This is a simple question. What is your legacy? As one generation leaves a legacy for the next generation, your legacy ultimately shows where your heart lives.

If you are reading this annual report, you probably know a courageous person with von Hippel-Lindau. You may have VHL yourself and understand intimately how the syndrome requires heroic effort in surveillance of tumors and dealing with tumors as they arise. The legacy of a Warrior is firmly in place for a person with VHL. Let's envision a cure with all our hearts, and consider your legacy as a fervent supporter of Curing Cancer through VHL.

As part of the VHL Alliance, we have similar stories and experiences to share. My daughter, Sarah, is a de novo mutation, or the first in our family with VHL. From the beginning of her VHL journey, she has been an inspiration. Sarah shows me how truly resilient and brave a person can be in the face of great uncertainty. At my first VHL Annual Family Meeting, I met many others with similar experiences whose children had successfully navigated this lifelong genetic cancer syndrome. Sarah learned to drive while dealing with vision issues. Sarah finished school papers, took finals, and did hard things within days of having surgery. This is the same as many others with VHL. The truth is that a person with VHL presses on with his or her life and models for all of us how to live life well.

How can we best honor and remember a person who battles von Hippel-Lindau? Raising VHL awareness is a way to leave a legacy and will help the VHL Alliance reach our vision of Curing Cancer through VHL. A donation is a way to leave a legacy. Financial gifts allow the VHL Alliance to push forward with perseverance and resolve.

The VHL Warrior understands more than anyone about perseverance and urgency. There is an urgency to raise funds to support the VHL Alliance's mission, dedicated to research, education, and support to improve awareness, diagnosis, treatment, and quality of life for those affected by VHL.

This year, the VHL Alliance board lost a beloved member and Warrior, Karen Ramsey. Karen was dedicated to moving the VHL Alliance forward, and we can credit her with much of our organizational health. Karen was courageous and fun, always positive and uplifting. She had a generous and loving heart. Karen's legacy is advancing the VHL Alliance forward.

Suellen is a VHL Warrior who has created a legacy of running races and fundraising in honor of her mom. Her legacy is the Mom's Day Run and Team VHL.

Abby is a VHL Warrior who wants to spread awareness of VHL and make VHL recognizable. She is helping to do this by using social media and other marketing ideas. Her legacy is helping make VHL a household name.

Rosie is a 14-year-old young woman who created an event in memory of a friend and loved one who passed away from VHL. Her legacy for her Aunt Julie is the Festival of Hope.

Wes is a VHL caregiver who is using his love of comedy to spread awareness and raise funds for VHL. His legacy is laughter.

What is your legacy?
With VHLA, I Never Feel Alone!

by David C., patient

Up until a couple of years ago, I had never met or spoken to someone with VHL outside of my family. Now, I am a regular on all three of the facilitated conference calls that the VHL Alliance offers: the Patient/Caregiver call (vhl.org/ptcgcall), the Parents of VHLers call (vhl.org/parentscall) and the Low/No Vision call (vhl.org/lownovisioncall). These calls take place monthly and they have given me the chance to learn and interact with VHLers all over the country.

Taking part in these calls has given me the ability to hear other people share about symptoms, surgeries, new procedures, and clinical trials. I admit that before joining these calls, I was not informed about many aspects of VHL. For many years I took VHL, put it in a little box, and tucked it away. But then I reached a point in my life that I couldn’t ignore it anymore. That is when I reached out to the VHL Alliance.

The Parents of VHLers call has been very helpful as, unfortunately, my son also has VHL. This call has provided me with great support from other parents. Helpful hints are offered about testing and scanning children. Support is offered for some of the guilt parents may feel as they watch their child(ren) go through the same things they may have gone through. In addition, the Patient/Caregiver call has enabled me to pay it forward and share with others some of my experiences.

I have also learned about the MyVHL: Patient Natural History Study (vhl.org/MyVHL) through this call. We all need to do whatever it takes to make the next generation's lives better. I have a feeling a cure is close!

The Low/No Vision call is the third conference call in which I take part. I personally have found this call to be the most helpful and informative. Over the last couple of years, I have lost my sight, leaving me to feel like I was in a hopeless situation. I couldn’t imagine what living my life was going to be like without vision. This call has changed everything. I have been able to form friendships with people dealing with the exact same situation as myself. We discuss topics on day to day living in our homes, such as cooking, cleaning, organizing the food in our refrigerator, using public transportation, or even going back to work. We have discussed all sorts of technology that is available for us as visually impaired individuals.

I’d like to thank the VHL Alliance for these group discussions and for everything else they do. There are a lot of people behind the scenes working very hard for us. Best wishes and good health to everyone.

Welcome Samantha Robinson!

Samantha Robinson came to join the VHL Alliance as Administrative Assistant in this fall of 2018. She provides everyday clerical support to her other team members while creating content for events and the quarterly newsletters.

