



Membership Renewal Issue!

Family, Friends, Physicians, & Researchers dedicated to improving diagnosis, treatment, and quality of life for people affected by von Hippel-Lindau.

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Reimbursement for DNA testing! YOU can help promote research!

We all know that a cure for VHL will come through research.

There are two essential ingredients needed to promote research: money and biomaterials.

So what are "biomaterials"? Biomaterials are biological materials from people we need to study – not just tumors that have been surgically removed, but also blood and urine samples – any biological materials that have the DNA characteristics of the people we need to study. In our case, this means biological materials from people with VHL.

Traditionally we have referred to the storage of such materials as the "Tissue Bank". But it's really become a "BioBank". In fact we need to shift our thinking – it's not just about "tissue" it's also about blood and urine, even spit! – any biological substance that might be of help to research.

Here's one example. You know that when you go to your general doctor for a checkup, they ask you to pee in a cup. They put a little dipstick in it to measure certain chemicals in the urine. In fact there are simple urine dipstick tests for pregnancy, urinary tract infections, blood or protein in the urine, or other abnormalities that may indicate the need for further testing.

Wouldn't it be great if there were a dipstick test for kidney cancer? Or a blood test? And that would not only benefit people with VHL, it would benefit all people. Most people in the general population who get kidney cancer are diagnosed late, when the cancer has already spread.

In order to create a urine test or blood test that might indicate the level of kidney cancer, researchers need to evaluate what chemicals are in higher or lower supply in the urine and blood of people who have kidney cancer, and figure out which measurements coordinate with the "burden of disease" -- the total volume of kidney cancer tumors -- this patient currently has. With a measure like that, we might be able to tell who needs to have a CT, or whether a treatment for kidney cancer is making the tumors shrink.

That is only one of the many kinds of research that can be conducted using blood samples, urine samples, and tumor tissue removed during surgery – all those precious biomaterials that only you can provide.

DNA Testing and Biomaterials

Increasingly the researchers who inquire at our BioBank are asking for biomaterials from people with a particular genotype – for example, tumor tissue from people whose mutation is in codon 2 of the VHL gene. Up to this point, we have not been able to answer this question, because we usually do not have DNA mutation information in the medical data that accompanies the samples.

Here's where you come in. May we please partner with you to add DNA information to the bank?

To help you get the DNA information that will move research forward, we are offering you an incentive payment. You don't have to be a member of VHLFA to participate -- but of course we hope you will join and help to sustain this and all our other programs!

You will find the details of the reimbursement program on page 3.

**Help for you – Help for us all
Together we can cure VHL!
Thank you!**

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Meetings: Orlando, Bellevue,
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Ballots and Challenge due June 25

We Need Your Vote! - See Ballot, p. 15

The Nominating Committee submits this slate of candidates for your approval.

Your vote counts! To be confirmed, each candidate needs the votes of 10% of the members.

☐ SUNNY GREENE, Falls Church, VA, candidate for re-election

In 1992, after many frustrating years of baffling neurological symptoms without diagnosis, my husband Ron was finally diagnosed with VHL. He died from VHL complications in 2002. Not long after Ron's initial surgeries my children were tested for VHL. My son David tested positive for VHL. Thanks to VHLFA David was directed to a VHL study at NIH and is being screened regularly. David's youngest child, daughter Elizabeth, who recently celebrated her first birthday, has also inherited the altered gene. As a widow, mother, and grandmother of VHL patients, I am deeply committed to help other VHLFA families. During many years as a college adviser my greatest challenge was helping students control stress. I am particularly keen to promote methods and dialogues to help VHL patients and their supporters deal with the tremendous tensions of this chronic condition.

Much progress has clearly been made over the past few years, yet much remains undone. Increased understanding of VHL both by physicians as well as the general public is vital. Expanded support to both patients and their caregivers and families is needed. Continued dialogue with other genetic disorder groups and researchers is essential. Dare we even dream of a cure for VHL? I'd like to continue on the VHLFA board toward helping that dream become a reality.

☐ TOM RATH, Washington, D.C., candidate for re-election

Tom Rath leads Gallup's workplace consulting practice and is the author of two bestselling books. In 2004, he wrote the #1 *New York Times* bestseller *How Full Is Your Bucket?* His latest book, *StrengthsFinder 2.0* -- based on the assessment that has helped millions around the world to discover their strengths -- is already a #1 *Wall Street Journal* and #1 *BusinessWeek* bestseller.

Tom has been with Gallup for 14 years. He earned degrees from the University of Michigan and the University of Pennsylvania. Tom and his wife, Ashley, live in Washington, D.C.

Some excerpts from Rath's How Full Is Your Bucket?:

"When I was 16 I started experiencing poor vision in my left eye and confronted my first big life obstacle. DNA test confirmed that I had VHL. Upon hearing this news for the first time I was shocked and nervous. But, on some level, I was surprised by how little the news dampened my spirits. From that day forward, instead of dwelling on the negative or uncontrollable aspects of this disease, my family helped me focus on what could be done. Within the first week of finding out about my condition, I immersed myself in learning how to manage and live with this disorder. The key was not viewing my prognosis as any type of curse or death sentence. Instead, I saw it as an opportunity to be proactive and stay on top of my physical health. I resolved to measure my progress with regular scans and checkups.

"Unfortunately there were more challenges ahead. In my senior year of college, an exam revealed a tumor in one of my adrenal glands. Five years later, doctors found cancerous tumors on my kidney. Later, scans revealed several new tumors on my pancreas, adrenal glands, and spinal cord.

