

## Welcome to our New Director of Wellness



The VHL Family Alliance is excited to announce that, as of July 16th, Suzanne Nylander, OD, BS, joined the VHLFA as the new Director of Wellness. With a 6-month overlap and training with Joyce Graff, we are confident that, in a short time, Suzanne will become an expert in VHL and other forms of hereditary cancer. Suzanne

brings with her the medical background, experience and passion to support patients and their families on their life-long journeys as we work for a cure.

Suzanne's background includes a variety of experience in healthcare. She grew up in San Francisco and earned her Bachelor of Science and Doctor of Optometry degrees from the University of California, Berkeley, while working her way through college as an optician and winning a national clinical research award. Suzanne then practiced in southern California for three years.

Following these years of direct clinical experience with patients, Suzanne worked with spectacle and contact lens manufacturers educating doctors and opticians about various prescription products. She also worked with lens designers and manufacturing to develop new products, and with marketing and sales to present the products to both eye care professionals and consumers. Her experience also included a multi-year research project with a federal agency and work with university professional programs in the U.S. and Canada.

Suzanne transitioned to working with health plans on survey research projects designed for quality improvement and accreditation. Suzanne worked with all types of health plans to design surveys and present the results, drawing insights from statistical analysis of the collected data.

She comes to the VHL Family Alliance from UbiCare where she was the Director of Business Development and Sales. In this position, Suzanne worked on developing new applications for UbiCare's healthcare content and software platform, expanding use of product lines to new hospital clients and developing interest with health plans, skilled nursing facilities, and school systems.

Suzanne's responsibilities will include educating and supporting patients, family members, and healthcare professionals on managing VHL; taking over leadership of our soon to be launched Patient Registry effort; working, strengthening, and expanding our Clinical Care Centers; helping to engage our volunteers and expanding their efforts; and contributing to the VHLFA newsletter.

Suzanne is looking forward to making a positive difference for the members of the VHL family. Please welcome Suzanne. She can be reached at the VHLFA office 800-737-8845 x4 or through email: [wellness@vhl.org](mailto:wellness@vhl.org).

## Keep Your Care Up-To-Date

by Joyce Graff, Founder, VHL Family Alliance

On an ongoing basis, VHLFA gets feedback from patients and works with our clinical advisors throughout the world to get better answers to the questions that arise regarding VHL diagnosis and treatment.

There are several important sections of the Handbook that were updated between 2005 and 2012.

**Scans and radiation exposure.** Because preventive scans are needed every 1–2 years, it is important to limit radiation exposure to when it is essential. The original recommendations for scanning came out of the research protocol at the NIH—they were expensive, and relied heavily on CT's (see article on page 3—*Radiation Safety*). Over the years, listening to the VHLFA clinical care centers worldwide, a better way to watch kidney tumors has been worked out. Clinical Care Centers in Denmark and England published scientific articles about their analysis of whether the scans were truly important to making treatment recommendations. In brief, they are indeed important.<sup>1</sup>

The 2012 Handbook recommends "quality ultrasound annually, and at least every other year MRI scan of the abdomen with and without contrast to assess kidneys, pancreas, and adrenals, but not during pregnancy."

Ultrasound is cheaper, but it misses more tumors than it sees, and is highly dependent upon the quality of the machine and the skill of the operator. It can be useful as a "quick check," but it cannot be depended upon to find all tumors, or to watch the incremental growth of tumors close to the 3 cm size.

MRI eliminates the routine use of radiation, saving it for times when a CT may be required before surgery or for another medical reason. It is still important to follow the guidelines for use of contrast dye. Kidney function should be tested before every MRI and precautions must be taken to protect you from a complication called NSF<sup>2</sup>. The radiologists have good guidelines. Be sure to remind your clinical team to order the kidney function test before the scan, or your scan may have to be delayed.

