By Doug Karle, VHLA Board Chair

Wow! The past few years have been remarkably exciting for VHLA, patients, and caregivers. As we begin our new fiscal year, we feel a few steps closer to our vision of Curing Cancer through VHL. We hope this upcoming year will be equally momentous.

Some specific accomplishments this past year include:
• The start of Peloton’s multicentered phase 2 clinical trial for the treatment of VHL-related RCC. If this is approved it will be the first drug for treating VHL as well as the ninth drug created as a result of research on the VHL gene! (By the way, VHLA is the leading funder of VHL research!) You can learn more about this and other clinical trials at vhl.org/trials.
• The launch of VHLApp (vhl.org/VHLApp), an incredible mobile app to help VHLers quickly access important VHL information. There is even a calendar specifically designed to help us keep track of medical appointments. The app also has a voice-recording function so we don’t have to remember everything that we are told at our appointments.
• A relaunch of MyVHL: The VHL Patient Natural History Study to help researchers identify patterns across VHL patients. MyVHL provides you – and researchers – with more complete information about VHL: how our lifestyle, medications, and other factors impact the disease and quality of life. These insights help us better understand the condition and help researchers know where to focus their efforts. When you participate in the study, you get to see the results. DISCOVER how your unique journey can help others. Help find a CURE for cancer through VHL. Be a part of progress in RESEARCH.
• More engagement from our young adults. They had their second retreat last month which was greatly appreciated and enjoyed. This astonishing group of young adults have forged new friendships and support. They will no doubt be the future leaders of VHLA.

Every year the Board and Staff update the strategic plan and we have many organizational goals this year. A few goals I would like to highlight are:
• One-on-one outreach to 100% of our database. The Board, Engagement Committee, Chapter Leaders, other volunteers, and myself, are all participating in this effort. I love connecting with fellow patients and caregivers and listening to your stories. What is most moving to me is when someone tells me that I am the first person with VHL with whom they have spoken.
• On these calls, a common theme I hear relates to quality of care. Most issues are related to uncoordinated care for patients who are not near a VHL Clinical Care Center (CCC). We have 12 Comprehensive Clinical Care Centers and 21 Clinical Care

continued on page 2
Centers throughout the U.S. (and 18 in other parts of the world). Patients have seen impressive results with the coordinated care at these centers. VHLA will continue to hold CCCs accountable to the required standards and we are working to expand the number of CCCs. If you are in a part of the country where there is not a CCC within an 8 hour drive, and you want your medical provider to become one, please contact Josh Mann (josh.mann@vhl.org). He can help facilitate this process.

• Outreach to health insurance companies around active surveillance guidelines. We have all had frustrating experiences with insurance companies. We hope to make some inroads. This is an intimidating task, but worth the effort.
• The continuing support of the remarkable grassroots fundraising efforts that take place each year, while expanding fundraising in other areas. The reality is that VHLA is solely dependent on the donations (both small and large) we receive. Every dollar helps move us closer to our vision: Curing Cancer through VHL.

I want to thank the Staff and Volunteers of VHLA for their dedication and commitment. I am humbled that I serve on the VHLA Board with so many incredible people. Most importantly, I am thankful beyond words that VHLA has connected me to hundreds of other patients, families, and friends over the years. This community is the boldest, strongest, and most compassionate group of people I know. Nobody wants to have VHL, but you have all made my experience one that has enriched my life in ways that people without a connection to VHL can never understand. Thank you!

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**BOARD UPDATE**

**WELCOME NEW BOARD MEMBERS!**

July 1st kicked off VHLA’s new fiscal year (FY19). We welcome four additions to the VHLA Board of Directors. These motivated individuals, who are at different stages of life and involvement with VHL, will nicely round out the team of the 12 returning board members.

**Jane Beasley** was diagnosed in 1973 with her first pheochromocytoma, when the tumor was removed along with her right adrenal gland. She never misses a chance to share her story and educate people about this rare disease. She looks forward to working with the VHLA Board.

As a VHL patient, **Stacy Lloyd** is personally and professionally invested in the future of healthcare. She enjoys being a resource in this space for family, friends, and other patients, helping them be better informed and empowered in their own healthcare journeys.

