

Building Momentum!

by Gayle Greene, Member of the VHLFA Board of Directors, Building Resources Committee

The end of 2012 was an exciting time for the VHL Family Alliance. In addition to hosting our annual meeting, we held our first fundraising dinner. The dinner honored Founding Executive Director Joyce Graff and prominent VHL researcher Dr. William G. Kaelin, Jr. We thanked Joyce Graff for her many years of dedication to the Alliance and Dr. Kaelin for his tireless efforts to identify a cure for VHL. The dinner raised more than \$80,000.

The Annual VHL Family Alliance Meeting featured presentations by prominent researchers and practitioners specializing in VHL. Drs. William Kaelin, Jr., Nikolaos Stathatos, John Libertino, James Gnarr, Othon Iliopoulos, and Steven Libutti were among the doctors who discussed patient care along with cutting-edge discoveries.

The Annual Meeting and dinner demonstrated the Alliance's continued focus on patient support, VHL research, and fundraising. Fundraisers, like our November benefit, allow the VHL Family Alliance to fund critical research. Every dollar we raise impacts treatment and care for those with VHL. Our hope is to continue to build our fundraising efforts. If you want to organize a fundraiser, we would be happy to assist by providing materials about VHL as well as donation information. Whether you organize a walk-a-thon, bake sale, or an auction, your contributions drive our success. Your efforts and your donations will help us towards our goal of raising \$378,000 by the end of our fiscal year—June 30, 2013. With \$267,000 raised thus far we have already reached 70% of our goal!!

Besides fundraising to support research, the Alliance remains committed to patient support. In the coming months, you may receive a telephone call, e-mail, or note from our team of "Outreach Volunteers" (led by Jule in Texas), soliciting your feedback. We want to hear what is on your mind about the VHL Family Alliance. We hope you will share your concerns, thoughts, ideas, and suggestions.

Mark your calendars for next year's annual conference and benefit dinner. It will be held on September 20-21, 2013, in Ann Arbor, Michigan.



Gayle Greene

Highlights from the Annual Meeting

by Joyce Graff, MA, and Anthony Horton, PhD

The 19th Annual Meeting of the VHL Family Alliance, held at the Dana Farber Cancer Institute and hosted by Dr. William G. Kaelin, Jr., was an excellent line-up of timely presentations.

Setting the Tone—Music Therapy: Harmonious Stress Management. *Suzanne Hanser, EdD, MT-BC, Berklee College of Music – Music Therapist*, presented her data on the use of music therapy in pain management. Music therapy is an underused complementary treatment that can be beneficial in managing chronic stress and chronic depression. Dr. Hanser has begun to use music therapy as an antidote to pain in cancer patients. She led a session on using music as a way of calming the spirit and renewing energy.

A Balancing Act—VHL in the Adrenal Glands. *Nikolaos Stathatos, MD, Massachusetts General Hospital, and patient panelists, Tina G and Mark P.* Dr. Stathatos' work with VHL patients has focused on clinical care and management of endocrine dysfunction (hormonal changes) caused by pheochromocytomas (pheos). Pheos are seen in 10–20% of people with VHL, resulting in disturbances in stress hormone levels. This produces a number of characteristic symptoms which may include: palpitations, headaches, increased sweating, pallor and feelings of nausea. Once a pheo is identified, it is usually possible to remove the tumor while leaving much of the adrenal gland in place to avoid the need for hormone replacement therapy. When hormone replacement is needed, however, it is important that the patient learn how to self-manage. "Cortisol varies normally day-to-day in response to stress. The patient needs to learn when and how to adjust their doses."

Tina and Mark, both living with no adrenals for many years, added their thoughts and experiences concerning self-management. They shared the signs of too little

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**Team
VHL!**

The VHL Family Alliance is organizing a running team.
Contact us at 800-767-4845 ext. 4 or office@vhl.org.

Highlights from the Annual Meeting

Continued from Page 1

learned to partner with their doctors in managing their condition. Both lead full and productive lives at work and at home and proved with their very presence that it is possible to survive and thrive without adrenals. Medical alert information should be worn by people with adrenal insufficiency using the following wording: "Adrenal Insufficiency--Needs stress dose cortisone."