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**Monitoring the brain and spine.** The 2005 Handbook recommended annual scanning of the brain and spine, which is often done as four scans: three of the spine and one of the brain. This recommendation means a lot of money, a lot of appointments, and a lot of time in the scanner making it necessary to find an alternative approach.

It is important to watch out and report brain and spinal symptoms since they can indicate a problem that needs to be explored. Symptoms may include: problems walking a straight line, nausea and headaches, weakness, or tingling in arms or legs. However, in the brain stem and inner ear, issues may be quite serious before they show symptoms. Therefore, the 2012 Handbook recommends “MRI with contrast of brain and cervical spine, with thin cuts through the posterior fossa and attention to inner ear/petrous bone to rule out both ELST and hemangioblastomas of neuraxis.” This screening method takes less time, costs less, and monitors the areas of the brain and spine that are most likely to sneak up and create a problem if you are not watching.

**Testing for Pheochromocytoma.** There has been confusion among many physicians about how to order a test for pheochromocytoma (pheo). There has been even more confusion about how to interpret the results. With this in mind, the 2012 Handbook includes extensive detail about how to request the “test for fractionated metanephrines, especially normetanephrine in ‘plasma free metanephrines’ blood test or 24-hour urine test.” Traditionally, doctors have looked at the summarized catecholamine levels, but that is not enough for VHL. The researchers say that, because of the way VHL interferes with the chemical process in the cell, the catecholamines can be normal even when there is a large active pheo. It is the normetanephrine, in particular, that provides the signal for VHL. Pheos of other genetic origins have different chemical profiles. The handbook includes references to scientific articles that explain this in greater depth.

***If you still have the blue Handbook (2005), then you need to upgrade to the new one (green 2012).***

**Intention/Value of the Handbook.** The intention of the handbook is to present in language that both patient and physician can understand the information that is unique to VHL. It also provides a way of providing the latest information from the research teams and expert clinical centers around the world to your clinical team. The list of physicians who have participated in creating this document are listed under “Prepared by” at the back of the book.

Scientific references are provided following each section if more reading of the primary sources is desired. You and your medical team are always welcome to contact any of the contributors or to contact the VHL office to get additional information in their specialty area.

Physicians have a tendency to challenge information downloaded from the Internet. With this in mind, please consider presenting a hard copy of the Handbook to your doctor. It can be purchased from the VHL Family Alliance ([www.vhl.org/handbook](http://www.vhl.org/handbook)), Amazon, or other online booksellers. It is also available as an ebook.

**What’s new since 2012 ...**

Learning about VHL won’t end until a cure is found. For example, since the Handbook was published in 2012, more has been learned about living with all those “innocent” pancreatic cysts. They may not be a cancer danger, but they can be a significant issue for

### ***Learning about VHL won’t end until a cure is found***

one’s quality of life. Be sure to read the article “Tummy Troubles” by Tina Gruner, and learn how a dietitian might be able to help improve your quality of life. <http://www.vhl.org/patients-caregivers/basic-facts-about-vhl/commonly-occurring-vhl-manifestations/pancreas>. Articles published in the Newsletter will be incorporated into the next version of the Handbook.

<sup>1</sup> See <http://www.ncbi.nlm.nih.gov/pubmed/19863552> and <http://www.ncbi.nlm.nih.gov/pubmed/17160432>. They determined that scanning at least every two years was especially important. Stretching the interval more than two years risked missing an important opportunity to do surgery with a good outcome. Grouping a patient’s appointments within one or two days was also very important to getting the patient to actually come. The center at Guy’s Hospital in London follows a plan of “one-stop-shopping.” They found that by grouping appointments their adult men patients, in particular, were many times more likely to keep the appointment.

<sup>2</sup> NSF, Nephrogenic Systemic Fibrosis, can occur following the use of some brands of gadolinium contrast dye if the patient has poor creatinine clearance. New cases of NSF have not been seen following the reformulation of gadolinium contrast and the use of the guidelines for creatinine clearance now in use.