"In each case, there was some fear and initial frustration. But my most memorable reaction was a sense of relief in knowing that these tumors were caught before they could metastasize and spread to other organs. My vigilance and awareness of the disease had paid off. Each condition could be managed with surgery.

"We are all certain to face major challenges as we progress through life. Often, we feel as if we were "dealt a bad hand" and that life is unfair. But we don't have to allow ourselves to be defined by our hardships. Our responses to difficult events and our emotional state are much more important. Positive reinforcement about our strengths can buffer us against getting overwhelmed with the negative. And understanding what we do best allows us not only to survive, but grow, in the face of adversity."



DNA Research Partnership Program

Be a Partner in Research!

Our goal is to help you help all of us. You will get the information you need to manage your own health, and you will also be making a priceless investment in your future health, the health of your family, and the wellness of all people with VHL.

DNA Testing Reimbursement – Here it is!

\$100 to register. Anyone U.S. resident who registers** with the VHL BioBank at NDRI before December 31, 2008, or who has already registered with the VHL BioBank at NDRI, may claim \$100 toward the cost of DNA testing if they will please deposit a copy of their DNA testing report with NDRI. Request certification from NDRI that your registration is in order, and submit this to VHL for reimbursement.

Up to \$400 to defray DNA testing costs. Any U.S. resident who registers** with the VHL BioBank by December 31 and has not already gotten DNA testing, will receive a coupon from NDRI good for half their out-of-pocket lab cost of DNA testing, up to \$400, whichever is less. In order to redeem this coupon, we will need to see a copy of their bill for lab testing, and they will need to deposit a copy of their DNA report with NDRI. Request certification from NDRI that your registration is in order, and submit this to VHL for reimbursement.

Already registered? Any U.S. resident who has already donated tissue to the BioBank can claim their coupon by depositing blood and urine and a copy of their DNA report by December 31. Request certification from NDRI that your registration** is in order, and submit this to VHL for reimbursement as described in 1 or 2 above. As long as your DNA report is on file, you do not need your lab bill for this reimbursement.

***** Registration means*** depositing blood and urine samples as well as completing the appropriate paperwork with the BioBank. Detailed instructions will be provided by NDRI. All information is kept in a “depersonalized” manner, and confidentiality is overseen by the IRB at the University of Pennsylvania. Your name will never be associated with any samples you file with NDRI. VHLFA does not need to see a copy of your DNA report; we only need confirmation from NDRI that it has been filed in their confidential files.

Once you have completed this registration, you are in position to donate tissue removed in any future surgery with one simple phone call – just call the bank to advise them of the date of the surgery and the name of the surgeon, and they will make all arrangements from there. Because your DNA information is on file, all tumor tissue you donate will be accompanied by the DNA mutation information, which makes it even more helpful to research.

Only by working together can we find a cure.

Please help all of us improve diagnosis, treatment, and quality of life for all people with VHL.

This is a pilot program. During this pilot phase, it is open only to residents of the United States and only until December 31, 2008. At the end of this year we will reassess the program to determine whether it is meeting its goals. At that point we may revise the program, end it, or extend it.

We will appreciate your help and feedback throughout the next six months.

A few commonly asked questions

Who will do the DNA testing? You should meet with a genetics professional near you to draw the blood and submit the test. We strongly recommend you send the blood to the Children’s Hospital of Philadelphia for testing, especially if this is the first test in your family, as they do the most thorough test. Please direct the doctor to vhl.org/dna for details.

Will it hurt? DNA testing involves drawing blood, so there may be some discomfort associated with the needle stick. A professional phlebotomist is usually best skilled. Talk with your doctor.

Can’t I just do a cheek swab? Unfortunately a cheek swab does not get enough information to find most families’ mutations. It would not be sufficiently accurate for research.

The lab costs are not all the costs associated with DNA testing. Who pays for the counseling and the doctor’s visit? You or your insurance company would need to cover those costs. We will see how many people sign up, and whether we are able to get an additional grant by the end of this year. Please provide feedback for us to consider.

To register, please call NDRI Rare disease hotline 877-221-6374

Questions? Call Ranjana 1-800-767-4845 ext 4, or write to bank@vhl.org -- Thank you!

This project is funded in part by a grant from Alex’s Lemonade Stand Foundation

Blind Filmmaker

By Adam Linn, actor and director, New York, NY

I am a blind filmmaker. It's not an obvious choice for someone who can't see – to work in a visual medium – but film is an extremely collaborative art form. In terms of affecting the public's consciousness, it is also the most relevant in today's society. Complications resulting from VHL caused me to go blind when I was eleven years old.

My interest in film began with writing. I studied screenwriting at New York University (NYU) and quickly realized you get a lot more respect in the movie industry if you make your own movie. Soon thereafter I shot my first short film, *Smell the Light*, with a crew of filmmakers I knew through school and some actors I knew from doing theater here in New York.

I would encourage anyone who wants to break into film to jump in and make your movie. Don't be afraid of making mistakes; of course you'll make mistakes. But that is the only way to learn. In my heart, I knew if I put the energy into an actual product, good thing would result from my effort. After the fun and excitement of actually shooting *Smell the Light*, my writing partner, Jim Phinney, and I holed up in an editing studio with our friend Dmitry Khavin and we painstakingly pieced the movie together. Editing is the most grueling aspect of making a movie. By the time you're done, your brain aches from the effort.

