

## VHLFA News

*by Ilene Sussman, Executive Director*

I am thrilled to report that I just returned from Houston where I had the honor of attending the 10<sup>th</sup> International VHL Medical Symposium. As the new VHL Family Alliance Executive Director, I had no idea what to expect. *INSPIRATIONAL* would be the one word to describe the three days of meetings. Many thanks to the M.D. Anderson Cancer Center for organizing such a sensational meeting!

Over 100 scientists and a good number of VHL patients and family members participated in two full days of scientific discussions ranging from the newest areas of VHL research to state-of-the-art medical treatment for controlling VHL tumors. Patients, caregivers, researchers, and medical professionals learning together to enhance VHL diagnosis and treatment and moving towards a cure—the excitement in the room was palpable! Even more exhilarating was to see how many of the experts in the room have been recipients of the research grants awarded by VHLFA!



### ***VHL diagnosis and treatment and moving towards a cure—the excitement in the room was palpable!***

The learning continued at the standing room-only Family Meeting. The crowd was comprised of equal proportions of VHL patients, caregivers, researchers, and medical professionals. Finding appropriate medical care, engaging children and young adults in a safe discussion about VHL, and DNA testing were the major focus of the discussions. The interactions were impactful for everyone in the room. I can't tell you how many researchers and medical professionals approached me to say how inspired they were to quickly return to their laboratory and further their efforts in finding a cure!

Let's continue our work together to find a cure for VHL. Your financial support is necessary to make this dream come true. Every dollar counts in reaching this goal.

## Advances in Medical Research

### ***Highlights from Houston***

*by Joyce Graff, Director of Wellness*

The 10<sup>th</sup> International Medical Symposium on VHL was a fabulous meeting. The meeting was hosted by M.D. Anderson Cancer Center (MDACC). Co-chairs Dr. Eric Jonasch, Dr. Ian McCutcheon, and Dr. Surena Matin organized the agenda to bring together researchers working in the same area to synergize their work on VHL and move the research forward.

As we learn more about what goes on deep inside the cell, we realize that there is still more to be explored. It's like exploring the universe of the sky, but in reverse—the universe that lives inside each cell. Just as we have had to invent new words to describe bigger dimensions—megabytes, gigabytes, terabytes—so too in the cell we have had to invent new words to describe the smaller dimensions, mechanisms, and interactions within our cells.

Most of the action in drug development, at this point, is focused on kidney cancer. Why? Because it turns out that VHL is the single most important genetic factor in creating kidney cancer—not only in VHL but also in 85% of the kidney cancer that occurs sporadically, at random in the general population. If you look inside a sporadic kidney cancer tumor, both VHL genes have been altered by some random events in order to kick off that tumor. The drug we are looking for in VHL is the drug that will help all people with kidney cancer.

There are already six new drugs approved and on the market because of VHL research. They were

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approved for advanced kidney cancer read – “metastatic” – that has already spread to other organs. These six drugs are also being used for breast cancer, ovarian cancer, small cell lung cancer, colon cancer – how is this? Because no matter where a cancer appears in the body, down deep inside the cell it is the same very basic set of factors that cause the cell replication to lose control, and eventually to acquire the potential to move from this one site out into the body, plant itself in other organs, and cause problems elsewhere. The key players in this process are VHL, HIF, and VEGF. They are part of an intricate system of sensors and controls inside the cell. They don’t just do one thing; they are all multi-function players. VHL, for example, senses oxygen and iron levels. When there is too little oxygen the VHL protein puts out signals that result in the building of new blood vessels to bring more oxygen. If its oxygen sensor is broken, and the VHL protein believes there is too little oxygen even though all is well, then it kicks off the process of building an excess of new blood vessels that become a hemangioma, a VHL tumor. Worse than that, when VHL is altered, the metabolic pathway in the cell gets hijacked, which then affects nearly everything.

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***“The VHL community has given so much to the kidney community. It is time now for us to give back.”***

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Introducing the Kidney session, Dr. Surena Matin, urologist from MDACC, said “the VHL community has given so much to the kidney community. It is time now for us to give back.” The drugs that have been developed for advanced kidney cancer are now in their third generation. They are beginning to be the type of kinder, gentler drug that might be taken over a longer period of time to keep tumors small, or perhaps keep them from developing at all. We are not quite there yet, but we are getting there. The pazopanib trial that is open now at MDACC is one such drug, and there will be more. [See page 5]

In the early drug trials with VHL we have seen that while the kidney tumors and sometimes the pancreatic tumors do respond to the drugs, the eye, brain, and spinal tumors do not. We need to add at least one additional drug target to get the tumors of the central nervous system (CNS) to respond. Pazopanib is the first of several new drugs that incorporate additional targets.