To order the newest print version of the Handbook for \$10.00, go to:

<http://www.vhl.org/vhlsales/>

To download a PDF for free, go to:

<http://www.vhl.org/handbook/>

## **2013 CFC Campaign**

***Are you a State or Federal government worker?  
Do you know someone who is?***

The 2013 CFC Associated State Campaigns are underway. Your donation to the VHLFA can be deducted directly from your paycheck. **You can fund VHLFA under its DBA: Alliance for Cancer Research and Support – VHL. Federal ID# 10934.**

## **United Way**

Support VHLFA through the United Way. **Check with your local United Way on whether this is an option in your area.** They can also provide you with the details for supporting VHLFA in this way!

# Radiation Safety

by Joyce Graff, Founder, VHL Family Alliance

In May, I spoke to more than 340 radiologists and radiation physicists at the UCSF\* Virtual Symposium on Radiation Safety in Computed Tomography (CT). I was invited to bring the patient perspective to the meeting.

My remarks represented the interests of people with a genetic cancer syndrome (i.e., VHL, HLRCC, and BHD), who need imaging to help manage their condition. Prior to imaging, early detection of problems was limited. With imaging, issues can be identified when they are small and a good plan of action can be developed early. Surgeries can be planned and metastatic cancer avoided.

Ultrasound is cheap, easy, and requires no radiation. The quality of the scan is highly dependent upon the quality and condition of the machine and the skill of the technician. Moreover, ultrasound misses more kidney tumors than it finds. It does not detect the tissue of some kidney tumors, especially those of HLRCC, and it will not see very small tumors (under 2 cm).

Physicians have tended to prefer CT because it provides clear pictures with precise measurements. CT, however, delivers a substantial dose of radiation with every scan. For a single scan, for example, to check following an accident, the radiation is generally not a concern. For people who need scans every year—and sometimes more frequently—this can be a problem.

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## *CT delivers a substantial dose of radiation.*

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An “average VHL patient” diagnosed at age 14 will have CT and/or MRI at least annually for a lifetime stretching to age 60 and beyond. That’s easily 100 MRI’s and/or CT’s over 46 years—and that may be a low estimate. In some research protocols, or to monitor a tumor, there are periods when the patient may undergo CT’s every 3–6 months. And that’s just one organ. With the possibility of various specialists ordering individual scans for each organ, coordination should be encouraged.

With the help of advances in imaging technology, lower radiation dosages are in the future. In the meantime, people who are smaller (children) or thinner require lower doses of radiation. Image Gently is a widespread program among radiologists to emphasize care in imaging children. There is general agreement that all children, especially those with some genetic condition, should avoid radiation unless truly medically necessary. While there is no data to clearly measure this, we do know that radiation can cause genes to change, adding risk to someone whose genome is already somewhat vulnerable.

There is also concern about the contrast dyes used for imaging. There are now very good guidelines for radiologists about the use of contrast dyes in people with compromised kidney function. The dye must be flushed out of the system in a timely manner. That means that the kidneys need to collect it and urinate it out within a few hours. If your kidneys are not working at the normal rate, this can become a problem. In order to verify your kidney function, the radiologists are required to have current kidney function tests. Without these test results in hand, the scan may be delayed or canceled. The patient may want to remind the ordering physician that, in addition to ordering the scan, the kidney function tests have to be ordered as well. For the patient, it is important to drink

water and be well hydrated before this test and also before and after the scan to assist the body in flushing out the contrast dye.

The amount of radiation the patient is exposed to is a function of

- The machine
- The operator
- The organ to be studied
- The density of bone on the path to the organ under study
- The amount of adipose tissue (fat) on the path to the organ (measured by Body Mass Index, or BMI)

“Protocols” for routine scanning of a particular organ have been developed by the manufacturers of the machine and/or the hospital. The protocol should include recognition of the BMI, sex, and age of the patient in order to avoid unnecessarily high amounts of radiation.

