

VHLFA: Year 20 and Beyond

by Jane McMahon, Chairman of the Board, VHLFA



Jane McMahon

In this our 20th year, I am honored to serve as the Board Chair of the VHL Family Alliance—an organization that has made a tremendous impact on the lives of those affected by VHL. Given my family's personal experience with VHL, I understand firsthand the value that an organization like the VHL Family Alliance brings in terms of improving diagnosis, treatment, and quality of life.

Looking at the year ahead, I am excited about the many changes taking place within VHLFA. For starters, we have a number of new Board members (introduced on page 8) joining the organization at a pivotal time. They will join longstanding Board members Michelle Cieslak, Robert Kramer, Jeanne McCoy, Sarah Nielsen and William Scheitler.

In addition, we have a number of strategic initiatives on the horizon. This year, we will be implementing an online VHL Patient Registry which will provide researchers with a wealth of information on genetic mutations and disease manifestations. The registry will also provide patients with an online mechanism for keeping track of their medical history. Similarly, we have formed a Clinical Trials Task Force aimed at providing a mechanism for testing each of the most promising drugs in an efficient manner.

Along with future changes, this year brings an opportunity for us to honor and celebrate those who have who have been instrumental in the VHL Family Alliance's success over the years. **Our November Annual Meeting will be followed by a Fundraising Dinner honoring Founding Executive Director, Joyce Graff as well as VHL Researcher, Dr. William Kaelin of Dana-Farber Cancer Institute.**

As always, our success is dependent upon your involvement! Please join me in working towards gaining increased visibility, community involvement, and funding towards research centered on finding a cure for VHL. For specific ways to assist the VHL Family Alliance, please contact the VHLFA office at office@vhl.org or 617-366-5667 x4!

PLEASE JOIN US IN NOVEMBER IN BOSTON!
2012 Annual Meeting / Fundraising Dinner & Auction

See page 6

Pheochromocytoma and Pregnancy

Reporting a new paper by Jacques Lenders, MD, St. Radboud University Nijmegen Medical Centre, the Netherlands

A pheochromocytoma in a pregnant patient is one of the most threatening medical conditions for mother, fetus, and physician. Although extraordinarily rare with a frequency of 0.002% of all pregnancies, or about one in 56,000 pregnancies, this tumor is notorious for its devastating consequences. Confusion with the much more prevalent forms of pregnancy-related hypertension is the main cause of overlooking the diagnosis. If undiagnosed, maternal and fetal mortality is around 50%. Conversely, with early diagnosis and appropriate treatment, risk to the mother drops to less than 5%, and risk to the fetus to less than 15%.

In families with any one of the ten genes that can cause a pheo, the risk of a pheo during pregnancy is much higher, so families need to be aware of the risks and the symptoms, and make sure that all women with VHL or any genetic tendency for pheos get the best of care during pregnancy.

In people who are not pregnant, the classic symptoms of a pheo are headaches, high blood pressure, and heavy sweating. In women who are pregnant, these symptoms can be more mild. In anyone with high blood pressure during pregnancy, it is important to be suspicious that it might be a pheo. The two most common misdiagnoses are gestational hypertension and pre-eclampsia.

As long as the pheo is diagnosed early, it can nearly always be treated successfully without injury to mother or fetus. It is possible to remove the pheo laparoscopically before 24 weeks of gestation, preferably in the second trimester. If the pheo is identified later,

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Pheochromocytoma and Pregnancy*Continued from Page 1*

Jacques Lenders,
MD

blocking medications can be used until the baby is delivered. Removal of the pheo during a caesarean section, or after delivery, can also work well.

The fetal risks are mainly from the effects of catecholamines on the circulation and include placental abruption and lack of sufficient oxygen to the baby.

The most important way to diagnose a pheo is by doing a thorough family history, since so many pheos run in families. A family with pheos should approach every pregnancy with caution and should help their doctors understand the risks. Test for pheos before, during, and after pregnancy.