After ten days of editing, we went out to a West Village restaurant to celebrate the completion of the film. It was 3:30 in the afternoon and we were the only people in the place. We were tired, but exultant. It felt great to have the film done and ready to go out to festivals.

We had just finished eating when Jim leaned forward and said, "Celebrity just walked in." That's always a little exciting; of course I wanted to know who it was. However, Jim appeared to have been rendered speechless, and I was left to guess. Finally, Jim whispered "Q.T." Then it clicked: the machine-gun delivery, the over-the-top exuberance, the profanity ... Quentin Tarantino.

For anyone who came of age in the 90's, *Pulp Fiction* holds a special place in their consciousness. Even today, people casually drop names of the characters into conversation with the implicit understanding everyone will know who they are talking about. The director of that film and our biggest idol was sitting three feet away from our table.

We sat in silence, chewing on falafel for what felt like an hour but was probably closer to five minutes.



Adam Linn and Jim Phinney, Good Look Productions

Finally Jim leaned forward, "I feel like a deer in the headlights." I felt like the rabbit between the deer's hooves. I knew we should do something, but what? With the sound of vanishing opportunity in his voice, Jim asked, "What do we do?" I didn't really think, I just said, "Get the film." Jim jumped up and was gone.

As Jim raced to his nearby apartment, I sat alone listening to Tarantino wax poetic about eating pizza with his dad in Tennessee. I prayed he would just walk out, while at the same time hoping Jim would make it back with our movie before he left. I knew Jim was hoping to come back and see me amiably chatting with Q., but I wasn't that brave. If I was going to approach him I had to have our movie in hand. So I just waited quietly and imagined the tiny pistol he'd shoot me with for disturbing his lunch, and the bodyguards that would suddenly materialize and break my arms as they hustled me to the street.

Jim slid back into the booth and handed me a fresh copy of our DVD with brand new cover art. "He's right behind where I'm sitting. Stand up, take one step and aim slightly to your left. You can't miss him."

Was I really going to do this? I sure as hell didn't want to, but I did not want to go home knowing I had let this kind of opportunity slip away. As I have done many times in challenging situations, I thought to myself, "I've made it through three brain surgeries and countless eye surgeries – nothing that is going to

**Take Action Now!
Before June 25...**

**...Please return your ballot
.....and pay your dues
.....and ask for a press kit
.....and register for Orlando!**

happen in this quiet restaurant will be as difficult as dealing with uncertain physical health."

Jim and I are currently raising money for our first feature film, *Anonymous Sex*. It's the story of Calvin Breeze, a blind gigolo, who steals two million dollars from the mob. We need to raise about \$50,000 to complete this project. With the success we had with *Smell the Light*, I'm confident *Anonymous Sex* will find an audience and make us some money. *Smell the Light* did very well on the festival circuit and I was amazed at the extent of our press coverage.

As for Tarantino, he turned out to be a great guy. I gave him our film and we shared a couple of laughs. I was aware of the wait staff and bartenders

watching us and I wanted to let him get back to lunch with his friend as quickly as possible. I thanked him for his time and Jim and I headed for the door. I like to think he saw a little bit of himself in us – a couple of young guys trying to break into the movie business.

We walked through Washington Square Park and talked excitedly about how cool it was to meet him and what he might think of our film. The intense vibrating thrum I could feel coursing through my whole body was the essence of being alive.

More about Adam and Jim and their films at <http://www.goodlookproductions.com> See page 15 to order a copy of *Smell the Light*.



FILM NOIR: Blind filmmaker Adam Linn has a unique vision

Adapted from articles from Time Out New York, and the Boston Sunday Globe

Adam Linn is a 36-year-old graduate of NYU film school living in Brooklyn and trying to make a go of his directing career. Big whoop, right? Actually, yeah. Since age 11, Linn has been completely blind. How can you make films if you're blind? It's the question everyone asks, and Linn's answer is that, rather than an obstacle, his lack of sight is an advantage. "I have an eerily vivid imagination," he explains. "My ability to visualize details of people, objects and paths has made directing and screenwriting a natural choice. In order to navigate my apartment and my neighborhood every day, I have to create extremely accurate visual maps in my head and memorize them," he says. "Being forced to visualize every single person and object around you makes screenwriting and directing a snap."

In 2004 Linn teamed up with West Villager Jim Phinney to form Good Look Productions; their first film, *Smell the Light*, premiered at the Boston Film Festival in summer 2005. Linn wrote, directed, and starred in the raunchy short about Manfred, a blind yoga student wrestling with inner cigar-chomping gangster-like demons; Phinney, 36, assistant directed (AD). After Linn wrote the screenplay, Phinney created crude, three-dimensional models as storyboards. They say their relationship is that of any director and AD. Linn describes the shots he wants and Phinney shoots them. In the editing room, Phinney describes the shots in each scene and Linn decides what to cut.

Smell the Light is about enlightenment," says the Dorchester, Massachusetts, native who, left completely blind at age 11 by a medical condition, went on to graduate from Boston Latin School and Harvard before quitting his job as a stockbroker in 2001 to pursue acting and screenwriting. "Manfred sees himself as a victim, because he's blind, he's broke, he split up with his girlfriend," he continued. "But until we learn to let go of such petty concerns, we're all alone in the dark – that's the idea behind the movie."

Good Look's next project is a feature film, *Anonymous Sex*, about a blind farm boy, Cal, who has a gift for making women feel beautiful. Characters like Cal and Manfred are part of Linn's plan to reinvent blind protagonists. "I want them to have lust, greed and envy, not just as devices to teach life lessons," he says. In doing so, he hopes to make life a little easier for the unsighted. "A lot of the stress of being blind doesn't come from the inability to see – it comes from how other people see us."