Dr. Rachel Giles of the Netherlands summarized the first day for the group on Sunday; Joyce Graff

summarized Day Two, the clinical talks. Their slides and video of their talks are available at <http://vhl.org/conf2012>. They will serve as a good overview and allow you to choose which of the given talks you want to explore in greater detail. The abstracts of the talks, the handouts, and the videos will be available also through [vhl.org/conf2012](http://vhl.org/conf2012).

The talks emphasized the improvements in surgical techniques, especially from laparoscopic to robotic surgery. Open surgery requires a very large incision. When it is possible to do one of these “percutaneous” procedures, the surgeon makes 2–5 small incisions, puts a television camera and various instruments through these “ports,” and operates beneath the skin. While the laparoscopic instruments are somewhat like working with chopsticks, the robotic instruments have a “wrist” that allows the surgeon to move in a more natural way, as with hands, so it is easier for the surgeon to master and has more capabilities than the laparoscopic instruments.

Treating eye tumors on or near the optic nerve continues to be a very large problem. Dr. Emily Chew at the US National Eye Institute is collecting cases and speaking with retinal specialists around the world to determine what works best. Ultimately, though, a drug is needed.

Methods of removing endolymphatic sac tumors (ELST) are improving, but the biggest problem is identifying them before hearing is lost, and reacting quickly enough to preserve at least a portion of the hearing. Dr. Marie Luise Bisgaard presented the work of the Danish VHL Study Group which is using annual audiology testing as a way of identifying trends, especially in low-frequency hearing loss, that might signal an ELST. She invites physicians and patients from around the world to contribute their own experiences to her study.

In a few cases, the patient may have all the symptoms of an ELST, but nothing can be seen on an MRI with thin slices through the Internal Auditory Canal (IAC) and the temporal bone. Dr. Russell Lonser and his team at the US NINDS has agreed to review the scans and possibly see patients in this situation, to determine better ways of identifying such very small ELST’s.

On Sunday a large group of patients, family members, physicians, and researchers discussed difficulties in diagnosis, problems in DNA testing, and how to serve the growing number of young people who have been diagnosed with VHL through DNA testing and preventive screening. What is the best way to serve young people, and help them take responsibility for managing their own health?

This report only scratches the surface of a very rich experience. The best part was meeting these

outstanding scientists in person, watching them network and joining forces to develop enhanced methods for diagnosis and treatment of VHL related tumors. Their commitment to VHL patients is evident as they provided contact numbers and sincere offers of help. It was also wonderful to meet face-to-face and interact with people with whom we have corresponded over the internet and telephone for as much as 14 years!

We hope that you will join us for one of the meetings planned for the future which are listed in the calendar of this issue or at [vhl.org/meetings](http://vhl.org/meetings). The next big Annual Meeting in the US, designed for families, is in Boston, November 17, 2012. The next International Medical Symposium will be 2014 in Madrid. See you there!

## NEW PROGRAM

### Summer High School Exchange Program with the Netherlands!

If you have a child with VHL who is in high school and would like to spend part of the summer with a VHL family in the Netherlands...or if you would like to host a high-schooler with VHL from the Netherlands in your home, please contact us at the VHL Family Alliance.

**1-800-767-4845 ext. 4, [info@vhl.org](mailto:info@vhl.org)**



## European VHL Associations meeting in Cologne, September 2011

*by Jean-Joseph Crampe, France*

We came together to further our health initiatives on a larger scale in order to raise money to advance research, to share information, and to open up our local meetings to participants from other countries.

This meeting, which included information and representation from eight European countries and US and Australia, was rich in information. The gathering permitted us to enrich our ideas and initiatives with ideas from other groups. For example, we discussed:

- What content and comment to elicit during periodic meetings of our associations
- How to augment the knowledge of VHL among doctors and health professionals
- The Dutch initiatives among adolescents and young patients: internet forum and weekend get-togethers to which other European young people might be invited who speak English.
- How to work together toward a system where we can share research data across country boundaries and preserve tissue for research.

We agreed to meet again in 2013 in Amsterdam or Budapest. Our thanks to Gerhard Alsmeyer for having taken the initiative to organize this meeting.

Note: Meet the delegates!  
See <http://www.youtube.com/vhlfa>.



