

2024 IMPACT REPORT





Salutations, Friends of the VHL Community!

2024 was an incredible year of impact, especially for VHL research! Uplifted by the generous support of families and partners, the VHL Alliance grew in both people power and mission accomplishments! Look at what we did together:

Community fortifying in-person events. 30 Young Adults with lived VHL experience gathered in Washington, D.C. for a weekend of social bonding and medical empowerment. 100+ members of the VHL Family and Clinical communities gathered for an enriching Family Weekend in Dallas, Texas. Over 30 teams walked “together, apart” on May 18 in neighborhoods across the country for the inaugural VHL Walk for awareness and we crushed our fundraising goals!

VHL Research, Multiplied. In addition to the annual award of VHLA research grants, our family led advocacy efforts enabled multiple VHL topic focused project applications to the Department of Defense Peer Reviewed Medical Research Program, resulting in over \$2 million of additional research funding. Over 250 researchers, clinicians, and medical students attended the 16th International VHL Medical Symposium in Milan, Italy for the largest ever thought exchange focused solely on von Hippel Lindau.

Adding More Educational Resources. We launched a new Monthly Blog along with a Virtual Education Series to bring to families important insights concerning topics like Belzutifan, VHL Research Literacy, and guidance on the financial management of VHL.

The Power of Our People. We added three new staff members to increase efforts in research initiatives, federal advocacy, family engagement, and diversification of our outreach, and built stronger relationships with NIH and Clinical Care Teams. We also piloted a re-envisioned nationwide Ambassador Program to leverage volunteers and expand the regional engagement footprint.

We are honored to continue our 31 year legacy of VHL patient empowerment and we look forward to serving you in 2025.

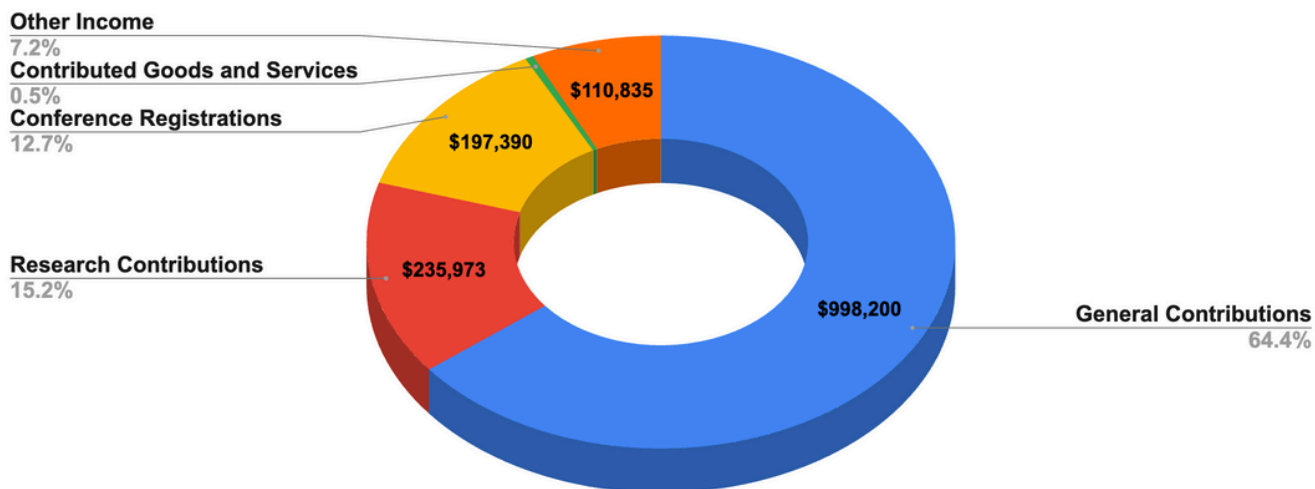
Warmly,
Janet Thompson
Executive Director
VHL Alliance

FINANCIALS

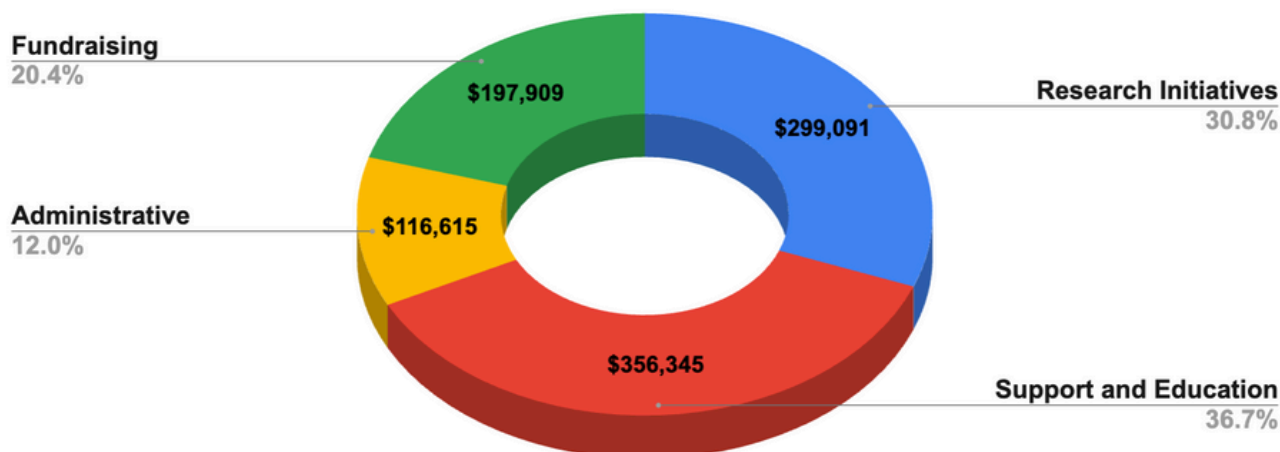
The VHL Community continues its legacy of generosity to support the strategic activity of the Alliance. A special gift this year from the Rath Family will super charge our research initiatives and sustain critical programming for years to come. Below is an audited summary of our financial activity for the year that ended June 30, 2024. For more financial information about the VHL Alliance please visit our website at www.vhl.org/about-us/reports