Genetic Information Nondiscrimination

Americans Can Take Advantage of Health Advances without Fearing Discrimination

For 13 years the VHLFA and a number of other health advocacy groups, led by the Genetic Alliance and the Coalition for Genetic Fairness, have been working to get a bill through Congress to protect Americans from misuse of their genetic information.

This year for the first time the Genetic Information Nondiscrimination Act (GINA) was passed by both houses of Congress in the same session, paving the way for final passage of the bill. The President has committed to sign it into law.

GINA paves the way for the responsible use of genetic information while protecting against discrimination with respect to health insurance and employment.

"We are grateful for the bipartisan efforts of our sponsors in the Senate - Senators Edward Kennedy (D-MA) and Olympia Snowe (R-ME) as well as the tremendous support of Senator Michael Enzi (R-WY). They are our champions and are making history today," said Sharon Terry, President and CEO of Genetic Alliance, and President of the Coalition. "Fears that genetic information could be misused hurts individuals, researchers, clinicians, and associated industries. Today, our fears have been addressed."

The bill passed in the House of Representatives with a vote of 414-1, thanks in large part to the help of Rep. Louise Slaughter and Rep. Judy Biggert.

Marla Gilson, Director of the Washington Action Office of Hadassah, said, "Just 10 years ago, only 100 genetic tests existed. Today, that number has grown to over 1,000 and everyday these tests are helping diagnose thousands of health conditions. Given the Jewish community's historical experiences with genetic issues, we worked hard to see that this bill was passed."

The Coalition has worked for thirteen years toward the passage of legislation to eliminate the misuse of genetic information. Discrimination on the basis of genetic information had led individuals to shy away from genetic testing that could help them manage their health proactively. It also has caused many to opt out of clinical trials for fear that their genetic information would be used against them. This lack of participation has slowed the research and development of treatments and beneficial drugs.

"We now have a huge task ahead of us," said Kathy Hudson, director of the Genetics and Public Policy Center at Johns Hopkins University, "to make sure that doctors, researchers, and the public are aware of the new protections GINA provides."

GINA protects Americans from discrimination by health insurers or employers based on genetic information by:

- Prohibiting group health plans and issuers offering coverage on the group or individual market from basing eligibility determinations or adjusting premiums or contributions on the basis of genetic information. They cannot request, require or purchase the results of genetic tests, or disclose genetic information.

- Prohibiting issuers of Medigap policies from adjusting pricing or conditioning eligibility on the basis of genetic information. They cannot request, require or purchase the results of genetic tests, or disclose genetic information.

- Prohibiting employers from firing, refusing to hire, or otherwise discriminating with respect to compensation, terms, conditions or privileges of employment. Employers may not request, require or purchase genetic information, and may not disclose genetic information. Similar provisions apply to employment agencies and labor organizations.

The White House has signaled its willingness to sign GINA into law and a signing ceremony is expected shortly.

President Clinton signed an Executive Order in February 2000 providing this kind of protection to all federal workers except the military. Members of the military are still not protected, and are still subject to discriminatory actions.

The military routinely denies medical benefits based on genetic information. That policy was originally designed to keep people who knew they would become ill from using the military for free care, but it's ended up affecting people very unfairly.

"You could be in the military and be a six-pack-a-day smoker, and if you come down with emphysema, 'That's OK. We've got you covered,'" said Kathy Hudson, from Johns Hopkins. "But if you happen to have a disease where there is an identified genetic contribution, you are screwed."

The upshot is that people in the armed services are discouraged by their doctors from taking genetic tests that could save their lives. After all, why get a test when the results could be used against you? It's precisely that situation that anti-genetic discrimination laws are designed to prevent.

The Coalition for Genetic Fairness educates policymakers about the importance of legal protections for genetic information. VHLFA is a member of this Coalition.



Primer for Researchers

The need for human tissue continues to grow apace. Over 80 percent of NDRI's researchers report a need for more tissues for their studies. Increasingly, the demand is for specialized normal and diseased tissues that are particularly difficult to procure. There is also a very significant trend towards a need for tissues suitable for molecular investigation, such as proteomics and nucleic acid analyses. This creates considerable challenges and requires a paradigm shift in the tissue procurement models currently employed.

NDRI is ready and willing to work with researchers to store tissue in the way you need it for your research. In order to do that, we need to hear from you -- earlier rather than later -- to understand your requirements. Even before your project achieves IRB approval, please let us know what you will need so that tissue obtained between now and then will be suitable for your project.

The VHL Tissue Collection is growing rapidly. People with VHL have shown their support for you and your efforts, and want to partner with you in moving the research forward, and finding better management -- and ultimately a cure! -- for VHL.

Please help us help you to achieve this goal.

Researchers, contact NDRI:

<http://www.ndriresource.org>

1-800-222-NDRI (-6374)

Medical Symposium in Denmark

Every two years, the world's leading VHL researchers and clinicians meet to share their results to date, and find collaborators.

This year the symposium will be in Roskilde, Denmark, outside Copenhagen, the ancient capital of the Vikings.

On the day prior to the VHL meeting, there will be a medical symposium on Birt-Hogg-Dubé syndrome, another genetic kidney cancer syndrome that many of these researchers are also studying.