**Front row L to R:** Ilene Sussman (US), Joyce Graff (US), Margrit Kopp (Switzerland), Jean-Joseph Crampe (France)

**2nd row:** Sue Buckley (US), Jennifer Kingston (Australia), Mary Weetman (UK), Helga Süli-Vargha (Hungary), Edith Lassus-Laurent (France), Philip Weetman (UK)

**Back row:** Rachel Giles (Netherlands), Gerhard Alsmeyer (Germany), Bruce Kingston (Australia), Jens Strandgaard (Denmark)

### *If you have expertise in*

• Web design • Marketing • Public Relations • Grant Writing • Fundraising • Videography

Please contact us at the VHL Family Alliance

**1-800-767-4845 ext. 4**



## ASK THE EXPERTS:

### Bicarb Flush

**QUESTION 1:** I have half a kidney. My local Nephrologist wants me to have CT with "Bicarb flush." I can't seem to get it ordered correctly. I need to protect what's left of my kidney. I have called and called, and explained repeatedly, all to no avail. Is there a better way to phrase my request so that it goes through more smoothly?"

– Linda A., California

**Response:** This is a strategy to protect people with low creatinine clearance from any potential side effects of imaging contrast dyes. The principal goal is to ensure that the patient has sufficient fluid in the body to flush the contrast dye out of the body in a timely manner.

In the Urology group at the National Cancer Institute (NCI) we found that many studies provide somewhat "impactical" protocols for hydration (3 hours before, 6 hours after, etc.)

Typically, for patients with eGFR less than 60 (and greater than 30) at NCI we used to hydrate people with 1 liter of bicarb solution (3amps of

bicarb in 1 liter of distilled water), and infuse this liter over the course of an hour immediately prior to IV contrast injection.

For those on long-term surveillance, for eGFR over 60 we used a full dose of gadolinium; for eGFR of 30–60 we used 1/2 dose of gadolinium; and no gadolinium or contrast if eGFR was less than 30 (due to the risk of NSF).

For those people with renal failure (eGFR less than 30) non-contrasted MRI with T1, T2, and fat suppression sequences usually give enough information. This was the policy we developed with the radiology department at the NCI.

Finally, here at Syracuse, if bicarb solution is unavailable we use 1 liter of Normal Saline.

The literature uniformly supports the role of hydration. There is still controversy even after the randomized trials whether bicarb is better than saline. As long as the patients are hydrated, they are safer.

– Gennady Bratslavsky, MD, Professor & Chairman, Dept. of Urology, SUNY Upstate Medical University, Syracuse, NY 13210. Tel +1-315-464-4473. Dr. Bratslavsky was formerly with the VHL program at the U.S. National Institutes of Health.

### Contrast with MRI

**QUESTION 2:** I have seen the recommendation that an MRI of the brain be done every two years. My question is: Should it be done with or without contrast? I asked my local neurosurgeon who said that "Contrast enhancement is necessary only if something suspicious is found." Is this true for VHL? I had a brain MRI done (without contrast) in a 1.5 tesla MRI machine in December 2009. The report was normal. Should I repeat that now or some time later?

– Aveek A., India

**Response:** Because hemangioblastomas enhance vividly on magnetic resonance (MR)-imaging after contrast administration, T1-weighted contrast-enhanced MR-imaging of the craniospinal axis (brain, cerebellum, brainstem, spinal cord and cauda equina) remains the imaging modality of choice for determining the extent of nervous

system hemangioblastomas and monitoring their growth over time. It can be difficult or impossible to accurately assess the extent and progression of hemangioblastomas using non-contrast enhanced MR-imaging. T2-weighted and FLAIR MR-imaging sequences are useful for determining the extent of peritumoral edema and/or size of peritumoral cysts [see note], as well as monitoring their progression over time. MR-imaging of the craniospinal axis (with contrast) is recommended if neurologic signs and symptoms develop. MR-imaging is often used to monitor the progression of nervous system hemangioblastomas at defined time intervals in the absence of neurologic signs and symptoms. Generally, 1–2 years intervals between imaging have been recommended for monitoring in asymptomatic patients.

