

## The CGIP Databank: Viewpoint from a User

By Deb Hogan, VHLA Board of Directors

Back in February, Suzanne Nylander, Director of Wellness for the VHLA, sent me a link to test and offer thoughtful feedback for the **Cancer in our Genes International Patient Databank** (CGIP Databank). I have to admit that I was busy, like so many of you are, and I didn't get a chance to respond. When Ilene Sussman asked if any of the board members would write an article on the databank, I knew I had to say yes. And I am glad that I did!

Let me first explain what a patient databank is. It is a place where medical information, family history, lifestyle, and other pertinent factors are collected and stored for medical research. The CGIP Databank collects information for VHL, HLRCC, BHD, SDH and other related diseases in hopes of finding a cure. The survey participant's data is initially collected then updated at least annually due to the fact that the research is longitudinal, following the progression of disease over time. Agreeing to participate authorizes the use of "de-identified" information (does not show name, address, or other identifying information) contributed in scientific studies.

So, I followed the link to the portal and entered my name, email and selected a password. There

was an extensive section on Informed Consent where I had to agree to Terms and Conditions. I was then asked about Contact Preferences. Did I want to be contacted regarding participation in clinical trials or would I agree to be a tissue donor? Next I was asked to add myself or someone else as a survey participant, including my preferred method of contact—phone, email or address. Data encryption is used to protect the privacy of the participant and information is shared only with the VHL Alliance. I also learned that to further ensure the protection of the patient's rights and welfare, an independent ethics committee, Chesapeake IRB, has approved the CGIP data collection.

I was then given the opportunity to select a survey such as "Genetics" or "Nutrition and Exercise". Imagine researchers using our information to answer questions such as, "Why do siblings, with the same genetic alterations, present with different symptoms?" or "What effects do diet and nutrition have on tumor growth?" I enjoyed answering the questions in each survey and I found it very user friendly. Questions regarding the databank can be sent via email to [databank@vhl.org](mailto:databank@vhl.org) or via phone at 800-767-4845 x4. So pour yourself some coffee or tea and enroll in the CGIP databank to find a cure!



**REGISTER HERE: <https://databank.vhl.org/>**

## A Participant's Perspective on the CGIP Databank

By Jule Fobert, VHLA Board of Directors

It wasn't until VHL patients shared symptoms and diagnosis of endolymphatic sac tumors (ELSTs) with the VHL Alliance that doctors learned that the inner ear was also a site of VHL tumors. It was through your input that VHLA informed doctors rather than the doctors informing us. Now, ELSTs are included in the recommended VHL screening guidelines.

VHLA works with researchers, doctors and VHL patients and caregivers to gather, share, and research information in a collective effort to find a cure for VHL. As we work towards the cure, we are looking for ways to better manage testing, lifestyle choices, and the disease itself. None of the work we do can be done without your sharing information about you and your family's experiences.

VHLA has built a worldwide databank to house all of the information about your VHL experience, which includes sharing your genetic testing, scans and other information such as your diet and oral care. Your

information will help researchers, doctors and other VHL patients and their families around the world learn more about VHL and make it easier to answer many of the questions we currently have.

We know a lot about VHL because you share with us your struggles (and triumphs) with VHL. But there is still more we need to understand and only you can help.

Lend your voice to help find the cure. Sign up today for the CGIP (Cancer in Our Genes International Patient) Databank at <https://databank.vhl.org/>. **We need you!**

### Inside this issue!

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# VHL Manifestation in the Eyes

*By Emily Chew, MD, Deputy Director, Division of Epidemiology and Clinical Applications; Deputy Clinical Director, National Eye Institute (NEI), National Institutes of Health (NIH)*

VHL has fascinated ophthalmologists for years; in fact, VHL was first described in 1927 by Von Hippel, an ophthalmologist. He described VHL as an eye disease and Lindau, a pathologist, connected the eye lesions with lesions seen in the central nervous system. VHL is an autosomal dominant disease with high penetrance. This means that people who are genetically positive for VHL almost always exhibit lesions in at least one organ and the disease is passed from one generation to the next.

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***We really see with our brains, which serve as the computers to our eyes.***

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VHL manifests in the eyes as non-malignant tumors (noncancerous). The problems occur when the tumors grow and displace normal tissue. This is more problematic on the optic nerve head as this is what connects the eye to the brain. The eyes send signals or input to the brain and the brain processes these signals into vision. In other words, we really see with our brains, which serve as the computers to our eyes. Approximately 30% of the brain is devoted to vision; therefore brain tumors can result in blindness with no tumors present in the eyes or hemangioblastomas in the retina (the retina is lining inside the eyeball that has the vision receptor cells); it is because it is really the brain that cannot “see.”

