As we begin our new fiscal year, I would like to boast about some of the VHL Alliance’s top accomplishments during FY17:

1. Six teens gathered and enjoyed an afternoon of bonding and fun at the Santa Monica Pier during the 2016 Annual Family Weekend. With such great feedback from the program, we are planning a similar event at Busch Gardens during this October’s Annual Family Weekend in Tampa. Registration is now open at vhl.org/teens.

2. The adolescent years are not just a challenge for the teen, they often leave adults at a loss. Adding VHL into the mix can lead to even greater stress for all involved. VHLA has created a Facebook discussion group specifically for parents of teens called VHL: Parents to Parents vhl.org/parent.

3. VHLA held its first ever Young Adult Retreat attended by six patients with VHL. Thanks to its great success, more programs are being planned, including at the Annual Family Weekend in Tampa (vhl.org/vhlweekend2017)! Please let the VHLA office know if you are a patient that fits into the “young adult” category (ages 19–34) so that they can keep you in the loop.

4. VHL can have an impact on vision. This year, VHLA initiated a monthly Low/No Vision Discussion and a Facebook groups (vhl.org/vision) geared especially for those who lost all or most of their vision due to VHL. Did you know that an audio version of the VHLA newsletter can be mailed to you? It is also available on our website. Please let the office know (info@vhl.org or 617.277.5667 x4) if you are interested in any of these services.

5. In FY17, the VHLA Clinical Advisory Council approved four new Clinical Care Centers (Johns Hopkins, MD; Indiana University, IN; Huntsman Cancer Institute, UT; Ohio State University, OH); promoted one current CCC for recognition as a Comprehensive Clinical Care Center (Massachusetts General Hospital, MA); and renewed 12 Clinical Care Centers in the US.

6. A handful of CCCs and their VHLA liaisons piloted a Health Wellness Coaching Training program. The video conference sessions provided participants with the skills to better communicate, listen, and empathize with patients and their loved ones while arming them with the tools to effectively deal with stress. With rave reviews from participants, a rollout to more CCCs is being planned.

7. Last, but not least, is our new collaboration with Elsevier’s PracticeUpdate (practiceupdate.com), which is helping healthcare professionals and researchers keep abreast of the newest medical literature. This is a key to improved diagnosis and treatment as well as greater awareness in the medical community. As we enter our new fiscal year, the VHL Alliance will capitalize on our current momentum to further expand VHLA’s efforts on research, education, and support.

One of the key features of our work to come is the creation of a new strategic plan which will direct our work from now until 2020! A truly effective strategic plan must represent our entire community (patients, caregivers, friends, loved ones, healthcare professionals, and researchers alike). As such, we need your input! What would you like to see? How would you like to be involved? Please let us know by emailing the office (info@vhl.org) or completing the volunteer form at vhl.org/volunteer.
NEW STAFF MEMBER

WELCOME JOSH MANN!

While I am not a VHL patient, I have devoted my entire career to healthcare and working with patient groups. I began my career in the private sector after earning an MPH in Healthcare Policy and Management.

In high school I suffered a severe spinal cord injury, requiring several surgeries. The recovery process was slow and painful, but it allowed me to fully appreciate and understand the patient experience and perspective. Dealing with my injury triggered a commitment in me to make a difference in the nonprofit healthcare world.

Joining the VHL Alliance is consistent with the promise I made to myself of working in and improving healthcare. I truly believe in VHLa and the people who work here. It is a place where I feel confident that I can make a positive difference in people’s lives.

There are a number of initiatives that I would like to achieve as part of my role of Director of Engagement and Outreach. For example, I want to establish a Young Leadership Council through which we encourage young adult participation as well as provide leadership opportunities. I plan to develop a mobile app to provide patients with the tools they need to better manage their healthcare. I also want to continue to grow patient participation in the VHL Patient Natural History Study (formerly known as the Patient Databank or CGIP, vhl.org/databank), a research project essential for enhancing VHL diagnosis and treatment. Finally, I would like to establish a CCC in every US state. I am so excited to be a part of this community, and I look forward to working together with everybody to make it the best that it can be.

When I am not working, I enjoy playing golf, cooking with my fiancée, Jenny, playing with my puppy, Kugel, and spending time outdoors.

I hope everybody will feel free to reach out to me, even just to say hi. (Especially if you are a NY Giants or Yankees fan! Don’t be fooled by my Boston address; I will always be a New Yorker at heart.) My email address is: josh.mann@vhl.org.