– Russell Lonser, Chief, Surgical Neurology Branch, National Institute of Neurological Disorders and Stroke, National Institutes of Health, Bethesda, MD. Tel +1-301-496-5728; Fax +1-301-402-0380

Note: peritumoral means "around a tumor"

## New CCC in North Carolina

by Cecile Skrzynia, MS, CGC, genetic counselor

UNC Healthcare has a long tradition and culture of multidisciplinary approach to medical problems. That approach is what is needed for evaluating and treating von Hippel Lindau syndrome, a condition affecting multiple organs. Creating a VHL Clinical Care center formalizes and unites what already is available on premises. We have specialists in every field where potentially complications can arise for patients diagnosed with VHL: neurologists, ophthalmologists, nephrologists, etc. We also have all the latest technology for imaging: MRI and PET scanners. Importantly for the field we also have a splendid research group focusing on understanding VHL on a molecular level. All the members of the group consult and communicate with each other, leading to the best possible, state of the art care of patients with VHL, our ultimate goal.

To make an appointment or contact a member of our team, please contact me:

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University of North Carolina, Chapel Hill  
Telephone: +1-919-966-9437; Fax: +1-919-966-4151  
E-mail: rcnp@med.unc.edu

## Clinical Trial Recruiting

A trial of the drug pazopanib (Votrient) from Glaxo Smith Kline Pharmaceuticals is now open and recruiting patients at M.D. Anderson Cancer Center in Houston.

Pazopanib, an angiogenesis inhibitor taken as a pill, has been approved by the U.S. FDA for use with advanced renal cell carcinoma. It is also being tested for ovarian cancer and small cell lung cancer. This clinical trial is to evaluate whether it may shrink or at least stop the progression of VHL tumors. People over 18 years of age with any measurable VHL lesion may apply, including brain and spinal cord.

This trial is much more inclusive than previous trials. The complete list of requirements for acceptance, and issues that would exclude a candidate, can be found at <http://clinicaltrials.gov/ct2/show/NCT01436227>

If you are interested in applying, please contact Dr. Eric Jonasch, Department of Genitourinary Oncology, M.D. Anderson Cancer Center, Houston, TX or call 713-792-2830.

Additional trial sites may be joining this effort. Call Dr. Jonasch for details.

## twitter Event!

Join us for a Twitter chat with Dr. Libutti of the Clinical Care Center at the Montefiore Medical Center on Wednesday, February 29th, beginning at 2 p.m. at #Monte\_NETs.

## Is your DNA diagnosis unclear? We need your help!



E. Rattenberry

Thanks to a VHL Family Alliance research grant, Eleanor Rattenberry, a member of Professor Eamonn Maher's team at the University of Birmingham in the UK is studying genetic changes in the VHL gene.

Your help is needed to advance her research study:

1. Do you have a genetic change but your doctor has told you that they can't be sure if it is causing your disease or not?
2. Do you have a definite clinical diagnosis of VHL disease, but a mutation has not been detected in your blood sample?

If you choose to help with the research then the following details are needed (a) your genetic change (if detected), (b) how VHL has affected you and your family and (c) a sample of your DNA or blood.

Please send email to Eleanor Rattenberry to discuss how to proceed.

*Thank you!*

Eleanor Rattenberry, *Clinical Molecular Geneticist and NIHR doctoral fellow*  
Email: [Eleanor.rattenberry@bwhct.nhs.uk](mailto:Eleanor.rattenberry@bwhct.nhs.uk)

## RARE DISEASE DAY

**February 29, 2012**

Help your friends and legislators understand how much we are learning from the rare diseases to cure more common ones.

*Host a "rare gene day" where families, coworkers, etc. donate money to VHLFA in order to wear jeans to work that day.*

# Triple Whammy Last Year

by Red Raider Eric, Texas, in *vhl.inspire.com*

This is my first journal post. I don't know if anyone will ever see this, but I hope they do (and I hope they read it even though it's crazy long—if I write another one it will be shorter I promise). I hope they know that life can be good with VHL, because I think mine is. I just try to remember to be thankful for yesterday and today, and hopeful for tomorrow.

December 10, 2010—one year ago—I had a Friday, Saturday and Sunday I won't ever forget. The three different antibiotics my family doctor had given me over the past six weeks for my "inner ear infection" hadn't helped at all. The lightheadedness had turned into really bad vertigo, so the nurse worked me into his schedule that day. He decided that I should see an ear, nose and throat specialist to see if they could help reset some crystals that sometime dislodge in the cochlea and cause dizziness. He explained that they had special maneuvers to do just that, and I remembered that one of my friends had actually had that procedure done to great effect. Out of an abundance of caution, however, he ordered an MRI to be able to send it off to the specialist.

I had accepted a new job offer earlier that morning, so before the doctor's appointment I made the difficult call to the really great company for whom I had worked for eight years. Being on the road 100+ nights a year was straining things at home, and this new job was with another very strong company with no overnight travel. It was the right move, I was sure.

