VHL ALLIANCE

IMPACT REPORT

2025

A YEAR OF RESILIENCE

JANET THOMPSON

Executive Director

Hello VHL Family! This past year was marked with challenges and significant uncertainty, most notably around US scientific funding. Despite this, the VHL Alliance achieved a year of tangible impact and growth, demonstrating profound resilience.

Our 2025 Impact Highlights:

- Secured $7 Million in VHL funding, directly supporting research grants.
- Hosted our largest VHLA Family Meeting to date alongside the University of Michigan, reinforcing educational empowerment and shared hope.
- Strengthened community via our successful new VHL Connect program and nationwide VHLA Walk.
- Launched the Digital Research Library to unify and democratize VHL knowledge for scientists and advocates.
- Expanded leadership with new ambassadors, advocates, board leaders, and volunteers.

2026 will usher in new programs and a new era of strategic focus.

VHL Research Forum: A dedicated summit for high-level investigator exchange and collaboration.
Clinical Care Network Expansion: Ensuring specialized VHL care is more accessible and expanded throughout the country.
MD Anderson-led VHL Patient Consortium: A major investment in sharing data to accelerate discovery in VHL treatments and quality of life.
Strategic Planning for VHL Alliance 2030: The newly formed VHLA Strategic Committee will assess strengths and opportunities to best serve our community in the next decade.

We want to sincerely thank you for your commitment to the VHL Alliance. Your support fuels everything we will accomplish together in the year ahead!

The Alliance is thrilled to welcome Kwame Garett-Price as our new board chair

FINANCIAL STATEMENTS

INCOME STATEMENTS

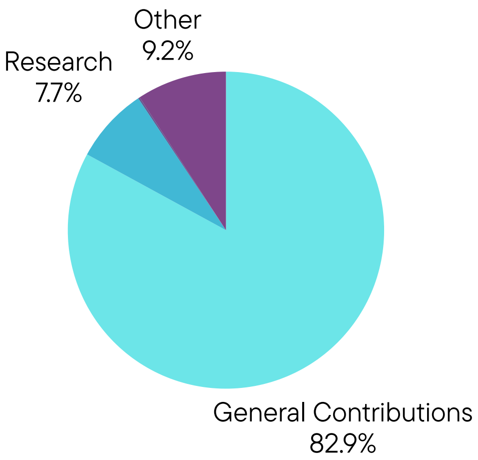
The VHL Alliance drove exceptional financial growth and mission impact in Fiscal Year 2025, powered by the sustained generosity of our community. We strategically invested nearly $800k directly into critical research and educational initiatives, simultaneously demonstrating fiscal responsibility by reducing overall overhead costs.

This approach ensured that our revenue significantly outpaced expenses, delivering a net positive increase in Net Assets for the year. The Alliance closed FY2025 in a robust and healthy financial position, ready to accelerate our fight against VHL.

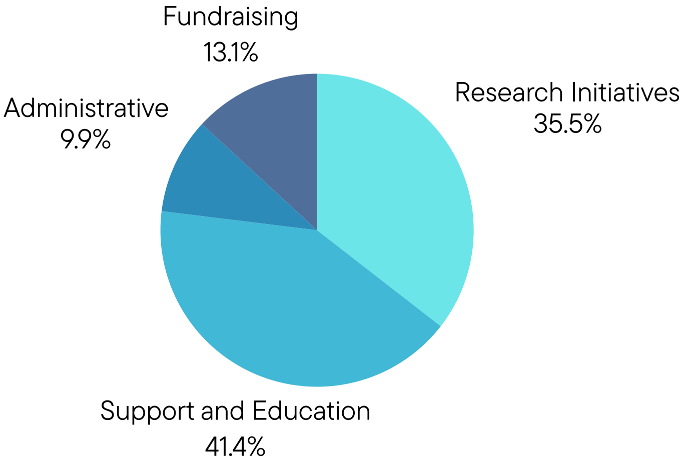
Below is an audited summary of our financial activity for the fiscal year ending June 30, 2025. For full transparency and detailed reports, please visit our website at www.vhl.org/about-us/reports.