For more information: <http://vhl.org/conf2008>

NDRI and Researchers

This year, we have made a special effort to encourage researchers to use the biospecimens on file at NDRI. Researchers are asked to fill out a detailed NDRI application, which requires among other things a research summary and local IRB* approval. NDRI functions as an honest broker, so that if medical history and VHL genotype are known, the information will be made available while maintaining patient confidentiality. Even if there are no samples currently on file that meet the specifications for this project, it is good to get the request on file. NDRI will watch for samples, or can try to recruit samples from their participating networks, and they will alert researchers when appropriate biomaterials become available.

Dr. Karen Block of Texas sent us the following reply:

"Thank you for the information about the VHL Biobank! I have already contacted the NDRI agency and have found the website and staff to be very nice and helpful.

"More researchers should use NDRI. I find it to be a wonderful resource for researchers that would like to initiate, expand and validate in vitro findings and animal studies using human tissue.

"The addition of genotype information to the medical data would greatly facilitate research.

"I have always been in the mind set, like all of us, that resources and research should be shared as much as possible for the greater good in hopes of finding cures or preventative strategies to help families and communities live an abundant quality of life."

-- Karen Block, Ph.D., Department of Medicine/
Division of Nephrology, University of Texas Health
Science Center at San Antonio

Progress!

In the 18 months since we moved our Biobank to NDRI, we have received 244 samples.

The folks at NDRI tell us that "the VHL donors are incredible! They are so willing to help, and so nice to work with -- we are delighted to be working with your group!"

We are developing cell lines for three different tumor types.

It costs money, AND we feel it is the wisest investment we can make to promote research.

May 2008 is VHL Awareness Month

Be Your Own Best Advocate:

Get Involved with the VHL Family Alliance

-- Camron King, Vice Chairman of the Board and Chairman for California

If you are reading this article then you recognize the importance of the VHL Family Alliance and you know what its like to either live with VHL or care for someone who is dealing with it. You know that in today's world, you have to be your own best advocate – each and every person has to take charge and be responsible for maintaining a grasp on their medical condition, their daily lives, their work and families, but can you do more? Some argue that there is just too much to do as it is, but I would assert that there is more every single one of us can do! Don't stop reading here – my assertions are simple and easy to implement – nothing too time consuming and nothing that takes anymore than saying hello (Ok, well maybe a little longer, but only if you choose)!

Get involved in the VHL Family Alliance! We see something like this and immediately our brains say, "I don't have any more time to give." Or maybe we do. Being involved can be simple. I hope the following ideas provide some thoughts for you to get more involved. You can act on any one or multiple items and in doing so you'll become a better advocate for yourself and the Alliance!

Educate your neighbors, friends, co-workers, business contacts. Speaking out and letting people know you have VHL is a very personal decision and its not for everyone, but if you are willing you can put a face and person behind VHL and that in turn creates greater awareness. Talk with people about your experiences, challenges and triumphs with VHL. Each and everyone of us has an amazing story and taking just a few minutes to teach and talk about VHL can make a world of difference. It always strikes me as amazing that VHL is no more rare than muscular dystrophy, but why does MD have such a greater amount of awareness? Maybe its Jerry Lewis, but maybe it's the fact that people are willing to speak up and act as a spokesperson and advocate for their condition – we can do it too!

Be involved in your community! Community is a very subjective word and can mean many things – neighborhood, city, county, interest group. I would say, be involved in as many as you feel comfortable. Simply being around people and working alongside

them allows everyone to get to know each other better. These opportunities are available for people to again get to know the face of VHL, in a positive light.

Take an active role in the Alliance! This is where we all stand to benefit a great deal. Since I was diagnosed I have been astounded at the amazing people I have had the good fortune to meet that are living with VHL. The caliber of talent and skills that people possess is incredible. Offer your talents to the betterment of the Alliance. Get involved in state chapters, start local groups with others in your local communities, offer to provide services, time and energy to the Board of Directors or committees, or make a contribution to help ensure the success of the Alliance. Just simply get involved. The more we all partner together, the more we are able to leverage our individual talents and skills to help move the Alliance into the future and continue to achieve great successes!

Now is the time to make these things happen. Tomorrow will always be there, but by taking one step forward to getting more involved today will help build a bridge to the future and allow the Alliance to be stronger, VHL to achieve greater recognition and help sustain our research efforts, services and educational programs far into the future! Getting involved in every little way helps you to be a better advocate for yourself, for VHL and for all of us dealing everyday with this condition.

To get more involved, contact the VHL Family Alliance office today at: (800) 767-4VHL or info@vhl.org. Call MaryLou Linn or Joyce Graff in the office, 1-800-767-4845, ext. 4.

**Educate your
community
Share your story!
Get involved!**

**See vhl.org/press
for an online press kit
and published press
stories**



Brayden and Addison K.

Minnesota Chapter

Creating a Provider List

by Sarah Simpson, Minnesota Chapter Chair

Every Summer/Fall at our annual Minnesota support group meeting, we discuss our year's experience living with VHL and the support teams surrounding us. This year several people expressed an interest in having a "master list" of sorts, with physicians' names and specialties. Upon further discussion and development, I began compiling this list.

I must admit that I have an inside edge, working in health care -- I have many contacts to begin the process. I started by contacting physicians, clinics, managers, etc. that I had experience with. This included not only current and former employers, but also my own team of physicians that treat me. I mailed packets of information from the VHLFA, including: the VHL handbook, a letter introducing myself and my mission, along with contact information to pass along to patients. My family also took packets to some of their own physicians.