**Connie Rath** has served on numerous boards. Her background in studying psychological patterns and designing educational solutions can be applied to how VHL patients live and thrive. Her son, Tom, was diagnosed with VHL as a teenager.

**Deanna Wickizer** was diagnosed with VHL as a senior in college when she began having vision issues. She brings a passion for finding a cure for VHL, along with creative and effective ideas for promoting awareness and raising funds for the organization.

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

Doug Karle, Chair
Seth Horwitz, Treasurer
Camron King, Vice Chair
Anna Waller, Secretary

Returning Board members are: Steven Angotti, Emily Billcheck, Gordon Cooke, Barbara Correll, Jennifer Galenkamp, Eric Jonasch, Mark Pallansch, and Soniya Sapre. For information on all board members, please visit vhl.org/about/people/board-of-directors.
Dear VHL Community,

I am writing to you to address the concern of many patients who have VHL-related pancreatic manifestations regarding their access to the NIH Clinical Center following the closure of VHL pancreatic protocol.

For patients with VHL-related pancreatic manifestations who are on any active NIH or NCI protocols, such as those conducted by the urology team, the neuro surgical team, or other services, the endocrine surgery team can evaluate pancreatic manifestations through a consultation request by the primary team. We will request the required imaging studies and laboratory testing to be performed by the primary team and we can evaluate the patients in our out-patient clinic.

For patients with VHL-related pancreatic manifestations who are NOT on any active NIH or NCI protocols, you may contact our team directly by email at ncieobinquiry@mail.nih.gov.

Sincerely,
Naris Nilubol, MD, FACS
Associate Research Physician
Thoracic and Oncologic Surgery Branch
NIH, National Cancer Institute

DOWNLOAD VHLApp TODAY!

VHLApp is a user-friendly mobile app that provides a quick and easy way for anyone affected by VHL to learn about living with the condition and its different manifestations. It also provides helpful resources for managing care.

[link to vhl.org/VHLApp]
Currently only available for iOS

HAPPENINGS

Durango Comedy Festival
August 23-25
Durango, CO
us-CO@vhl.org

Cornhole for a Cause
September 8
Sunset Tiki Bar Grill
Westford, MA
katieandjus@gmail.com

International Medical/Research Symposium
October 4-6
Houston, TX
vhl.org/symposium

Victoria, BC Marathon
October 7
British Columbia, Canada
teamvhl@vhl.org

Annual Family Weekend
October 19-21
Denver, CO
vhl.org/familyweekend
On June 8th, VHLA welcomed 12 young adults (18-30 years old) for a weekend of fun, education, support, and friendship. For most, this was the first time they had ever spoken to another VHLer, let alone had the opportunity to meet face-to-face. The weekend’s agenda included a good balance of learning, sharing, and enjoyment. When they left, each felt uplifted and armed with information, #thrivingwithVHL both physically and emotionally. There is no doubt in my mind that the weekend was a huge success! (see Alie’s story, page 5)

The Young Adult Retreat is one of the many programs that VHLA holds in its effort to achieve its mission “dedicated to research, education, and support to improve awareness, diagnosis, treatment, and quality of life for those affected by VHL.”

Two important events that also demonstrate VHLA’s effort in this area will be taking place in the month of October. Both of these programs are wonderful opportunities for the VHL community to advance their knowledge about VHL while at the same time develop friendships made possible by the VHL Alliance.

**International VHL Medical/Research Symposium**

The biennial International VHL Medical/Research Symposium is an excellent opportunity for internationally renowned and early career researchers and healthcare professionals to discuss the tremendous advances in VHL research and clinical care. It is also an opportunity to start new collaborations on innovative research that brings us closer to more effective treatments for VHL.

This year’s symposium will take place in Houston with an agenda that includes presentations and discussions on important topics. Examples are the VHL active surveillance guidelines, gene editing: fact or fiction, and optimal treatment of hemangioblastomas.

Saturday is directed towards VHL patients, their families, and friends. The inclusive approach provides researchers with the unique opportunity to see the bigger picture: the effects of VHL on patients and caregivers regarding self-perception, career path, family dynamics, and the transition of medical decisions from child to adult.