CAREGIVER PERSPECTIVES

A MOTHER’S HOPE

Written by Beverly A

My son Steven was diagnosed with VHL when he was 16 years old and a sophomore in high school. The steps to diagnosis began in January 2005 with a trip to the pediatrician because of ongoing dizziness. Through a series of MRIs, doctors visits, surgery, blood work, and more doctors appointments, a final and definite diagnosis of VHL was made with genetic testing results in May 2005.

He was the first person in our family with VHL, a “de novo” case of this disease.

As his parent and caregiver, I immediately made it my mission to learn about this rare, genetic cancer syndrome. I read voraciously about treatments, tumors, genes, and proteins. I searched for doctors, clinics, studies, and kindred spirits in the VHL world. I studied MRI pictures of my sweet son’s brain, and meticulously kept records of radiology reports. I learned that the odds of a long and healthy life were stacked against my oldest child.

I also immediately and adamantly made it my mission to help Steven live a life beyond this disease.

VHL presents ongoing difficult and uncontrollable obstacles in life. Steven has had four surgeries to remove brain tumors since his diagnosis. One surgery left him unable to swallow or stand for three months. Another brain tumor resulted in hydrocephalus and all of its many issues before it was removed. Each surgery, understandably, carried its weight in pain and fear.

It is important to realize, however, that these difficult times are but moments in life. Life is a culmination of all the moments...and...is defined by how you react to these moments.

“Life is a culmination of all the moments...and...is defined by how you react to these moments.”

Living with VHL is tough. The disease can tear away at your soul just as easily as it breaks your body, and that is ugly. Choosing to live a life beyond the scars, however, is beautiful.

As the parent of a VHL patient, I live a conundrum. Every second of every minute of every hour of every day I realize the implications of my sweet son’s life with VHL. Yet not a day nor an hour nor a minute nor even a second passes that I don’t give thanks for the life he lives.
IS PALLIATIVE CARE RIGHT FOR ME?

By Zoe Walters, University of Iowa, PharmD Candidate Class of 2018

Palliative care is a healthcare specialty that is focused on improving quality of life for anyone with a serious illness. It is appropriate at any age and at any stage of illness from the time of diagnosis until the end of the person’s life. It is provided by a team of healthcare professionals that may include doctors, nurses, pharmacists, social workers, chaplains, and other specialists. In the case of VHL, this team collaborates with the VHL specialists in order to provide patients and their loved ones with an extra layer of support.

The palliative care team meets with a patient to determine his/her values and priorities so together Goals of Care can be established. They help patients address the many forms of pain and distress that may accompany a serious illness, whether that be physical, emotional, spiritual, or social. The palliative care team specializes in symptom management, which may include pain, anxiety, depression, nausea, constipation, dizziness, fatigue, and difficulty sleeping. The focus is on the patient as a whole person. The team wants to help support patients and improve their quality of life.

That’s not to say VHL had spared any of us. In fact, as I learned through our conversations with a social worker from Vanderbilt (a VHL Clinical Care Center), between the 6 of us, we have had operations on most of the 10 organs where VHL can rear its ugly head. And we have scars to prove it! In addition, some participants also have had to serve as caregivers or even had to bury parents whose lives were cut too short by VHL.

To thrive with VHL requires a tenacious spirit to face challenges over and over again. It requires gratitude to be rooted in our hearts for the many members of our care team and extended support system who work tirelessly to keep us as healthy as possible. It requires humility to reach out when we need help quelling “scan-xiety”, performing easy tasks while recovering from surgery, or sticking to healthy lifestyle habits. It also requires hope for a cure and commitment to contribute to research efforts that are bringing about better understanding of and treatments for VHL.

Thank you to the VHL Alliance for helping us thrive with VHL! I can’t wait to see everyone again and meet others during our next get-together at this year’s Annual Family Weekend in Tampa!

PALLIATIVE CARE

#THRIVINGWITHVHL

I wasn’t quite sure what to think when I first learned that the VHL Alliance would be hosting a retreat for young adults, but with the promise of stargazing, I figured it couldn’t be too bad.

Six VHLers made it down for the weekend. While there were some familiar faces from VHLA’s 2016 International Medical Symposium and last fall’s Annual Family Weekend, there were also new people. It sort of felt like a blind date. To be honest, I was apprehensive that my “dates” would only want to focus on VHL. While it was the one thing we all had in common, I’ve never been super keen on sharing my VHL journey with others. That is because they have a tough time really understanding what I’m going through.

I suppose I shouldn’t have been too surprised that it felt comfortable sharing my story with these people, They didn’t just listen, they really understood what it is like to live with VHL. As I solved an Escape Room game, played VHL Jeopardy, shared some home-grilled surf and turf, hiked in a state park, listened to live music at a famous local hangout, and even had a little karaoke fun during the car rides, I came to realize that these folks seemed like they were not just surviving, they were thriving with VHL.