To further expand the list, I then contacted an extended network of physicians. I looked through my insurance booklet at all the specialties that VHL would encompass (general practice, endocrinology, nephrology, general surgery, neurosurgery, neurology, ophthalmology, and even ob/gyn clinics) throughout the state. I mailed packets to some, and phoned others to ask their experience with VHL.

I asked all physicians to forward the information on to other providers in their network that might have exposure to or benefit from having more information about VHL. I also asked that they keep my contact information, and furnish it to anyone who is either a VHL patient or would like more information about VHL.

The mission was two-fold; 1) create a list with the physicians that we all have personal experience with and appreciate, and 2) get the word out to those that may not know about the disease. People browsing the VHLFA website can click on a link for more information, and will be able to obtain the list by contacting me. They can get anecdotal evidence from others who have visited specific physicians. The list will constantly change and evolve, but our goal is to have more resources available to people who need them. One by one, we work to get the word about VHL out to the community.

"We can trace VHL in our family back to the 19th century. During that time people have been diagnosed as 'insane', 'water on the brain', 'kicked in the head by a pony', 'congenital abdominal deformity', 'hysteria', and 'slipped disc'." - Greta, in *Inspire*

Changes to our Online Discussion Group

As many of you know, last year we contracted with ClinicaHealth to host an online community for VHL members. More than 400 people have joined this online community -- it is a wonderful way to support other people who are dealing with VHL, to learn from their experiences with this disease, and to find support yourself.

If you haven't been to our online community before, please check it out. You can find it at vhl.inspire.com. It's a place where you can read stories from people like yourself who are dealing with VHL, and post your own. You can post a question and hear answers from all over the world. If you see a conversation that interests you, please join and participate. The community is what we make it -- and your participation can mean so much to others who are coping with VHL.

Recently, ClinicaHealth changed its name to Inspire, and upgraded the software platform which powers our community. We have recently posted a "differences" document to help people moving from the earlier version of ClinicaHealth, and Inspire is building more documentation online.

For those of you who were used to the old ClinicaHealth community, there are lots of changes in the new platform. Change is never easy -- especially when it involves computers. There are many important improvements, especially security features to keep our community safe. Both VHLFA and Inspire are committed to keeping this environment safe and comfortable for you.

We hope to see you soon at <http://vhl.inspire.com>. Among the Journals, you will find Joyce's journal from the Africa trip (page 10).

If you have any problems with getting started, or in getting comfortable in the new version, please send an e-mail to our support team at Inspire. You can file a help request on the site by clicking on "Help" at the bottom of any page, or you can send an e-mail to team@inspire.com. They will respond back to you, usually within 24 hours.

Please feel free to send in your questions or ask for help. There are no "dumb questions" -- as my father used to say, "the only dumb question is the one you didn't ask." We learn from your questions how to make the system better for everyone. Beth from Inspire and Gale Lugo from VHLFA are ready and willing to help you. Write to ussouth@vhl.org or team@inspire.com.

**Start Near to Home!
Help your local Chapter!**

First VHL Meeting in South Africa!

Our 18th International Affiliate, and a new Continent!

-- Joyce Wilcox Graff, Executive Director

The first meeting of the nascent VHL support organization in South Africa took place at the Sappi headquarters on March 15. Fifty-five people came to learn about VHL, and to talk about how to organize the support group. Six of those present signed up to help organize the group.

The facilities for the meeting were provided by Sappi, and lunch was donated by SAIDA, the South African Inherited Disease Association.

I have been privileged to visit 26 countries where I have visited with people with VHL.* It is fascinating to see VHL through the eyes of another culture, another health care system. And as always, the families are wonderful people who deal with difficult situations with great grace, and who understand what is important in life.

Dr. Lizette van Rensburg, a geneticist from the University of Pretoria, explained the genetics of VHL, and how to go about testing for VHL. She has been working with VHL families for some ten years, and has identified two large progenies and several smaller ones. Nearly all the people studied so far are of European descent. There are still significant health disparities in South Africa, and most native Africans look first to their traditional healers for help. She is hoping that with the improved health care under the democratic government, we will see the disparities soften over time.

Dr. Engele Honey, a pediatrician, also from the University of Pretoria, explained the screening protocol. She stressed the need for proactive screening, to make sure that if a problem occurs, we will find it early and treat it successfully.

I explained the history of the VHL Family Alliance international, and invited the group to join the international network of VHL support organizations worldwide. We need to learn from everyone, to get the broadest possible understanding of VHL.



Altheada speaking at the meeting

Annerita has been corresponding with Joyce for nearly ten years.



For example, these families whose ancestors came to South Africa from England, Holland and Germany in the 17th, 18th, and 19th centuries, may well have relatives in those European countries. It would be interesting to see whether the experience of their family members in Europe is the same or different from the experience of the branches of these same families in South Africa. We might learn that there is something in the environment in South Africa that changes the experience of VHL -- something that might lead to a treatment.

I also explained how we as patients can "shift the odds" of getting tumors by taking good care of that second copy of the VHL gene.

Altheada Johnson shared her own family history with VHL, and her own philosophy of living with VHL, and encouraged others in the room to share their own stories and learn from one another. Fred Johnson answered questions from Markus and others about his experiences as a caregiver for Altheada for the past twenty years. We went around the room, with some people speaking in English and others in Afrikaans, the local language based on Dutch. There are 11 official languages in South Africa -- English, Afrikaans, Zulu, and eight other African languages.

We had a wonderful and exciting day together. It was hard to say goodbye. We are looking forward to working with this enthusiastic group over the internet as they coalesce into a formal organization. We are also hopeful that Dr. van Rensburg will attend the Medical Symposium in Denmark in September, to present her findings to date and begin to make connections with the VHL research projects in Europe.