Pregnancy-related hypertension generally develops after 20 weeks. With a pheo, hypertension can appear at

any time. Pheos tend not to result in swollen ankles or cause protein in the urine or elevated plasma uric acid which are often seen in pre-eclampsia. If a pregnant hypertensive patient has a sudden drop in their blood pressure while standing, that should arouse immediate suspicion of a pheochromocytoma since this feature is uncommon in pregnancy-related hypertension.

Source: Jacques Lenders et al, "Pheochromocytoma and pregnancy: a deceptive connection." *Eur J Endocrinol.* 2012 Feb;166(2):143-50. Epub 2011 Sep 2.

Full text: <http://eje-online.org/content/166/2/143.long>

The VHL Family Alliance has a new website!

CHECK IT OUT AT

www.vhl.org

ASK THE EXPERTS:

Blood Pressure

I read that for people who are taking the latest drugs, like Pazopanib (Votrient), elevated blood pressure is actually a sign that the drug is working! Does this mean that as my blood pressure rises, I should not worry about it?

— Steve M

RESPONSE: There are two separate but important issues raised by your question.

- 1) Angiogenesis inhibitors (AI) (e.g., pazopanib, sunitinib) commonly cause elevations in blood pressure (BP). Patients need to be monitored closely for these increases and BP lowering medications often need to be given to return the pressure to a safe level. So if/when your BP rises significantly, it will need to be lowered with medication.
- 2) There is preliminary evidence that patients whose blood pressure rises during AI therapy are more

likely to benefit from this class of drugs. We are attempting to confirm this theory in ongoing trials. In some trials, patients who do not obtain an increase in BP are having their AI dose increased. This increased dose may prolong benefit in some patients. This does not mean that patients who do not notice a BP increase do not benefit. They do benefit. It also does not mean that patients with a BP increase should not be treated with BP lowering meds because they should. Treatment with blood pressure medication does not diminish the effectiveness of the drug.



David F.
McDermott, MD

— David F. McDermott, MD, Director, Biologic Therapy and Cutaneous Oncology Programs, Beth Israel Deaconess Medical Center, Boston, MA

Please see:

http://www.health.harvard.edu/special_health_reports/hypertension-controlling-the-silent-killer

Sharing Scans On-line



Raym
Geis, MD

Why can't scans be made available electronically to any doctor located anywhere?

— Jenny M, Washington State

RESPONSE: The ability to move medical images easily from one site to another is available in its early stages now and should be generally available in the next few years.

For the last few years there has been a great deal of committee work worldwide to reach agreement on a common imaging format, DICOM. In addition to painting the image, medical image files contain additional data: the patient name and ID, etc.

Using DICOM, several companies now provide 'cloud storage' of medical images, similar to common photo sharing systems like Picasa and Flickr. Medical cloud storage companies use a variety of mechanisms to keep images private and secure. The files, though, are still huge and internet speed is still an issue.

One example of an image sharing system is the RSNA Image Share network. It has been in demonstration phase and is expanding into clinical practice. As more hospitals adopt these standards, it will be easier to exchange images electronically.

— Raym Geis, MD, Chair of the Society for Imaging Informatics In Medicine (SIIM)

Legislative Progress in the U.S.

As we get closer to having a drug to help us with VHL, the issue of “access” to these drugs looms ever larger. While the drugs are free during a clinical trial, once they are approved they can cost as much as \$50,000 a year, or \$2,000 per treatment. Thus for the VHL community we need (1) to encourage the development of new drugs, and (2) to make them accessible to the people who need them.

There are two important new pieces of legislation that are helping with these goals.

On July 10, 2012, President Obama signed into law the **Food and Drug Administration Safety and Innovation Act** (FDASIA), S. 3187. This bipartisan law will spur the development of lifesaving treatments for 30 million Americans suffering from rare diseases.¹

There are currently fewer than 400 FDA-approved treatments for nearly 7,000 rare diseases. Investment and interest in development will surge if there is access to the Accelerated Approval pathway. Special thanks to Sen. Tom Harkin (D-IA), Sen. Mike Enzi (R-WY), Rep. Fred Upton (R-MI), and Rep. Henry Waxman (D-CA) who helped to shape this new law.