California is now requiring that the radiation dosage be noted in the patient’s record to track cumulative radiation dosage. However, there is still a debate among radiation physicists how to collect and note information in a useful way. Not all the older machines report this information. This is an important debate. Hopefully, California will set the standard encouraging other states and countries to record this information.

Meanwhile, should patients who are “frequent flyers” have radiation exposure badges that track cumulative exposure? Should radioprotectors, like those being implemented for people undergoing radiation therapy, be implemented?

I asked the radiation professionals to help describe the risks and benefits of each scan in terms that the patient and the ordering physician can understand in order to make smart decisions about the ordering of scans. Why CT versus MRI? When is x-ray or ultrasound appropriate or not? What are the costs and the medical risks for the patient? What value does this picture add for the physician? Is there a way to answer the medical question with a test other than a scan?

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## *We know that there are instances where the precise imaging of CT is important.*

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We know that there are instances where the precise imaging of CT is important. Before surgery, for example, it provides a precise “road map” for the surgeon. But for routine screening, we want to minimize the amount of radiation we are adding to our lifetime total.

If we could design our ideal scan, it would be a new ultrasound type of machine with no radiation that would give an excellent picture to our doctors, showing clearly what’s a tumor and what’s a cyst, and finding very small structures as well as big ones. But that is not yet a reality. The closest we can come to that today is an MRI with thin cuts when we are looking for very small structures.

Most of all, I emphasized that medicine is a team sport...and that the patient is an integral member of the team.

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\* UCSF—University of California, San Francisco. This “virtual symposium” was designed for all the Univ. of Calif. hospitals, with registration open to all radiation professionals and vendors. More than 500 physicians registered. With their registration they have unlimited access to all presentations on the internet for one year.



# Welcome New Board Members!

See <http://www.vhl.org/about-the-vhlfa/vhlfa-organizational-structure/board-of-directors/>



Manuel Greco

Manuel Greco is a physicist, working as a quantitative researcher at Morgan Stanley and enjoys his spare time as a music producer. Originally from Rome, Italy, he now lives in Brooklyn, NY with his wife. He enjoys a great life and spells of good health.

Manuel had his first VHL-related surgery in 1990. Since then, he has had several surgeries—in the cerebellum, kidneys and spine. Once diagnosed, thanks to his family support and search for knowledge, he managed to reach out to the best VHL experts and doctors. By joining the VHLFA Board of Directors, Manuel looks to forward his quest to know more about the VHL genetic disorder and help find a permanent cure for it.



Jule Fobert

Jule Fobert owns a small virtual Administrative Consulting business. With her Associate's Degree in IT Networking in tow, Jule brings 22+ years of administrative experience to every project she touches, including VHL tasks such as heading up the VHLFA Outreach Committee and Chapter Leaders. Jule has a strong desire to ensure that all VHL patients and their families are well educated in their disease and have all the resources that are due to them.

When Jule was diagnosed with VHL, she thought death was sure to follow soon. When Jule found VHLFA, she learned all she could about VHL.



Deb Hogan

Deb Hogan lives outside of Boston and is married with two daughters in college. Deb has had VHL symptoms—kidney, brain, spinal cord and retinal involvement—for over 15 years. The spinal cord tumor has left her with chronic nerve damage affecting the skin around her mid-back.

Deb has been a Physical Therapist since 1988 and specializes in Aquatic Therapy. She is an inspirational speaker with Walk Out of Worry ministries and serves as a soloist and youth leader in her local church. She is excited about joining the Board.



Eric Lipp

Eric Lipp was diagnosed with VHL a day before his 30th birthday. A tumor had grown on his spinal cord leaving him partially paralyzed. Personally experiencing restrictions that the disabled face in everyday life, Eric became the Founder and Executive Director of the Open Doors Organization (ODO).

Open Doors Organization educates businesses in the travel and tourism industries how to correctly serve the disabled community while also encouraging the disabled community to become a stronger consumer group. Eric has traveled around the globe, working with more than 30 airlines and railroads, training wheelchair pushers and documenting stowage procedures for wheelchairs.

