

If the Hat Fits... Wear it Proudly!

By Robert Kramer, Board of Directors Vice Chair and Chair of Enhance Programs Committee



Robert Kramer,
DMD

Each of us wears many hats as our lives unfold. The hats change from time to time. Some we keep for later use. Others are used for a short time and discarded. Some we want to keep. Some we can't wait to get rid of! Some hats are placed on our heads through the actions or circumstances of others. Some we seek out or wish for. Think about those you have worn over your

busy life: child, parent, employee, boss, teacher, friend, mentor, spouse, patient, caregiver, etc. Some of these hats bring us great joy in life. Others drain our energy or take up much of our time. Hats can be worn proudly or feel like a heavy burden on our souls. Why were we chosen to wear some of our hats? We may never know. Each of us can make a hat represent an opportunity for learning and growing. And so it goes with one of my favorite hats...the VOLUNTEER HAT! This hat is a giving hat. You give of yourself to others, not necessarily expecting anything in return, but are often rewarded with great returns. Sharing your special talents, however great or small, can have significant impact!

Our organization runs on volunteer energy. We need each of you to put this hat on your head! Each of you possesses some special quality or talent that, when used in combination with others, can springboard our efforts to the next level. Do you love to connect with others? Have a penchant for writing? Love to chat on Facebook? Like to be connected to others on LinkedIn? Like to plan events or make phone calls? We need you. Our loved ones need you! Together we can make a difference. Together we can end this rare disease (and maybe others while we're at it!) Want to be a part of our cause? Each of you is welcome. We can find a you a role if you desire. Whether it is a small role or a big one does not matter as each is significant. **Hotline volunteer. Regional Chapter Leaders. Local fundraiser organizer. Participant in an online chat. They ALL matter.**

If you would like to wear a VHLFA volunteer hat, please contact the office (office@vhl.org or 800-737-4845 x4)! *We welcome you!*

Join the VHLFA LinkedIn Group

Search for VHL Family Alliance

Hemangioblastomas and Pregnancy

by Joyce Graff, Director of Wellness

Reporting two new papers by Thera Links, M.D., University of Groningen, the Netherlands, and by Russell R. Lonser, MD, Ohio State University.

There have been many case reports that seemed to indicate that hemangioblastomas (hB) of the retina, brain and spinal cord are somehow promoted during pregnancy. Based on these concerns, some physicians have recommended operating earlier or avoiding pregnancy altogether. Two recent studies attempted to understand what influence, if any, a pregnancy might have on the course of VHL disease in women with VHL.

The two studies approached the problem in two very different ways. Dr. Thera Links and her graduate students performed a "retrospective study" examining the electronic health records for 29 women with VHL and their 48 pregnancies. If necessary, additional information was obtained from the physicians or from the patients. (A retrospective study proposes a scientific question, and then "looks back" at existing data.) Note that 40% of these births occurred before 1990, when much less was known about VHL and presymptomatic scanning was less available.

In eight out of the 48 pregnancies, complications were observed. Two women had pheochromocytomas (pheos), and one baby died as a result of a phео. Pheos are a known high-risk factor during pregnancy (see Lenders article, *VHLFF* September 2012). If the data of the two phео patients are removed from the data set then complications were only seen in 6 of the 48 pregnancies or about 12.5%. If hormones were causing more rapid tumor growth, a rate of complications greater than 12.5% would be expected.

Dr. Russell Lonser, formerly at the US National Institutes of Health, was part of a 12-year "prospective" study of a large number of people with VHL, both men and women. (A "prospective study" proposes a scientific

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Hemangioblastomas and Pregnancy

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question, decides what information is needed to answer the question, and collects data moving forward to collect the information necessary for the study.) Of the women of reproductive age (age 16 to 35 at the beginning of the study) there were 36 women with 177 hemangioblastomas, followed for an average of eight years. Nine of these women (25%) became pregnant during the course of the study.

This study did not look at retinal lesions, but it did evaluate hemangioblastomas of the central nervous system, including brain and spinal cord. The influence of pregnancy on growth of renal and pancreatic tumors is not well known at this time.

It is important to continue watchfulness for CNS concerns during pregnancy.

Dr. Lonser found no difference between the rate of development of new tumors and cysts in these pregnant women than in the same women when they were not pregnant. Similarly, the rate of tumor growth among the pregnant women did not differ significantly from the women in the larger study who did not become pregnant.

