL Children's Book.

**Kids**, do you like to draw? If so, we need illustrators (children with VHL) ages 5 to 18 years old! The VHL Children's book group will be adding pictures to *The VHL Handbook: Kids' Edition*, and we're looking for volunteers! The first 18 volunteers to contact us will be able to draw one picture for the book. Each child who illustrates will have his or her name published with their drawing in the book (Ann F, Ohio, age 8). We will need our illustrators to draw pictures of themselves, family members, friends, doctors, etc.

**Parents**, we'd also like to include photographs of your children having one of these medical procedures done, like for example:

- your child having an eye exam
- your child having a hearing exam
- your child getting ready to have an ultrasound
- your child getting ready to have an MRI
- your child with his or her doctor

Also, parents, we'd like to include pictures of your children (all ages) with VHL in their normal everyday life - happy, smiling face pictures! The first 20 parents to contact us will have a picture of their child published in the book as well.

If you would like to contribute a drawing or photograph, or for more information, please email Melissa Kruger at [kidsbook@vhl.org](mailto:kidsbook@vhl.org) or call 1-800-767-4845 ext 721.

**Deadline: March 31 2009.** Every child who participates will receive a wristband and a VHL Frisbee.

## Video Contest ... "My Life with VHL"



The VHL Family Alliance is sponsoring a contest on YouTube -- make up a video showing your own adventures with VHL. The video should tell your story and what VHL Family Alliance means to you

Videos will be judged on creativity, originality, inspiration, and viewing popularity.

Upload your video directly to YouTube by **April 29, 2009.**

You must include: "VHL Family Alliance" in the title line, description line and tag line to be considered eligible for the contest.

The winning video will be selected by VHL Family Alliance (staff and board) on April 30<sup>th</sup>, 2009

The winner and one parent or companion will win a trip to Anaheim, California, for the VHL Family Alliance 2009 convention near **Disneyland**. (domestic airfare and two nights' hotel, up to \$1000).

The top ten YouTube videos will have featured links on [www.vhl.org](http://www.vhl.org)

## T-Shirt Design Contest!



Have you ever thought about designing a T-Shirt? Want your design to represent the VHL Family Alliance?

Here's your chance to design a t-shirt of your own that the VHL Family Alliance will use across the nation on VHL Awareness Day. The only rule is that you include VHL Family Alliance anywhere on the T-shirt. We want you to get creative with phrases, art work, whatever you think will help catch people's attention and get people asking about VHLFA. If you have ever dreamed of being of being a designer and having people wearing your clothes, here's your opportunity. Or simply do it if you want to help out VHLFA. Give it a shot!

Whether you chose to draw your design or use a computer program, please scan the design onto the computer and send it to [anita@vhl.org](mailto:anita@vhl.org). If you have any questions feel free to call 1-617-277-5667, Ext. 4. We will pick the lucky winner on **March 31, 2009.**

**Everyone who submits a design will receive a wristband and a Frisbee.**



Alex  
Anderson

## International VHL Day May 9, 2009

by Karen Anderson, New Jersey

On May 9th, 2009 my son Alex, a VHL warrior, will be holding a local fundraiser. It is his wish that all people around the world, also touched by VHL, will hold a fundraiser in their community on the same day. We are looking for VHL friends and families to participate and spread the word about VHL. In working with my son, it is our hope that we can all connect via the Internet, the media and in our small towns to mark this important day with global awareness.

I know that sometimes finding new and innovative ways to raise funds and awareness can be challenging. Please consider the ideas below. I welcome correspondence from you to support and guide your endeavors in this enormous undertaking. There is power in numbers and together we can raise global awareness for research and funding, and help to cure VHL, united as one family.

Consider the following fundraising options, or create one of your own:

- Dress up day/dress down day at your schools or place of work pay for the privilege of dressing differently at work or school)...usually about \$3 to \$5 per person
- Popcorn sales
- Candy sales
- Bake Sales
- Contact local restaurants to ask for a percentage of an evenings profits
- Hold your own "High Tea" in exchange for a donation
- Hold a "penny" drive, or loose change drive at schools in your town
- Use Tupperware, Pampered Chef, CandleLight, or any home based party company to do a presentation and have profits go to VHL
- Golf Tournaments
- Covered Dish Dinners with donations

Thank you for all your efforts! Together we can raise awareness and cure VHL.

Let's all be sure to tell Anita in the VHL office about our plans too, so that she can put them on the VHL calendar and include them in her national press releases! Together, we will have more access to the press than any of us can as an individual. Let's make some BIG noise in the press! Send to [anita@vhl.org](mailto:anita@vhl.org)

**Already signed up:** Florida, Massachusetts, Minnesota, Washington state, and Germany -  
*please join the fun!*

## Raising Visibility

Declaring a "Day" helps to give the press a reason to publish something about our cause within a given timeframe.