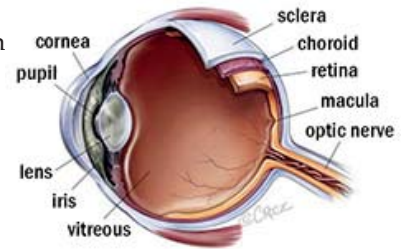
It is important to note that most people with VHL have good vision. We looked at the records for 400 patients at NIH and found that approximately 80% have 20/20 vision in at least one eye. The other 20% have moderately impaired vision in their better eye (15%), impaired vision in their better eye (5%); only 5% are legally blind.

Most VHL tumors in the retina are located peripherally, outside of the macula, which is the center of detailed vision (the reason we turn our eyes to look directly at something we want to see clearly). Only about 15% of lesions are on or near the optic nerve. The other

good news is that tumors in the eye tend to grow slowly, especially in adults. Children and young adults may have more active lesions that grow quickly and are more difficult to control.

The goal of treatment for VHL lesions in the eyes is to destroy the tumors. Even peripheral lesions generate growth factors that can affect central

vision. This is common in VHL. Treatment of peripheral lesions is usually done using laser or cryotherapy (a freezing technique). Anti-VEGF (Vascular Endothelial Growth Factor) treatment, by itself, has had no real



*Credit: bionicvision.org.au/*

effect on VHL eye tumors since it only attacks one arm of the disease. Therefore, we need to look at other aspects of VHL tumor growth to find multiple approaches to attack in this disease.

Peripheral lesions are relatively easy to treat, assuming that they are not too large, but therapy for tumors located on or near the optic nerve is fraught with difficulty as the treatment can damage vision. The end stage for untreated tumors in the eye is retinal detachment (pulling the vision receptor cells away from their blood supply), followed by blood vessel growth in the iris (the colored part of the eye), leading to angle closure glaucoma (high pressure of the fluid in the eye) which can then cause enough damage and pain to require removal (enucleation) of the now blind eye.

Sunitinib, or Sutent, a drug approved for kidney cancer, acts on tumors in two different ways. In studies where VHL patients have taken Sunitinib for another reason, they have shown no eye tumor growth. We therefore evaluated oral Sunitinib for optic nerve tumors. Our study was difficult to complete because finding patients who would be eligible proved challenging. We are planning a study in which Sunitinib is directly injected into the eye. We hope to launch that trial soon.

**In conclusion, if you have VHL, you should have an annual eye examination by a retinal specialist and treat tumors while they are small and peripheral.**

Eye examinations are usually more urgent for younger patients to detect early disease that might be more responsive to treatment and result in a better outcome. VHL does not affect the front of the eye (the cornea) and most tumors are not an emergency. Only tumors near the macula and retinal detachments that cause painful glaucoma require prompt care.

**DON'T FORGET TO REGISTER, INCLUDING ALL OF YOUR CURRENT AND PAST RELATIVES WITH VHL, FOR THE CGIP DATABANK**

**<https://databank.vhl.org/>**

# The Benefits of Relaxation

*Jill Buchanan, Director of Marketing at the Benson-Henry Institute for Mind Body Medicine at Mass General Hospital*

While medical practitioners increasingly recognize the role of stress in illness, they have been more skeptical about the role of relaxation to reduce stress-related illness. For years, that was because there has been a relative shortage of scientific research demonstrating the benefit of relaxation to health.

But today, a growing body of clinical and genetic research demonstrates that the simple act of changing ones thought patterns through meditation can decrease metabolism, heart rate, and blood pressure, and ultimately can decrease the severity and extent of illness and build long-term resiliency or ability to cope.

Places like the Benson-Henry Institute for Mind Body Medicine at Massachusetts General Hospital have been at the forefront of studying and teaching resiliency for over 40 years. The Relaxation Response, a physical state of deep rest that changes the physical and emotional response to stress, is central to their approach. While any number of techniques can be used to evoke this response—meditation, prayer, yoga, tai chi and physical activity, to name a few—there are two essential aspects of these practices that are common throughout. These are the repetition of a sound, word, phrase, prayer, or movement, and the passive setting aside of intruding thoughts.

