VHL Alliance

# SPRING 2024 NEWSLETTER

# Hello Friends of the VHL Community!

Leading the VHL Alliance this past year has been an incredible honor, and one that I deeply cherish. Serving at the helm of an organization dedicated to supporting individuals affected by von Hippel-Lindau (VHL) disease and advancing research into this rare condition has been immensely rewarding. Witnessing the resilience and determination of our community members in the face of challenges has inspired me beyond measure. I'm so proud of our accomplishments in the past 12 months that include:

- Growing our Clinical Care Center Network to 40 with the addition of the University of Florida Health
- Receiving 27 VHL research applications for the 2024 VHLA Research Grant Program, the highest number since our inception in 1993
- Awarding over $300,000 towards the next generation of VHL research projects, bringing us closer to improved treatments and a cure
- Receiving the largest single donation in VHLA's history, a generous $500,000 grant from the Rath Family to advance research collaboration and VHL family member education
- Celebrating the appointment of Dr. Kim Rathmell, a former VHL Research Council member, as the Director of the National Cancer Institute at the National Institutes of Health
- Hosting the largest cohort of Young Adults with VHL for a weekend in D.C. of community building and medical education alongside NIH leaders
- Opening the aperture of federal research funding opportunities specifically for VHL related projects and securing the congressional support required to do so by our dedicated team of patient advocates

As we head into May VHL Awareness month, I am excited to see the worldwide VHL community come together virtually and in person for our first VHL Alliance Walk on May 18th. This event is an opportunity to show our strength and collective determination to live lives to our fullest potential in spite of obstacles.

We are gearing up for the largest Family Meeting to date this September in Dallas, Texas and our international VHL Medical Symposium in October with our partners from San Rafael Medical Center in Milan, Italy.

It has been a privilege to work alongside passionate individuals united in our mission to improve the lives of those impacted by VHL. As I reflect on the past year, I am filled with gratitude for the opportunity to lead such a dedicated and compassionate team, and I look forward to the continued journey ahead, knowing that our collective efforts will make a meaningful difference in the lives of countless individuals and families affected by VHL.

Warmly,

Janet Thompson

*Executive Director*

# The VHL Alliance Community Survey

In our ongoing commitment to better understand and serve the VHL community, we launched a comprehensive survey last fall, aimed at capturing insights and perspectives from individuals affected by VHL, caregivers, and healthcare professionals. This initiative underscores our dedication to fostering a deeper understanding of the unique challenges and needs within the VHL community, ultimately guiding us in our mission to provide enhanced support, resources, and advocacy efforts.

**400+**

Recorded responses from the community

**84.5%**

Of respondents feel empowered to advocate for their own healthcare

**85%**

Of respondents are satisfied with current programs and services

## Key Takeaways

### 1. VHL Research

VHL research continues to be a top priority for our community. We are committed to continuing to support leading VHL researchers across the globe via our research grant programs and growing network of Clinical Care Centers.

### 2. Financial Focus

Navigating the insurance and financial challenges that come along with VHL is an ongoing issue. We are working internally to better understand how we can adjust our programs to better meet this need.

### 3. CCC Network

The CCC network is highly rated, and most respondents expressed that they'd like to see the Alliance continue to grow the network of Clinical Care Centers across the United States.

### 4. Volunteering

Community members are eager to volunteer their time, especially in the areas of patient/family mentorship and local community building events.

## Looking ahead

Be on the lookout for dynamic developments in:

1) The VHLA's approach to research with new collaboration opportunities and improved communication tools

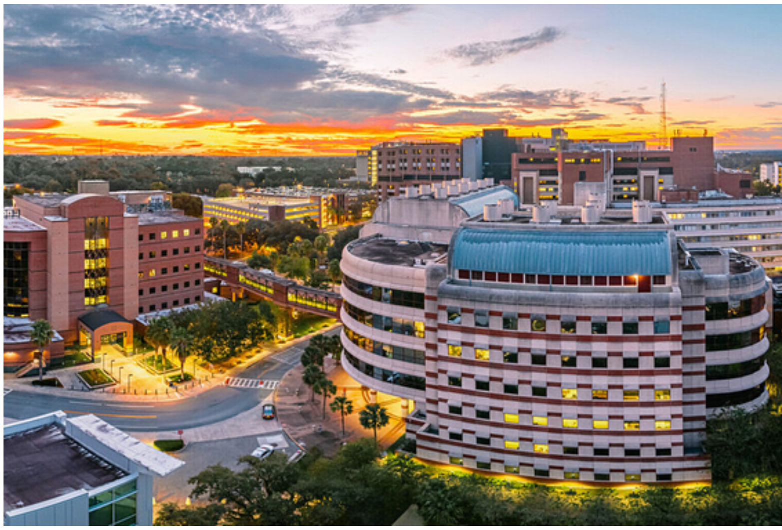
2) Expanding and strengthening the network of VHL CCC's with intentional initiatives to engage with Spanish-speaking communities

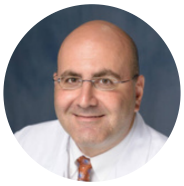
3) Leveraging the power of volunteerism through a re-launch of ambassador, patient-to-patient mentorship, and grassroots engagement programs

# Welcome UF Health!

We are ecstatic to welcome University of Florida Health (UF Health) in Gainesville, Florida as the newest VHL Clinical Care Center. UF Health joins the VHL Alliance network of 40 Clinical Care Centers across the United States.