A complete list of the participants is on the NORD website.² NORD's new Legislative Action Center makes it easy for you to get updates on what's going on in Washington, and to communicate with your Members of Congress. By entering your zipcode, you can quickly and easily send emails to your specific Members of Congress, letting them know that you appreciate their support on these issues.³

Access to care in the United States means having insurance. Some provisions of the **Affordable Care Act of 2010** have already been implemented, and others are due to be fully implemented by 2014.

Under this law, for example, insurers are now required to cover a number of recommended preventive services, such as cancer, diabetes and blood pressure screenings, without additional cost sharing such as copays or deductibles. For people with VHL, this is huge.

Insurance companies for a long time have denied coverage to people with “pre-existing conditions” — everything from pregnancy to use of antidepressants to chronic conditions. Many states have tried to end this practice. Their experience has shown that it only works when there is also a requirement that people who can afford it carry at least minimum coverage health insurance.

Having health care insurance provides people with access to care on an ongoing basis, for everything from the flu to accidents to scans for VHL. Staying healthy for people with VHL requires regular screening and appropriate treatment when needed. Emergency Room care alone is not sufficient to maintain health.

What the Affordable Care Act means to people with VHL is summarized in this quick list:

HEALTH REFORM BENEFITS THE AMERICAN PEOPLE

The Supreme Court's decision to uphold the Affordable Care Act ensures hard-working, middle class families will get the security they deserve and protects every American from the worst insurance company abuses.

- ✓ Lets millions of young adults stay on parent's insurance until age 26
- ✓ Ends insurance company power to cap the amount of care a person can receive in their lifetime
- ✓ Stops insurance companies from canceling coverage when someone gets sick
- ✓ Lowers the cost of care for those on Medicare and helps seniors save money on their medication
- ✓ Requires insurance companies to cover preventive services like mammograms free of charge
- ✓ Strengthens and protects Medicare by increasing penalties for fraud
- ✓ Stops insurance companies from denying coverage to children with pre-existing conditions
- ✓ Ends insurance company power to jack up rates without justification
- ✓ Provides Americans with rebates from insurers who spend too much on CEO bonuses or ads
- ✓ Gives tax credits to small business owners so they can afford to offer quality health care for employees
- ✓ Builds and improves hundreds of community health centers
- ✓ Gives hard-working Americans tax credits so they can afford insurance beginning in 2014
- ✓ Ends discrimination against adults with pre-existing conditions beginning in 2014
- ✓ Prevents insurance companies from charging women more than men, and overcharging those who need care the most beginning in 2014
- ✓ Creates state-based marketplaces where people can easily compare and shop for insurance beginning in 2014

Resources:

National Organization for Rare Disorders:
<http://www.rarediseases.org/>

Health Insurance information by State:
<http://www.healthcare.org/>

¹Please see complete article at www.vhl.org/press/nord

²See <http://www.rarediseases.org/news-events/news/fdasia-applause-congress>

³Click on “Take Action Now” under the Advocacy button on the top of NORD's home page at www.rarediseases.org

Get Busy Living!

Agnes B., England

This is the first time I have written about VHL. I was not diagnosed until 1998. My granddaughter was only six weeks old when I took ill. My husband was told I might not make it to the next morning. Obviously I did!

They operated, and I was a bit mixed up for a while. I did not even realize that I was a granny until my husband brought me a photo of me holding her in my arms. It finally began to sink in. I had always dreamed of being a granny, and now I could not even remember her being born or holding her!

I recovered from that first surgery, and tried to make the most of everything I could still do. I was lucky to have a great husband and family support. They may not always agree with me, but nevertheless they back me up, and that is all anyone can ask for.

I have a great medical team working with me too. I have had four brain operations, spinal surgery, lost half of one of my kidneys, and just last year had a second kidney operation. I also have problems with the pancreas and liver. I have more brain and spinal tumors but will deal with them when the time comes. I am hoping to get two years without more surgery.

Nonetheless I count myself lucky. Why? Because if I had not been ill, I would not have met so many people who have given me so much support and—believe it or not—happiness. They taught me to be able to laugh again and have fun. They also taught me that sometimes a wry sense of humor can go a long way to helping you and others around you to cope.

I know that sometimes it's hard to laugh when you are scared. God knows I've been scared more times than I care to remember! But a little laughter can go a long way to helping, and it can get you out of a hospital quicker as well.