There are relaxation techniques for people of every age and in every state of physical and emotional health. CDs can be purchased to help in your pursuit to reduce stress and increase your ability to face of life's physical and emotional challenges.

Fortunately, not all relaxation methods require hours or a defined environment. There is always the "Mini" which you can do anywhere, anytime and no one will know that you are doing them. Mini-relaxation exercises help reduce anxiety and tension immediately. You can do them with your eyes open or closed (open when driving, of course!)

Some good times to "do a mini" are when you are:

- Stuck in traffic
- Put on hold on the phone
- In your doctor's waiting room
- Upset by something someone has said to you
- Waiting for a phone call
- Sitting in the dentist's chair
- Feeling overwhelmed by what you need to accomplish in the near future
- Standing in line
- In pain

"Minis" are most beneficial for people who utilize relaxation techniques, or elicit the relaxation response, on a regular basis. Minis quickly recall this relaxation state, but they can help anyone feel refreshed, calmer and better able to concentrate.

The basic method for doing a mini is quite simple:

Put your hand just below your navel. Take a deep breath, bringing the air in through your nose and out through your mouth. You should feel your stomach rising about an inch as you breathe in, and falling about an inch as you breathe out. This is diaphragmatic breathing.

Here are some variations:

## • Mini Version 1

Count very slowly to yourself from 10 down to zero, one number for each breath. With the first diaphragmatic breath, you say "10" to yourself, with the next breath; you say "nine", etc. If you start feeling light-headed or dizzy, slow down the counting.

## • Mini Version 2

As you inhale, count very slowly up to four; as you exhale, count slowly back down to one. Thus, as you inhale, you say to yourself "one, two, three, four," as you exhale, you say to yourself "four, three, two, one." Do this several times.

## • Mini Version 3

After each inhalation, pause for a few seconds; after you exhale, pause again for a few seconds. Do this for several breaths.

## New VHLA Mentor Program

VHLA is setting up a new program to match those of you who would like to be a mentor or a mentee. Those interested in serving as mentors will be trained through a collaboration with the 4th Angel program giving you specific skills to better answer questions and be there for another member with VHL through part of the VHL journey.

Let us know if you would like to be a mentee or a mentor. A teen who attended a recent in-person New England Chapter meeting found it valuable to see adults with VHL who were married and leading successful, happy lives. If you are new to VHL or have just been diagnosed with a new manifestation, a mentor familiar with this experience can be a great guide.

Please contact [wellness@vhl.org](mailto:wellness@vhl.org) with your interest in being a mentor or mentee.

## Three New Clinical Care Centers

The VHL Alliance is committed to finding quality, coordinated care for VHL patients wherever there is the need.

• **Alabama** — The University of Alabama at Birmingham, sponsored by Dr. Bruce Korf of the Dept. of Genetics. Contact Vickie Garmon at (205) 934-5567 or [vgarmon@uab.edu](mailto:vgarmon@uab.edu).

• **Arizona** — Mayo Clinic, Scottsdale, AZ, sponsored by Dr. Donald Northfelt of Hematology/Oncology. Please contact Katherine S. Hunt, MS, CGC at (480) 301-4585 or at [hunt.katherine@mayo.edu](mailto:hunt.katherine@mayo.edu).

• **Virginia** — University of Virginia in Charlottesville, VA, sponsored by Dr. Ashok Asthagiri, Associate Professor of Neurosurgery and prominent neurosurgeon. Contact Nancy Staton, RN, or Vicki Aylor at (434) 243-2757 or [vhl\\_surgery@virginia.edu](mailto:vhl_surgery@virginia.edu)



## Cancer in our Genes International Patient (CGIP) Databank

**Add your knowledge and experience to find a cure! Both US and international participants are asked to be part of this important clinical research study. Additional information and a link to participate are online at [databank.vhl.org](http://databank.vhl.org).**

### Why is it important to participate?

The CGIP Databank has been developed with input from NORD and the FDA to provide:

- An international “natural history” of VHL and related diseases. This provides clinical researchers around the world with the comparison tool needed to prove the efficacy of new medications.
- Lifestyle and nutrition information for analysis against tumor growth and location. We hope this will allow us to finally answer some questions on food and exercise.
- Researcher access to potential research subjects. Researchers will not be able to contact you; the VHLA will notify you, then you may respond if you are interested.
- Your privacy is our priority, so only the VHLA can grant access to data.