## Saving My Eye

by Mark S., Pennsylvania

In 1994, I was a young man of around 23. I was full of the false bravado, and the stubbornness of youth. I rarely listened to the advice of my doctors, or anyone else for that matter.

However, I finally did what had been dreading: I gathered my courage and went to see an ophthalmologist.

In fact, I saw two. The first referred me to a retinal specialist in Camp Hill, Pennsylvania.

We discovered that I had a fairly large tumor in my left eye close to the optic nerve, making it problematic to treat. The position of the tumor, coupled with my real hate of having bright lights or fingers anywhere near my eyes, made the lesion one that the doctor "didn't relish the thought of treating".\* So for the following six years we watched it, and luckily it remained stable.

About 2000, I signed on for a study of VHL at the US National Institutes of Health and met Dr. Emily Chew, who is a caring and compassionate physician researcher at the National Eye Institute. Again, I was lucky and we watched it some more.

After some time, Dr Chew decided it was appropriate to try to treat the tumor with the laser. It had gotten much larger and the fluid leakage was enhancing to the point she feared it would start to cause me real vision problems.

Your eye can not tolerate fluid buildup behind the retina for long. The retina swells and distorts your vision.

Squeamish as ever about my eyes, I was hesitant.

With some misgivings, I went ahead with the laser treatment.

After the procedure, I was basically blind in that eye. Dr. Chew assured me that temporary loss of sight was normal and would only last about 20 minutes. This is absolutely true in most cases.

However, after getting out into rush hour traffic on Route 355 on a Friday evening, I found out that things weren't going as planned. As I was driving, I was looking at a vortex or black hole on the tailgate of the pickup truck stuck in traffic ahead of me. It looked like a black hole was forming on the car in front of me.

Losing vision in one eye can be quite shocking. Something is missing from the picture you are accustomed to seeing when there is no depth perception. My vision in that eye was seriously impaired for weeks. The laser treatment had caused the tumor to secrete even more fluid, disturbing the macula and essentially blinding me in that eye. Once again, Dr. Chew assured me that the vision would return. Worried, I sought a second opinion at Johns Hopkins from Dr. Campochiaro.

Seeing how my eye had responded to the treatment, Dr. Campochiaro worked to find a drug that might shrink the tumor without more laser. It took years, but eventually he suggested that I apply to a study of a new drug, Aflibercept (VEGF Trap-Eye) by Regeneron Pharmaceuticals. I qualified, and his assistant, Dr. Gulnar Hafiz, coordinated every step for me.

Beginning February 2006, I received a total of five intraocular injections. Although this was not a fun experience, the drug worked like a charm in me. I noticed an improvement in my eyesight from the second injection on through the last. The drug shrank the tumor about 50%.

After some time, however, the tumor grew back, and started to leak again. Dr. Campochiaro came up with a new plan of treatment. The goal this time was to shrink the tumor to a safe level with intraocular injections of VEGF Trap and then treat it with the laser, hoping I wouldn't experience the swelling I had in my first laser treatment at NIH.

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### ***Be an involved participant in your health.***

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I started my second round of injections in March 2008, and received 4 more injections. Again the tumor responded remarkably to the drug; I swallowed my fear to do my second ever laser treatment in that eye. To my relief, the procedure went as planned. No abnormal swelling, and my vision did improve after 20 minutes this time. No scary vortex in front of me.

The second laser treatment killed most of the tumor, but there was still some left and the main blood vessel that fed that tumor was coming back. A third laser treatment in April 2009 finally killed the last of it. The tumor I had lived with for most of my life and had watched with some trepidation for 15 years was finally gone.

If I had not been fortunate enough to find a doctor willing and open enough to find innovative solutions, and if I hadn't tried that drug, we probably would have still been watching that tumor destroy the vision in that eye.

I encourage you to be an involved participant in your health. Never blindly follow anyone's advice. Listen to what your doctors say and weigh what they have to offer along with your own beliefs and feelings.

