

Message from Incoming VHLA Board Chair

Karen Ramsey, *Chair, VHL Alliance Board of Directors*

As our new fiscal year begins, I am delighted to report the VHL Alliance has made great strides in supporting its mission which is dedicated to research, education, and support to improve diagnosis, treatment, and quality of life for those affected by VHL. In the past year, we accomplished the following:



Karen Ramsey

- 1) Re-designed and spruced up our image and brand
- 2) Launched a comprehensive patient databank (CGIP, **Cancer in Our Genes International Patient Databank**, www.vhl.org/databank) which is focused on collecting data and finding a cure for those of us affected by VHL and other related diseases
- 3) Bolstered the ranks of medical institutions certified as Clinical Care Centers, and
- 4) Allocated \$150,000 towards VHL research

And that was just a few of our accomplishments! Many thanks to outgoing Board Chair Jane McMahon and Executive Director Ilene Sussman and the VHLA team for making these initiatives a reality!

During Jane's two-year term as Chair of the Board of Directors, the organization has risen to a new level and is more effective and productive than ever. One of Jane's greatest gifts was facilitating the recruitment and selection of Ilene as our executive director. In addition, Jane supported the process to bring a number of highly skilled and dedicated new members to our board. This year, we have six outstanding additions. Each of these individuals will provide talent, wisdom, and hard work to make a cure for VHL a reality someday. We are delighted to have them join our team. More information about the incoming Board members can be found on page 6, as well as on the vhl.org website: <http://tinyurl.com/vhla-board>.

The VHLA's dedicated staff continues to implement existing programmatic efforts. At the same time, they are busy with new initiatives focused on an all-inclusive approach to treating VHL. A mentor/mentee program launched this spring, a new section on wellness will be posted shortly on our website, www.vhl.org, and the fall will bring the initiation of telephone support groups for patients and caregivers. See page 6 for more details.

For the Board, the focus for 2015 will be three-fold:

- 1) Implement processes and procedures to continue to improve our organizational effectiveness
- 2) Expand our committee structure to engage more volunteers and expand program offerings, and
- 3) Enhance revenue to support additional cancer research

If you are interested in getting involved, please contact me at kwr@leadforgood.org or get in touch with Ilene Sussman, our wonderful executive director. She may be reached at director@vhl.org or 617-277-5667 x4. We could really use your help. Our ultimate goal is to find a cure for VHL and other cancers and that is going to take all of us pulling together to make it happen.

Looking forward to a great year!

IMPORTANT

New Testing Standard for Pheochromocytoma and Paraganglioma (PPGL)

New clinical guidelines were recently approved by the Endocrine Society (June 2014) for testing for the presence of pheochromocytomas and paragangliomas (PPGL).

1. **Screening for PPGLs should always include measurements of plasma-free metanephrines (obtained from a blood sample) or urinary fractionated metanephrines (obtained from a urine sample).**
2. **For a blood sample, patients are now required to be supine (lying down) for a minimum of 20 (ideally 30) minutes between the time the needle is inserted and the time the blood is drawn.**
3. **Blood sample analysis should be done using norms (a reference standard) from supine tests, not seated tests, to minimize the chance of a false negative result (missing a PPGL that is present)**

The decision was made based on the finding that seated blood testing results in increased false positives, meaning that these patients must be retested. The

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New Testing Standard for Pheochromocytoma and Paraganglioma (PPGL)

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reason for this is that the release of catecholamines by peripheral nerves and the adrenal gland is stimulated by upright posture resulting in increased blood levels of metanephrines in seated compared to supine positions of blood sampling.

Based upon the new guidelines, the VHLA guidelines will be revised to read:

Annual measurement of plasma free metanephrines (with blood drawn following 20–30 minutes in

supine/lying down position following needle insertion) or urinary fractionated metanephrines (with patient adherence to recommended collection and refrigerated storage). Analysis performed using liquid chromatography with mass spectrometric or electrochemical detection and using supine norms for plasma test results. All positive test results should be followed up. Follow-up may involve repeated biochemical studies (e.g. a clonidine test) or a CT scan or MRI (if a CT scan is not appropriate).