*"We are very excited at UF Health to be recognized as a VHL Clinical Care Center. This will allow us opportunities to share knowledge with other VHL clinics, promote the care of patients with VHL to improve their quality of life, and participate in future clinical trials targeting new therapies, within our geographic region of North Central and West Florida. "*





**Hans H. Shuhaiber, MD**
*Sponsoring Physician*
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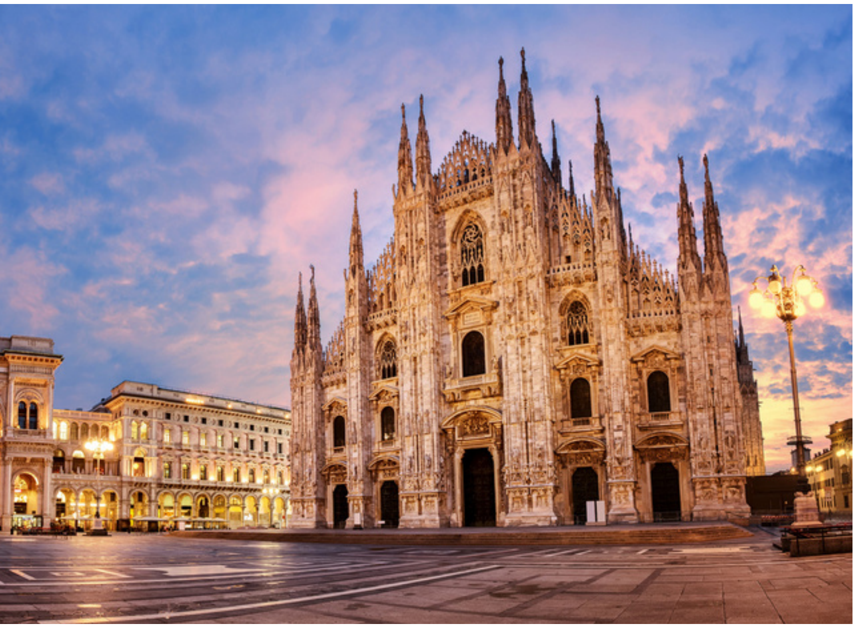


# Medical Symposium Announced

The 16th International VHL Medical Symposium will be held in **Milan, Italy, October 18-20, 2024,** in partnership with San Raffaele Scientific Institute. Leading VHL researchers and clinicians will convene to present and collaborate on the latest advances in basic and translational biology.

# VHL Research Funding Opportunities

Outside of the National Institutes of Health and the Department of Defense, the VHL Alliance offers the largest amount of annual VHL research grants in the world, awarding $300,000 on average every year. **Since 2014, the VHL Alliance has awarded over $3,000,000 in support of VHL research projects.**

For the 2024 research grant season, we received a record number of 35 Letters of Intent and 27 full applications submitted to our Research Council, all of which were of an extremely high caliber. This grant program is meant to award projects designed to obtain sufficient data to apply for government-funded resources.

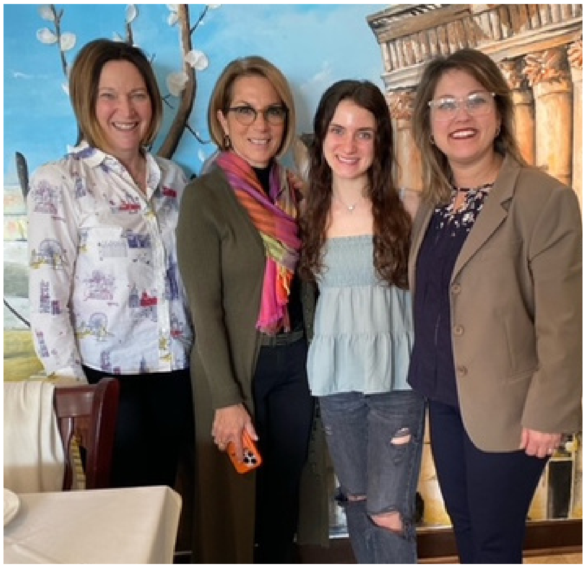
One example of this is Betty Garde. In 2020, Betty was awarded a VHL Alliance Impact grant for her study using reprogrammed adult stem cells (iPSCs) to model the VHL disease "in a dish".  The aim is to identify potential therapeutic targets and develop new treatment strategies for VHL and related conditions. She later applied to the DoD's Congressionally Directed Medical Research Program (CDMRP) and successfully won a federal grant in 2023 to continue with this line of research.