*The goal of the CGIP Databank is to shorten the time needed to find a cure!*

### Using the databank

It's simple and can be done over as many sessions as you need; you don't need to complete all of the questionnaires in one sitting.

- Go to the button at [databank.vhl.org](http://databank.vhl.org).
- This will take you to a “Portal” where you will register as a “User,” then as a “Participant.”
- Then you can go to any of the questionnaires (except for a few that require completion of a previous questionnaire).
- At the end (or part-way through) a questionnaire, you have the option to “Save.”
- When you have completed a questionnaire, click “Submit” to send it to the databank
- If you do not use a computer, the person using the computer and entering information will register as a “User.”
- Then, they will register you as a “Participant.” (One user can have multiple participants, for example, their children, grandparent, etc.)

Information can be updated at any time by completing the relevant questionnaire(s). These will be saved and submitted in addition to the original version.

## Mosaicism and VHL

An individual with mosaicism has two genetically different populations of cells. This can occur during the process by which two DNA molecules exchange genetic information during mitosis. Mitosis is the process of cell division which takes place when an embryo is developing. Mitosis normally results in two identical cells. Depending on which stage of embryo development unequal genetic exchange happens, mosaicism can occur in only one organ or in multiple organs.



An example of mosaicism that you may have seen is heterochromia where the iris of one eye is a different color from the iris of the other eye. This may also be seen within the iris of one (or both) eyes, making them part blue and part brown. Genetic heterochromia in animals is usually associated with white markings or distinctive coat colors (such as blue merle Australian Shepherd dogs).

Mosaicism is also present in some patients with VHL. The VHL-positive cells may be restricted to a single organ such as the kidneys and thus not picked up during genetic testing of the blood or cheek swab. These patients are generally diagnosed when a lesion is removed and tests positive for VHL. Others may be diagnosed when a child is positive for VHL and the parent has testing performed that shows one organ with lesions that appear related to VHL, or VHL mutations are found in the egg or sperm cells.

Researchers in France have just identified a more efficient genetic test to find VHL mosaicism. Next Generation Sequencing (NGS) was able to detect the VHL mutation in 8 patients who tested negative for VHL using standard methods (Sanger sequencing and deletion search). The researchers emphasized that VHL mosaics are not restricted to mild symptoms of VHL. One patient had severe symptoms of VHL with early onset. The researchers state that VHL mosaicism is underdiagnosed, leading to fewer people being diagnosed by DNA testing.\*

A person with VHL mosaicism will not pass along VHL to his or her children unless the VHL gene is present in the egg or sperm cells. A mosaic “germline” mutation affects only the egg or sperm cells; a “somatic” mutation affects cells in the body other than egg or sperm cells. It is possible to have both germline and somatic mosaicism if the mutation took place early in development of an embryo. A mosaic mutation can even cause identical twins to be different, with one twin having a condition which the other twin does not have.

A germline-only mutation (those only in the egg or sperm cells), whether male or female, does not result in the disease symptoms for the carrier. In these cases, VHL is generally only diagnosed when the child tests positive. Once a child is shown to have VHL, clinicians usually will follow up with the parents to see if they are the VHL carrier. Since the mutation can only be found in the egg

*Continued on next page*

or sperm cells, the parents will test negative on standard DNA blood tests.

If the mutation is a true germline mutation, the chances of passing VHL along to future children is difficult to predict since it depends upon the proportion of eggs or sperm cells that carry the altered gene. Researchers have estimated anywhere from 1% up to 30%.\*\* No matter how the child inherits the mutation from the parent, the child will show the altered gene in all body cells—the child will not be a mosaic.

Somatic mutations (affecting cells other than eggs or sperm) affect the person in a way that symptoms may only appear in one organ, instead of a more typical presentation. For example, a person with a somatic mosaic mutation for VHL may only exhibit lesions in the ear. This means that only the ELST lesion will have cells with the VHL mutation; a standard blood test will be negative. A somatic-only mutation cannot be passed along to any children.

\*Coppin, et al, "VHL mosaicism can be detected by clinical next-generation sequencing and is not restricted to patients with mild phenotype," *Eur J Hum Genet*, Dec 4, 2013

\*\*hihg.miami.edu; Lesson 3: "Non-Mendelian Inheritance"

## Emily B on The Voice

Emily B performed on NBC's "The Voice". She got as far as The Battles. Emily has VHL and has had 2 brain tumors removed. She is a true VHL warrior!