"Guidelines on Pheochromocytoma and Paraganglioma"; J Clin Endocrinol Metab, June 2014, 99(6) 1916-1917

IMPORTANT CHANGES TO SCREENING GUIDELINES

The VHL Alliance has learned that the current brain and spinal cord guidelines are a barrier to some patients receiving insurance authorization or coverage for MRIs of the spine/brain. To alleviate this issue, the guidelines have been updated.

- **CNS MRIs should include brain, cervical, thoracic, and lumbar spine**
- **Scans should be ordered as no less than a 1.5T MRI with and without contrast**

This wording will be added to our online Screening Guidelines and online version of the VHL Handbook. The next edition of the print version will also include this update.

For complete screening guidelines, see our website: <http://tinyurl.com/screenguide>

Should VHL-Related Emotional Distress be Considered the “Sixth Vital Sign”?

ARTICLE SUMMARY: “Psychosocial impact of von Hippel-Lindau disease: levels and sources of distress” (Lammens, et al; *Clinical Genetics* 2010)

In 2010, Chantel Lammens, PhD published a piece of her PhD thesis focused on the emotional impact of VHL. This was the first study of its kind within the VHL community. Working with VHL patients at nine family cancer clinics in the Netherlands, Lammens and her team evaluated the prevalence of psychological distress among members of 48 families with VHL. All types of family members were included: those diagnosed with VHL, those at risk for VHL, and those negative for VHL.

Psychosocial distress, which is a term for the various impacts on a person's life and ability to cope caused by sadness, fear, and vulnerability, in both patients and family members has been studied for the more common forms of hereditary cancer such as breast and ovarian cancer. Distress is measurably increased in 10–20%. Among VHL families, however, 40 to 50% of those positive or at risk, and 36% of those negative reported heightened levels of distress. This markedly higher rate for VHL is likely due to the fact that VHL is more difficult to predict, both in timing and in organs affected. VHL is a risk for the patient's entire life and testing/scans are the only preventative options.

Frequent worries about future development of VHL-related tumors affect 41% of everyone surveyed, indicating that VHL has effects both on those positive for VHL and their family members who are either untested or negative. Significant factors associated with VHL-related distress are the experience of losing a close relative during adolescence and being female.

Measurements of “health-related quality of life,” were the same as for a reference group from the general population with a single exception for “general health.” All VHL family members (positive, at-risk, and negative) scored significantly worse on this measure. The VHL-positive group scored significantly below other VHL family member groups on general health perceptions, “physical functioning,” and “role limitations due to physical health problems.” This means that **ALL** family members are affected by VHL. The person with VHL has the most negative score, but even others in the family who do not have VHL, score lower on their perception of health-related quality of life.

One-third of the VHL family members who had indicated that they were moderately to severely distressed had received professional psychosocial support and another 28% would have liked to have. The most important issues addressed during counseling (in order) were:

- Coming to terms with VHL in general, fear of developing additional VHL-related tumors
- Learning to cope with the DNA test result
- Learning to cope with the loss of a family member due to VHL.

Those who had not received counseling, but would have liked it, added fear of family members developing additional VHL-related tumors and worries about insurance and home mortgages to the list. The majority (62%) of VHL family members felt that counseling should

be offered to everyone at the time of genetic or clinical diagnosis and when having a VHL-related operation.

The researchers concluded that psychological distress should be considered the “sixth vital sign.” However, while physicians routinely check standard vital signs such as blood pressure, pulse, and temperature, their ability to recognize patient distress is “suboptimal.”

The VHLA encourages you to register for the CGIP Databank. Make sure to complete the “Measuring Your Mood” section to contribute your experiences: www.vhl.org/databank.

Monthly Telephone Discussions

Living with VHL is not always simple for both the patients and their loved ones. Wishing that there was someone with whom you can connect and understands you emotionally is natural and important.

This fall, VHLA will proudly introduce a **telephone discussion group**. Join others who are living with VHL and find support centered on the unique issues and long term effects that a VHL diagnosis can present into one’s life and well-being. Caregivers, friends and family who have been impacted by VHL are welcome to join the group and find peer support throughout their experiences.

The group will meet monthly for one hour on the first Monday evening of each month from 7–8 pm (CST). If there is sufficient interest, two groups will be formed – one for patients and one for caregivers.