Total Assets	**$2.5M**
Total Liabilities	**$326k**
Net Assets	**$2.2M**
Change in Net Assets	**$143k**

REVENUE: $1,176,601



EXPENSES: $1,032,869



FAMILY WEEKEND 2025

The 2025 VHL Family Weekend in Ann Arbor brought together patients, families, and experts for a weekend of learning and community. Highlights included a welcome tailgate and tour of the Big House, followed by a full day of expert presentations in partnership with the University of Michigan Clinical Care Center. "It feels really good to share with people who understand my situation and what I've been through." shares, Lily W. who came to FW2025 with her husband and daughter. "We can be ourselves, be comfortable, and have that community to lean on."

VHL CONNECT

- VHL Connect brings patients, caregivers, and clinicians together to share knowledge, ask questions, and build community. Hosted in partnership with VHL Clinical Care Centers, these gatherings provide trusted information and direct access to experts, helping individuals and families affected by VHL feel informed and supported.
- This year's VHL Connect events took place in Houston, Philadelphia, Salt Lake City, Boston, Costa Mesa, and Atlanta. Each featured expert presentations, Q&A sessions, and opportunities for peer connection, creating spaces for learning and support across the VHL community. Visit vhl.org/events for 2026 locations!

100+
Family Weekend
Attendees

6
VHL Connect
Events in 2025

PSYCHOSOCIAL SUPPORT

Living with VHL often takes an enormous toll on a person's mental health. The VHL Alliance is committed to supporting the emotional well-being of individuals and families affected by VHL through a range of psychosocial programs.

MONTHLY SUPPORT CALLS

Our regular Patient/Caregiver and Low/No Vision support calls provide a safe, understanding space for open discussion and shared experience, and we're honored to welcome **Devon Ciampa, DSW, LCSW-C,** as the new moderator for the Patient/Caregiver call! These sessions offer guidance and connection from experts who have dedicated their careers to helping people navigate moments of uncertainty and change.

1:1 WELLNESS COACHING

Through our Wellness Coaching Program, participants receive personalized, one-on-one support focused on coping strategies, lifestyle balance, and emotional resilience.

WEBINAR SERIES

In 2025, we hosted several webinars exploring the mental, emotional, and medical dimensions of living with VHL. Visit vhl.org/events to stay informed about upcoming webinars!

RESEARCH & ADVOCACY

Picture provided curtesy of KidneyCan

2025 VHL GRANT RECIPIENT IAN FREW

Dr. Ian Frew, Professor of Oncogenic Signaling at the University of Freiburg, studies how genetic mutations shape the behavior and treatment response of kidney cancer cells. With support of a $100,000 research grant from the VHL Alliance, his team is developing a new mouse model that more accurately reflects VHL-related kidney cancer. By strategically inactivating four key genes involved in tumor formation - Vhl, Pbrm1, Bap1, and Setd2 - this cutting-edge model is expected to provide insight into the complex biological processes that drive VHL-related tumor formation and guide the development of future therapies.

DIGITAL RESEARCH LIBRARY

The new VHL Research Library makes scientific knowledge accessible for everyone in the VHL community, including patients, caregivers, clinicians, and researchers. This free, user-friendly database gathers the latest VHL research and educational resources in one convenient place, making it easier than ever to explore relevant studies, understand treatment options, and make informed health decisions.

$7 MILLION IN CDMRP

This past year, advocacy efforts yielded remarkable success! Nine VHL research applications were submitted for CDMRP funding, and three received funding totaling over $7 million—an outstanding achievement for the VHL research community.

VHL PATIENT CONSORTIUM

The VHL Patient Data Consortium is a collaborative project between four VHL Clinical Care Centers who seek to collect, analyze, and share VHL natural history data from 80+ individuals. Using genetic, quality of life, tissue, and imaging data, the consortium aims to enhance understanding of von Hipple Lindau and accelerate treatment breakthroughs. The VHL Alliance is a proud sponsor of this work and seeks to expand participation that will multiply patient centric outcomes.