**Annual Family Weekend**

A full weekend of fun, education, and support is planned for this year’s Annual Family Weekend in Denver. Activities begin on Friday evening with a Comedy Fundraising Dinner at the Hard Rock Café. Six local comedians, led by Wes Stein (VHL father and husband), will entertain us with their wit as we dine and raise VHL awareness (and funds) to support the VHL Alliance. (The comedy will be appropriate for all ages.)

Saturday is the Annual Family Meeting. The meeting will take place at the University of Colorado Hospital and Cancer Center, Anschutz Medical Campus – a new VHLA Clinical Care Center.

The agenda is designed to empower attendees to become active partners in clinical care. Topics will include presentations and discussions on the most up-to-date approaches to treating people with VHL. In addition, the Emotional Roller Coaster of VHL will be addressed. Simultaneous to the meeting, teens (12-18 years old) are invited to a fun activity of their own. The day will end with a Young Adult gathering and a pizza social for all.

Finally, Sunday will feature our annual Team VHL 5K Walk/Run fundraiser. Even if you don't walk or run, you can cheer your fellow VHILers on!

To learn more, check out vhl.org/events.

I look forward to seeing many of you at one of the October events! In fact, it would be great to see you at both!

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**MyVHL: The VHL Patient Natural History Study**

**PARTICIPATE NOW!!!**

Register for MyVHL today at vhl.org/MyVHL! Learn more about your VHL and contribute to finding a cure.
I AM A WARRIOR

by Alie I, VHL patient

You've gotten the news. You've somewhat come to terms with it. Now the inevitable question: how do you tell people?

That is the thought that has consumed me since being diagnosed with von Hippel-Lindau syndrome six months ago. The genetic disease, which was passed along to me through my father, causes tumors and cysts to grow in ten hotspots in your body. MRIs found a small one on my spine and several in my pancreas that will need to be monitored and could lead to surgery in the future.

I know what you're thinking: with all she's dealing with, telling people is what she's worried about?! For those who know me, this is not a surprise.

All my life I have been a nurturer, taking care of the people around me. It's always been a struggle to ask for help, mostly because I don't want to burden my friends and family with my problems when they are dealing with their own. The thought that my diagnosis could upset those nearest and dearest to me has proven to be more terrifying than the disease itself. For that reason, I've only shared the news with a small number of people.

In June, I went to a retreat for young adults who, like myself, are also dealing with VHL. Most of the brave men and women I met that weekend didn't have a choice on when or who they would tell. Many had undergone scary surgeries and brutal recoveries that forced them to make their stories public. But instead of seeing it as a negative, they use it as an opportunity to educate.

Sometimes I have to remind myself that dealing with a disease is nothing to be ashamed of. Most people in the world are struggling with something; we as VHL patients just may have visible scars to document our journey. What I learned from these stories of strength and courage is that being open about our battle will only inspire others to do the same and, most importantly, it serves as a reminder that we are not alone.

So this is my story.

Yes, I may have been dealt a bad gene. But I'm a warrior. And I will fight this with everything I have.
THE MOM’S DAY RUN

by Suellen L., VHL patient and caregiver

July 31, 2010. We all met at Mom’s house for BBQ; it was her 71st birthday. She wasn’t answering my questions with the proper response. Her face began to droop on one side…we suspected a stroke. On August 2nd, she was gone.

A few weeks later, my children and I got together to come up with a way to remember my Mom. A garden at the senior center, where she taught braille? A plaque? A bench? Nothing seemed right. Then someone said, “How about a Race?”

I run and it seemed simple enough. On that day, the Mom’s Day Run was born. I didn’t know how to advertise and get the word out, other than posting on my social media pages. I invited friends and family. We made our own shirts.

Then on Sunday, May 8, 2011, 48 friends and family came out to run/walk along the beach and celebrate my Mom. My daughter, Shana, had just had brain surgery and was in a wheel chair. She wore her hoodie and held several pillows in her lap. She insisted on being there, no matter what. The night before, my husband and I stayed up all night making breakfast burritos.

It felt intimate and sweet…home grown. We raised $1500 for the VHL Alliance. We were so proud of ourselves.

The participants, mostly family and friends, sprinkled with a few strangers, were all so kind to come out on Mother’s Day and run along the beach with us. Some spoke to my daughter, giving praise and commenting on her remarkable spirit. Hugs, words of inspiration and encouragement...it was a beautiful day.