The next day—Saturday—my wife, daughter and I moved into our brand-new house. I have a very low risk tolerance, so we had waited to start construction of our new house until after our old house sold. I had helped the movers all day when we moved out of the old house, but now I couldn't stand up or walk without the use of a cane. The vertigo was terrible.

On Sunday afternoon, after a relatively lazy morning, I got a call from my doctor. I was due back to the clinic later that day to get a routine TB skin test read, and he asked me when I planned to do that.

"Around 3:00, I guess," I replied.

"OK. I'll meet you up there," the doctor said.

"Do I need to be there sooner?" I asked.

"No, 3:00 is fine," he said.

"This doesn't sound good," I said.

"Hopefully it will be. I'll see you at 3:00," he said.

My mom was in town helping to babysit during the move, so I told my wife that we needed to leave our daughter with her while she and I went up



there together. "Something's wrong with me," I said.

The MRI had detected a golf-ball sized lesion in my cerebellum, most likely a hemangioblastoma. I had sold medical books for eight years and in that

time picked up a lot of medical terminology. I knew what the doctor was saying, but I still made him repeat it a couple of times. My wife cried. I froze. "What do we do now?" I asked the doc.

What do we do now? We just bought a new house. I just quit my job. My new job doesn't start until January 3. My recovery will be at least 6 weeks. I can't start on January 3! Will my old job take me back? Will my new job hold my spot for me? Will I have health insurance? Disability insurance? LIFE insurance?

Monday I called both companies. The old company, with whom I had been very successful, told me that my announced leave date of December 31 was final, and that my benefits would expire on January 1. I was a manager—I anticipated that.

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***I could ask for time off under the Family Medical Leave Act. They wouldn't pay me, but my job and benefits would be continued!***

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My new company did all I could realistically hope for. They extended my start date out to February 7, with more time if needed. However, that left a large question mark leading up to the surgery. What if I couldn't go back to work? What then?

I only had a week between the diagnosis and surgery. I couldn't sleep. I was worried about how I was going to provide for my family. I was the breadwinner so my wife could be there full-time for our daughter. They depended on me completely. I had to do something to ensure they'd be OK.

I prayed. Hard.

And then it hit me. I was still an employee at my old company, so I could ask for time off under the Family Medical Leave Act. They wouldn't pay me, but my job and more importantly my benefits would be held for well past the surgery date and



expected recovery—even if I had to pay for them out of pocket. Not COBRA insurance, but my real insurance. At least that's what I hoped. I really had no idea if I was right, but it was the only option I had left.

I applied for leave the next day, and got a call from Human Resources on the Friday before my surgery informing me that my request had been granted. The company said they wanted to do what was right, and I believed them then and believe them now. I would have leave extended to my new tentative start date. I can't begin to tell you how much stress that relieved, and I finally felt like I could go into the surgery with some peace of mind.

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***You can't fight VHL with ignorance.  
Be your own advocate, learn what  
you need to learn...***

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Ten years earlier I had a pheochromocytoma resected which went undiagnosed and misdiagnosed for almost two years. However, once it was diagnosed and removed, life went back to normal very quickly. "This will be no different," I thought. Let's get in there, get it out, and get on with it. Positive thinking = positive outcomes.

It's strange how you can trick yourself into naiveté if you really try hard enough.

The tumor was a hemangioblastoma. Luckily, although I only live in a small city of 250k, there is a great neurosurgeon here who was able to resect it. The six-hour surgery was on the 20th, and I was home on Christmas Eve. I'm a tough son of a gun.

However, this time it was much harder to just move on. The recovery was much harder, and the pain was much worse. I started four weeks of physical therapy. While it was hard at first, by the end was doing things I would have had trouble doing as a healthy, athletic teenager.

I started my new job on February 7, as planned. I made my quota for the second quarter. Our new house is great. Our daughter loves her new school. I finished the San Antonio half marathon in November. I still have some vertigo which limits my recreational activities and tinnitus that makes it hard to sleep, but I am very pleased with the outcome of the surgery.

However, it's not easy to just move on. I now know that the pho that I closed the book on ten years ago was really only one chapter of a larger book. The hemangioblastoma is the second.

I've been clinically diagnosed with VHL syndrome. I'm one of the 10% or so who have the

clinical symptoms but test negative genetically with the blood test. Fortunately, my daughter tested negative too, so it's highly unlikely she has it unless I have some weird, unknown (and therefore untestable) mutation rather than simply mosaicism—and I passed that mutation on to her. I pray that's not the case. I see specialists and get scans regularly.