THE UNIVERSITY OF TEXAS
MDAnderson
~~Cancer~~ Center

Penn
Medicine

VANDERBILT
HEALTH

BC
CAN
CER

80+

Individuals with VHL

4

Collaborative CCC’s

1

Comprehensive look at historical VHL data

- The 2025 VHL Awareness Walk brought together hundreds of participants across the country in a powerful show of unity and commitment to our mission.
- Together, we raised more than $100,000 to fuel critical research, improve care, and support families affected by VHL disease.

VHL AWARENESS WALK

$100k
Raised in 2025

25+
Walk locations nationwide

JOIN VHL FAMILIES, FRIENDS, AND SUPPORTERS ACROSS THE COUNTRY AS WE WALK TOGETHER TO RAISE CRITICAL FUNDS FOR VHL RESEARCH AND PATIENT SUPPORT PROGRAMS.

We're excited to share that the **2026 VHL Awareness Walk will take place on Saturday, May 16, 2026,** uniting our community once again in support of VHL research and patient programs.

The VHL Awareness Walk is more than a fundraiser. It's a celebration of resilience and progress! Whether you join from your local park or your own neighborhood, every step you take helps support new VHL research and improved health outcomes for people living with VHL.

Getting involved is simple: register to walk, start a fundraising team, or make a donation to support the cause. Mark your calendar for May 16, lace up your shoes, and join us as we walk for a future free from VHL.

POWERING PROGRESS

ONLINE

With a credit card
or bank transfer

P2P

Set up a peer to peer
fundraiser with
fundraise your way

CARS

Donate your vehicle
via our cars program

BECAUSE OF YOU, WE'RE ABLE TO ADVANCE RESEARCH, SUPPORT FAMILIES, AND BRING HOPE TO THE VHL COMMUNITY.

There are many ways to give and stay involved. You can make a one-time donation or become a monthly supporter, helping sustain programs and research all year long. Many in our community give in honor or memory of loved ones, participate in workplace giving or matching gift programs, or even donate a vehicle, turning cars, trucks, and boats into impact.

We extend our heartfelt gratitude to our VHL Visionaries, a dedicated group of supporters whose generosity and commitment fuel lasting impact for the VHL community.

2025 VHL VISIONARIES:

Bakke • Borg • Brooks • Buckley • Cooke • Dixon • Engel • Friedman • Greene
Horwitz • Lawson • Mitchum • Modrall • Nirody • Rath • Stalvey • Zarro

MERCK

LYDA HILL
PHILANTHROPIES

LOOKING AHEAD

- ✱ We're thrilled to announce that VHL Family Weekend 2026 will take place August 7–9 in Los Angeles, California, in partnership with the UCLA Clinical Care Center team!
- ✱ We're adding a new Young Adult focused track in 2026. This will feature sessions and social events designed specifically for young adults navigating life with VHL. More info to come soon!

FAMILY WEEKEND 2026

32nd
Annual Family Weekend

150+
Expected Attendees

MARK YOUR CALENDARS!
VHL FAMILY WEEKEND RETURNS AUGUST 7–9, 2026

Join us for **VHL Family Weekend 2026 in Los Angeles, California!** This annual gathering brings together individuals and families affected by VHL for a weekend of learning, connection, and support. Over three days, participants will have the opportunity to hear from leading VHL experts, share experiences with others who understand, and strengthen connections within the VHL community.

Here's a look at what's ahead:

- Friday kicks off with a welcome dinner and community gathering, setting the tone for a weekend of togetherness.
- Saturday will feature engaging medical presentations and breakout sessions, including clinical professional and patient panels designed to inform and empower.
- We'll wrap up on Sunday with a wellness brunch focused on psychosocial wellbeing.