Comments from the attendees:

"... Amazed at how positive people with VHL are..."

"Good to see old people with VHL around."

"... the family members of the people with VHL have more to cope with than the VHL person himself."

"The moment that touched me the most as the organizer was when everyone voted like one man to establish a support group in South Africa. The moment was so great that I struggled to swallow the lump in my throat. That was the best recognition that I could ever have asked for."

Altheada: Best of luck with the operation.

Fred: Thanks to you for the valuable lesson to "Take time for yourself."

* Note: all but two of Joyce's international trips were privately funded, with no cost to VHLFA.

What can we learn from South Africa?

Let me give you a little background on South Africa -- things I learned as we went along. When I visit another country, I always look at the differences -- not to criticize, but rather to see what we can learn from their experience.

As most people know, South Africa went through a painful period of Apartheid -- institutionalized segregation that was at least as bad as the worst problems in America. From 1948 to 1990, everyone had to carry a card "white" or "non-white", and blacks were excluded from most non-menial jobs. There was no training of black doctors until after 1994.

There were riots and political unrest from 1990 to 1994, until the new constitution was adopted and the government was formed. During that time, South Africa was a dangerous place to live. More than 230,000 people left the country, mostly middle-class professionals, including many doctors. There are approximately 2000 job openings for doctors and nurses today in South Africa.

There are fine medical schools, but medical jobs are stressful. Because of the staffing shortages, everyone is overworked and underpaid. 25% of the population has AIDS, which increases risks for medical personnel. Australia, New Zealand, and Canada advertise in South African medical journals, luring well-trained doctors to better-paying, lower-risk jobs in their countries. As one example, 20% of the doctors in Saskatchewan, Canada, were trained in South Africa.

What are the prospects for diagnosing a rare disease in an over-burdened medical system? Very low. Statistically, one person in 32,000 live births will have VHL. But until that person gets a proper diagnosis, he is at very high risk of serious medical problems.

Among people who already have good medical care, the chance of diagnosis is reasonably good. All of the people we met at this meeting were of European descent, settled in South Africa since the 17th, 18th, or 19th centuries. They represent 9% of the South African people. Another 9% are "colored" (mixed race), 2% are Asian (mostly from India), and 80% are native black Africans. In addition to the racial differences, there are significant differences in the historical health care access of these



Fred and Altheada Johnson, Joyce Graff, and Markus Jansen van Vuuren

other races. Health care for whites has been quite good for a hundred years. You may remember that the first heart transplant in the world occurred in South Africa. Not so for the other 91%.

How does a country achieve equal access to health care after such a history? Very slowly. People with good professional jobs have health insurance and a health care system similar to the U.S., plus a "safety net" of government-supported health care. But people in the vast rural areas, or people whose only health care is the government-supported hospitals come to the walk-in clinic in the morning and sign up on the list of people to be seen. Perhaps 125 people are on the list. At the end of the day probably 75 people have been seen and treated. The rest are asked to please come back another day. And so it goes.

This is not a good scenario for diagnosis of any rare disease, including VHL.

While we understand the issues, we cannot give up. Dr. van Rensburg is working to raise the consciousness of doctors so that they will think about a brain tumor or a kidney cancer, and send people to her for genetic diagnosis. VHLFA South Africa will raise the visibility of VHL among the people as well.

It's a start, and an admirable start. We applaud our colleagues in South Africa and hope that you too will do whatever you can in your piece of the universe to raise visibility, improve diagnosis, and help others get the information they need to manage their health.



*Dr. Lizette van Rensburg
geneticist*

Hear more about this trip at <http://PowerfulPatient.org>

On-demand radio shows or podcasts:

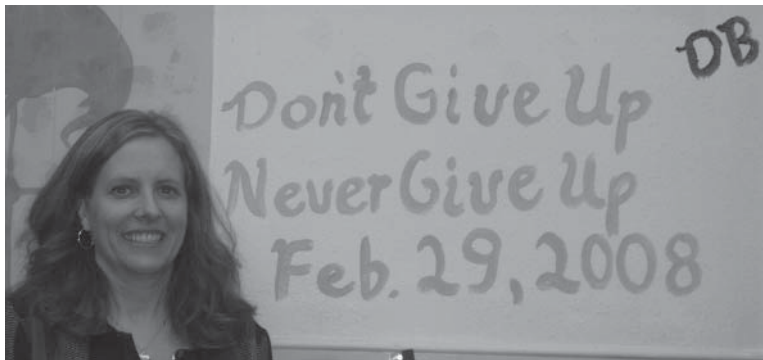
Long-distance Travel, Eric Lipp, Altheada, and Joyce
The Healthy Traveler, Judy Fern RN, Kevin Cahill MD
Our Trip to South Africa, Joyce and Altheada
Conversation with Markus, Joyce and Markus
Caregiving: A Heartbeat Away, Joyce and Fred
...or request copies on CD for \$10 each

***Read Joyce's journal at
<http://vhl.inspire.com/joyceg98>***

VHL Happenings in Washington State

Diana Beal celebrates 5 years of living with VHL

"They were redoing our building and painting over our hall. So we got out paint brushes and did a little art therapy. I painted on the wall some lyrics by Seattle rock band, Moneta, 'Don't Give Up. Never Give Up. February 29, 2008.' This was the date I celebrated the five year anniversary of my VHL diagnosis."