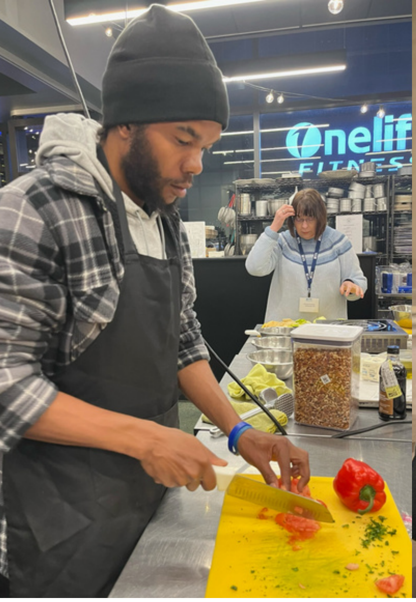
CDMRP
DEPARTMENT OF DEFENSE
CONGRESSIONALLY DIRECTED
MEDICAL RESEARCH PROGRAMS

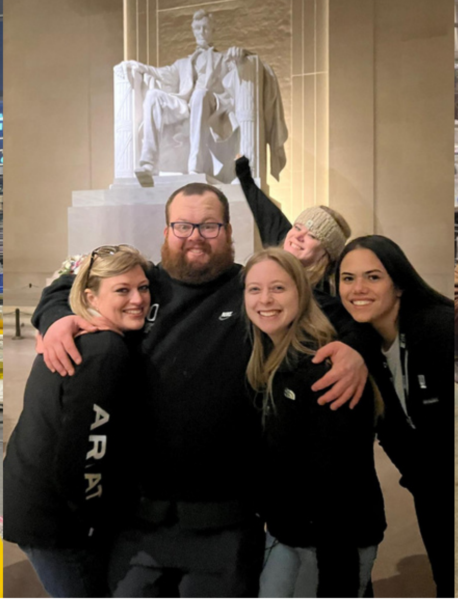
The VHL Alliance understands the power of the patient voice to drive VHL research. Since 2020, our Patient Advocacy team of volunteer patients and family members engage with lawmakers every spring in Washington, D.C. to garner the critical support of Congress that is required to keep VHL federal funding opportunities open to our research community. Today, research projects studying basic and translational VHL science are eligible to apply to the $370 million funding "bucket" through the Peer Reviewed Medical Research Program under a VHL-specific topic.

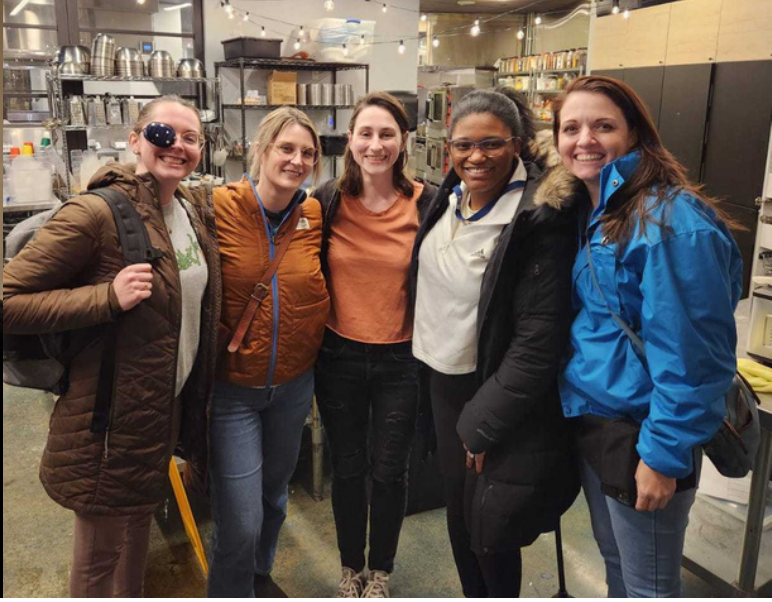
If you are a researcher interested in VHL and want to learn more about how the VHL Alliance can support your work, please contact us at research@vhl.org.

If you are interested in becoming a patient advocate for your state, please contact the VHLA Advocacy Manager, Marissa Beasley at Marissa@vhl.org.







