



VHL ALLIANCE

Impact Report



2022

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Hope Elevated

A Letter from VHL Alliance Chair of the Board, Stacy Lloyd

As I kick off my tenure as Chair of the Board for the VHL Alliance, I can't help but be grateful for this organization and the community it's built over the years. I'm constantly amazed and inspired by the positivity, resilience, dedication, and hope shown by my fellow VHL patients and families and the healthcare teams that care for us.

The last few years have been both transitional and transformational for the VHLA and our community! We have new team members, the first FDA-approved drug for VHL, and a new strategic framework. We have reinforced our commitment to diversity, equity, and inclusion by training and developing a new DEI task force. Our advocacy efforts have added VHL to the CDMRP, which means more opportunities for VHL research funding. And the VHL Alliance became a member of the National Health Council, which further ascertained our growth as an organization.

As we continue to thrive as an organization, I'm excited to work alongside the VHLA staff, board, and community to operationalize our new strategic plan that will undoubtedly lead the VHL Alliance into its next growth phase. It's an honor to have the opportunity to serve, and I look forward to continuing the work of the VHL Alliance to positively impact VHL patients, families, and healthcare teams!

Stacy Lloyd

Developments Bringing Hope

1

Welireg Approved!

The approval of Welireg for treating VHL-associated renal cell carcinomas, CNS hemangioblastomas, and pancreatic neuroendocrine tumors was a game changer for patients with VHL. The VHL Alliance conducted three town halls with hundreds of VHL patients from around the world to inform the community about the new medication.

2

VHL Clinical Care Centers

"VHL Clinical Care Centers are designed to be a one-stop shop, with experts who know the ins and outs for virtually every issue that may arise. Because the VHL centers are connected with each other, when one center has a unique area of expertise needed by a patient for a highly specific issue, we can also readily draw on the nationwide expertise of our colleagues – all part of a bigger team."

W. Kimryn Rathmell, MD, PhD

3

Virtual Tumor Boards

One of the most impactful medical initiatives taken by the VHL Alliance is the establishment of a virtual International VHL Tumor Board (IVTB), a cooperative body of healthcare providers who gather to present complex cases for discussion and input from their colleagues and experts. IVTB is a significant step in promoting the frequent worldwide exchange of clinical experience with the treatment of VHL patients.

4

2023 MyVHL Update

In early 2023, VHLA is coordinating with the National Organization for Rare Disorders (NORD) to roll out a new and evolved *MyVHL* platform. The upgrades will feature such developments as integrated language translations (initially French and Spanish) and a more intuitive user experience.

2022

Julie Flynn HOPE Retreat
for Young Adults

Thank you to all who attended the 2022 Young Adult Retreat, presented as a virtual event to build community and learn together - it wouldn't have been the same without everyone involved. The Retreat seeks to build a network and strong peer support system that makes dealing with everything a whole lot easier. Details of the 2023 Young Adult Retreat will be released soon, for February, and we look forward to seeing everyone there!



2022 Event Highlights

International Medical / Research Symposium

Held in partnership with the Canadian VHL Alliance and the Toronto VHL Network, the 15th International VHL Medical/Research Symposium was a success. Over 120 researchers and clinicians from around the world attended to hear presentations on developments in care, research, treatment, and work in various parts of the world. Highlight presentations were provided by VHL champions and experts such as W. Marston Linehan, MD, Chief of Urologic Surgery and the Urologic Oncology Branch at the National Cancer Institute, and Gregg L. Semenza, MD, Ph.D., recipient of the 2019 Nobel Prize in Medicine or Physiology.

More information about the 16th International VHL Medical/Research Symposium, held in partnership with IRCCS San Raffaele Hospital in Milan, Italy in 2024, will be released soon.

VHLA Annual Family Weekend

Stanford University Medical Center and the VHL Clinical Care Center team hosted 94 members of the VHL community in person for a vibrant session of presentations, updates, sharing, and collaborating on October 22, 2022. Attendees came from throughout the country and abroad to learn about VHL care and innovation in treatments and to build a robust connection between patients, caregivers, and the medical community.

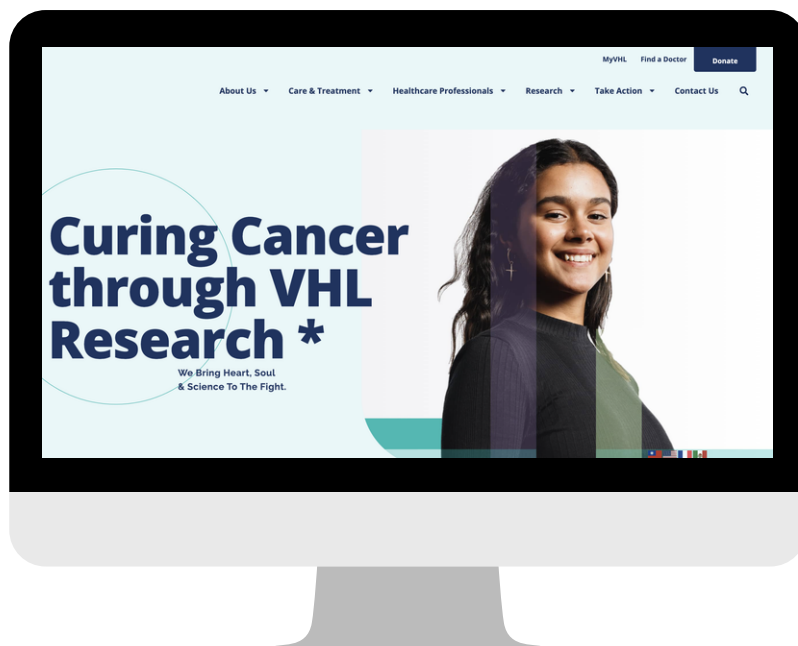


Looking to the future

Our mission is improving the quality of life and health outcomes for VHL patients, families, and caregivers with inclusive community building, connections to excellent education and treatment options, and advancements in medical research.



In 2023, the VHL Alliance will celebrate the organization's 30th Anniversary! So many advancements have been made in this time, and the future holds more hope than ever. As an exciting component to the anniversary we've updated our website and our branding. The vibrance of the community is the bedrock of VHL's success and we encourage everyone to join in building a more hopeful and bright future.



Thank you for your ongoing support!

Acknowledgements

The VHL Alliance is supported by an incredible staff, volunteers, families, clinicians, and partners. Without the following, and countless others in the community, progress and development would not be possible.

**Please note that this is a partial list. An incredible note of appreciation goes out to the VHL community and volunteers that bring the activities of the Alliance to life.*

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