Bloomsday Fundraiser, Washington State

Joining forces from both sides of the state, Jenny Mathison of Spokane, Kim Hall and Alice Coday of Seattle, are walking the Lilac Bloomsday Run in Spokane to raise funds for VHL research. A native of Spokane, Jenny is participating in Bloomsday for the first time to celebrate her good news that she has no pending surgery for the first time in 5 years!

VHL Washington State Chapter Meeting

We invite you to attend the Washington VHL meeting June 21, 2008. The meeting will begin at 1:00 p.m. and end at 3:00 p.m. or whenever the last story is shared or all desserts have been consumed! The meeting will be conducted in an informal setting where we will share experiences, provide informational resources, discuss new treatment options, and gather information from each other that we've found helpful in dealing with VHL.

Please RSVP to either Jenny or Diana via phone or email whether or not you will be attending and include the total number of people coming so we can plan accordingly. We look forward to sharing our stories and VHL information with you!



Jenny Mathison: (509) 922-5862 or us-wa@vhl.org
Diana Beal: (425) 252-3193 or us-wa@vhl.org

Attached is a photo of me and Clancy. Clancy is a three year old Portuguese Water Dog. We are a member of the Delta Society and we visit patients once a week at Bailey Boushay (part of Virginia Mason Hospital in Seattle). He will be joining us at our June Washington VHL Meeting. Clancy doesn't have VHL, but is a VHL supporter and hopes to become a member of our group.

June meeting in Orlando! p. 16
September in Denmark! p.

Snippets:

Alyssa H. of Iowa sold wristbands and did a very nice Powerpoint presentation at her High School, and raised \$389.25 for VHL!

Scott S. wrote a college class report on VHL.

Ranjana S. did a research paper and presentation on VHL for a graduate school course.

Astronaut Frank Caldeiro was diagnosed with a brain tumor. He made a video which is on YouTube. See vhl.org/press

Ariel and Rosita have created "cause" pages for us in Facebook. Please join their causes and help to raise money for VHL.

Ariel is also constructing a presence for us in MySpace. Would you like to help?

Our thanks for donations from:

The Thank-you list appears only in the print version of the newsletter.

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Challenge Grant!

**Research donations beyond your membership
received by June 25, will be matched by the DFHCC Renal SPORE***
Please send your donation today! -- And don't forget to vote!

* Dana Farber/Harvard Cancer Center in Boston will pay up to \$20,000 to co-fund one research grant this year

Membership Renewal & Ballot

If you have already paid your dues in 2008, thank you! -- and Please Vote!

Name: _____

Address: _____

City: _____ State: _____ Zip: _____ Country: _____

Home phone: _____ Work phone: _____

E-mail: _____

Preferences:

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

Ballot: *vote for two*

___ I vote for both candidates as proposed by the Nominating Committee
or individually: ☐ Sunny Greene ☐ Tom Rath

☐ write-in candidate: _____

Public Awareness:

☐ Please send me a press kit

☐ Please send me a copy of Adam Linn's film, Smell the Light (9 minutes) @ \$12 each \$ _____

Registration:

Please register ___ people for Orlando (\$99 per person for Saturday meetings and banquet) \$ _____

You will need to book your own room with the Courtyard Lake Buena Vista Center at (407) 239-6900

Registration and hotel information for the Symposium in Denmark is posted at <http://www.vhl.org/conf2008>

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: _____

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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: \$ _____

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Annual Meeting - Orlando

Saturday, June 28, 2008

***Come make new friends on Saturday
and play in the many parks in Orlando with
them on Sunday***

Speakers at this meeting will include:

Dr. Li-Ming Su, Shands Hospital of the University of Florida, "Minimally Invasive Surgical Approaches to Kidney Tumors and Pheochromocytoma," including robotic surgery

Dr. Russell Lonser, U.S. National Institute on Neurological Disorders & Stroke, "Understanding the Natural History of VHL Tumors, and what this teaches us for treatment"

Ann Fonfa, Director, The Annie Appleseed Project, "Nutrition, Complementary and Alternative Therapies for cancer and tumor conditions"

Dr. Gary L. Wood, Wood & Associates, Employee Assistance Programs, "Managing and thriving with VHL in the family - understanding and managing stress"

Following Dr. Wood's presentation, there will be individual breakout sessions for adults with VHL, adult spouses/friends/caregivers, and a third group for children with and without VHL, each with a professional facilitator provided by Wood & Associates, Employee Assistance Programs, Tampa.

** Dr. Mark Hughes, pioneer of the pre-implantation genetic diagnosis technology, has been invited to give one of the keynote addresses at an international conference on PGD in Barcelona on this same day. We are working to secure a substitute for him, but do not have a confirmation at this



Courtyard Orlando^{*}
Lake Buena Vista Centre
8501 Palm Parkway,
Lake Buena Vista, FL, 32836,
(407) 239-6900

Other meetings:

for details see vhl.org/meetings or call 800-767-4845

June 21, 2008 - Bellevue, Washington

Washington state chapter meeting -- all welcome!

September 4-6, 2008, Roskilde, Denmark

VHL Biennial Medical Symposium - where doctors share ideas and accelerate the research. Families are welcome too!

October 18, 2008 - Sandusky, Ohio

Lyman Harbor Black Tie Gala - raising money for VHL research at Cleveland Clinic

time. We will post information at vhl.org/meetings as soon as it is available. Even if there is no formal speaker on this topic, we can discuss your questions privately.

***-- Get all your questions answered!
and meet some truly wonderful people!***



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