For us, that makes it a good excuse to send out a press release and work with local and national media to get something published about VHL.

Please help by contributing your story, ideas, interesting pictures, etc.

**Contests! -- Great Prizes -- see page 9**

**T-shirt design contest,**

**YouTube video contest**

**add color and fun to VHL Day!**



## Rare Disease Day

February 28, 2009

The National Organization for Rare Disorders (NORD) is coordinating the observance of Rare Disease Day in the United States on February 28, 2009. On that day – and in the weeks leading up to it – we will join with others around the world to conduct a variety of activities to raise awareness of rare diseases and the need for safe, effective treatments.

This will be the 2nd Annual Rare Disease Day. The special day was observed for the first time last year in Europe and was coordinated by NORD's partner organization, EURORDIS. It is the hope of NORD and EURORDIS that this will become an annual global event, taking place on the last day of February each year. If you would like to participate and help us spread awareness of VHL, here is a great idea:

If you are willing, please submit a human interest story about yourself or someone you know affected by VHL to [rarediseaseday@rare diseases.org](mailto:rarediseaseday@rare diseases.org), copy to [anita@vhl.org](mailto:anita@vhl.org)

*These may be shared with media contacts to help increase awareness of what it's like to live with VHL.*

# Reporting 3 Exciting Conferences, Fall 2008

## ***Symposium in Denmark 2008***

In September 2008 the 8th Biennial Medical Symposium on VHL was held in Roskilde, Denmark, outside Copenhagen. One hundred twenty-four people from 16 countries on five continents gathered in this ancient capital of the Vikings to learn from one another and build up our knowledge of VHL. There were 82 people from 10 countries of Europe, 17 from the U.S., 2 from Canada, one from Brazil, 4 from Australia, 5 from Japan, 2 from China, and for the first time, one from India.

Conference chairman, Dr. Marie Luise Bisgaard, and conference chairman Vibeke Harbud did an outstanding job of organizing the meeting and treated all the attendees very well indeed. The First International Medical Symposium on Birt-Hogg-Dubé syndrome was held on Wednesday before the VHL meeting, to leverage the travel of the many scientists who work on both hereditary kidney cancer syndromes.

Thursday was a day for the molecular scientists to share their findings, put forward their hypotheses, and find collaborators to answer some of the open questions. Even to those of us who understood about ten percent of the content of this highly technical day it was clear that the amount we have learned in the past fifteen years has been nothing short of phenomenal.

Dr. Peter Maxwell of Imperial College, London, England, noted that when he began attending these meetings ten years ago (Paris 1998) we were only beginning to understand what VHL did. Now we know a number of additional steps in the many pathways where VHL plays a role. We have learned a great deal, which in turn has taught us more about what we don't know.

Those "Types" of VHL, for example, are helpful to scientists in understanding the role VHL plays in the cell. They are not, however, particularly helpful in the clinic. The percentage risk of a particular tumor type varies from one mutation type to another, but none of them is zero. In the clinic, we still have to screen for all possibilities.

Thursday was spent working to understand what happens in the cell. Friday and Saturday were spent on clinical work – how to improve diagnosis and management of VHL tumors, and how to assist people in living with the stresses of VHL.

Detailed reporting on the conference is available at <http://vhl.org/conf2008>

- A one-hour webinar with Joyce Graff,
- Joyce's detailed report of the conference
- The abstracts submitted by the presenters

## ***NCI Translational Science meeting***

In November Dr. Michael Atkins, Dr. Othon Iliopoulos, and Joyce Graff were invited by the Director of the National Cancer Institute (NCI) to participate in the NCI Translational Science meeting in Washington.

Since 2005 a committee of researchers and patient advocates has been evaluating the projects currently being funded by the NCI, to determine how we can speed up the "translation" of research from basic research in the laboratory to actual treatments in the clinic.

They determined that the process of translation requires a much more managed process, like an engineering process in any other industry. In November more than 500 researchers who are currently being funded by the NCI, plus 72 advocates and NCI staff, came to Washington and review posters summarizing the state of their research, and to identify what components are missing to speed their translation.

As one example, there is an urgent need for "biomarkers" to identify people at risk for various cancers, and to measure how much disease is present, so that we can choose the best treatment approach that will benefit this patient.

NCI will be continuing this process throughout the year, and more advocates will be needed to help guide the process, and to keep the scientists focused on delivering solutions to patients. If you are interested in becoming a research advocate, please contact Joyce Graff, [director@vhl.org](mailto:director@vhl.org)

## ***Texas Regional Meeting, Houston***

In November Dr. Eric Jonasch of M.D. Anderson Cancer Center in Houston hosted the second annual Texas Regional Meeting of the VHL Family Alliance. There were a number of excellent presentations, some of which have already been captured as Webinars, available for replay on the web.

Replays of the 2007 Houston meeting are also available for replay – now free on the VHL website.