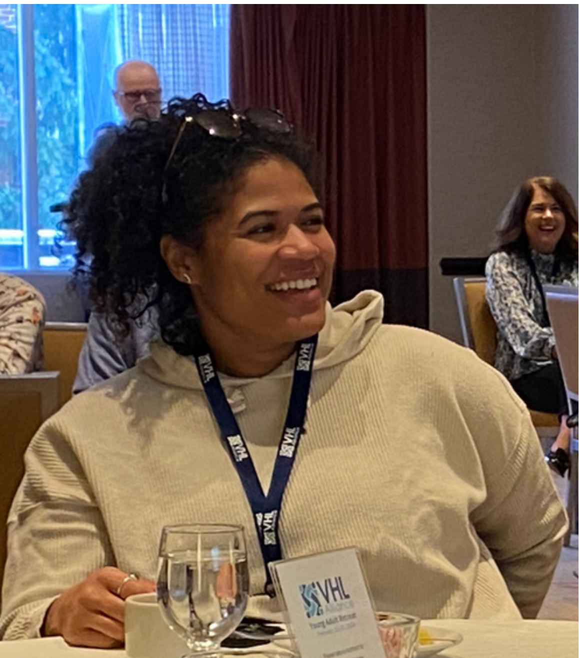


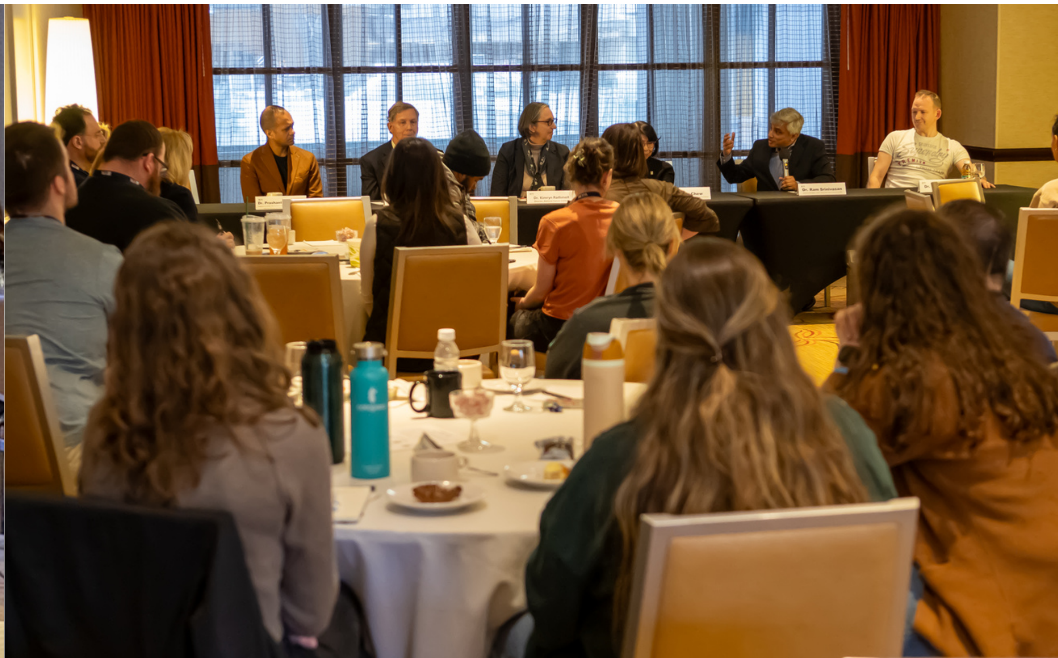
# Young Adult Retreat 2024

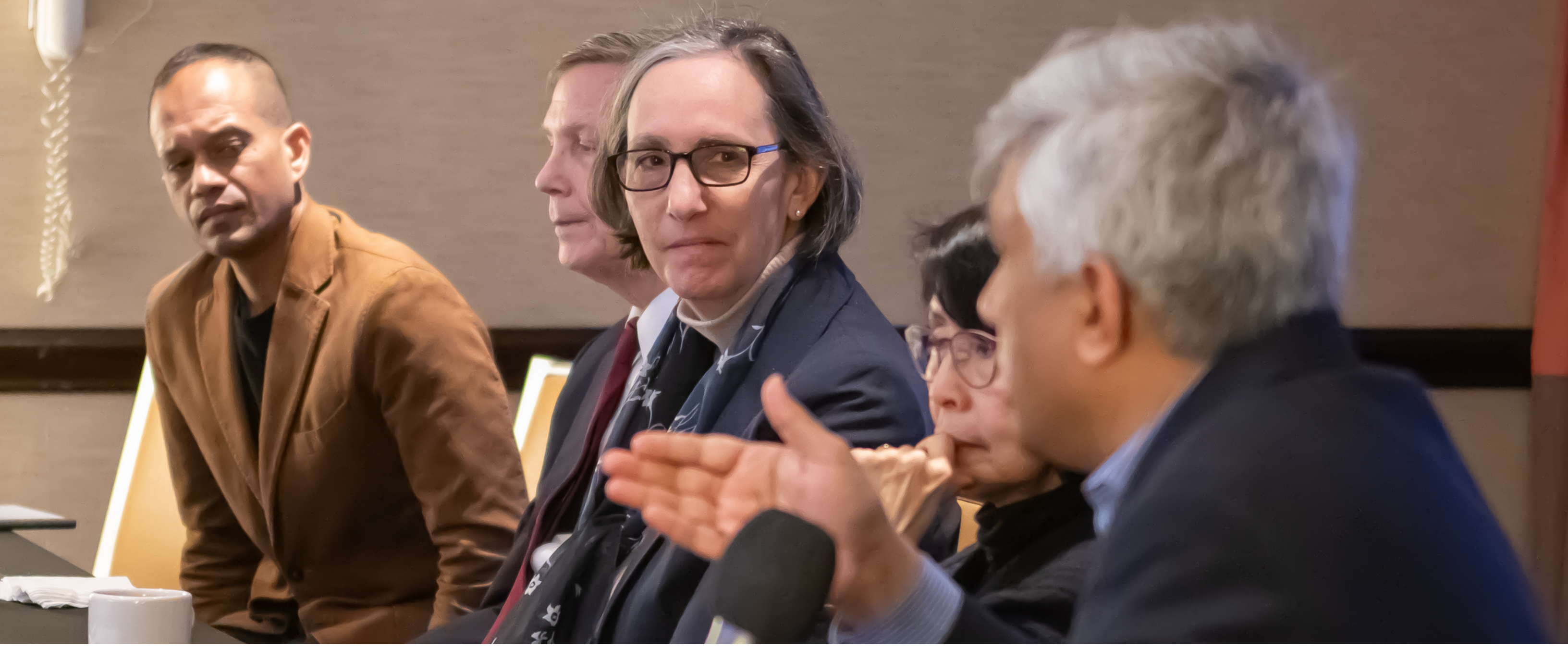
In February, we hosted the VHL Alliance Young Adult Retreat in Washington, D.C., bringing together 27 individuals living with VHL for a weekend of connection and learning. This event featured panel discussions from VHL experts at the National Institutes of Health (NIH) and Rare Disease Speakers from Everylife Foundation who led workshops on medical financial navigation and self-advocacy. Participants met with Oncology Therapists for insights on self-care, hope and coping, and peer encouragement. Iron Chef-style cooking classes and DC monuments tour provided the fun for the weekend!

*"...It only took 18 years, but this weekend I finally met another VHLer, 27 of them! Instant connection, instant understanding, instant family. What a powerful, inspiring and life changing weekend. Thank you to the VHL Alliance for making this happen!"*