After the Run, we went to the beach (we had spread my mother’s ashes at sea) and had a moment with my Mom. We miss her so much. We will honor her memory every day...especially on Mother’s Day with the Mom’s Day Run, raising money and awareness for VHL in her name!

May 13, 2018. We arrive at 5:30am. Team VHL, my husband, kids, grandkids and a handful of volunteers all help setting up. How we have grown! Over 500 participants (and an additional 200 spectators) run or walk with us along the beach.

We have Vendors now, selling their wares. Lots of stuff is donated for FREE. We have a Free Raffle, Free Breakfast burritos (made to order), Free Treats, Free Coffee, Free Massages, Free Kona Ice, a performance by Emily B (a fellow VHL Warrior), DJ Picazzo keeps us moving and even the Helpful Honda People came out to help. Heidi Leone from the VHL Alliance came all the way from Boston to man the VHL Booth. And YES! She is coming again next year.

We’ve learned what works, what doesn’t. I’ve learned to JUST ASK. I’ve learned not to take NO personally. That next YES keeps me motivated. My mother is my inspiration and I know she would be proud.

I’ve also discovered that belonging to the VHL Community gives us all HOPE, that one day WE WILL find a CURE and that each and every one of us can help bring us one step closer to that cure.

For the 8th time, we all walk down to the beach. We take our places in the same order as that first year. The sound of waves crashing on the sand. We watch dolphins play in the waves…a gentle breeze feels like a hug. I know my Mom is out there dancing in the surf...

We are so grateful, for today! Team VHL, to date, has raised over $180,000 for the VHL Alliance.
The VHL Alliance is pleased to recognize the University of Texas Southwestern Medical Center as the newest VHL Clinical Care Center. The VHL team at UT Southwestern is led by Drs. Kevin Courtney and Jonathan Wickiser.

Dr. Courtney is a medical oncologist specializing in the treatment of genitourinary malignancies. He has expertise in the treatment of renal cell carcinoma, including RCCs that arise in HLRCC, BHD, and VHL patients. Dr. Wickiser is a pediatric oncologist focusing on pediatric cancer predisposition syndromes. He is an expert in the treatment of pediatric renal tumors, as well as other rare pediatric tumors.

The VHL team at UT Southwestern has the latest technology and a knowledgeable staff, comprised of a wide range of specialists, who meet regularly and are experienced in treating patients with VHL. They are ready, excited, and well-equipped to address any and all needs of the VHL community in the Dallas/Fort Worth area and beyond.

If you are interested in pursuing care at the University of Texas Southwestern, you can reach out to the team’s Point of Contacts (Brian Reys, Amber Gemmell, or Remington Fenter) by phone at 214.645.2563 or by email at: CancerGenetics@UTSouthwestern.edu.

Do you or your family members with VHL receive care at a VHL Clinical Care Center? If so, we want to hear from you! We invite you to submit any feedback that you have about your experience at vhl.org/cccfeedback. You are welcome to remain anonymous. Your feedback is vital to helping us improve the quality of care for all.

Learn more about volunteering to be your CCC’s Patient Liaison. Contact Josh at josh.mann@vhl.org or call: 617.277.5667 x4.

Clinical Trial Recruitment

PT2977-202: An open-label phase 2 study to evaluate PT2977 for the treatment of von Hippel-Lindau disease-associated renal cell carcinoma

Now Enrolling
The University of Texas MD Anderson Cancer Center

Sites Opening Soon
Massachusetts General Hospital
National Institutes of Health’s National Cancer Institute
University of Michigan Medical Center

More information can be found at: vhl.org/clinical-trials or clinicaltrials.gov
(Study Number NCT03401788) or VHL Alliance: josh.mann@vhl.org, 617.277.5667 x4
Study sponsor: Peloton Therapeutics, Inc.
REGISTER NOW!
2018 VHLA ANNUAL FAMILY WEEKEND

OCTOBER 19-21, 2018 — DENVER, CO

Comedy Night Fundraising Dinner
Annual Family Meeting
Teen Event
Young Adult Get Together
2018 Team VHL 5K Run/Walk

Tickets and Registration for all events
vhl.org/familyweekend