In addition, the rate of development of peritumoral cysts was not different between the pregnant patients and those who were not pregnant, indicating that pregnancy does not appear to have an effect on the development of new peritumoral cysts. However, the Lonser study observed that women who had become pregnant experienced higher growth of cysts post-pregnancy.

Peritumoral cysts (cysts that grow around a tumor) are caused by increased leakage of the tumor vessels into the immediately surrounding tissues. This fluid first appears as edema, or swelling, of the surrounding tissues as they become engorged with fluid, much as a sponge swells when it is full of water. After the tissues are fully engorged, a cyst forms. Cysts often grow much faster than the hemangioblastoma itself and, thus they are often the cause of symptoms. The rate of development of cysts was not different between the pregnant patients and those who were not pregnant, indicating that pregnancy does not appear to have an effect on the development of new peritumoral cysts.

The Links study suggests that VHL causes an increase in hemangioblastoma progression; the Lonser study concludes that pregnancy is not associated with increased hemangioblastoma or associated cyst development or progression in VHL patients. Both agree that new hemangioblastomas continue to develop throughout all pregnancies at a variable and unpredictable rate. While the tumor rate is not increased, it is also not decreased during pregnancy. At the same time, the pregnancy hampers regular screening; symptoms may be more difficult to identify. For example, is the nausea and vomiting due to the pregnancy or to CNS tumor activity?

There remain special concerns for women with VHL in pregnancy. It is important to continue watchfulness for CNS concerns during pregnancy. While CT's are not possible due to radiation concerns for the fetus, MRI's are possible. If a pregnant woman has worrisome symptoms, an MRI without contrast can help investigate the cause. Serial clinical and imaging follow-up at 1-2 year intervals

or upon symptom development is recommended for all VHL patients.

There are three key questions that women with VHL want answer to:

1. Do the hormones of pregnancy spur tumor growth? or were those tumors ready to grow anyway, with or without the pregnancy? The Lonser study, while small, provides well-controlled data that hormones do not contribute to these problems.
2. If hormones are a factor, do birth control pills spur tumor growth? Specifically what hormones are to be avoided? There are many different kinds of birth control pills and devices with differing hormone levels. Which one(s) are safest?
3. In this age of in-vitro fertilization and pre-implantation genetic diagnosis, hormone shots are necessary to mature sufficient eggs to be harvested for the IVF process. Will this surge of hormones cause her tumors to grow?

Neither of these studies provides adequate answers to questions two and three. The French have also been retrospectively examining their data looking for answers. All three study groups as well as the VHL Family Alliance agree that wider additional study is needed. We hope that this will be facilitated through collaboration among major groups of patients worldwide, and through data collected in the global Patient Registry going into beta test this spring. The more information we can gather from all women, worldwide, the more we will learn about these important questions.

References:

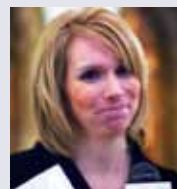
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Frantzen C et al., Letter to the Editor, *J. Neurosurg*, 2013 March, calling for a larger global study.

Rare Disease Day 2013 at the MA State House



Julie F.,
Massachusetts

The Most Important Medicine I Take Every Day is Hope

Julie F. told her story at the State House in Boston, Massachusetts, on February 28, 2013 at the Rare Disease Day Ceremony. The audience was spellbound as she talked about her life with VHL. It was beautiful and emotional. You can see it on our YouTube channel: <http://bit.ly/YXPm99>

Joyce Graff Reinventing Herself Again



I have announced my intention to retire from VHL Family Alliance at the end of 2013.

As you know, much of my life has revolved around VHL for a very long time. First from 1962 until 1977 when my husband died, and then again since 1986 when my son was diagnosed with VHL. My goal throughout has been to maintain my son's health and his quality of life, learning from history and from others with VHL, and applying those lessons as best I can. Now that Ilene Sussman is the Executive Director, and has been doing all the necessary work of running the organization for nearly two years, I have had more time to focus on patient support and quality of life issues. I am leading the effort on the soon to be launched Patient Registry, collecting patients' experiences with VHL and two other genetic cancer syndromes, working to assemble that data in a consistent manner so that we can learn as much as possible about how these genetic pathways work, and what happens when they don't work quite right.