People who hear my story always comment on my great and positive attitude. They usually realize that things they were upset over are small potatoes, and they become thankful. I think we all realize that life is too short to wallow in misery. *Time to get busy living!*

2012 CFC Campaign

Are you a State or Federal government worker? The 2012 CFC Associated State Campaigns are underway; your donation to the VHLFA can be deducted directly from your paycheck. **You can fund VHL under its DBA: VHLFA under Alliance for Cancer Research and Support—VHL. Federal ID#: 10934**

Washington State Meeting

Everett, Washington – VHL Informational Meeting
October 20, 1:00–3:00 p.m. at Compass Health, 4526 Federal Avenue, Bldg 2, Everett, WA 98203.

RSVP to: 206-251-7705: Alice – during the day

509-922-5862: Jenny – in the evening

us-wa@vhl.org: Diana – via email

Task Forces Going Forward

VHLFA has initiated two new Task Forces this month. Each one is tackling an important strategic area.

The **Clinical Trials Task Force** is putting together a strategy for evaluating drugs that might be helpful for VHL. For each drug, a pool of people will be needed to try it and help us learn where it is most beneficial, and what its limitations might be. The goal is to make each drug available in multiple sites, so that more people can conveniently join the trial, enroll the needed number of patients in the study quickly, achieve results and hopefully approval for that drug, and then move to the next drug until the optimal treatment is found.

If you have suggestions that would make it easier for you to participate, please contact Ilene Sussman, director@vhl.org

The **Patient Registry Task Force** is working to make it possible to add data from multiple sources together so that a research project has the largest possible pool of patients to study. Learning from thousands of people with VHL is always more valuable than learning from 20 or even 100. The greater the number of people in the study, the more we are likely to learn.

We have been accepted into the Global Rare Disease Registry project sponsored by the Office of Rare Disease Research (ORDR), a division of the National Center for Advancing Translational Science (NCATS) of the U.S. National Institutes of Health. ORDR is working with EURORDIS in Europe to create a global vision.

The VHL Patient Registry Task Force is also global, with participants from US, UK, Germany, Netherlands, and Singapore.

The Patient Registry project in particular will need one or more volunteers from the patient community to participate on the Task Force. If you are interested, please contact Joyce Graff, wellness@vhl.org

New CCC, Chicago



Sarah Nielsen, MS

The University of Chicago has joined our Clinical Care Centers Program, sponsored by Dr. Raymon Grogan in Endocrine Surgery. Sarah Nielsen, genetic counselor and member of the VHLFA Board, has recently moved to University of Chicago from University of Pittsburgh, where she was involved in VHL research and care. She is already working closely with the endocrine surgery group in Chicago.

"We have developed an Endocrine Genetics clinic specifically to see people with all pheo syndromes, including VHL, and have many research projects underway. We are planning to expand the services we already provide, educating other physicians and providing comprehensive care. We look forward to working with more people with VHL!" All participating centers are listed at www.vhl.org/ccc

Auction Items for VHLFA Fundraising Dinner Needed

On November 17, 2012, along with our Annual Meeting, we will be holding a Fundraising Dinner and Auction (see page 6). We are looking for items to sell at our auction.

If you have a have something you'd 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 or call us at 1-800-767-4845 ext. 4.

The money from the auction will help fund our VHL National Registry!

Thank You for Your Fundraising Efforts!

McCoy Family Tri for a Cure



On June 9th, the McCoy family completed a 25 km triathlon in Clemson, South Carolina. Brooks swam 5 km, Jeanne and Mary Ellison each biked 5 km, and Ford and Ellison ran 5 km. We expected to raise \$2,500, but instead raised \$3,635! All money raised through the McCoy Family Tri for a Cure went directly to the VHL Family Alliance for research.



The Risk to Blossom
Art song recital benefit for VHL Family Alliance

Jennifer Behnke and Fred Johnson organized a concert performed on May 13th 2012. Jennifer sang inspirational songs about creating beauty in the world. They raised \$1,180 in addition to individual on-line donations. You can listen to the audio at: <http://jenniferdbehnke.com/audio/>

Mom's Day Run

My family and I are deeply moved by the love and support shared with us on Mother's Day.

