A new year provides us all with a fresh start and opportunity to make positive changes and shifts in perspective in life. So too, is the case with VHLA and our perspective moving forward is one of hope! Hope is a sentiment that rings true personally and collectively and is born from a place of recognizing that we have seen incredible progress in research, policy, and medicine that holds promise for us all in the VHL community, but it is much more than that. It is also the recognition that we all are in a community based in support, positivity, and growth, together. When I reflect on the past and the opportunities that are before us all, I am very hopeful and optimistic for the coming year and beyond! Let us all celebrate this hope as a united society and unified VHL community!

Camron King
VHLA BOARD CHAIR

ST. JUDE CONFERENCE RECAP

On December 2–3, 2021 the Division of Cancer Predisposition at St. Jude Children’s Research Hospital held its annual Family and Provider Conference on Cancer Predisposition, with this year’s conference focusing on von Hippel-Lindau (VHL) Syndrome. The conference provided ample opportunities for parents, children, and other family members living with VHL, as well as providers who care for individuals with VHL, to learn the latest advances in VHL biology, tumor surveillance, and targeted cancer therapy. Many suggested approaches surrounding psychosocial and other health issues were also discussed. Twenty families and nearly 250 individuals registered for the conference, representing 36 states and 23 countries! The conference was a great success and a wonderful experience for all who attended.

Kim E. Nichols MD
DIRECTOR, DIVISION OF CANCER PREDISPOSITION, ST. JUDE CHILDREN’S RESEARCH HOSPITAL

If you were unable to attend, you can find a link to the conference webpage, which includes speaker information, recordings of several presentations, and other valuable resources from the conference, at vhl.org/StJude.

FINANCIAL SUMMARY

As COVID-19 continues to ravage individuals, families, businesses, and non-profits on a global scale, a ray of light has been the perseverance of the VHL Alliance. Many non-profits saw significant drawdowns in services provided, had deteriorating fiscal health, and/or simply ceased to exist. Among such uncertainty, VHLA was able to continue providing the services that our community has come to expect, allot funds for three new research grants, and strengthen its balance sheet.

Revenue for Fiscal Year 2021 was $1,162,645 compared to $651,702 in the prior year. VHLA received forgivable PPP loans in both years, the first of which was forgiven in FY21 with the remaining already forgiven in FY22. Expenses in FY21 were roughly in line with those in FY20, with $836,495 and $806,310 spent, respectively. As a result, VHLA was able to show an operating gain in FY21 of $326,150 after a loss of $154,608 in FY20.

Virtually all of VHLA's assets closing out FY21, $1,162,645 compared to $1,138,238, were held in U.S. Government insured accounts. Unlike prior years, there were no short term fixed income investments made, as the organization sought maximum operational flexibility in a period of uncertainty and looming inflation. The Finance Committee continues to monitor market conditions, as well as the needs of VHLA, to adjust any investments as necessary. Research grants payable of $358,333, plus deferred revenue of $110,204 (that has, largely, already been recognized in FY22), make up the lion's share of FY21 yearend liabilities of $547,746. As such, VHLA reports net assets of $1,590,492, a healthy increase from $1,264,342 in the prior year.

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MESSAGE FROM THE BOARD CHAIR

Seth Horwitz
TREASURER

ST. JUDE CONFERENCE RECAP

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Kim E. Nichols MD
DIRECTOR, DIVISION OF CANCER PREDISPOSITION, ST. JUDE CHILDREN’S RESEARCH HOSPITAL

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Welireg Townhall Meeting
Want to learn the newest updates about Welireg (belzutifan)? You can find the latest information on the drug, including Town Hall videos (in both English and Spanish), Q&A videos, links to important resources, and more at: vhl.org/Welireg

VHL Handbook
The VHL Handbook is one of the most important resources for people who want to learn more about VHL. You can order a hard copy, or download it for free, at: vhl.org/handbook
Descarga gratis el Manual de la VHL en español en: vhl.org/handbook
Скачать Справочник VHL на русском языке бесплатно можно по адресу: vhl.org/handbook

Surveillance Guidance
Active surveillance is critical for managing VHL. Early detection, monitoring, and appropriate treatment can greatly reduce the risk for the most severe consequences related to the disease.
You can find the VHL Surveillance Guidelines at: vhl.org/surveillance-guidelines

2022 Warrior Call! Save the Date
WEDNESDAY, MAY 18, 2022
HONORING: Othon Iliopoulos, MD, PhD
Clinical Director, von Hippel-Lindau Disease/Familial Renal Cell Cancer Program, Associate Professor of Medicine, Center for Cancer Research, Massachusetts General Hospital, Boston, MA
For more details, including ticket and sponsorship opportunities, please visit vhl.org/warriorcall
The Heisler family journey with VHL Syndrome began over 30 years ago, and within our greater family experience, it has been quite different for each of us. For me and my mother, this journey has been closely tied to our cultural roots and the languages we speak. We have traveled near and far and have facilitated communication in a variety of settings, through translation and interpreting. After many years on a path toward living our best lives, we have recently been drawn closer to VHLA. The opportunity to translate the VHL Handbook together, was an epic return to the community.

There was never any doubt that translating the handbook would be a tremendous undertaking. What we didn’t anticipate, was the personal journey we would take with each new page and chapter. As we got deeper into the work, the handbook became a living thing, inhaling our efforts and exhaling our very own lives with VHL. The handbook became an element of nostalgia and in some instances even provided us a chance at closure.