That's not to say VHL had spared any of us. In fact, as I learned through our conversations with a social worker from Vanderbilt (a VHL Clinical Care Center), between the 6 of us, we have had operations on most of the 10 organs where VHL can rear its ugly head. And we have scars to prove it! In addition, some participants also have had to serve as caregivers or even had to bury parents whose lives were cut too short by VHL.

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Thank you to the VHL Alliance for helping us thrive with VHL! I can’t wait to see everyone again and meet others during our next get-together at this year’s Annual Family Weekend in Tampa!
July 1st is the kickoff of VHLA’s new fiscal year (FY18). We welcome five additions to the VHLA Board of Directors. These five motivated individuals, who are at different stages of life and involvement with VHL, will nicely round out the team of the 12 other board members currently serving.

**Steven Angotti** brings his background of law and policy to the VHLA Board. Steven was diagnosed as a first in the family with VHL when he was 16, but does not let that stand in his way. In addition to his professional career, he has also played professional soccer in Brazil!

**Emily Pinto Billcheck** is passionate about empowering patients and families who are affected by VHL. As a licensed social worker, as well as one of several in her family with VHL, she knows the importance of being an advocate for your health. Emily was diagnosed at the age of 17.

**Jennifer Galenkamp** has a rich history of communications and public affairs, both domestically and internationally. Jennifer is passionate about research and finding a cure for VHL as a close family member is a first in the family with VHL.

**Seth Horwitz** is a financial consultant who lives in New York City. Seth was diagnosed at the age of 13 as the only one in his family to have VHL. Through VHLA, he has connected with other VHLers and is involved in the NYC Benefit Dinner. Seth seeks to offer any assistance possible to other patients and help achieve the goal of a cure.

**Camron King** is coming back to serve on the Board of Directors after a several year hiatus. Camron is a dynamic leader. Because of his personal relationship with VHL, he wants to work with volunteers and staff to improve the quality of life for families and friends with VHL.

The new fiscal year also brings along a new leadership team on the Board of Directors. Those positions are as follows:

- **Manuel Greco**, Chair
- **Doug Karle**, Vice Chair
- **Andrea Rafael**, Treasurer
- **Anna Waller**, Secretary

Returning Board members are: Gordon Cooke, Barbara Correll, Jessica Everett, Eric Jonasch, Bettina Micheli, Mark Pallansch, Karen Ramsey, and Soniya Sapre. For complete bios on all board members, please visit [vhl.org/about/people/board-of-directors](http://vhl.org/about/people/board-of-directors).
Welcome to the newest VHL Clinical Care Center.

Ohio State University
Wexner Medical Center
460 W. 10th Avenue
Columbus, Ohio 43210

Contact: Rachel Queen, RN
Tel: 614.685.6916
rachel.queen@osumc.edu

Clinical Study Recruitment

Announcing a new Phase 2 clinical study for patients having 1 or more measurable ccRCC tumors with no tumor greater than 3.0 cm and has a VHL diagnosis based on a germline vhl alteration.

The National Institute of Health (NIH) is currently recruiting patients.

If interested, contact Martha Nonos, RN: 301.435.8897; mninos@mail.nih.gov

Principal Investigator: Ramaprasad Srinivasan, MD
Study Sponsor: Peloton Therapeutics, Inc.

To learn more about the trial, visit clinicaltrials.gov. More information about the drug, PT2385, can be found here: bit.ly/VHLClinTrial

42% of patients treated with pazopanib responded in Phase II study for von Hippel-Lindau disease

This study was performed at M.D. Anderson by Eric Jonasch, MD

Learn more: bit.ly/practiceupdate-vhl

New Retina Clinical Study

Announcing a new Phase 1/2 trial for the intravitreous treatment of severe ocular von Hippel-Lindau disease using a combination of the PDGF antagonist E10030 and the VEGF antagonist ranibizumab. This study is for patients with a VHL diagnosis based on a germline vhl alteration.

The National Eye Institute (NEI) is currently recruiting patients.

If interested, contact: Katherine Hall Shimel, RN; 301.402.2863 (office), 240.383.7047 (cell); katherine.shimel@nih.gov

Study Sponsor: National Eye Institute (NEI)

To learn more about the trial, visit clinicaltrials.gov. Additional information can be found here: bit.ly/VHLClinTrialEye
2017 VHL FAMILY ANNUAL WEEKEND
JOIN US IN TAMPA, FLORIDA!

