



IMPACT REPORT 2023

Celebrating 30 years of service through building community, advancing research, and improving health outcomes for the VHL community.

The VHL Alliance advocates every day for people living with VHL, supports the latest research for treatments, and empowers families to live their lives to the fullest.

Advancing VHL Research

The VHLA Research Council **awarded \$325,000 for three new grants** to leading and emerging researchers, furthering efforts to create new treatments and improve health outcomes.

The VHL Alliance Advocacy Team successfully **opened access to millions of federal research dollars for VHL specific research** through the DoD's Peer Reviewed Cancer Research Program.

Connecting the VHL Community

The **2023 Young Adult Retreat in Washington D.C. and the Annual Family Meeting in Nashville, TN**, brought together hundreds of families navigating VHL with clinicians and counselors for knowledge sharing, emotional support, and community building.

36 Virtual Support Groups and webinars connected hundreds of individuals across the country, to educate and empower the VHL community. The VHL Alliance facebook group, [VHL: Spreading Awareness of von Hippel-Lindau](#) is the largest of its kind in the world, hosting over 4,800 members in a safe and moderated space.

The **VHLA 30th Anniversary Gala honoring Dr. Eric Jonasch** was held at the Franklin Institute in Philadelphia, PA, for a celebration of the impressive strides made to improve health outcomes for individuals with VHL.

Delivering Tools for Health Empowerment

9 VHL Tumor Boards were hosted by the VHL Alliance and leading VHL medical experts, enabling 27 VHL cases to be presented by clinicians from around the world.

Over 1200 VHL patients accessed superior coordinated care through our **network of 39 Clinical Care Centers** across the U.S. with three additional centers in the certification pipeline.

Developing stronger **partnerships with the National Institutes of Health (NIH)** for newly diagnosed patients seeking additional information about VHL at no cost.

After 14 years, a newly revised **Kids' VHL Handbook** is available for download. Learn about VHL and how families navigate the condition in a child-friendly presentation.

A new **VHL Alliance website** was launched in five languages making all handbooks, guidelines, and resources freely available.

Looking ahead to 2024

Research: The 2024 VHLA Research Grant Program will review the largest number of project applications to date. We are expanding engagement and education to our research community to support and incentivize future advancements in VHL research.

Patient Support: Clinical Care Center Network expansion. Exploring new and innovative medical guidance opportunities. Growing local patient engagement and education, through a re-envisioned ambassador program.

Hosting Impactful In-Person Events:

Young Adult Retreat | *Feb 23-25 in Washington D.C*

Family Meeting | *Sept 6-8 in Dallas, TX*

International Medical Symposium | *Oct 25-27 in Milan, Italy*

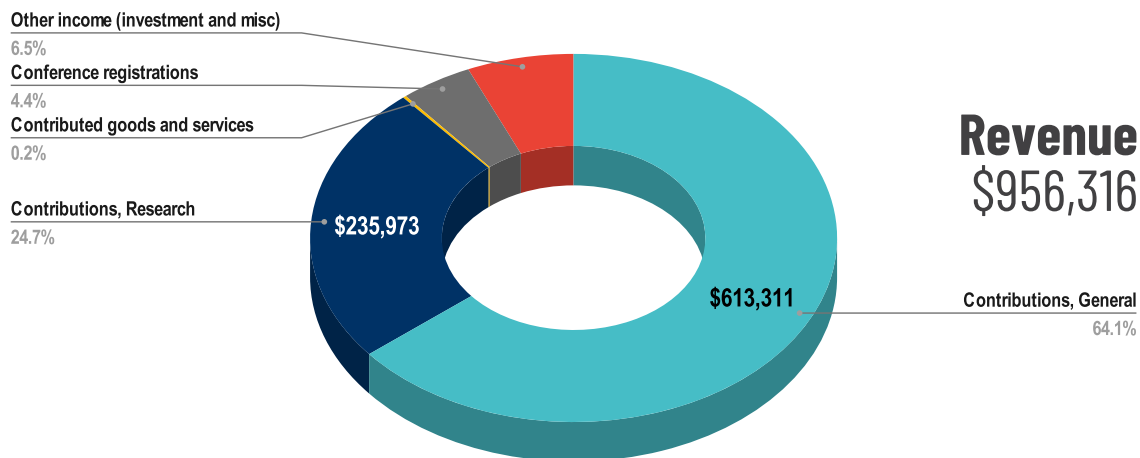
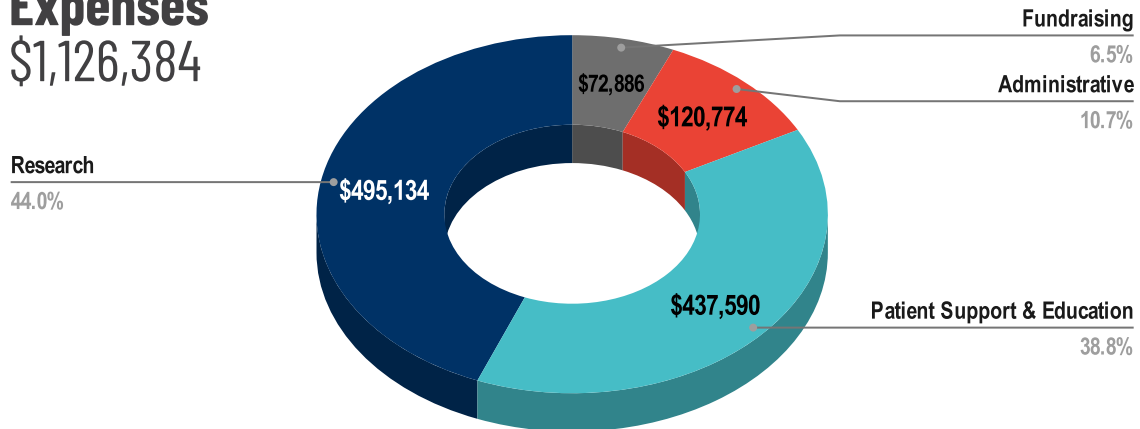
FINANCIAL SUMMARY

Fiscal Year July 1, 2022 - June 30, 2023

The VHL Alliance continues to leverage the generosity of our partners, as well as our financial reserves, to advance our mission throughout the fiscal year. Below is an audited summary of our financial activity for the year that ended June 30, 2023. For more financial information about the VHL Alliance, please visit our website at www.vhl.org/about-us/reports.

| | |
|---------------------------------------|--------------------|
| Total Assets | \$1,871,941 |
| Total Liabilities | \$357,980 |
| Net Assets | \$1,513,961 |
| Change in Net Assets from FY22 | (\$170,068) |

Expenses \$1,126,384



ACKNOWLEDGEMENTS

Our dedicated volunteers and generous donors play a crucial role in making our mission a reality. Their commitment and contributions empower the VHL Alliance to continue making strides in research, providing crucial support networks, and raising awareness to ultimately improve the quality of life for those facing the challenges of VHL. Together, our collective efforts exemplify the spirit of compassion and community that drives progress in the fight against VHL.

VHLA Staff and Support

Janet Thompson, *Executive Director*
Josh Mann, MPH, *Director of Health*
Michelle Dicken, *Director of Development*
Anders Bjella, *Marketing Manager*
Katherine Taylor, *Administrative Assistant*
Kathy Arnstein, *Finance Assistant*
David Grant, *Human Resources*
Camron King, *ARC*
Andres Polanco, *ARC*
Mark Vieth, *Advocacy Advisement*
Seth Horwitz, *Financial Advisement*
John Kilgo, PMP, *CSM Data Analysis*
Jennifer Galenkamp, *Advocacy Committee Co-Chair*

Thank You To Our Premier Corporate Sponsor



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Special Thanks To The:

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