Don't be afraid to try an innovative and new procedure. Without people trying to find innovative ways to treat this disease, we will never get anywhere in finding better treatment.

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\* It is usually best not to treat a tumor near the optic nerve. They tend to grow slowly, and all surgical treatments (laser, cryo, radiation, etc.) risk damage to the optic nerve, which is worse than no treatment.

## **VHL and Smoking—A Bad Combination**

*by Joyce Graff, Founder, VHL Family Alliance*

May 31st was World No Tobacco Day as determined by the UN's World Health Organization's (WHO) Resolution WHA42.1938 passed in 1988. Countries and communities around the world are joining the transformation to a smokeless society by passing laws against smoking in public places, advertising or sponsorships by tobacco companies, and single cigarette sales.

Smoking is not only hazardous to the user, but second-hand smoke is dangerous for those nearby. According to WHO, tobacco use kills six million people each year of which more than 600 thousand die from second-hand smoke.<sup>1</sup>

Smoking is known to accelerate kidney cancer in particular. And it's not just about kidney cancer—according to the US Center for Disease Control (CDC), for every 1 person who dies from tobacco use, another 20 suffer from one or more serious smoking-related illness—more than 8.6 million in the US. For everyone in the household, it is important to remove the contamination of the many toxic gases released in cigarette smoke—over 4,000 chemicals, at least 50 of which are known carcinogens.<sup>2</sup>

Nicotine in tobacco is known to be addictive. It has now been proven that the cigarette manufacturers added ingredients to cigarettes to ensure that people would become addicted.

Quitting is hard to do on your own. Over 13 million smokers try to quit each year, yet less than 5% of those who attempt to quit unaided are cigarette-free after 6–12 months. There are many good programs and methods to help. There is a good list of resources at <http://tinyurl.com/quit-smoking-cdc>. They will even send encouraging text messages daily.

People often use smoking as one method of stress control. People who have VHL and their family members,

especially if there is something tense going on just now, will need to replace smoking with another healthier method of stress management. Support groups, a telephone buddy, or daily text messages are a way of keeping you on track. Electronic cigarettes or a healthy snack can help to ease the hand-mouth habit that often accompanies smoking.

Nonetheless, there are folks who have tried multiple times to stop smoking and just can't seem to do it. There are products that will deliver a small amount of nicotine to appease the addiction, without the smoke, tar, and chemicals in cigarettes.

In Scandinavia, where smoking is not permitted in any public place (including the out-of-doors!), they have been using smokeless tobacco products for a very long time, and their rates of respiratory and digestive cancer have dropped significantly, while in most other countries these rates are rising.<sup>3</sup> For the user there is a much lower risk, and the smoke—the biggest problem—is not going into the lungs, and is not affecting other people in the household or office. There is a chewing gum, and there are tiny teabag-looking pouches that can be placed in the mouth to provide a dose of nicotine to satisfy the addiction more safely, without exposure to smoke and without the unpleasantness of chewing tobacco.<sup>4</sup>

The bottom line is: one way or another, it is important to your health, and to the health of your entire family, to get tobacco smoke out of your house and out of your life.

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<sup>1</sup> See <http://www.who.int/mediacentre/factsheets/fs339/en/>

<sup>2</sup> See <http://www.stop-smoking-programs.org/chemicals-in-cigarettes.html>

<sup>3</sup> See <http://tinyurl.com/cancer-se> and <http://tinyurl.com/cancer-us2013> and <http://tinyurl.com/cancer-world>

<sup>4</sup> For more information about smokeless alternatives, see <http://www.powerfulpatient.org/?p=613>

## The Cure for Cancer is in Our Genes

Through Twitter and Facebook, we asked our constituents to vote for the best tagline for the VHL Family Alliance. This was the winner! **Thanks to all who voted.**

## Support Services Survey

How well are we supporting you? Are there things you wish we were providing? Are there things we do now that you would like us to change?