Treating the VHL Kidney Tumor – Novel Techniques in Partial Nephrectomy. Dr. John Libertino, Lahey Clinic Institute of Urology, shared his latest research in the best methods for partial nephrectomy without clamping. It is now well established that for anyone (VHL or not), clear cell kidney cancer tumors up to 3 cm can be safely removed without removing the kidney. It is important to the long-term health of the patient to retain as many "working nephrons" as possible. The more kidney tissue removed during surgery, the greater the chance of problems with kidney function down the road.

It has also become clear from research on surgical outcomes that the health of the kidney after surgery depends in large part on the amount of time the kidney was deprived of oxygen during surgery by clamping off the major arteries that feed the kidney. This oxygen-deprivation time is called "ischemia" time. It had been thought that it was safe to clamp the kidney for up to 20 minutes, but further research is showing that even this can result in damage to the long-term kidney function.

Dr. Libertino and his team have devised a method of computer-modeling the kidney and its vascular structure, and determining how to cut off the supply of blood to the tumor itself, while keeping the blood flowing as normally as possible to most of the kidney. This research is reported in <http://www.ncbi.nlm.nih.gov/pubmed/21811227> and other papers. In PubMed, search for Libertino and ischemia.

VHLFA Research Grants – Steps Towards a Cure.

William Kaelin MD, Dana Farber Cancer Institute and Brigham & Women's Hospital, provided an update on the progress that has already been made toward finding a cure for VHL and what it will take to get the job done. We now know that a change in the VHL gene is responsible for 85% of the kidney cancer in the general population. But we also know that change in the VHL gene is not enough to actually kick off a kidney cancer. Other changes must also happen—in that same cell—in order for kidney cancer to occur. VHL is one of the regulators of HIF, but not the only

one. As we do more whole-genome sequencing for an increasing number of people, we should be able to identify some of these additional factors, which may provide us with more "druggable targets" to manipulate the levels of HIF and manage VHL. Most of all, he shared with us his enthusiasm. As always, he is an excellent explainer of difficult concepts. We encourage you to listen to his presentation.

VHL Research – Where is it Going? James Gnarra PhD, University of Pittsburgh Cancer Institute, Chairman of our Research Advisory Council, added his thoughts on where the research is going from here and how the VHL Family Alliance is helping to move things forward. He reported on the progress of the projects under Haifeng Yang (Jefferson Medical College, Philadelphia, PA) and Eleanor Rattenberry (University of Birmingham, England) in learning more about how the VHL gene operates. The Second Generation Sequencing technology (SGS) in use at Birmingham allows these investigators to quickly obtain the DNA sequence of 9 different genes in patients with pheochromocytomas. SGS is also helping to identify VHL gene mutations in people for whom a DNA alteration was not found. The VHLFA research program helps to focus attention specifically on VHL disease and assists researchers in learning from our community. The International Patient Registry, which will open in the Fall of 2013, will be a rich resource for research. In addition, he encouraged us to "make noise on [Capitol] Hill." Patient groups have been successful in influencing how research money is spent by the government.

What is Happening in the World of Clinical Trials?

Othon Iliopoulos MD, Massachusetts General Hospital, provided an update on the status of clinical trials for new drugs with VHL. Early trials with Sunitinib (Sutent) and other drugs approved for advanced (metastatic) kidney cancer have helped to some degree in the kidney, but have not been successful in changing the course of tumors of the central nervous system (CNS: eye, brain and spinal cord). While there are individual case studies of successes with early drugs, most people have not benefitted from these drugs. They all target individual HIF-target genes, mainly VEGF. But it is becoming clear that something more is needed, particularly for treatment of CNS hemangioblastomas. Pazopanib adds an FGF inhibitor which we are hoping will be more effective in the CNS, and there are more drugs coming that will give us slightly

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2013 Annual Meeting in Boston



Meeting Room at
Dana-Farber Cancer
Institute

The Geek Corner:
Looking at Zebrafish
through special glasses



Zebrafish ↓



Rick Bracey attended
the meeting in spirit.
Ilene Sussman holding
flyer for the 29th fund-
raiser for Rick Bracey

different combinations of factors which are expected to do better. For more information on clinical trials, keep an eye on <http://vhl.org/trials>.