EmilyBMusic @EmilyBeMusic

Holding back tears as I read the stories of so many #vhlwarriors- Honored to be an inspiration @VHLFA #nbcthevoice #TeamShakira #teamemilyB — from Twitter



## VHL Scavenger Hunt in NYC to Raise Awareness

Have an adventure of a lifetime, raise awareness, meet new people, explore, take photos, all while raising money for a great cause—VHL!

This 2 hour scavenger hunt 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 scavenger hunt fun is over relax at our Wrap-up Party; where we will announce the scavenger hunt and prize winners.

**Date: June, 28th 2014**

- **Location:** Union Square, NYC
- **Meeting Place:** TBD
- **Registration Time:** 1:00-1:45 pm
- **Hunt Time:** 2:00-4:00 pm
- **Hunting Grounds:** Union Square
- **End Location:** TBD
- **Wrap up Party:** 4:00-5:30 pm
- **Price:** \$40



Ticket Purchase and more information, go here: <http://www.vhl.org/wordpress/?p=9980>

**WE HOPE YOU JOIN US!**

## May is VHL Awareness Month!

### WHAT CAN YOU DO?

Talk to your local news, talk to family and friends, host a fundraiser, sign up for the CGIP Databank!

## HAPPENINGS AT VHLA

### Mom's Day Run 2014



Suellen is planning the 4th Annual Mom's Day Run on Sunday, May 11th, 2014 to support VHLA. You can run or walk or skip or stroll along the beach with your mom to celebrate the day. Breakfast burritos will be provided to all of the participants along with other goodies at the finish line.

The event will take place at 8 am at San Buena Ventura State Beach, 901 San Pedro St, **Ventura, CA.**

See the event Facebook Page for more details!

<https://www.facebook.com/MomsDayRun> or to register, see: [www.tinyurl.com/MomsDayRun-Registration14](http://www.tinyurl.com/MomsDayRun-Registration14)

### 4th Annual Rick Bracey Tournament

**LIVE-LAUGH-LOVE.** Year 4's Inspiration for the Rick Bracey "LIFE IS GOOD NO REGRETS" FUNdraiser.



Rick Bracey died four years ago after a long and courageous battle with VHL. The 29er (Rick's number) Softball Tournament was founded in his honor to create awareness and to raise funds for families battling VHL.

On Saturday, June 14, 2014, Softball City in **Surrey, BC** will host the 4th Annual Rick Bracey 29-er Softball Tournament, presented by Scotia Bank.

If you would like to donate or participate in this event, please email [29ertournament@gmail.com](mailto:29ertournament@gmail.com) or donate directly to VHL in the name of Rick Bracey by visiting: <http://www.canadahelps.org/gp/32611>.



### Appalachian Trail—2185 Mile Hike

Our youngest son Bobby was diagnosed with VHL as a teenager. It is our fervent hope that researchers will find a cure in his lifetime. We are hiking from Georgia to Maine and are asking 10 cents a mile. See FirstGiving page: [bit.ly/1qYpys4](http://bit.ly/1qYpys4) — Mike & Jacque de Sosa

### NYC Fundraising Dinner

On January 30, 2014, Manuel Greco hosted a New York City Fundraiser to benefit VHLA at Il Gattopardo Restaurant. It was a huge success. We raised \$135,000!

### Lisa's Miles for Mom

Lisa B ran the Boston Marathon in memory of her mom, Kathy Neimann. She raised over than \$4,000 for VHLA!

### Lisa H's Fundraiser—Tallahassee, FL

Lisa H's husband pedaled 100 miles for VHLA. Almost \$1,000 was raised!



## EVENTS OF OCTOBER 18-19, 2014 • ROCKVILLE, MD

### 2014 VHL Annual Family Meeting

October 18, 2014: Registration: 8:00 AM • Meeting: 8:45-4:300 PM • Rockville Hilton Hotel

See: [vhl.org/meeting/meeting2014/](http://vhl.org/meeting/meeting2014/)

