The VHL Alliance is a group of patients, families, friends, researchers, doctors, and supporters – a community! As with any other community, VHLA functions, grows, and progresses by the work done by Us All!

Founded almost 25 years ago as a small volunteer-based organization, the VHL Alliance has grown, progressed, and made great strides towards improving the quality of life for those impacted by VHL. Our vision is to ultimately find a cure. The work has been complex, the hours draining and tiring, and there is still much to be done. No matter what your role or position is in this community, there is something of significance, of importance, and of relevance that makes you, your action, and your story special and critical. As VHLA has developed and continues to progress, it is our collective story, our blood, sweat, tears, and laughter that brings us to a place with a common shared goal – finding a cure.

When I was first diagnosed, I wondered “How?” “Why?” “What?” It was VHLA that was there with answers, resources, and friends. Over 20 years later, I often find myself thinking about the astounding commitment of people all over the world supporting each other in the battle against VHL. I commend the advances made in research, clinical trials, and earlier diagnoses and those who provide the time, talent, and treasure to make it all happen.

Time – Our most precious resource. We all have numerous strains on this valuable resource. But no matter the pressures in life and the demands on our schedules we all can spare a few minutes (or more) to help make our community thrive. Help advance VHL research by taking time to register and enter your data into the VHL Patient Natural History Study (a vital information resource for our research community, vhl.org/databank). Help build awareness by sharing your story or that of a loved one or friend. Plan a fundraiser. We can ALL share some of our precious time!

Talent – Every person has a special set of skills that can be offered to VHLA. Do you love to speak in front of groups? Write? Listen? Do you have a network of friends or business relationships that can help raise needed funds or awareness? Do you enjoy finance? Have organizational skills? The list goes on and on. We all have talents that can be tapped to help VHLA. Consider offering yours.

Treasure – The VHLA community has been fortunate to raise millions of dollars to fund important research toward a cure as well as education, outreach, and support programs to ensure that diagnosis comes earlier, quality of life is improved, and that we move toward our vision of Curing Cancer through VHL. Research is expensive, and services do not come for free. It is through the generosity and kindness of financial contributions, large and small, through gala dinners and garage sales, marathons, penny drives, individual checks and corporate matching – It Takes Us All.

There have been many successes over the years and the VHL Alliance is stronger than ever, but there is still room to progress, still more work to do, still lives to positively impact. It Takes Us All! If we all do our parts, big or small, raise funds, donate our time, share our talents, we will continue to make life-changing developments and, in the near future, find a cure! Please join the community with your active support of time, talent, treasure – It Takes Us All!
Welcome Diamond Tarwoe!

The VHL Alliance welcomes Diamond Tarwoe as our new Office Manager! She brings over 3 years of managerial and administrative experience, working in the health industry. Diamond joined the VHL Alliance in late September of 2017. Her duties include serving the VHL constituency as well as communicating with staff and board members about the needs of the community. Her enthusiasm and ambitions contribute in her efforts to make a difference in today’s society.

Diamond was born in Abidjan, Ivory Coast. She moved to the United States with her family when she was two-years-old. Diamond holds a bachelor's degree in Political Science and is currently pursuing her master's in Public Administration at the University of Massachusetts Lowell. In her free time, Diamond enjoys being a coach for her school's step team, eating, reading, listening to music, and spending quality time with her family and friends.

Thank you to the Buckley, Bakke, Greene, Horwitz, and Anonymous Families who have donated a total of $55,000 to match YOUR Donation!
Dear VHL Alliance,

We would like to take this time to express our heartfelt appreciation for the work you do!

My 37 year old husband Scott has VHL. He was diagnosed with it when he was 13 years old. Since then, he has experienced numerous and reoccurring health problems. Over the past 24 months, he has been hit with brain, pancreas, spinal cord, and kidney tumors, some of which were cancerous. He has had a number of surgeries and had consultations with doctors at multiple hospitals.

After each medical appointment, our hope faded. Why was there such a rapid onset of tumors attacking Scott’s organs? Why did the medical team feel that there was nothing to be done? And where could we find help? We needed a second opinion.

It was then that we reached out to you, the VHL Alliance. The staff was filled with much compassion and a will to help in any way that they could. You (VHLA) helped us get the process started to have him seen by a top von Hippel-Lindau neurologist in the United States.

After my first conversation with the VHL Alliance, you used your network to contact three top neurosurgeons specializing in VHL. We had spent months feeling like we were spinning our wheels, but within the next few days we heard back from these neurosurgeons, each suggesting that there may still be treatments that could work for Scott. After much effort to convince the insurance company, Scott has received insurance approval to be seen at a Clinical Care Center.

My husband and I are feeling very hopeful that we will be able to receive good news and find the help we are seeking for him. The VHL Alliance was able to accomplish things that we would not have been able to do in months or even years. The staff were exceptional in all they did for us. Our “Thank You” is filled with much emotion and gratitude.