I often look back at what we knew in 1993 and what we know today, and wonder at how far we have come. We have learned more in the last 20 years than we ever imagined we *could* learn! In this age of DNA research, we know that we will learn dimensions more in the next 10 or 20 years! At the November dinner I shared my vision for the future with VHL – much like aspirin therapy – take one pill a day and you'll never get another tumor! But just as we said in 1993, while we work toward a cure, we have to be mindful that today there are still lots of people dealing with a lot of tumors. We have to work together to help people understand what's going on, know when to go for medical help, know how to find things early when they are most likely to be successfully treated, and find the best treatment for their situation.

Throughout these last two decades I have been sharing the strategies I have learned from VHL – and learning more myself – by interacting with folks with many other conditions. To do that I began a weekly radio broadcast in 2007, the *Powerful Patient*, as a means of spreading awareness of VHL and the broad benefits of VHL research to the general population. This year I have spun it out as my personal project, and have recruited my friend Mike Lawing from North Carolina as co-host to the show. Mike and I have been reporters for the Kidney Cancer Symposia the last several years. See our 2012 report and follow us at powerfulpatient.org.

So as I reassess the new balance in my life, I am shifting my focus toward other pursuits.

First on my agenda, of course, is spending time with my dear son and his wonderful wife and two boys, and our three dogs and a cat. I want to enjoy every one of their many plays, math contests, joys and achievements. They are great guys, with very wonderful parents.

I made a quilt for the Silent Auction that sold for \$3000, and I have taken on a couple of commissions this year which have been fun and rewarding. Quilting is my artistic outlet and a craft that relaxes me and helps me manage the stresses in my life.

Writing is probably my favorite endeavor. I have been writing and publishing since I was six when I wrote my first children's book. My master's thesis (in French) was on Molière's quite negative attitude toward the doctors of his day, as he had seen more than one friend bled to death by well-meaning doctors. I have helped to create the VHL and HLRCC Handbooks, and have three articles in medical journals. I have been the editor of the *VHL Family Forum* for the past 20 years. I enjoy taking scientific articles and reporting them in patient-accessible language. Powerful Patient will see more blogging from me once I retire.

This year, with my brother Jim Wilcox, I completed a labor of love: the publication of *A Life in Art*, a biography of our grandfather, Harry Wilcox Sr., a commercial artist in the Depression and World War II. (Available from Amazon, etc.) It is a catalog of his work, and includes some of our father's own art – wonderful scientific drawings and a series of ships in pen and ink – and lots of family history and genealogy thanks to Jim.

I am deeply moved by the outpouring of support I was privileged to receive from all of you in November. It has been my honor and joy to work with this wonderful, strong community of survivors for more than 20 years. Now it is time for me to reinvent myself again, and spend time with my own family, and especially with my mother, now 96 years old, who is my role model.

The VHL Family Alliance Dinner was not only a way to honor me and Dr. Kaelin and to make money to support the important continuing work of the VHL Family Alliance, it was also a way for me and my family to acknowledge the powerful contributions to our lives of my late husband, Frank Graff, and of my father, Harry Wilcox Jr. Both of them were very dear to all of us. They taught us many lessons – love and care, patience and understanding, strength in adversity, curiosity and research, willingness to tackle new things, perseverance and loving care to the end, the value of life and love.

Please come visit me from time to time at the Powerful Patient, and share your own story there. Love and strength to you all.

Joyce will be immensely missed.

While no one can replace Joyce's vast knowledge, we are thrilled that she has graciously agreed to help train a suitable replacement before her Dec. 31st departure. If you are interested in learning more or applying to be our new Director of Wellness, please email or call me: director@vhl.org; 617-277-5667 x4. Ilene

ASK THE EXPERTS:**Green Tea and Drug Interactions**

Question: I read in a magazine that green tea can interact badly with some medications, especially the drugs used for cancer. I thought green tea was good for you! If I were in a clinical trial for Sutent or pazopanib or another of the new drugs, are there foods or herbal remedies that I should be wary of? What should I discuss with my oncologist?

Response: There is no strong data on the interaction of green tea with sunitinib or pazopanib. In general, green tea in moderate amounts will likely be safe. Green tea can interact with some other drugs such as some antibiotics, beta-blockers (blood pressure medications),

blood thinners and others. Also, there is the issue that all the different brands of green tea have various amounts of green tea extract and various amounts of caffeine that can increase blood pressure. Since both sunitinib and pazopanib are known to increase blood pressure, blood pressure should be monitored regularly.