Please share your thoughts with us at:  
<http://tinyurl.com/vhl-survey>

## Safe, Secure Facebook Group for Teens

Contact the office: [office@vhl.org](mailto:office@vhl.org) or 1-800-767-4845 for more information.

## Fundraising Dinner Auction

On Friday, September 20, 2013, we will be holding our annual Fundraising Dinner and Auction honoring James Edward Montie, MD, and Fran Mott. We are looking for items to sell at the auction.

If you have something you would like to donate—a product, a crafts item, a gift card from a national chain, or a special skill that you have—anything that will help raise funds for research, please let us know. You can e-mail [info@vhl.org](mailto:info@vhl.org) or call 1-800-767-4845 ext. 4.

We have some items on sale at eBay that you buy right now at <http://tinyurl.com/vhlebayssales> or visit our web page and bid on some of the auction items at <http://tinyurl.com/vhlsilentauction>.

Here is a preview of some of our items for sale.

- Another exquisite quilt by Joyce Graff
- Our popular *Holiday in Ireland* donated by our Ireland affiliates.
- Fine jewelry at reasonable prices handmade and donated by the VHL Minnesota Chapter.
- On eBay, there are some fine lamps and mirrors donated by Quoizel Lighting.



## Walter Wolff Jazz Benefit Concert in The Netherlands

The VHL Benefit Concert put on by Walter Wolff and the Dutch VHL Organization on June 11 at the North Sea Jazz Club was an incredible success! It was a great evening with amazing music. Over \$8,000 was raised!

Walter Wolff is a famous Dutch jazz pianist who has VHL. Because of his health problems, he had to retire from active performing. This benefit concert was to honor Mr. Wolff for his distinguished career and to raise money for research.



## 3rd Annual Rick Bracey 29er Softball Tournament



Thank you to everyone who attended and supported this year's 29er FUNdraiser on June 15th in Surry, British Columbia—sunshine, ball and friends all came together for the love of the game and for Ricky. Final final numbers confirmed that we surpassed

our goal and raised **over \$31,000!!!**

We are so fortunate to have such support and love on this day. Due to our fundraising efforts and success at this annual event, they have named a medical student travel and research bursary for VHL in Rick Bracey's name. Thank you for leaving a living legacy in Rick's name; this is an unexpected gift and we are grateful. Thank you also to our presenting sponsor Scotia Bank!

— Stephanie Kaes

## Mom's Day Run 2013

My mom didn't know the legacy she would leave. She did say she wished she could do more to raise awareness and money for VHL.

So after she passed away, I made a promise that I would do this.

The Mom's Day Run was born on May 8, 2011. 48 family and friends showed up to run or walk our little race. We raised \$1500.

This year was our 3rd Annual Mom's Day Run and 161 people came and we raised almost \$2500 for the VHL Family Alliance! I walked out to the first turn. I wanted to take Starting Line photos and catch shots of the participants as they passed me by. As I turned towards the Starting Line, my eyes brimmed with tears. "Momma, can you believe this?"

"Look, what we've done." My heart was overflowing with pride.

*I kept a promise...*  
xoxo Suellen





**Donations are seen on the printed version only.**

***Your help is greatly needed***

**DONATE**

**We also need volunteers. Call 1-800-767-4845 ext. 4**

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## ***It's Not Too Late***

**Register for the Events  
in Ann Arbor, Michigan  
for the weekend of  
September 20–22, 2013!**

### **2013 Annual Patient/Caregiver Meeting**

<http://www.vhl.org/meeting/annual-meeting-2013>

### **Fundraising Dinner & Auction**

*honoring James Edward Montie, MD, and Fran Mott*

<http://www.vhl.org/meeting/dinner2013/>

### **Team VHL 5K Run/Walk**

<http://www.vhl.org/meeting/team-vhl-run-walk-2013>

and

<http://www.crowdrise.com/vhl5krun>

**See overview of all events: <http://www.vhl.org/meeting/>**