Videos and handouts are available at www.vhl.org/meeting-2012

Nutrition – Does it Really Matter? *Meir Stampfer, MD, Harvard School of Public Health, Harvard Medical School*, reviewed the importance of nutrition in keeping our immune systems strong. He emphasized that not all fats are bad – some are in fact essential – but that we should use vegetable fats rather than animal fats as much as possible. He pointed us to myplate.gov and to the book *Eat, Drink, and Be Healthy*, which is a major source of the information on nutrition in the *VHL Handbook*.

Update on Diagnosing and Treating Pancreatic Neuroendocrine Tumors (pNETS). *Steven K. Libutti MD FACS, Montefiore-Einstein Center for Cancer Care, Montefiore Medical Center*, spoke about diagnosis and treatment of pancreatic neuroendocrine tumors (pNETs). While pancreatic cancer is a virulent disease, pancreatic neuroendocrine tumors are relatively slow-growing and have a much more encouraging outlook. They do, however, need to be carefully watched to avoid the nastiest consequences

of metastatic cancer. Differentiation of the three kinds of tumors in the pancreas is essential (see the *VHL Handbook*). In his study of 108 patients with pancreatic NETs from VHL, none of them had “functioning” tumors that emit hormones that can be found in the blood. For that reason, careful imaging studies are critically important to determine whether the tumor is benign (and therefore not a problem) or a malignant pNET (and needs careful monitoring). If a pNET should metastasize, there is now a clinical trial open at a number of sites in the US and other countries using everolimus (afinitor) for metastatic pNETs (vhl.org/trials).

Putting it all Together: The VHL Patient. *Gayun Chan-Smutko, Massachusetts General Hospital: Genetic Counselor* Gayun Chan-Smutko provided a reminder of the many aspects of care in which a genetic counselor can help, including discussing risks and benefits of genetic testing; facilitating genetic testing; helping to cope with a new diagnosis; and helping identify resources and specialists necessary to manage the medical and psychological impact of the disease. In addition to assembling a family health tree, genetic counselors can help identify which members of the family are potentially at risk and would benefit from information on VHL. Genetic counselors can help you strategize about how to share information with your relatives. To find a genetic counselor near you, go to <http://www.nsgc.org>.

Fundraising Dinner Honoring Joyce W. Graff and William G. Kaelin, Jr.



Dinner Hall



Michael McDermott, MD; Joyce Graff; Sunny Greene; William Kaelin, Jr., MD

Preventing Complications After Surgery

by Joyce Graff, MA, and Ilene Sussman, PhD

Lois woke up from brain surgery. She and her family had been fearful since before surgery the doctor had warned her that she might be left with some deficits. She took inventory and spoke to her family. Everything wiggled! Except for some weakness in one foot, she was soon walking and talking normally. She went home to recuperate.

Ten days later she was back in the hospital. A blood clot in her leg had broken loose and gone to her lung. It's been a difficult journey, but she is making a full recovery.

Jim was not as lucky as Lois. Five days after surgery, a blood clot traveled from his leg to his heart. After all he had been through with VHL, it was not VHL that ended his life. It was a blood clot.

We often hear of the dangers of blood clots from long-range air travel. Sitting in one place for too long or lying in

bed can result in blood pooling in our legs and potentially forming a clot. The heart pushes blood down into our legs; our leg muscles massage the veins in our legs and push blood back up to the heart. When our leg muscles are not working, the blood does not get recirculated properly.