Sincerely,

Maria D.

Congratulations to VHLA Researchers

Each spring, the VHL Alliance invites researchers to submit grant applications to its competitive research grant program. Experts in VHL research around the world are asked to thoroughly review submissions using a process similar to that employed by the National Institutes of Health (NIH). The reviewers’ task is to identify grants with the greatest potential of advancing VHL treatment and a path towards a cure.

The final step of the review process is a presentation of reviewers’ input to the VHL Alliance’s Board of Directors. It is up to the board, as “guardians” of the hard-earned dollars generously donated by the VHL constituency, to exercise fiduciary responsibility. (In this way, VHLA will fund the highest quality research with the highest prospect of bringing us closer to VHLA’s vision of Curing Cancer through VHL.)

Ruhee Dere, PhD, an Assistant Professor at Baylor College of Medicine, is the recipient of this year’s Research Grant; an award of $100,000 over the next 2 years. Dr. Dere recently discovered that a protein called Aurora Kinase A (AURKA) is a novel target of the vhl gene. The mechanism of action is independent of hypoxia-inducible factors (HIFs) on which the drugs currently being tested are based. Using a mouse model, the impact of AURKA inhibition will be assessed. The overall goal of Dr. Dere’s work is to develop an alternate therapy for patients with VHL, particularly for patients who may not respond to the drugs described by Dr. Jonasch on page two.

Dhuval Patel, MD, a Staff Clinician at NIH’s National Cancer Institute, has been awarded a Pilot Grant. The Pilot Grant, $25,000 for one year, is seed money allowing a researcher the opportunity to acquire early data on an innovative research project. The goal of Dr. Patel’s project is to personalize the management of patients with pancreatic neuroendocrine tumors (pNETS). Data acquired through this study will lay the groundwork for determining the aggressive nature of pNETS in order to determine the best clinical approach for individual patients.

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Medical Wellness Coaching Piloted by VHLA

by Xia Wang, MD, PhD, Member of VHLA Clinical Care Center Team at Moffitt Cancer Center, Tampa, FL

As healthcare professionals, we went through schools, trainings, and professional development. We have confidence in our understanding of a condition, such as VHL. We counsel patients and their families to help them to make the best decisions so they get the best outcomes. But things do not always turn out as we expected they should or would. How can we make it better?

In the last six months, VHLA piloted a program designed specifically to enhance the work of the VHL Clinical Care Centers. Leona deVinne (Accendo Consulting) led us on a journey aimed at enhancing the mental and emotional well-being of our patients as well as ourselves, the healthcare professionals. On this journey, we made many discoveries of the emotional and psychological forces in our personal and work lives. For example, the Medical Wellness Coaching has opened us to practices such as introspection by unedited self-reflection, or building resilience by making connections or simply accepting a situation.

We learned how vastly different we are as human beings in terms of characteristics and core values, and how much these differences impact our daily communications. We also learned that exercising empathy for others can do much to break the barriers impeding communication. It is important to acknowledge that there are different languages to use when engaging patients in a discussion or decision making. In the wellness coaching sessions, we learned that when we encounter difficulties, instead of hitting the wall again and again and feeling defeated, we must step back, take deep breaths, allow inner-ease to take control, and regain the power.

Thank you to the VHL Alliance for providing us tools to enhance our VHL patient care!

FY17 Financial Report

by Andrea Rafael, VHLA Treasurer

The vision of the VHL Alliance is Curing Cancer through VHL - a cure that can only be found through research: research that takes years of work - not just by scientific researchers but by the entire VHL community. It takes dedicated people to contribute and raise the funds required to reach this dream. This is why research is one of the greatest expenditures of the VHL Alliance. In 2017 alone, $250,000 was earmarked to support research, a doubling from $125,000 in years past. These funds will be distributed over the next four years.

As we continue to dream of a cure, the VHL Alliance strives to fulfill its mission dedicated to research, education, and support to improve awareness, diagnosis, treatment, and quality of life for those affected by VHL. This includes education and support of the VHL community. Each year the VHL Alliance expands its reach by developing and implementing new initiatives to help a broader population. For example, this year marked the inauguration of VHLa’s Young Adult Program with a retreat in Tennessee. Mark your calendar for the 2018 retreat in Boston on June 8-10!

As we enter the giving season, this year, like every year, we ask you to dig as deep as possible. We at the VHL Alliance know that the amount is going to be different for each individual, but we also know that together we can reach our goal of raising $275,000 by the end of the year and $850,000 by June 30, 2018, the end of our fiscal year. We owe this to ourselves, our children, our grandchildren, and generations to come. Together, let us each commit to paying it forward in a meaningful way!

Report for Fiscal Year 2017
(ended June 30, 2017)

Double your Money and DONATE TODAY!

vhl.org/donate