Fundraising Dinner & Auction
HONORING

Steven Angotti, J.D. is a native of Tampa Bay and earned his law degree from the University of Miami. Steven was diagnosed as a “first in the family” with VHL when he was 16. He became an attorney, worked with a member of the US House of Representatives, and is passionate about the environment, education, and policymaking.

The Moffitt Cancer Center
VHL Clinical Care Center Team
Under the leadership of Dr. Phillipe Speiss, Moffitt’s Clinical Care Center exemplifies outstanding and comprehensive care for patients and families. The excellence of the center is acknowledged by the growing number of VHL patients being seen.

Friday Evening, October 13
Busch Gardens, Gwazi Pavilion, Tampa, FL

For more details, tickets, and sponsorship opportunities: vhl.org/vhlweekend2017

Annual Family Meeting
Saturday, October 14
Moffitt Cancer Center, Tampa, FL

To register: vhl.org/vhlweekend2017 • Early registration discount ends September 6th

AGENDA TOPICS — Speakers include doctors associated with Moffitt and others associated with the VHL Alliance

- Initial and annual evaluation of patients with VHL
- The Emotional Roller Coaster of VHL
- Why is a regular ophthalmological exam critical in VHL
- Endocrinological advances in the management of VHL
- Role of minimally invasive surgery in the management of VHL
- Liver and pancreatic manifestations of VHL
- Neurological manifestations of VHL
- Advances in genetic screening for VHL
- Applications of personalized medicine; important lessons learned from our patients and their families
- Caring for young patients with VHL
- The Past, Present, and Future of VHL

Teen Event • Saturday, October 14 • Busch Gardens, Tampa, FL
Young Adult Happy Hour • Saturday, October 14 • 6:30 pm, Embassy Suites Atrium

To register: vhl.org/vhlweekend2017

Team VHL 5K Run/Walk
Sunday, October 15
Check-in 8:00 am, Embassy Suites Lobby

Register and start fundraising here: vhl.org/teamvhl2017

Lodging
Discounted rooms available at the Embassy Suites Tampa USF location, 3705 Spectrum Blvd., Tampa, FL 33612. Call 813.977.7066 or make a reservation at: bit.ly/embassytampa2017

The special room rate will be available until September 6th or until the group block is sold out, whichever comes first.
THANK YOU!
The 2017 VHL Awareness Month was the best ever!

So many people stepped up to the plate to create VHL awareness with the goal of making VHL a household name. Awareness month is about VHL awareness, supporting the VHL Alliance, and funding research to find a cure.

I would like to especially thank those who organized events in their regions, whether they raised $5 or $25,000, it does not matter... each one was essential to our mission: Anna H., Haley M. and Sabrina M., Amy D., April R., Emily L., Wes and Melissa S., Deanna W., Greg T., Maria R., Rayven and Mandy B.

Let's get started thinking of events for next May, or better yet, celebrate EVERY month as VHL Awareness Month! Thank you for all you do. Want to get more involved? Please let us know. Email Heidi at heidi.leone@vhl.org.

HAPPENINGS
UPCOMING

Sunday, August 27
Cornhole Tournament
Stony Brook Fish & Game
Westford, MA
Contact: us-ma@vhl.org

Saturday, September 9
Cornhole for a Cause
Sunset Tiki Bar & Grill
Westford, MA
RSVP: katieandjus@gmail.com

Sunday, October 22
Halloween Fun Run & Party
Irish American Heritage Center
4626 N. Knox Ave. Chicago, IL
Contact: us-il@vhl.org

SAVE THE DATE!
January 25, 2018
The fifth annual New York City Benefit Dinner in support of the VHL Alliance at The Harvard Club of NYC. More information to follow.

VHLA FACEBOOK GROUPS

VHL Facebook Fan Page: facebook.com/VIHLAlliance

VHL: Spreading Awareness of von Hippel-Lindau (now private): facebook.com/groups/VHLAwareness

Caregiver Discussion Group: facebook.com/groups/vhlcaregivers

Parents of Teens Group: facebook.com/groups/teenVHLparents2parents

VHLA Low/No Vision Discussion Group: facebook.com/groups/vhlvision

VHL ALLIANCE | Summer 2017 | 7
Early registration discount ends September 6th
REGISTER NOW!

2017 VHLA ANNUAL FAMILY WEEKEND

OCTOBER 13–15, 2017 — TAMPA, FLORIDA

Fundraising Dinner & Auction
Annual Family Meeting
Teen Event
Young Adult Happy Hour
2017 Team VHL 5K Run/Walk

Tickets and Registration: vhl.org/vhlweekend2017
Team VHL Run/Walk Registration: vhl.org/teamvhl2017