Our little event, starting with a promise...is now on the map!!! Exceeding all of my wildest expectations.

Thank you for your your support, your kind words and promises to return next year!!! Together we raised a total of \$2,714 for VHL Research!



A small group of amazing individuals came together for a common cause...and made a difference. Thank you for helping me keep my promise!!!

xoxo Suellen

Rick Bracey 29er

On Saturday, June 16th, 140 friends, family and supporters braved the rain and cold to play ball for a very important cause. The 2nd Annual Rick Bracey 29-er Softball Tournament, presented by Scotia Bank, raised **\$25,000** for von Hippel-Lindau (VHL) Syndrome

awareness and research in memory of Rick Bracey, a long-time resident of Crescent Beach, British Columbia, Canada, who died two years ago from VHL.



As tribute to Rick, all 140 players and volunteers wore Rick's number 29. "The love and generosity for both Rick and the spirit of this event leaves us speechless," says Stephanie Kaes, Bracey's sister-in-law and Tournament Treasurer. "All this on what would have been Rick's 54th Birthday."

Roller Derby



Amy B. participated in the Providence Roller Derby on June 9th. She helped raise \$200 and awareness for the VHL Family Alliance. It was a blast!

Susie's Run for VHL



Susan Kramer will run the NY Marathon for VHL on Nov. 4, 2012. Her goal is to raise **\$10,000**. Please support her efforts! www.crowdrise.com/susiekramer/fundraiser/susankramer

Amy Takes the Gold!

Amy Riter competed in the 32nd Veterans National Wheelchair Games in June in Richmond, Virginia. She competed in two swimming events (50m backstroke and 50m freestyle) and three field events (shot put, discus, and javelin)—and took home five gold medals! Amy is the VHLFA Chairman for Ohio and was Miss Wheelchair Ohio in 2010. Congratulations, Amy!



TWO BIG EVENTS ON NOVEMBER 17, 2012 • BOSTON, MA

Register for Both

2012 VHL Annual Family Meeting

Registration: 8:00-8:30 AM • Meeting: 8:30-5:00 PM

Educate and Empower Yourself

Simultaneous Teen Fun Day Program

AGENDA

- **Introduction and Welcome:** William G. Kaelin Jr., MD, Harvard Medical School, Dana-Farber Cancer Institute
- **Setting the Tone:** Suzanne Hanser, EdD, MT-BC, Berklee College of Music
- **A Balancing Act—VHL in the Adrenal Glands:** Nikolaos Stathatos, MD, Harvard Medical School, Mass. General Hospital
Panel Discussion: Mark Pallansch & Tina Gruner, RD, CDE
- **VHL Family Alliance—Looking at Today and the Future:** Jane McMahon, Chairman of the Board, VHLFA
- **Treating the VHL Kidney Tumor:** John Libertino, MD, Lahey Clinic
- **VHL Research: Where is it Going?** James Gnarr, PhD, University of Pittsburgh
- **What is Happening in the World of Clinical Trials:** Othon Iliopoulos, MD, Mass. General Hospital
- **VHLFA Research Grants—Steps towards a Cure:** William G. Kaelin Jr., MD, Harvard Medical School, Dana-Farber Cancer Institute
- **Nutrition: Does it Really Matter?** Meir J. Stampfer, MD, Harvard School of Public Health
- **Update on Diagnosing and Treating Pancreatic Neuroendocrine Tumors:** Steven K. Libutti, MD, Montefiore Medical Center
- **Putting it all Together: The VHL Patient: Panel Discussion:** Gayun Chan-Smutko, MS, CGC, Mass. General Hospital, and Kathy Schneider, MPH, Dana Farber Cancer Institute

Fundraising Dinner & Auction

7:30-10:30 pm • Kehillath Israel, 384 Harvard Street, Brookline, MA

Honoring



William G. Kaelin, Jr., MD

Professor of Medicine, Harvard Medical School and Leading Cancer Researcher, Dana-Farber Cancer Institute

Joyce Wilcox Graff

Founder and Founding Director of the VHL Family Alliance



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If you'd like to donate an item for the auction, please contact us at 617-277-5667 ext. 4.