In fact it is a good idea to keep a list of all your vitamins and herbal supplements and show it to your doctor regularly, just to make sure there are no medication interactions that you need to be aware of. That list would also be helpful to emergency medical staff too.

— Toni K. Choueiri, MD, Director, Kidney Cancer Center, Dana-Farber Cancer Institute/Brigham and Women's Hospital and Harvard Medical School, Boston, MA 02113

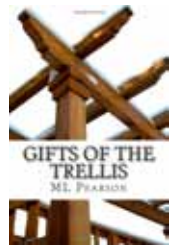
My Greatest Gifts

by M.L. Pearson, Wyoming

Those of us with VHL understand that receiving a diagnosis of a rare genetic syndrome changes our perspective on life. We live under a shadow of uncertainty, striving to live with hope while cancer and tumors are present and possibly growing. This rare disorder presents many unique challenges.

As I shared my story with my writing group, I soon realized that having VHL gave me a unique vantage point on life that unless I shared, they would never appreciate or understand.

The most powerful lessons I had learned were the ones that impacted my relationship with God. These were also the ones that refined my character and defined my life. *Gifts of the Trellis*



was intended to be a private record for my posterity. I considered my life as a whole built on a trellis of tragedy. Yet it was through this framework of despair that I had come to know God. He had revealed Himself to me, covering a bitter lattice with sweet and beautiful mercies. My challenges had been my greatest teachers. They were blessings in my life—Gifts of the Trellis.

Gifts of the Trellis is full of my sacred things. I have been amazed at the hundreds of copies already sold, and most of the readers do not have VHL. The challenges we face and the lessons learned are resonating with the world.

My purpose in letting you, my VHL Family, know about this book is to encourage you to think about the challenges you have faced, and how you have navigated your way through this disease. And then I would ask you to share your own story.

Her book, *Gifts of the Trellis*, is available from Amazon.com. An interview with M.L. can be heard at <http://www.powerfulpatient.org/?p=244>

Shawn—Laces Up and Runs, Because He Can!

Adapted from an article by Janet Oberhotzer, from her running blog, "Because I Can," www.janetober.com

Last year sometime I started following a page called L.U.N.A.R. (Lace Up Now And Run) which posts sayings related to making the most of life and running. Clearly it is the page of someone who loves to run, but a few months ago he posted a picture that told me it is also the page of someone who has and continues to face tough physical challenges.

The picture was subtitled "First race after my second brain surgery—VHL Warrior."

Brain surgery? Second brain surgery?! I had to find out more about the story behind L.U.N.A.R.

Q: Tell us a little about yourself.

My name is Shawn Mastrantonio, I'm 43 years old and live in Sayre, Pennsylvania, with my wife, Kim, who is my rock. I have a rare genetic cancer syndrome called VHL (von Hippel-Lindau). As young child, I was familiar with this disease as my dad, brother, and cousin had it. Most of my relatives with VHL had died. My brother Brian

has had more than 30 surgeries. I didn't realize it then, but through the challenges that VHL had handed to my family I was learning lessons about faith, acceptance of what is given you, and finding the strength to make the best of it. My mom, who is one of the strongest people I know, taught me so much through the way she lived her daily life.

Q: There's a common thought that we can overcome obstacles...I've found that sometimes we can and sometimes we can't, but we can learn to live well even with difficult obstacles. What obstacles have you learned to live with and/or overcome?

I was diagnosed with VHL in 1993 when it was discovered that I had a large hemangioblastoma and cyst in my right cerebellum. This with the family history



Shawn Mastrantonio

quickly pointed to a diagnosis of VHL. I had surgery and lived life for quite a while as a “passenger.” My outlook seemed dismal due to what I had seen people go through with VHL, so, I lived a dual life. I took care of my body through working out, but I also abused it by consuming alcohol. I didn’t think it really mattered. There were times that I didn’t think I would make it too far into my 40’s.

That changed when I met my wife in 2002. It didn’t happen overnight and is still an ongoing process as I carried a lot of anger and fear regarding VHL. Life was going well for us but I had stopped doing my annual MRI checkups to monitor any new brain tumors. In 2009 I scheduled an MRI at the insistence of both Kim and my Mom. The MRI found 3 tumors, 2 new. The 3rd (and most concerning) was a recurrence from my previous tumor.