Surgery is a risk for blood clots – not just in the hospital, but as much as 12 weeks after. That is the reason why in the hospital, they put on inflatable leg balloons or compression devices, replacing the action of your leg muscles while you are in bed for extended periods. After hospitalization, fitted compression stockings can be helpful. Depending on your other risk factors (diabetes, body mass, age, genetics) the doctor may prescribe a blood thinner to keep your blood from clotting. However, “blood thinners” (anticoagulants) are not always

Continued on next page

recommended after surgery, such as brain surgery, where the risk of excessive bleeding may outweigh the risk of blood clotting. Based on each individual's case and risk, a physician will determine if blood thinning agents should be used at some point during the recovery. This makes it even more important that we as patients follow all the clot-prevention advice carefully.

The most important thing you can do is to speak with your doctor before and after surgery. Ask them what precautions you should take: Is a "blood thinner" appropriate?

Even people in peak condition can have a blood clot. Serena Williams, the tennis pro, had clots in 2011 that traveled to her lung and nearly killed her. "It was the

scariest moment of my life," she said. Surgery is among the risk factors for blood clots, as are prolonged periods of inactivity and long airline flights.

Williams said she was not "moving and not doing as much as I normally do. I started flying a lot...thinking I was OK. And obviously, I wasn't."

Simply put: Drink water and walk. Follow instructions regarding compression stockings. It is best to get stockings specially fitted at a medical supply store. Yes, they can be annoying and difficult to put on and off, but they are truly essential to your health. Ask the nurse about gadgets to help put them on, or ask a family member or friend to assist you.

ASK THE EXPERTS:

The Danger of Blood Clots After Surgery

Formation of a blood clot (thrombus) within one or more deep veins in the body can cause partial or total blockage of the vessel, preventing blood from flowing normally. Most commonly, DVT occurs in the leg veins. This can be a serious condition as the blood clot is at risk of detaching, moving through the bloodstream, and lodging in an organ. For example, you could experience a pulmonary embolism (PE) if it lodges in the lungs or a stroke if it affects the blood vessels supplying the brain.

Some DVT risk factors are:

- **Prolonged bed rest or immobility**, the lack of calf muscle contraction when our legs remain still for lengthy periods of time result in poor blood circulation which increases the risk for formation of blood clots
- **Surgery and trauma**, the risk remains elevated for as long as 12 weeks after surgery
- **Family history or prior history** of developing DVTs or PEs
- **Medical co-morbidities** such as heart failure, inflammatory bowel disease, or kidney diseases can increase the risk of forming blood clots
- **Obesity**
- **Older Age**. DVTs can occur at any age but the risk increases when you are 60 years old or older
- **Smoking**
- **Increased levels of estrogen** (due to birth control pills or hormone replacement therapy) or pregnancy

Steps you can take to prevent a blood clot:

- Speak to your surgeon before surgery, during your hospital stay, and before you are discharged.

- Preventative measures during your hospital stay should include mechanical compression devices on your legs and may include "blood thinners" (anti-coagulation medication), as appropriate.
- Preventative measures for at least 90 days after surgery:
 - Compression stockings (purchased and fitted at a surgical supply store)
 - Walking and staying active
 - Drinking fluids
 - "Blood thinners" or anticoagulation therapy, where appropriate

Symptoms of DVT include:

- Discomfort, heaviness, pain aching, throbbing, itching, or warmth in the legs, often starting in the calves
- Skin changes in the leg(s), such as discoloration, thickening, or ulceration
- Swelling of the legs, ankles, or feet

Symptoms of PE include:

- Unexplained, sudden onset shortness of breath
- Chest pain or discomfort which worsens when you cough or take a deep breath
- Coughing up blood
- Rapid or irregular heart rate
- Lightheadedness

This information is meant to provide general health information. Please seek advice from your physician or other health care professional to discuss your specific symptoms or conditions.

Chia-Ling Phuah, MD, Neurocritical Care Fellow, MGH/BWH Fellowship Training Program in Neurocritical Care, 55 Fruit Street, Lunder 6 ICU, Boston, MA 02114.

Tissue Needed

Surgically-removed tissue from people with VHL is always needed for research. Our tissue bank at NDRI stores tissue until it is needed. To donate tissue, call or e-mail the VHL Biobank (bank@vhl.org or 800-222-6374) preferably a week or more before your surgery to arrange for tissue to be transferred to the bank.