**Nicky H.**
*YAR 2024 Participant*



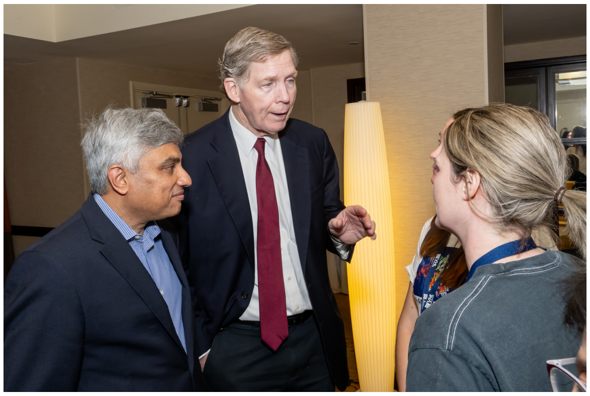


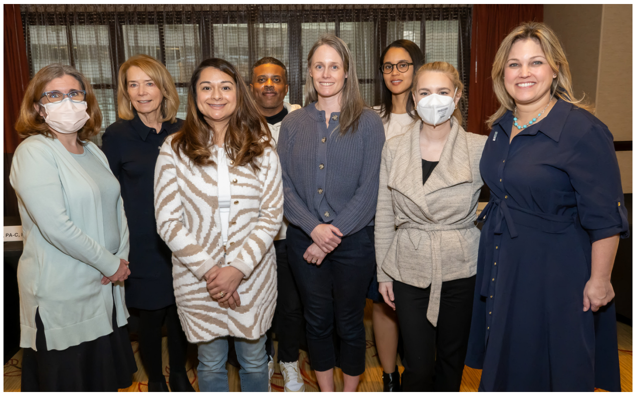


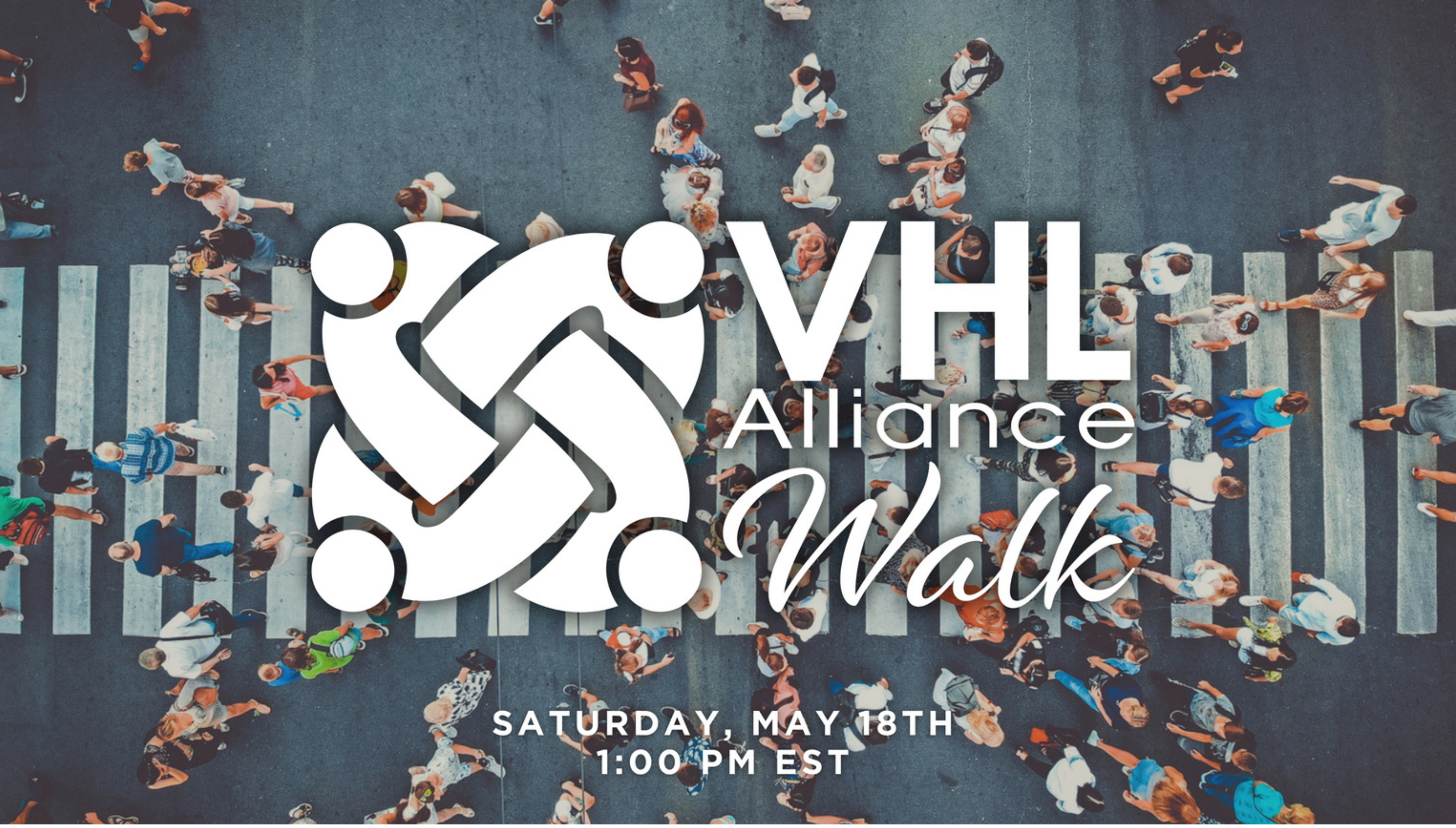
# NIH and the VHLA: 30 years of patient-centric research

Since 1993 when the VHL gene was discovered by Dr. Marston Linehan and his team, VHL Alliance families have partnered with researchers from the National Institutes of Heath to learn and treat von Hippel-Lindau. Working across disciplines, experts like Drs. Srinivasan, Chew, Chittiboinia and others collaborate to understand this condition and to discover better treatments for all VHL manifestations from the eye to the brain to the kidney. Today, our connection to NIH spans to the highest levels of leadership. We are fortunate to have a former VHLA Research Council Member, Dr. Kim Rathmell, as the newly appointed Director of the National Cancer Institute.

Medical professionals like Lidenys O'Brien and Mary Beth Morrow go beyond the research and attend to the whole patient providing insights, second opinions, and psychosocial services. For more information about joining the VHL patient registry at the NIH or inquiring about an individual patient concern, please contact the VHL Alliance at info@vhl.org.







## Be a part of VHLA history by joining walkers all over the country in the first ever VHL Alliance Walk!

Sign up as a team or individual walker to fundraise. Then on walk day, gather with your team (and maybe even other teams in your area) to watch our kickoff video online, then walk around your neighborhood or park at the same time as other walkers all over the country!

All donations will support the VHL community through the work of the VHL Alliance!

**Visit vhl.org/walk or the QR code to register today.**

## When?

**Saturday, May 18th**
1:00 p.m. EST (10:00 a.m. PT)

## Where?

Your town!

## Who?

Anyone and everyone who wants to have some fun and connect with the VHL community while raising funds to support VHL patients and families

# Family Meeting 2024

That's right. It's already time to start thinking about VHLA Family Weekend! Immerse yourself in the VHL community as we come together to share our VHL experience, build lasting connections, and learn directly from VHL experts. Scan the QR code to register today!