That night I had my “pity” party and the next day I started running.

Join Shawn as We Launch Team VHL

You’ve never thought of being part of a Run or Walk before? Have no fear! Team Captain Suellen has a training schedule just for you!



Suellen promises that even the most devoted couch potato can train to run a marathon in just 6 weeks! Age and shape doesn’t matter (no disclaimer).

Join Team VHL on September 22, 2013 in Ann Arbor, Michigan!

Visit **Crowdrise** to register and/or to sponsor a runner: <http://www.crowdrise.com/vhl5krun>.

To print out the training schedule, sponsorship forms and for other details, see our web page: <http://www.vhl.org/meeting/team-vhl-run-walk-2013/>. Have your friends, family, and local businesses help.

Or call us at the office at 1-800-767-4845 ext. 4 or write us at office@vhl.org.

At that time, I was trying to run away from the new challenges I faced. I ran out of anger and fear. But over the course of a few months that changed. Running began to be a testament to the strength I didn’t realize I had. I used running as a tool to prepare to face battle—surgery—rather than run away from it. For two years I prepared myself. Then in January 2012, I had surgery to remove the tumor recurrence. I came out of surgery well, thanks to a great surgical team. And my body recovered very quickly; I was only in the hospital for 3 days post-op.

Q: What goals have you reached that you or others thought you couldn’t?

Since surgery, I have run a few local 5k’s and 2 half marathons. The first was in less than 9 months after surgery, setting a new Personal Record! I have some races planned this year as well. My overall goal is to continue to enjoy running, as it is truly a gift. I am blessed every day that I get the opportunity to run, so I try not to take it for granted.

Q: What motivates you to keep on doing what you can?

What I have learned from running is hard to explain. To me, it has helped me find strength I didn’t know I had, to face a challenge and the beauty of overcoming it. We were born to run. I love taking in nature on runs, and thanking God for the beautiful earth he has given us. I’m sure it is different for everyone, but one thing I am certain of is anyone who runs will definitely say that running has changed their life.

Q: What does a well-lived day look like to you...or in other words, if you knew you were dying tomorrow, what would you do today?

If I knew that I was dying tomorrow it would be a day filled with family, friends, laughing, tears, love, and of course I would have to squeeze in a run. It’s like the song by the Rascal Flatts, “I wanna be running when the sand runs out.”

“The main purpose of my page is to spread awareness of VHL. I am just one of many VHL WARRIORS fighting the battle.”

See original article and pictures at <http://www.janetober.com/2013/02/20/shawn-laces-up-and-runs-because-he-c/>

Call for Creativity: Design the New VHLFA T-Shirt



Help us raise VHL Awareness by designing a new VHLFA T-Shirt. Please send us your design. Winner will receive a free T-shirt and free registration to the September 21st Annual Family Meeting in Ann Arbor, MI. Submit your design to office@vhl.org by May 1, 2013. Use your imagination!

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Special discount if you order through VHLFA.



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For more than 50 years, MedicAlert has been providing valuable information for those **with or without** a medical condition. Their 24-hour emergency response services relays pertinent medical information to emergency responders and provides family and caregiver notifications so that members can be united with their families.



EVENTS OF SEPTEMBER 20-22, 2013 • ANN ARBOR, MI

FRIDAY

Fundraising Dinner & Auction

Bronze Sponsor
Kidney Cancer Association

September 20, 2013: 6:30-10:30 pm • The Ann Arbor Regent Hotel, 2455 Carpenter Rd. Ann Arbor, MI

Honoring



James Edward Montie, MD

Valassis Professor of Urology, Former Chair of the Department of Urology, Senior Urologist of VHL Clinical Care Center, University of Michigan

Fran Mott

Long-Term Chapter Leader of Michigan, Founding Member of the VHLFA



SATURDAY

2013 VHL Annual Family Meeting

September 21, 2013: Registration: 8:00 AM • Meeting: 8:30-5:00 PM • The Ann Arbor Regent Hotel