There is currently a need for metastasized kidney

tumor tissue—a portion of the primary tumor and/or a metastatic spot. For this project, frozen tissue is preferred.

The Biobank will send you the kit of paperwork needed before they can collect your donated tissue from your hospital. If you have previously had a VHL tumor or metastatic spot removed, whether it is frozen or in paraffin, it can also be donated. Please contact the bank as described above and they will work with the hospital to have it transferred.



VHL Bravelet—\$35.00

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Joyce W. Graff accepting her award



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Othon Iliopoulos MD and the
Babineau family



Ilene Sussman, Executive Director, VHLFA, and Jane McMahon,
Chairman of the Board of Directors, VHL Family Alliance



William G. Kaelin Jr., MD
accepting his award

New CCC in California—Stanford

Stanford Hospital and Clinics
Stanford University School of Medicine

Contact: Vee Vo at veevo@stanfordmed.org

Phone: 650-736-0262 / Fax: 650-320-9443

Visit: <http://tinyurl.com/vhlstanford>

New! Group for Teens

Contact the office: office@vhl.org or
1-800-767-4845 for more information.

Thank You for Your Fundraising Efforts!

Cornhole for a Cause



On August 25th, 2012, we held a fundraiser called **Cornhole for a Cause** to benefit the VHL Family Alliance. The event was held at the Tikki Bar at Nashoba Valley Ski Area in Westford, MA. We had 90 people show up to the event. Many people donated items for the silent auction and raffle. The day was a success! We raised almost \$8,000, and the positive response to the event was overwhelming. We have no choice but to make it an annual event!

The event was put together with the invaluable help of Michelle, Kurt, and Dana Andjus, as well as my husband Matt Andjus. We look forward to next year's event!

— Katie Andjus

Renaissance Hotel Event



The Renaissance Blackstone Hotel in Chicago raised \$2,000. The money was raised by the hotel and restaurant employees by paying \$5 to wear jeans on Fridays and a bake sale. Raffle items included a gift basket donated by The Pampered Chef, a stay at another local hotel, a piece of jewelry donated by a local artist, and a 42" flat screen TV.

All of the bartenders' tips at the holiday party were donated.

— Cristin Hock

Amelia Fund Tournament

The Amelia Fund in New Jersey raised \$8,000 at a golf tournament in memory of Amelia Amalfitano.

Macaroni Dinner



James Bray

This fundraiser was a macaroni, meatball, and antipasto dinner held in Warwick, RI, on November 11, 2012, to raise awareness and help fund research.

There were 43 raffle baskets and prizes donated by many generous people and companies. 83 people attended. American Idol's Erica Van Pelt attended to meet and greet people. James, his sister Kaylee, his mom, and his grandfather all have VHL. \$2,300 was raised!

James is 16 yrs old and wants to help find a cure for VHL. He plans to do more fundraising in the future. A few years ago, he illustrated a page in the *VHL Handbook, Kids' Edition*.

Thank You to Our Fundraising Dinner Sponsors!

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James & Mary Anne Babineau

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Calendar of Events



Annual Patient/Caregiver Meeting, 2013

September 21, 2013 at the University of Michigan,
Ann Arbor, Michigan

See draft agenda: <http://www.vhl.org/meeting-2013>

The 11th International VHL Medical Symposium

October 23-25, 2014, Madrid, Spain

More details to follow: See <http://www.vhl.org/conf2014/>



Jackson, MS Regional Meeting March 23, 2013

at the University of Mississippi Medical Center, 2500 N. State St., Jackson, MS 39216

Join us for the VHLFA Regional Meeting during the day.

That is the same weekend as the Sweet Potato Queen Festival. There will be a Sweet Potato Queen parade in the evening, which you can watch, or possibly participate in? We hope you will come and have fun with all of us!

For further information and directions to the meeting room, write to Vanessa and Sue at us-ms@vhl.org, call the office at 1-800-767-4845 ext. 4, or see vhl.org/meetings.

Suggested hotel: Drury Inn, 610 E. County Line Rd., Ridgeland, MS 39157, 601-956-6100 (about \$110/day). **Book early!**