The group will be facilitated by Merritt L Benz, LCSW. All who have been impacted or are living with VHL are welcome to join.

In order to participate in this group please call Susan Milliken (800-767-4845 x4) or email office@vhl.org to register in advance.

About the Facilitator: Merritt L Benz, LCSW

Merritt is a licensed clinical social worker with 13 years of experience in working with individuals and families who face life threatening or chronic illness. Most recently she helped to open and establish Gilda’s Club Kansas City, an affiliate of the Cancer Support Community, so that no one faces cancer alone. While at Gilda’s Club Kansas City, Merritt facilitated groups for people living with cancer and their family members and friends and also provided individual support and educational programming. Currently, she is a therapist in private practice and any free time she has is taken with teaching her two young boys how to fly fish in a land locked city.

Find out more about Merritt Benz here:

The Bedford Therapy Group

Facebook: The Bedford Therapy Group:
<https://www.facebook.com/hebedfordtherapygroup>

The Wellness Collaborative:
<http://www.thewellnesscollaborativekc.com/>

Psychology Today and Good Therapy.org listings:

Merritt L Benz, LCSW- Psychology Today:
<http://tinyurl.com/Benz-PsychologyToday>

Merritt L Benz, LCSW- Good Therapy.org:
www.goodtherapy.org/merritt-benz-lcsw-therapist.php

Talking about VHL and VHLA...

How long does it take to ride an elevator or how long can you speak without taking a breath? Did you ever want to explain VHL and the work of the VHL Alliance in that amount of time? The Board of Directors has created the following “elevator pitch” to help. Don’t worry about memorizing it; you can use your own words. Try it! How long does it take you?

Von Hippel-Lindau (VHL) is a genetic cancer syndrome which causes vascular tumors throughout the body (e.g., brain, spinal cord, eyes, and kidneys). With no known cure, VHL is a lifelong disease; patients battle their entire lives. However, with constant monitoring, early detection, and appropriate treatment, the most harmful consequences of this gene can be greatly reduced or even prevented.

The VHL Alliance (www.vhl.org) is the preeminent resource dedicated to research, education, and support to improve diagnosis, treatment, and quality of life for those affected by VHL. Since the VHL gene is involved in many other forms of cancer; finding a cure for VHL will play a vital role in curing cancer!

Quick Punch Bullets:

- Genetic Cancer Syndrome
- Causes and feeds vascular tumors throughout the body
- No cure as of yet
- Monitoring/screening can save lives
- VHLA is dedicated to research, education and support
- Finding a cure for VHL will play a vital role in curing cancer

CALL FOR AUCTION ITEMS

IF YOU HAVE AN AUCTION ITEM TO DONATE TO VHLA’s BENEFIT DINNER & AUCTION IN ROCKVILLE, MD, PLEASE CONTACT OFFICE@VHL.ORG OR CALL 1-800-767-4845 X4

The Challenges of Deciding about Genetic Testing

Patient satisfaction is one of the factors on which your doctors are evaluated. An important measure that is a big change for 20th century health care is “shared decision-making.” Physicians are no longer expected to make your medical decisions for you and tell you what to do; instead, you are expected to be an active partner in your diagnostic and treatment plans. This means that you need to be well-informed and carefully weigh the options presented by your doctor. If only one option is given, it may be a good idea to use your right to get a second opinion. Also, the decision to wait and see is a decision in itself as you cannot stop time and postpone making choices indefinitely.

When you carry a rare gene mutation that predisposes you to tumors, medical decisions become more challenging. The expressions of the mutations that comprise VHL vary tremendously from person to person, even within the same family. Currently, the knowledge and technology is unavailable to accurately predict the course of VHL, although for certain tumors, there have been good guidelines developed. Added to the difficulty of making decisions for your own care, you may need to make decisions for your children.

Logic and emotion are part of every decision we make...

Two factors are part of every decision we make in our daily lives: logic and emotion. It is impossible to predict the outcome of any decision as no one can predict the future. For example, when selecting a grocery store, logic plays a part as you look at location, product choice, and prices. Emotion comes into play as feelings about the effects of the choices on health or other feelings you have about the cost, or the store, such as the overall shopping experience. It is easy to see that there are a range of successful stores, meaning that not everyone makes the same decision. There is no single “correct” decision; a particular organic food may turn out to carry bacterial contamination or the additional money spent at a high-end store may have been better spent in saving to move to a safer home.