AGENDA

- **Introduction and Welcome:** James O. Woolliscroft MD, Lyle C. Roll Professor of Medicine; Dean, Univ. of Michigan Medical School, Ann Arbor, MI
- **Monitoring the VHL Patient:** Elena M. Stoffel, MD, University of Michigan, Ann Arbor, MI
- **VHL and the Central Nervous System:** Panel Discussion: Moderator: Stephen E. Sullivan, MD: Univ. of Michigan, Ann Arbor, MI; Ghaus M. Malik, MD: Henry Ford Hosp., Detroit, MI; Ian E. McCutcheon, MD: MD Anderson, Houston, TX
- **Ophthalmology Issues in VHL:** Mark W. Johnson, MD, Univ. of Michigan Kellogg Eye Center, Ann Arbor, MI
- **Endolymphatic Sac Tumors & VHL:** Ian E. McCutcheon, MD: M.D. Anderson, Houston, TX
- **Evaluation and Treatment of Kidney Tumors:** Panel Discussion: Moderator: J. Stuart Wolf, Jr., MD: Univ. of Michigan, Ann Arbor, MI;
- Elaine M. Caoli, MD: Univ. of Michigan, Ann Arbor, MI; Khaled S. Hafez, MD: Univ. of Michigan, Ann Arbor, MI; W. Marston Linehan, MD: National Institute of Health, Bethesda, MD
- **Update on VHL Research and Clinical Trials:** W. Marston Linehan, MD: National Institute of Health, Bethesda, MD
- **VHL and the Adrenals and the Pancreas:** Tobias Else, MD: Dept. of Endocrinology, Univ. of Michigan, Ann Arbor, MI
- **State of VHLFA, 2013:** Jane McMahon: Chair, VHLFA Board of Dir.
- **Genetics and Childhood Issues:** Panel Discussion: Victoria Raymond, MS, CGC: Univ. of Michigan, Ann Arbor, MI; Gayun Chan-Smutko, MS, CGC: Mass. General Hosp., Boston, MA; Parents of VHL Patients: Andrea Berkemeier, Danielle Krupp, Jeff York
- **The Emotional Roller Coaster:** Wendy R. Uhlmann, MS, CGC: University of Michigan, Ann Arbor, MI. Patients: Amber Madigan, Robert Kramer

SUNDAY

2013 Team VHL 5K Run/Walk

September 22, 2013: Registration: 8:00-8:30 AM • Run/Walk: 8:30 AM

Gallup Park, 300 Fuller Rd, Ann Arbor, MI

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

Print out the sponsorship forms and training schedule: www.vhl.org/meeting/team-vhl-run-walk-2013/

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 Family 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 8-20-13	<input type="checkbox"/> \$125.00	<input type="checkbox"/> \$192.50 Before 8-20-13 (with discount)		\$ _____
	<input type="checkbox"/> \$100.00 After 8-20-13	<input type="checkbox"/> \$125.00	<input type="checkbox"/> \$200.00 After 8-20-13 (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 director@vhl.org					\$ _____
Total Enclosed					\$ _____

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VHL Family Forum, Newsletter of the VHL Family Alliance and the Alliance for Cancer Research and Support - VHL

Volume 21, Number 2, April–June, 2013, ISSN 1066-4130
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Calendar of Events

2013 Annual Patient/Caregiver Meeting

Fundraising Dinner & Auction

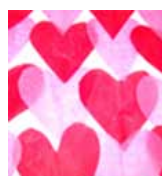
honoring James Edward Montie, MD, and Fran Mott

Team VHL 5K Run/Walk

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

Weekend of September 20–22, 2013, Ann Arbor, Michigan

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



Mom's Day Run May 12, 2013 5K/10K

San Buena Ventura State Beach, CA, 8:00 a.m.

To raise money for VHL (von Hippel-Lindau Family Alliance) and LLS (Leukemia & Lymphoma Society)

The Greatest Gift! ♥ What better way to celebrate Mom's Day then with a gift of life?

See our FirstGiving Page: <http://www.firstgiving.com/fundraiser/VHLFA/momsdayrun20135k10k>

3rd Annual Rick Bracey 29er Softball Tournament



On Saturday, June 15th, 2013, we join together as friends and family to raise awareness and funds all in the memory of Rick Bracey – who passed away in 2010 from VHL.

Raising \$25,000 in 2012, we strive to raise \$30,000 in 2013!

Hope to See you at the Park – ALL WELCOME!

Softball City, Surrey, British Columbia CANADA

If you would like to contribute in any way, thank you in advance for your consideration. <http://www.canadahelps.org/GivingPages/GivingPage.aspx?gpID=21580>.

Please feel free to contact Tournament Committee member Stephanie Kaes at 29ertournament@gmail.com.