#### AGENDA

- **Introduction and Welcome:** W. Marston Linehan, MD: Urologic Oncology Branch; Branch Chief; Center for Cancer Research; National Cancer Institute; Bethesda, MD; Ilene Sussman: Executive Director, VHL Alliance; Boston, MA
- **Imaging and VHL: What You Need to Know:** Peter Choyke, MD, FACR: Senior Investigator Molecular Imaging Program; National Cancer Institute; Bethesda, MD
- **Management of VHL-Associated Kidney Cancer:** Adam R. Metwalli, MD: Senior Staff Clinician; Urologic Oncology Branch; National Cancer Institute; Bethesda, MD
- **VHL-Associated Retinal Angioma: Features and Management:** Wai T. Wong, MD, PhD: Staff Clinician; National Eye Institute; NIH; Bethesda, MD
- **Management of VHL-Associated Pancreas Tumors:** Panel Discussion: Electron Kebebew, MD: Chief; Endocrine Surgery Branch; National Cancer Institute; Bethesda, MD. Steven K. Libbuti, MD: Director of Montefiore-Einstein Center for Cancer Care Montefiore Medical Center; New York, NY
- **The Emotional Roller Coaster: Separate Break-out Sessions:**  
**Caretaker Group:** Quinn Cassidy, MSW: NIH; Bethesda, MD  
**Patient Group:** Emily Hershenson, MSW: NIH; Bethesda, MD
- **Targeted Therapeutics—Approaches in VHL Patients:** Ramprasad Srinivasan, MD, PhD: Staff Clinician; Urologic Oncology Branch, National Cancer Institute; Bethesda, MD
- **State of VHLA, 2014:** Karen Ramsey: VHLA Board of Directors, Phoenix, AZ
- **Management of VHL-Associated CNS Hemangioblastoma:** Kareem Zaghloul, MD, PhD: Staff Clinician; Surgical Neurology Branch; National Institutes of Neurological Disorders and Stroke; NIH; Bethesda, MD
- **Pregnancy and Gynecologic Concerns:** Pamela Stratton, MD: Chief, Gynecology Consult Service Pediatric and Reproductive Endocrinology Branch; National Institute of Child Health and Human Development; NIH; Bethesda, MD
- **Impact of Affordable Health Care Act/GINA:** Diane Dorman: Vice President of Public Policy; National Organization for Rare Disorders (NORD), Washington, DC

### Benefit Dinner & Auction

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

*Honoring*

See: [vhl.org/meeting/dinner2014/](http://vhl.org/meeting/dinner2014/)



#### 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

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

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

See: [vhl.org/team-vhl/](http://vhl.org/team-vhl/)

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!

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

or mail in Registration Form below to:

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

### MAIL-IN REGISTRATION FORM

# People	Family Meeting only	Dinner only	Both (Combination)	5K Walk/Run Registration	Totals
	<input type="checkbox"/> \$90.00 Before 9-18-14	<input type="checkbox"/> \$125.00	<input type="checkbox"/> \$192.50 Before 9-18-14 (with discount)		\$ _____
	<input type="checkbox"/> \$100.00 After 9-18-14	<input type="checkbox"/> \$125.00	<input type="checkbox"/> \$200.00 After 9-18-14 (with discount)		\$ _____
				<input type="checkbox"/> \$25.00	\$ _____
DONATION <input type="checkbox"/> \$ _____					\$ _____
SPONSOR A RUNNER <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 <a href="mailto:director@vhl.org">director@vhl.org</a>					\$ _____
Total Enclosed					\$ _____



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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E-mail: *info@vhl.org*; Tel: 1-617-277-5667; Fax: 1-858-712-8712  
Toll-free in the United States and Canada: 1-800-767-4VHL

Editor: Ilene Sussman, 1-617-277-5667, extension 4  
Internet website: <http://www.vhl.org>  
2001 Beacon Street, Boston, MA 02135-7787 USA

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ALL EVENTS OPEN FOR REGISTRATION



**October 23–25, 2014**

**International VHL Medical  
Symposium 2014, Madrid**

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

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**Saturday, October 18, 2014**

**2014 VHLA Annual Meeting, Rockville, MD**

[vhl.org/meeting/annual-meeting-2014](http://vhl.org/meeting/annual-meeting-2014)

**3rd Annual Fundraising Dinner & Auction**

*honoring W. Marston Linehan*

*Special Guest: Tom Rath*

[www.vhl.org/meeting/dinner2014](http://www.vhl.org/meeting/dinner2014)

**Sunday, October 19, 2014**

**Team VHL 5K Run/Walk**

*Road Runner Sports, Rockville, MD*

[www.vhl.org/team-vhl](http://www.vhl.org/team-vhl)

See website for more details or call the office at 1-800-767-4845 ext. 4