Studies show that “the decision-making process, whether it be driven by logic or emotion, initially triggers the part of your brain associated with subconscious thought rather than conscious thought. In other words, even when you apply logic to your decisions, the subconscious mind leads the research...”¹ It turns out that no one can make a decision without emotion. A study was conducted with patients who had damage to the part

of the brain where emotions are generated (orbitofrontal cortex). The patients “seemed normal, except that they were not able to feel emotions. But they all had something peculiar in common – they couldn’t make decisions. They could describe what they should be doing in logical terms, yet they found it very difficult to make even simple decisions such as what to eat.”² Emotions are based upon an individual’s past experiences and these important “gut instincts” must feel “good” for you to go with the “logical” choice. “Logic isn’t (usually) motivating, but emotion most definitely is. Emotion is powerful, but (usually) needs to include a trajectory that logic can supply.”³

There have been shown to be specific challenges in certain decisions associated with having a genetically-based medical condition. The BRCA1 and BRCA2 mutations for breast and ovarian cancer are also autosomal dominant genes. Researchers have found that in the case of BRCA, rates of genetic testing have been lower than expected – even among women with family histories that put them at high risk. All of the women participated in clinical studies which covered the cost of testing, removing the challenge of cost. One study showed that women who tested positive, when compared with those who tested negative, “reported significantly greater perceptions of stress surrounding making medical decisions and managing familial concerns one month following test result disclosure...It is possible that mutation carriers need additional support following test result disclosure to integrate this complex information into their risk management plans.”⁴ Just having the knowledge did not consistently result in increased use of cancer screening tests.

The decision to learn if you test positive for VHL, screening test decisions, surgical or other treatment decisions, and the decision to have children are all important decisions affected by both logic and emotion. Obtaining professional assistance from a genetic counselor and/or a psychological professional can help you work through the decision and feel confident that you made the best choice using the available facts and your personal preferences.

1. Davis, Sean; “Using Both Logic and Emotion to Fine Tune Your Decision Making Process;” *yousetthepace.com*; Jan 2, 2012
2. Camp, Jim; “Decisions are Emotional, not Logical: The Neuroscience behind Decision Making;” *bigthink.com*; Jun 11, 2012
3. Helmericks, Amy Jane; “Thinking vs. Feeling: Logic and Emotion in Decision Making;” *wynmag.com*; August 2013
4. Halbert, CH; “Decisions and outcomes of genetic testing for inherited breast cancer risk;” *Annals of Oncology* 15 (Supp. 1) i35-i39, 2004.

Would you like to know if diet has any effect on VHL?

SO WOULD WE!

We need you to help answer the question that we regularly hear from people wondering about the benefits of a special diet, usually vegan or vegetarian. **You can help us find the answer when you participate in the CGIP databank!**

By the way, with only 160 participants, we only have a combined 12% who report that they are following a vegan or vegetarian diet. Another 11% omit red meat from their diet.

We need a lot more participation to confirm if these percentages are true and to answer the more important question of whether diet has an effect on VHL!

Participate now in this important clinical trial that you can do from your own home!

www.vhl.org/databank

Picture Safari—New Date!

Have an adventure of a lifetime, raise awareness, meet new people, explore, take photos, all while raising awareness about VHL!

This 2-hour Picture Safari will have you exploring New York City like never before! Adventure through the streets while solving puzzles, clues, and riddles to get you to your next destination.

When the safari is over, relax at our Wrap-up Party where we will announce the safari and prize winners.

Date: September 6, 2014



- **Location:** West Village, NYC
- **Meeting Place:** Downtown Galway Hooker 133 7th Ave South, New York, NY 10014
- **Registration:** 1:00 pm/ **Safari:** 2:00-4:00 pm
- **End Location:** Downtown Galway Hooker
- **Wrap up Party:** 4:00-6:00 pm
- **Cost:** Registration \$40; Beer, well & wine \$4

Ticket Purchase and more information, go here:
www.cityhunt.org/vhl-alliance

11th INTERNATIONAL VHL SYMPOSIUM MADRID 2014

October 23rd / 25th

October 23–25, 2014

**JOIN US FOR
the International VHL Medical
Symposium 2014, Madrid**

**APPLICATION DEADLINE:
September 23, 2014**

The Biennial International VHL Medical Symposia, which brings together the leaders in VHL basic, translational, and clinical research, as well as the leading clinicians in clinical treatment for VHL. These professionals will spur the pace of progress in understanding and treating VHL.