Go to [vhl.org/meetings](http://vhl.org/meetings) for the Meetings Archive. Individual presentations may now be played **free** on the website, or a DVD of the full meeting is available for purchase.

In the same way, presentations from the 2008 and 2007 Annual Meetings (Boston and Orlando) are now available for **free** viewing on the website

*Don't forget:*

***VHL Annual Meeting, Anaheim, California,  
June 27, 2009***

***VHL Symposium, Rio de Janeiro Brazil,  
October 10-12, 2010***

## **Our thanks for donations from:**

*The thank-you list appears only in the print edition of the newsletter. Many thanks to all our supporters!*

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# Membership & Orders

If you have already paid your dues in 2008, thank you!

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E-mail: \_\_\_\_\_

**Preferences:**

I would like to receive occasional alerts via e-mail       Please send the newsletter on paper only

**Yes, I want to help!**

I can help in my local area

I have the following talents to share: \_\_\_\_\_

**Public Awareness:**

Please send me a press kit

Yes! I want to help with International VHL Day!

Yes! I've got some great ideas \_\_\_\_\_

**Join us in Anaheim, California, for the 16th Annual VHLFA meeting! June 27, 2009**

Please register \_\_\_ total people for Anaheim (includes Saturday meetings, lunch and snacks)

First person @ \$100 before May 15 (after May 15, price goes up to \$130)      \$ \_\_\_\_\_

Others in your party @ \$75 before May 15 (after May 15, price rises to \$130 per person)      \$ \_\_\_\_\_

You will need to book your own room with the Hyatt Regency Orange County at +1 714 750 1234  
or <http://orangecounty.hyatt.com> - special rate for the VHL meeting, \$139 for a standard room  
Be sure to book before May 15 to obtain this special rate.

**A Gift to the VHL Family Alliance is a living gift of love - Sent with Hope for a Cure!**

Remember VHLFA when you want to celebrate an occasion or a loved one (minimum \$10 per honoree)

in Honor of     in Memory of \_\_\_\_\_

Acknowledgement card to be sent to: \_\_\_\_\_

**Payment information:**

Annual dues: \$25 per mailing address (\$35 outside U.S.\* credit card preferred for international payments)      \$ \_\_\_\_\_

Yes, I want to help fund another research grant! My additional contribution:      \$ \_\_\_\_\_

My check is enclosed     Please charge my Visa or Master Card: \$ \_\_\_\_\_

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# Calendar of Events

**Please join us at one or more of these exciting events! All meetings and further details are listed at <http://www.vhl.org/meetings>, or call 800-767-4845 ext 4.**

January 4, 2009 - fundraising event in Ireland!

January 29, 2009 - **Webinar** with Jessica Everett, Genetic Counselor:

**Pregnancy and Family Planning with VHL**

February 1, 2009, Massachusetts Meeting - Watertown, Massachusetts

**Laughing Matters, with Sandy Boris-Berkowitz.** Come laugh with us!

2-4 pm at the Watertown Library. See page 3 for more information.

February 28, 2009, **International Rare Disease Day!** sponsored by NORD and EURORDIS - see page 10

Help us participate in events in your local area! Call 800-767-4845, ext 722

March 22-28, 2009, **CoverTheUninsured Week!** (U.S. only) - see page 8

Help us participate in events in your local area! Call 800-767-4845, ext 722

March 25, 2009, VHL Regional meeting, **Austin, Texas.** See [vhl.org/meetings](http://vhl.org/meetings) for details

March 31, 2009, deadline to submit **T-shirt designs** for the T-shirt contest - see page 9

March 31, 2009, deadline to submit **drawings and photos** for the Kids' Book illustration contest - see p. 9

April 29, 2009, deadline for submissions for the **YouTube Contest.** - see page 9

May 9, 2009 - **International VHL Day!**

Help raise visibility of VHL, and raise money to support VHL awareness education and research.

See page 10 for ideas! -- *We need YOU to help make it successful worldwide.*

Call 800-767-4845, ext 722, or write to [anita@vhl.org](mailto:anita@vhl.org) for further information

Second Wednesday - **Global call-in telephone line** with Joyce Graff, 2 or 8 pm Eastern US time

February 11, March 11, April 15\*, May 13 (April shifted due to holidays)

Saturday, June 27, 2009, Hyatt Regency Orange County, 11999 Harbor Blvd, Garden Grove, CA 92840

**VHL Family Alliance Annual Meeting**, June 27, 2009, all day, Saturday, 8 AM to 5 PM - see p. 15

Make your own hotel reservations by May 15, +1-714-750-1234 or <http://orangecounty.hyatt.com>

**Reserve the dates!**

**German VHL Family Alliance** - 10th birthday celebration, October 16-18, 2009, in Berlin

**9th International VHL Medical Symposium**, October 10-12, 2010, in Rio de Janeiro

Bilingual meeting, English and Spanish



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