**Date:**
September 6-8, 2024

**Where:**
UT Southwestern campus in Dallas, Texas

**Price:**
$25 per attendee. The registration fee will increase on June 1, so act soon!

UT Southwestern will serve as the backdrop for a series of engaging events, informative sessions, and collaborative activities. Experts in VHL research and treatment will be on hand to provide valuable insights and presentations for the VHL community.

### Connect With Fellow VHL Families

Share experiences, exchange advice, and connect with a supportive network who understands the VHL experience.

### Engage With VHL Experts

Participate in interactive workshops with leading VHL researchers and clinicians and gain a deeper understanding of the latest advancements in VHL research and treatment.

### Enjoy Dallas Activities & Entertainment

Beyond the informative sessions, indulge in family-friendly activities and entertainment in Dallas. We'll share more details about additional activities soon!

# Did you know that the work of the VHLA would not be possible without individual donations?

Our donors are the reason we can accomplish our lifesaving work for the VHL community!

Can we count on you to contribute? Simply scan the QR code to donate online or use the enclosed envelope.

We are grateful for you!

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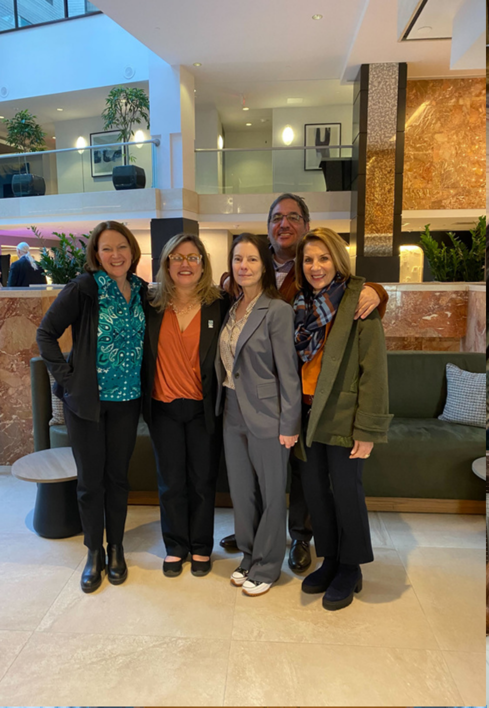
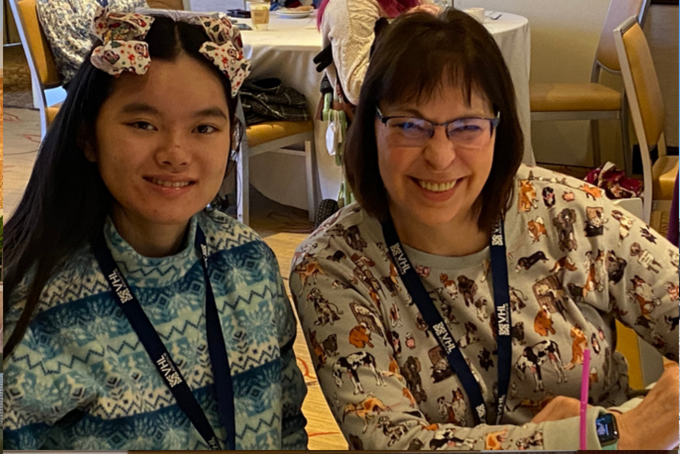
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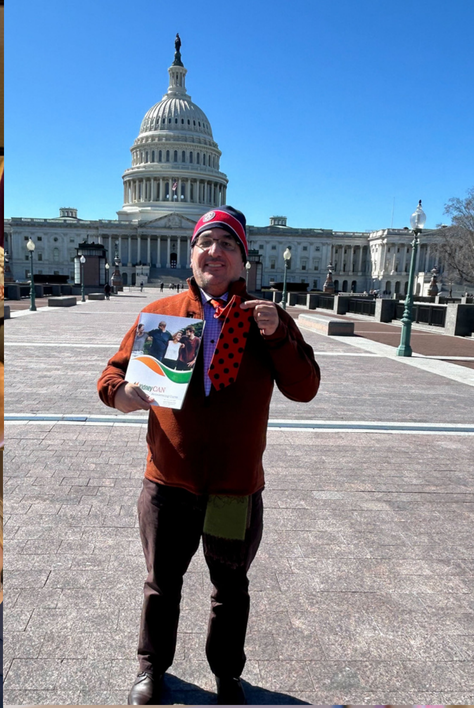
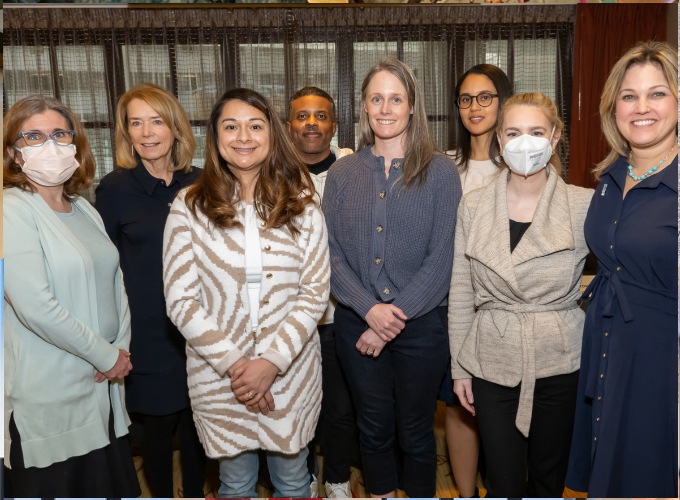
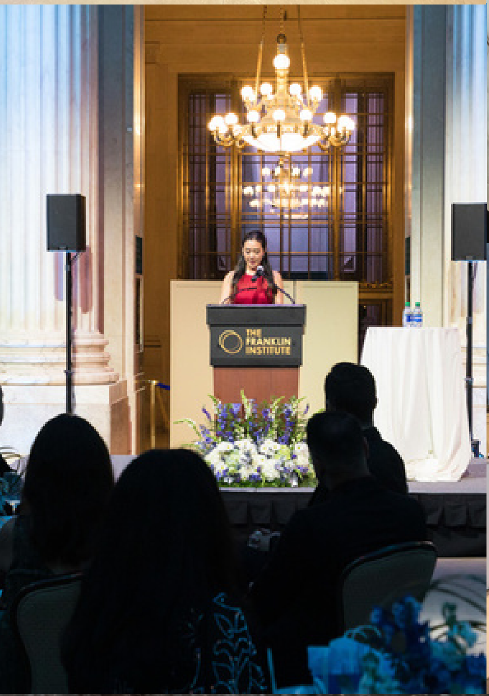
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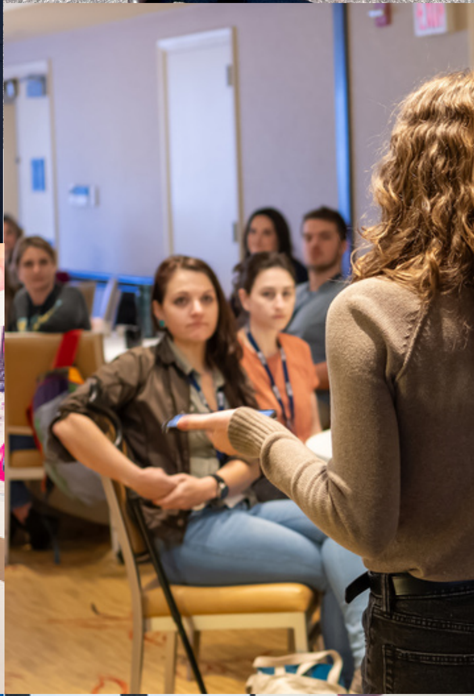
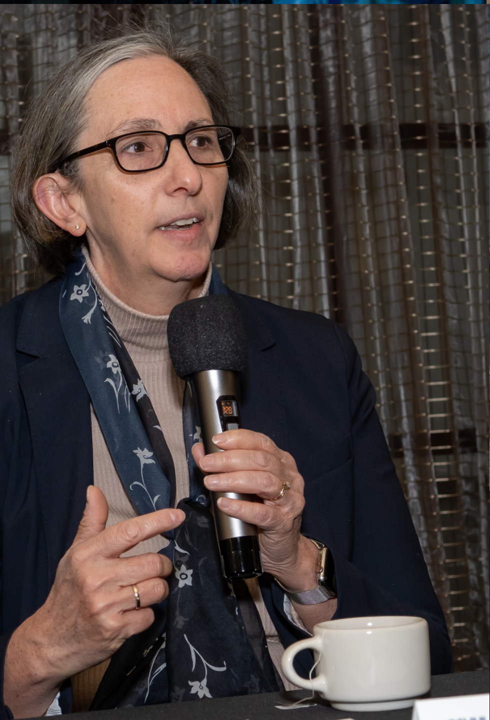

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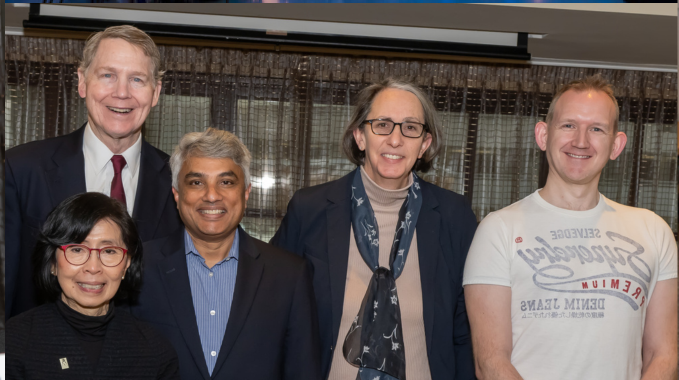
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