The old cliché is, "none of us know what the future holds for us," right? The problem is, I know that sooner or later, somewhere in my body, some cell is going to start dividing uncontrollably. Will it be my retina? My brain? My spine? My kidney? My pancreas?

I find it debilitating to think about. So I try not to. I work. I exercise. I help with homework. I do chores (though not enough). I try to be a good dad, husband, and friend. I try to help others when I can, but need to do more. I try. And I keep trying. And I keep trying. Eventually, I start to forget.

Then, about the time I get on with life, I have another checkup or scan and I find myself here, alone, looking not for answers, but questions. I've asked lots of questions and gotten lots of answers. I'm never sure, though, that I've asked all the questions and gotten all the answers, or that I've asked the right questions and gotten the right answers.

You can't fight VHL with ignorance. Be your own advocate, learn what you need to learn. Tell your doctor what you need—don't expect them to do it all for you. Doctors don't like hypochondriacs, but they appreciate well-informed patients who ask high-level questions about their conditions. If your doctor doesn't appreciate that, then fire him or her and find one that does. It's your health.

The one thing I hope can inspire in you is that by taking control of your situation you become empowered. Empowerment is inspirational. Good luck to you.

I am so grateful to each and everyone of you out there.

Every day I read the new posts on our site. I am amazed by the strength, courage, hope and even love that exists between people who only know each other through a rare disease and shared feelings.

Thanks to everyone on this site and Happy 2012 to all !!!!

— TinaDiane@Inspire, <http://vhl.inspire.com>

## Running for VHL

By Pascal Kerbellec, France

I remember a phrase that went something like this: "In order to receive, you have to know how to give."

I think that all of us, whoever, wherever, at any given moment of our lives can give help, hold out a hand, offer a smile.

I am a marathon runner and I decided to support the VHL Family Alliance in France and take advantage of the opportunity offered by my sport to communicate their message.



At the beginning we were two, my wife and I, later joined by our nephew. Then friends joined us. Intrigued by our project, they wanted to wear the T-shirts that I had made with the inscription "VHL". Now at each of our races we wear the colors of VHL France.

You cannot imagine our satisfaction when the other runners ask: "What is VHL?" It is our pleasure, the opening of a door to invite them to join in our endeavor.

I want to help as much as I can, and why not start a movement to support the VHL Family Alliance wherever you are?

I am pursuing this project with the means at my disposal, with my group of friends. We are going to continue to run for the Cause and try to help the volunteers of the association, who deserve our support. All help is welcome.

I want to help advance research, to raise the visibility of VHL, and I want to find others to help.

On the other hand, I do not want to raise false hopes. We will do what we can.

My primary motivation is to help a dear friend who is touched by VHL. My slogan for this person is, "There is no age for being sick, one is always too young to be ill."

**VHL AWARENESS  
MONTH IS  
MAY!**

***What can you do to  
raise awareness?***



## VHL Tattoo

By Brian Cudnik – as posted in Facebook – VHL: Spreading Awareness of von Hippel-Lindau

Over the summer I got a VHL tattoo on my right calf. This has been one of the best things I have done for myself. I

wear shorts all summer and constantly have people asking what it means and that just gives me the chance to educate, share and brag.

I do this for me, I do this for my brothers and sisters, and I do this for those that ask. Maybe I am advertising...hey that's a great idea – maybe I will get VHL.ORG tattooed under it. That way, I can even share with those who don't ask.  
facebook.com/groups/VHLawareness

## Follow Your Heart

by Renée Gresock, North Carolina

Follow your heart to a distant land  
With palm trees, surf and white beach sand

Follow your heart to a distant land  
Laugh and enjoy life while you can

Follow your heart and go anywhere  
Just close your eyes and you are there

Follow your heart to the mountains  
Drink water from the natural fountains

You don't need cash. You don't need a car.  
You can go near or you can go far

Just follow your heart. Let it take you away  
It's up to you ... just where you stay

From Renée Gresock, "Emotions,"  
2010. Available from online bookstores.  
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### Donations in memory of PEGGY AND DON MARSHALL

may be made through their First Giving page at:  
[http://www.firstgiving.com/fundraiser/VHLboard/peggy\\_marshall](http://www.firstgiving.com/fundraiser/VHLboard/peggy_marshall) or send a check to the VHL Family Alliance at 2001 Beacon St., Suite 208, Boston, MA 02135.



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