If you are not able to attend, but would like to show your appreciation, please send a note and/or donation in with this form

REGISTER NOW!

Register on-line at <http://vhl.org/meetings/meet2012/bostonmeeting2012.php> or mail in Registration Form below to

The VHL Family Alliance, 2001 Beacon St, Suite 208, Boston, MA 02135

MAIL-IN REGISTRATION FORM

# People	Family Meeting only	Dinner only	Both (Combination)	Totals
	<input type="checkbox"/> \$90.00 Before 10-17-12	<input type="checkbox"/> \$125.00	<input type="checkbox"/> \$192.50 Before 10-17-12 (with discount)	\$ _____
	<input type="checkbox"/> \$100.00 After 10-17-12	<input type="checkbox"/> \$125.00	<input type="checkbox"/> \$200.00 After 10-17-12 (with discount)	\$ _____
	<input type="checkbox"/> \$50.00 Teen Fun Day*	<input type="checkbox"/> \$125.00	<input type="checkbox"/> \$175.00	\$ _____
DONATION <input type="checkbox"/> \$ _____				\$ _____
Show your support! Put a message in the program: <input type="checkbox"/> \$25.00—your name among the well-wishers <input type="checkbox"/> \$50.00—3-line message (enclose your text—maximum 100 characters) For larger ad options, write to director@vhl.org				\$ _____
*Bowling and parent-free discussions for teens with a professional moderator				Total Enclosed \$ _____

Donations are seen on the printed version only

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New Board Members—Meet them in November



Sue Buckley is a retired Senior VP with the YMCA. She has 25 years experience in the nonprofit sector. Sue graduated from Illinois State Univ. and continued her career within the national YMCA system. Over the last three years, Sue has founded a new non-profit called Club VIBES (Visually Impaired/Blind Enhanced Services). Club VIBES strives to create greater independence for blind or low vision young people. Sue currently is serving as President of the Club VIBES Board. Sue and her family are also directly impacted by VHL, thus creating her strong interest in the VHLFA.



Jan Capinegro is an executive with The Pampered Chef, a company that specializes in the distribution of quality kitchen tools. Experiences include corporate strategic planning, oversight of sales, policy, financial services, and risk management. Jan has worked closely with corporate charitable giving. Jan's son Tony was diagnosed with VHL at 15 and has endured 5 brain and spinal cord surgeries in the following 15 years. VHLFA became the lifeline to education, information, and hope that research will one day find a cure to VHL. Jan would like to use her experiences to further research, education, and patient support for the benefit of all VHL patients and their families.



James Gnarra is an Associate Professor of Urology and Pathology at the University of Pittsburgh Cancer Institute where he directs an active VHL research program. He received his B.S. degree in Biological Sciences from the University of Pittsburgh, and his PhD in Microbiology and Immunology from the University of Virginia. He did post-doctoral research at the National Institutes of Health. Dr. Gnarra is committed to serving as liaison between the research and the patient communities. He has served as Chair of the Research Advisory Committee for VHLFA and is dedicated to advancing VHL research.



Gayle Greene became aware of VHL through her husband, David. When David's father received a VHL diagnosis in 1992, the family discovered through genetic testing that David had inherited the disease. Gayle and David have three children, ages 5, 7, and 11. Their youngest child also has VHL. In coordinating medical care for her family and because of her training as a medical social worker, Gayle has become interested in patient care issues. Through the VHLFA, she would like to see continued and growing relationships with Clinical Care Centers providing coordinated care for VHL patients. She also would like to see broadened awareness and funding for VHL research.



Karen Ramsey is President and CEO of Lead for Good, a nonprofit organization dedicated to helping individuals become great nonprofit leaders. Karen has over 20 years of leadership experience. She holds a BA in Economics from the College of William and Mary and an MS in Communications from Virginia Commonwealth University. As a recently diagnosed VHL patient herself, Karen has relied heavily on the information provided by VHLFA. She is committed to raising awareness about the syndrome as well as supporting others who seek practical information that will help them be informed consumers of medical treatment.