Total Assets	\$2,316,168
Total Liabilities	\$222,617
Net Assets	\$2,093,551
Change in Net Assets	+ \$579,590

Revenue: \$1,549,550



Expenses: \$969,960



Our 2024 Achievements:



Young Adult Retreat in DC

We hosted a successful young adult retreat in Washington, D.C., providing a space for connection, support, and empowerment among young adults navigating VHL.



New VHL Research Fellow

We welcomed a VHL research fellow dedicated to translating cutting-edge research into accessible content, ensuring our community stays informed about the latest advancements in VHL.

Patient Centered Programs

Our ongoing patient programs, including the VHL Handbook and monthly support calls, continue to provide essential resources to those affected by VHL.



First VHL Walk

The first annual VHL Awareness Walk in May 2024 brought together the VHL community to raise awareness, support research, and foster a sense of solidarity among patients, families, and advocates.



Community-Wide Survey

The VHL Alliance conducted a comprehensive community survey last year, garnering over 400 responses which will guide the enhancement of our programs to better meet the needs of our community.



Family Weekend in Dallas

In partnership with UT Southwestern, VHL Family Weekend in Dallas, Texas, was a huge success, fostering connections and sharing valuable resources for families affected by VHL.



Tumor Board

The impact of the Tumor Board has grown internationally, including cases from China and Australia, and continues to facilitate expert discussions to enhance treatment outcomes for individuals with VHL.



16th VHL Medical Symposium

The 16th VHL Medical Symposium in Milan brought together the largest gathering of VHL experts globally, fostering collaboration and sharing the latest findings in VHL research.

Looking Ahead:

Educational Webinar Series

In 2025, we will continue our Educational Webinar Series featuring leading VHL experts, providing the community with valuable insights and updates on the latest research and treatment options.



VHL Research Library

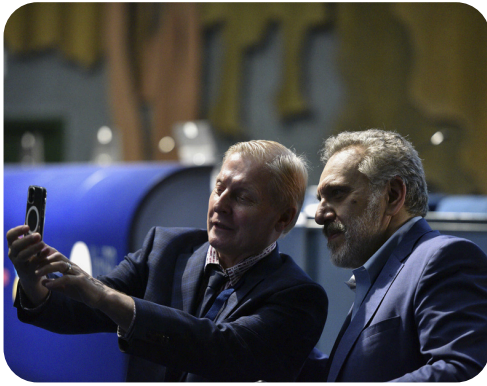
We are working to curate a comprehensive research library of VHL studies, creating a centralized resource for our community to access important findings and advancements in VHL research.



VHL Patient Registry 2.0

We plan to launch a revamped patient registry database, designed to be more user-friendly, streamlining the process for patients to contribute valuable health data and insights.





Monthly Blog Content

Our commitment to addressing the unique needs of the VHL community will continue with monthly blog pieces, offering relatable content and practical advice tailored to those affected by VHL.



**photo courtesy of KidneyCAN*

Patient Ambassador Program

The redeployment of our Patient Ambassador Program will enhance peer support, connecting newly diagnosed individuals with experienced members to foster understanding and empowerment.

Medical Education

We plan to expand our impact on medical education by developing and deploying continuing medical education (CME) programs and increasing our focus on educating primary care physicians to improve early detection and treatment of VHL.



Advocating for Federal Funding

We will continue to advocate for increased federal funding in Congress, working tirelessly to ensure that VHL research and patient support programs receive the necessary resources to advance treatment and improve outcomes for our community.



Support Our Mission

Donate before Jan 1st to double your impact!

Did you know that every donation made between now and Jan 1 will be matched 1:1 up to a total of \$100k? **This is the only time this year you can double your donation.**

You can make a difference for VHL patients and families by supporting our end-of-year campaign today. Your gift to the VHL Alliance sustains life-changing programs and initiatives. The generosity of individual donors like you provides the majority of our funding, allowing us to offer crucial programs such as the Family Weekend, Young Adult Retreat, and research grants that bring us closer to new treatments for VHL.

We've also made it easier than ever to give. In addition to traditional donations, you can now support the VHL Alliance through our "Fundraise Your Way" platform, as well as real estate, vehicle, and stock contributions. These new options offer more flexibility in how you choose to make an impact, helping us further our mission to improve the lives of those affected by VHL.

With your help, we can continue to deliver these vital resources to the VHL community.



Scan the QR code or use the enclosed envelope to support our mission.

