As COVID-19 continued to impact individuals, families, businesses, and non-profits on a global scale, a ray of light has been the perseverance of the VHL Alliance. Among such uncertainty, last year, the VHLA was still able to continue providing critical programs and services for our community. In addition, funds in the amount of $275,000 were awarded for three new research grants as we continue our mission.

Revenue for Fiscal Year 2021 was $1,162,645 compared to $651,702 in the prior year. Our expenses in FY21 were roughly in line with FY20, having spent $836,495 and $806,310, respectively. As a result, the VHLA was able to show a profit in FY21 of $326,150 after a loss of $154,608 in FY20.

The VHLA continues to thrive thanks to the generosity of our donors, the passion of our volunteers, and the dedicated work of our staff. Exciting things are happening in the world of VHL, in clinics and research laboratories, and your continued support allows us to serve our global community. Please remember that the VHLA is able to accept, and assist with, the direct transfer of approved assets, which may be tax-advantageous for certain donors. Thank you for partnering with us in 2021, and know that we are filled with an increased sense of hope as we prepare for 2022.
For the VHL community, the summer of 2021 was most notably characterized by the FDA approval of Welireg (belzutifan), a first-of-its-kind oral medication for treating patients with VHL-related renal cell carcinoma, pancreatic neuroendocrine tumors, and hemangioblastomas. This is a breakthrough that gives VHL patients and others hope.

The VHL Alliance (VHLA) stood up to the challenge of spreading awareness of this incredible news to the patients and their treating physicians. This was accomplished by frequently updating our website with the most current news, links to drug information, and relevant resources. A short guide was also emailed out to inform all listed patients and physicians about the availability of the drug and guidelines for its use. In order to personally connect with patients, two “Town Hall” type virtual gatherings were held to get further information to the community and answer questions. This is yet another example of our commitment to making sure that all VHL patients have access to quality care. There were more than 230 attendees on the English call and 50 on the Spanish call. The discussions were followed by a supplementary video to answer additional questions. To ensure the medical community was well aware of this breakthrough, VHLA also held a nationwide conference specifically for physicians of all VHL Clinical Care Centers to share experience and initiate an academic discussion on the optimal use of Welireg and the need to explore the potential for additional clinical trials using the new medication.

Help us reach the next breakthrough!

In light of the recent breakthrough for VHL patients, we are encouraging you to double your donation to the VHL Alliance this year! We would be honored to receive your continued support as we look to the future of the next life-changing breakthrough!

If you are unable to match your gift from last year, please consider having someone donate in your honor to help you meet that goal! All new and increased donations will be matched, up to $70,000, between now and the end of 2021.

Thank you for partnering with us as we seek to Cure Cancer through VHL; with your support the possibilities are endless.

Special thanks to the following families who have made this match possible:

Bakke, Buckley, Greene, Horwitz

To make your donation, please visit vhl.org/donate
Clinical Care Centers (CCCs)

Over the past year, the VHL Alliance added 2 new US institutions and 1 new International institution to our VHL Clinical Care Center network.

“We are proud to expand our reach even further and excited to partner with world-renowned institutions like Roswell Park Comprehensive Cancer Center and UT Health San Antonio, in providing access to expertise and the best possible care for patients and families affected by VHL. The centers we work with have reputations for excellence and are dedicated to providing holistic, coordinated and knowledgeable VHL care to all of those who need it. We look forward to continuing to facilitate the life-changing impact that the CCCs make in the lives of patients and families affected by VHL. Chandra Clark, MEd - VHLA Executive Director

A GLOBAL PRESENCE

For you, for the children, the natural history of the VHL Disease will change, with a totally different and brighter future... Smile. Things are going to be better!”

Othon Iliopoulos, MD, PhD
Associate Professor, Medicine, Harvard Medical School, Associate Professor of Medicine, Center for Cancer Research, Massachusetts General Hospital

Legislative Advocacy

At the start of 2020, the VHL Alliance had never participated in any legislative advocacy efforts. After just one year of dedicated efforts to legislative advocacy, VHL is currently included in the FY22 Department of Defense Appropriations draft budget for the Congressionally Directed Medical Research Program (CDMRP), specifically in the list of conditions eligible for funding in the Peer Reviewed Cancer Research Program (PRCRP). Armed with our stories, we set out to convince influencers in Washington of the value of research into VHL. Our accounts of the challenges of living with VHL have resonated with several members of Congress who have VHL patients in their districts. Though we are currently waiting for the final budget to be passed, we are tremendously hopeful for the future of our advocacy efforts and the impact that these research funds will have. If you would like to get involved in our future advocacy efforts, please visit vhl.org/advocacy or email info@vhl.org.