<http://www.vhl.org/symposium2014>

HAPPENINGS AT VHLA

Mom's Day Run 2014



Total raised for VHL **\$3,445.50!**

See article: <http://www.vcstar.com/news/2014/may/11/ventura-run-raises-money-for-cancer-research/>

"THANK YOU SO MUCH! We couldn't raise this much money without your love and support.

We hope to grow the Mom's Day Run each year and provide the participants with a fun Mother's Day."

– Suellen xoxo

4th Annual Rick Bracey Tournament

Exceeded goal of \$100,000 in 4 years. **Total Raised: \$100,140!!**

The Rick Bracey 29er Tournament was once again a huge success. As suspected, the rain came down, but spirits were high and the smiles wide!!



The theme of the tournament **LIVE-LAUGH-LOVE** was everywhere!!

Thank you to the 29er Fine Nine Committee, all the volunteers, TA's and 50/50 girls who, were it not for all of you, this event would not be a success!!

We didn't know we were making memories we just knew were having fun!!

– Stephanie K

Lisa's Miles for Mom

"It was amazing running the Boston Marathon this year and even more amazing to fundraise for the VHL Alliance in memory of my mother. Thank you for all the work you do for all of us living with VHL. Keep up the great work!" **\$4,315** was raised! Thank you!

– Lisa B

Motorcycles/Cookout for VHL

It has been an extremely hard year for my family and me. Therefore, on May 17, 2014, my boyfriend and I held a motorcycle run out of Billerica, MA, to raise awareness for VHL. We had 25 motorcycles, followed by a cookout with family and friends. About 55 items were raffled off. We had an amazing turnout and raised **\$3,183!** I also created a Firstgiving account where we also raised **\$1,070:** www.firstgiving.com/fundraiser/razzinothrone.



Our families plan on making this an annual event after the wonderful turnout we had!! "

– Regards, Michaela R and Matthew T

Fundraising in the "Burg"

Did you know that Board Member Bobby Kramer and our Executive Director Ilene Sussman share the same hometown? Together, they returned to Harrisburg, PA, for a joint fundraiser hosted by a common family friend as well as Ilene's mother. The small tea-time get-together raised **\$3,400** and more is expected!



It is amazing what one can do in a couple of hours while having fun reconnecting with friends and family.

Georgia's Chapter Meeting at Panera



Anna W and Marie C organized Georgia's first chapter meeting on June 28th. Its founding members discussed

ways to support each other, and they shared experiences. It was a small friendly gathering to start. They are hoping to get bigger as time goes on. For more information, contact us-ga@vhl.org.

2014 CFC Campaign

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

The 2014 CFC Associated State Campaigns are underway. Your donation to the VHLA can be deducted directly from your paycheck. **You can fund VHLA under its DBA: Cancer Research and Assistance - VHL. Federal ID# 10934.**

United Way

Support VHLA 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 VHLA in this way!

2014 VHL Annual Family Meeting Topics in Rockville, MD, October 18th

- Gynecology and Reproductive Health Issues in VHL
- Management of VHL-Associated Kidney Cancer
- VHL-Associated Retinal Angioma: Features and Management
- As VHLers, What You Need to Know about Pheos
- Update on VHL-Funded Research
- The Emotional Roller Coaster (Separate Breakout Sessions for Patients and Caretakers)
- Targeted Therapeutics—Approaches in VHL Patients
- State of VHLA, 2014
- Management of VHL-Associated CNS Hemangioblastoma
- Imaging in VHL: What You Need to Know
- Impact of Affordable Health Care Act/GINA

TO REGISTER: vhl.org/meeting/meeting2014/

Welcome New Board Members



Dan Gahl has over 35 years of medical group management experience. He has a 20-year association with Cincinnati's first HMO and a 14+ year career as COO, CEO, Administrator at the University of Cincinnati Physicians, Inc. Dan received his BA with honors from the University of Dayton and his MA with honors from the University of Cincinnati.