We are very grateful to be a part of this important work and it’s our hope to continue supporting VHLA for years to come.

Spanish Translation of the VHL Handbook by Joseph Heisler

Para la familia Heisler, el viaje con la enfermedad de VHL comenzó hace más de 30 años. Dentro de nuestra experiencia familiar, el viaje ha sido bastante diferente para cada uno de nosotros. Para mí y mi mamá, este viaje ha sido estrechamente ligado a nuestras raíces culturales y a los idiomas que hablamos. Hemos viajado juntos, cerca y lejos, en busca de medicina tradicional y recursos para vivir nuestra mejor vida, y hemos facilitado la comunicación en una variedad de entornos, a través de la traducción y la interpretación.

Después de muchos años, nuestro camino nos ha acercado recientemente a la VHLA, y tomar la oportunidad de traducir el Manual de la VHL fue un regreso a la comunidad épico.

Ahora, nunca dudamos de que la traducción de este manual sería una empresa tremenda, pero no anticipábamos el viaje personal que haríamos con cada nueva página y capítulo. A medida que nos adentramos en el trabajo, el manual se convirtió en algo vivo, que inhala nuestras experiencias y exhala nuestras propias vidas con la VHL – en un elemento de nostalgia que en algunos casos nos proporcionó una oportunidad de cierre.

Quedamos muy agradecidos de ser parte de este importante trabajo y esperamos seguir apoyando a la VHLA y la comunidad en los próximos años.

WHAT IS A WARRIOR?

When I was asked what VHL means to me, the first word that popped into my head was: Strength. VHL is my superpower. When I am faced with a new difficulty, my experiences with VHL allow me to take it in stride. VHL has made me strong–made me a warrior.

Warrior is a word that gets used frequently in the VHL community, what does that mean? Of course, we fight, but dealing with VHL is not all about fighting. Sometimes it’s hours on the phone talking to insurance, or making appointments, or lying still in a small space with an awful racket shaking our whole world–test, test test, appointment, test test. That’s the day in, day out boring and sometimes frustrating routine of VHL.

VHL Warriors stay calm in the face of adversity, endure procedures, and are brave when it’s the last thing we want to be. And occasionally we have to fight for our rights as patients, for our health and survival. We didn’t volunteer to be warriors, but here we are, ready to face what lies ahead.

Until recently, it seemed no matter how many battles we faced, that we would never win the war. The new drug, Welireg, has become our New Hope (cue Star Wars theme song) that one day we won’t have so many battles to face—if any at all.

Like any good warrior, we are not just fighting for personal victory. I take comfort in the fact that my fight is not for nothing. Every time we face a new manifestation of VHL, the science gets better. New surgeries and drugs come from our adversity. Each time we go into the hospital gets us closer to a cure, not just for VHL but perhaps even cancer itself.

So, stay strong warriors, keep supporting each other, keep on fighting. This is your superpower. This is why you’re here.
Announcing Our 2022 Grant Recipients

**Alessandro Larcher**
MILAN, ITALY
Dr. Larcher and his team will create a map of renal cancer in VHL disease on multiple levels: they will investigate diversity between different renal tumors in the same patients with respect to anatomy, histology, and molecular biology. The ultimate goal of such analysis will be to investigate features suggestive of potential success or failure of existing or new systemic agents. Dr. Larcher has been awarded a pilot grant for 2 years from the VHL Alliance.

**John Chappell, PhD**
ROANOKE, VA
Von Hippel-Lindau (VHL) patients often suffer from abnormal blood vessel changes that can directly affect organ function and fuel the aggressiveness of certain VHL-associated cancers. In genetic models of VHL disruption, Dr. Chappell and his team recently found defective growth and expansion specifically of arteries, which likely contribute to VHL disease progression. Their study will determine which blood vessel cells are most affected by VHL gene mutations, and how a specific pathway (the TGFβ pathway) exacerbates these changes and may offer potential drug targets in the development of next-generation therapies for treating VHL disease, either alone or in combination with other pharmacological treatments. Dr. Chappell has been awarded a pilot grant for 2 years from the VHL Alliance.

**Patricia Dahia, MD, PhD & Alice Soragni, PhD**
Patricia Dahia, MD, PhD, and Alice Soragni, PhD, will be working together to create a new organoid model to study VHL-related pheochromocytoma. Pheochromocytomas and paragangliomas (PPGLs) occur in approximately 50% of patients with VHL disease and are presumed to result from a VHL defect distinct from that causing renal cancers and hemangioblastomas. To gain insight into potential novel VHL functions they propose to define the cell type composition, cell state, developmental trajectory, and expression signature of VHL-mutant PPGLs and their derived organoids at single-cell resolution, as well as their drug response profile, to identify unique vulnerabilities that can be explored for future therapy. Drs. Dahia and Sorgani have been awarded a research grant for 3 years from the VHL Alliance.

**RDLA’s Rare Giving Grant**
We are proud to be recipients of RDLA’s rare giving grant. These funds will go towards expanding our growing federal advocacy program.

Explore the PracticeUpdate Von Hippel-Lindau Disease Spotlight

A content channel dedicated to Von Hippel-Lindau Disease, including features like:

- Editor’s Picks – gain insights from PracticeUpdate’s key opinion leaders
- Expert Opinion – watch exclusive video interviews and read commentaries from leading experts
- Tumor Boards – join interactive, ongoing patient case discussions

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