Partnerships

The VHL Alliance is always looking for new ways to serve our community and spread VHL Awareness. This year we have embarked on several new partnerships to do just that. In June, we announced our collaboration with Angel Flight NE (angelflightne.org). Angel Flight helps VHL patients coordinate free air transportation to care centers that might otherwise be difficult to reach. More recently, we have partnered with CURE® (curetoday.com) to spread awareness of VHL. CURE® is the largest consumer magazine in the United States focused entirely on cancer. In August, two VHL patient’s stories were featured in an article in their Rare Cancer issue. We are thrilled to be educating outside of our new collaborators, we are proud of our continued relationships with organizations such as NORD, KidneyCan, RDLA, the American Urological Association, The Mighty, and more. Each partnership brings us closer to Curing Cancer through VHL.

What does the VHL Alliance mean to you?

“It’s a lifetime, pure and simple. It provides us with information, connections to others, and the most updated info on research.”

Amanda E. - Caregiver

What does VHL mean to you?

“Persistence, strength, fight, tenacity, never giving up, choosing joy (even in the hard times), and community! They don’t call us warriors for nothing.”

Joseph Heider - Patient and VHLA Ambassador

MyVHL Day

MyVHL Day, a new signature event that took place on May 22, was a massive success. Over 200 MyVHL surveys were submitted that day from VHL patients all over the world! This event was a wonderful way to celebrate and engage with other VHLers but also a unique opportunity to increase what researchers and healthcare professionals know about VHL.

Coacht Program: Surviving and Thriving Together

“My just a few weeks, the VHLA Surviving and Thriving Coach Program has already proven an invaluable resource for members of the VHL community, connecting us with each other, VHLA, and the medical professionals working toward progress with this illness. It’s a brilliant forum for patients to ask some of the more complex questions that accompany a life with a VHL, and know that we are addressing our questions to the most fore thinking individuals, regarding our very lives.”

Joseph Heider - Patient and VHLA Ambassador

Young Adult Retreat

The annual Julie Flynn Hope Retreat for Young Adults was held virtually on June 26. The conference presented our young VHLers with the opportunity to be among the first to learn about the latest results from the Phase 2 Belzutifan trial, in an intimate and safe setting, with VHL experts and peers. Numerous other meaningful discussions that took place included transitioning from dependence to independence, self-care, and advocacy. We look forward to hosting future Young Adult Retreats in Boston, including in 2022.

First Virtual Regional VHL Family Meeting

“On Saturday, August 21, VHL patients and caregivers gathered virtually for the first of its kind regional family meeting. Attendees had the opportunity to hear from physicians from the Texas based VHL Clinical Care Centers, MD Anderson Cancer Center (Houston), UT Southwestern (Dallas), and UT Health San Antonio. In breakout sessions, patients were able to learn more about center specific patient resources. To cap off the event, Dr. Eric Jonasch spoke and answered questions on FDA approval of Welireg. The VHL Alliance plans to host similar meetings to promote community and share patient and caregiver resources at the VHL Clinical Care Centers.”

Marissa Beasley - Patient and VHLA Ambassador

Social Media Impact in 2021

The VHL Alliance’s social media engagement has increased by roughly 200% this year, with Instagram Stories drawing the most direct engagement with the VHL community. Instagram Takeovers were massive draws for VHL Warriors to engage with the VHL Alliance community, and VHL Warrior Spotlights received the most engagement across all social media platforms. The presence and visibility of the VHL Alliance vastly increased on all of our social media accounts in 2021.

What does VHL mean to you?

“Endlessness, hope, perseverance, strength, fight, tenacity, never giving up, choosing joy (even in the hard times), community! They don’t call us warriors for nothing.”

Jordan McGuire

A Better Life

Would you like to increase happiness, sleep better, recover from traumatic events all while strengthening your immune system? Yes, of course, please sign me up for this immediately. I am a parent and caretaker of a child with VHL, and I need all the help I can get. It just so happens that we are all in luck, there is a way to navigate the most challenging of situations while increasing our wellbeing.

Numerous studies and research have proven that there are direct social, physical, and psychological benefits of gratitude. The benefits mentioned above are available to anyone that practices gratitude. Gratitude is the appreciation of what is valuable and meaningful to oneself. Basically, it is declaring that there is goodness in life, even in the smallest of things.

You may be thinking, this all sounds great, but how do I foster gratitude? I will share two ways that have increased my life satisfaction, even after learning of my daughter’s diagnosis which led me to feel helplessly overwhelmed. First, I kept a gratitude journal, and it started as a weekly list of 5 things I was grateful for, which evolved into daily practice. I started going for walks most days, and I purposely looked for birds, butterflies, flowers, anything that brought me joy. It is about noticing the good in one’s life. These two activities have helped me live a better life. There are numerous science-based ways to cultivate gratitude and you can find which works best for you. Give it a try, gratitude is good. Modeling gratitude in your daily life will make a direct positive impact on your family and children as well.

Gratitude is an attitude, one that I boastfully share.

Amanda E. - Caregiver

REFERENCES