He currently devotes most of his time assisting nonprofits in the areas of strategic planning and development. Dan lives in Cincinnati, Ohio. His daughter was recently diagnosed with VHL; this sparked a new passion to "do more" in support of VHL research.



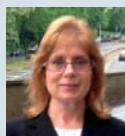
Eric Jonasch, MD, is Associate Professor in the Department of Genitourinary Medical Oncology at the MD Anderson Cancer Center of the University of Texas in Houston. Since 2003, Dr. Jonasch has been the Director of the VHL Clinical Center in Houston. He is also the Chair of VHLA's Research Council, Clinical Advisory Council, and Clinical Trials Task Force.

Dr. Jonasch has been and continues to be the principal investigator on numerous clinical trials hoping to find an effective treatment for VHL.



Bettina was born and raised in Italy and moved to the US to attend Boston University for her BA in Political Science/Mass Communication. Bettina now lives and works in NY City where she is a producer for photography and online video content.

Bettina does not have VHL, but she has a friend who does. It was through him that she learned about VHL. Helping this organization raise awareness and funding for future research and a cure is a way of helping a friend and other people impacted by VHL. It also means contributing to advances in research and a cure for other types of cancer, including breast cancer, which has affected her mother.



Andrea Rafael, a mathematician by training, works as Director of Investment Analytics & Risk Management at Yeshiva University Investment Office.

Andrea has a BS with Honors and an MA in Mathematics from Indiana University and recently completed her MS in Mathematics at New York University.

Andrea's family has a history of VHL. Her uncle passed away from VHL, and she has two cousins with VHL. As a member of the VHL Board of Directors, she is looking forward to helping with research for VHL.



Soniya Sapre lives in New York City. For the past several years she has helped build technology startups in the digital media and e-commerce industries. She attended the University of Pennsylvania and began her career working in finance and international development before heading to business school at Stanford.

Having experienced firsthand the challenges of dealing with VHL, she is passionate about using technology to connect with patients and families and about furthering the research agenda. Soniya also co-chairs the VHLA NYC chapter.



Karen Shields has ongoing experience with VHL. One of her sons was diagnosed with VHL and, since then, Karen has made sure her son completed his annual battery of tests and learned about the pheochromocytoma aspect of VHL. In 2013, she attended the VHL Annual Meeting in Ann Arbor, MI, and realized there was a lot of information she wanted to learn. Karen felt the desire to get involved.

She has approximately 20 additional family members with VHL. Through her work on the VHL Board, Karen is eager to help her son, family members, patients, and caregivers to ensure a brighter and healthier future.

To see all of the VHLA Board Members and to see more detailed bios, please go to <http://tinyurl.com/vhla-board>

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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VHL Alliance News, Newsletter of the VHL Alliance and the Cancer Research and Assistance – VHL

Volume 22, Number 3, July–September, 2014, ISSN 1066-4130
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Newsletter of the VHL Alliance
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REGISTER NOW!

See all three events and register on-line at <http://www.vhl.org/meeting/>

2014 VHL ANNUAL FAMILY MEETING

Saturday, October 18, 2014: Registration: 8:00 AM • Meeting: 8:45-4:30 PM • Rockville Hilton Hotel

vhl.org/meeting/meeting2014/

See topics on page 6

BENEFIT DINNER & AUCTION

October 18, 2014: 6:30-10:00 pm • Rockville Hilton Hotel, 1750 Rockville Pike, Rockville, MD 20852

vhl.org/meeting/dinner2014/

Honoring

W. Marston Linehan, MD

Chief of Urologic Surgery and the Urologic Oncology Branch, Center for Cancer Research, at the National Cancer Institute, National Institutes of Health, Bethesda, Maryland

Special Guest

Tom Rath

#1 New York Times Bestselling Author of *Eat, Move, Sleep*. Former Vice Chair of the VHL Alliance, and VHL patient



2014 TEAM VHL 5K RUN/WALK

Sunday, October 19, 2014: Check in: 8:00-9:00 AM • Run/Walk: 9:00 AM

Road Runner Sports, 1807 Rockville Pike, Rockville, MD 20852

vhl.org/team-vhl/