Save the date today and start planning your trip to sunny Los Angeles. We can't wait to see you there! More details, including registration information and a full schedule, will be shared soon.

100 YEARS OF VHL RESEARCH

CENTURY OF PROGRESS

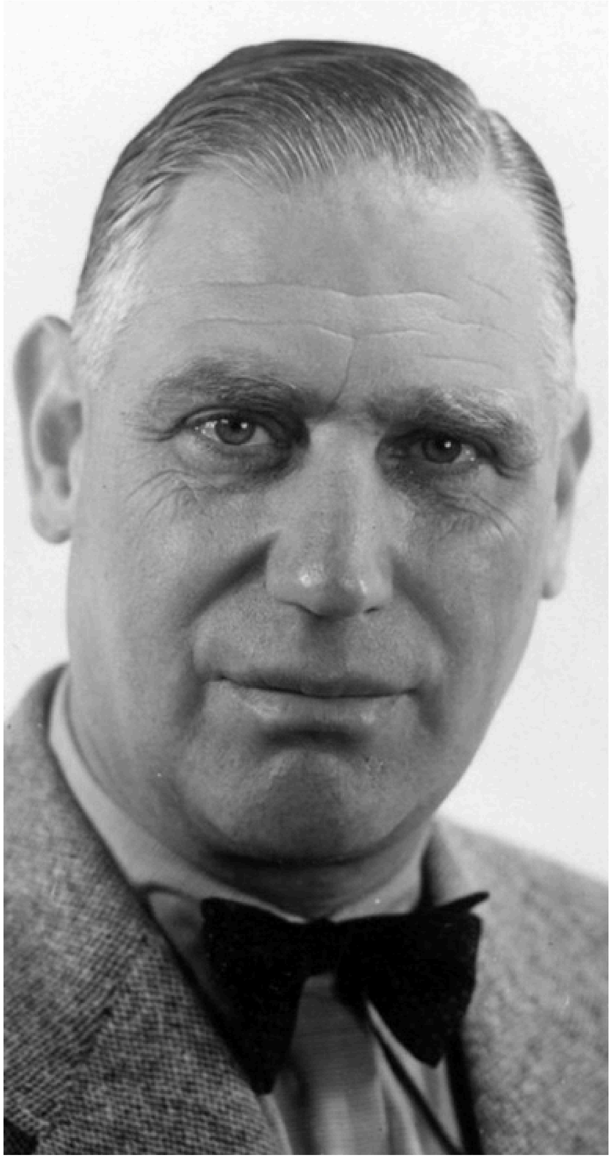
2026 will mark 100 years since Arvid Vilhelm Lindau's discovery connecting retinal and central nervous system tumors, laying the groundwork for all modern VHL research.

AMPLIFYING RESEARCH

With support from the VHL Alliance, Dr. Eric Jonasch's multi-institutional team is creating a data-sharing platform and virtual tissue bank to study the natural history of VHL-related tumors and how specific VHL mutations influence response to belzutifan and other treatments.

RESEARCH FORUM

The inaugural VHL Research Forum brought together leading VHL scholars for an intensive, two-day think-tank-style meeting focused on accelerating progress in VHL research. Through solution-driven discussion, participants identified new opportunities for collaboration and translation of research into real-world impact.



1926

In 1926, Dr. Arvid Vilhelm Lindau, a Swedish pathologist, published his landmark doctoral thesis describing the relationship between central nervous system hemangioblastomas and visceral lesions (particularly in the kidneys and pancreas).

DOUBLE YOUR DONATION

All gifts made to the VHL Alliance between now and **January 1 will be matched 1:1, up to $100,000.** Your generosity helps advance research, education, and care for the VHL community.

$100

sponsors a one-to-one professional wellness coaching session for a newly diagnosed individual with VHL

$250

affords a post-doctoral professional the opportunity to present their VHL poster to a national scientific research conference

$450

covers the cost to run an average sized VHL research lab for 1 hour.