Samantha is a fairly reserved person who enjoys ballet, animals, and embroidery. With a medical secretarial background and experience working in a hospital environment, she is excited to join a cause such as the VHL Alliance. Samantha hopes that by assisting in her tasks it can lead to the productivity and efficiency needed to help Cure Cancer through VHL.

65 Years of the Double Helix

Ilene Sussman, Executive Director of the VHL Alliance, contributed an editorial to the August issue of Endocrine-Related Cancer (erc.bioscientifica.com). The article is entitled “Could Watson and Crick have envisioned the true impact of their discovery?”. “...the best way to honor the 65th anniversary of unraveling the structure of DNA, may be to rededicate the pyridines and pyrimidines to Health, Optimism, Perseverance, and Encouragement. By doing so, we will also be honoring the feelings of hope further ignited by each scientific breakthrough by anyone person suffering from a genetic disorder”.

VHL Alliance Annual Report

Vol 26, No. 4, Fall 2018

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Leaving a Legacy

by Maggie W., VHL Advocate

Julie Flynn said the medicine she took every day was HOPE. I met Julie at the age of 10 and she has been my BFF ever since. When she was 13, Julie failed the school eye exam and this is when we all first heard and learned about VHL. Julie spent the next 30 years living her BEST life despite the challenges that VHL threw at her. Most people did not know that Julie had an illness, because it simply never defined her. We lost Julie this year at the age of 43.

Julie was the school adjustment counselor at Grafton Middle School where she provided HOPE and guidance for so many struggling teens. My 14 year old daughter, Rosie, who had the honor of calling her “Aunt Julie”, was one of those lucky students. Julie had an unbelievable impact and her passing was devastating to the staff and students at Grafton Middle School.

Soon after Julie’s passing, Rosie decided to host the “Festival of Hope” to honor her Aunt Julie’s legacy and bring much needed awareness to VHL. Rosie, along with my support, secured thirty-five vendors to come showcase their products. She also secured local artists, provided kids activities, food, and ran a drawing with over one hundred prizes! Rosie promoted the event on the radio and TV, which spread the word about the festival, awareness about VHL, and honored Julie’s memory. The June event was very successful and we had nearly one thousand people come through the doors!

The Festival of Hope was truly embraced by the entire town of Grafton. The day resembled just what an extraordinary human being my BFF Julie Flynn was. She was, and will always be, a true shining example of the word HOPE. Rosie and I are dedicated to making the Festival of Hope an annual event and to continue keeping Julie’s legacy alive! The legacy of Julie Flynn will live on each and every day through the simple word HOPE.

VHLA Awards $275,000 in Grant Money

The VHL Alliance’s FY18 Competitive Research Grant Program brought in the greatest number and highest quality of grants than ever before. This year, we are pleased to be awarding a total of $275,000 to be distributed to three highly deserving grants. Funds will be disbursed over the next three years.

Othon Iliopoulos, MD, PhD from Harvard Medical School and Massachusetts General Hospital Cancer Center in Boston has been awarded a Research Grant. He and his research group are the first to develop a model to study hemangioblastomas found in the brain and spine of VHL patients. The research team will utilize this model to explain why some hemangioblastomas remain “dormant” for many years and others grow “actively”. Using cutting edge technology, their work will lead to the identification of potentially “actionable” pathways that can be targeted for effective treatment and prevention of hemangioblastomas.

Raymond Kim, MD, PhD at Princess Margaret Cancer Center in Toronto, has also been awarded a Research Grant. His research involves an international collaboration working to collect a complete set of genetic data of VHL mutations. The team will continue collecting and examining information about VHL patients and will use these data to create uniform care plans. This VHL data-sharing efforts will improve the care for VHL patients and their families. This study is an outgrowth from the success of Dr. Kim’s VHLA Pilot Grant in 2015.

Haifeng Yang, PhD at Thomas Jefferson University in Philadelphia, is the recipient of this year’s Pilot Grant. Using a mouse model, Dr. Yang’s lab discovered the involvement of a factor ISGF3 in tumor growth of VHL-defective cancer cells. They will test the impact of various chemotherapies on expression of ISGF3.

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As we enter the giving season, this year, like every year, we ask you to dig as deep as possible. We at the VHL Alliance know that the amount is going to be different for each individual, but we also know that together we can reach our goal of raising $275,000 by the end of the year and $960,000 by June 30, 2019, the end of our fiscal year. We owe this to ourselves, our children, our grandchildren, and generations to come. Together, let us each commit to paying it forward in a meaningful way!

by Seth Horwitz, VHLA Treasurer

2018 has proven to be a very successful year for the VHL Alliance. The VHL Disease Spotlight and Virtual Tumor Board, a collaboration with Elsevier’s PracticeUpdate, as well as our new online “VHL101” videos, are among VHLA’s new tools for educating the medical community on best practice for VHL diagnosis and treatment. The headlines of this year’s research agenda are: the extremely productive 13th International VHL Medical/Research Symposium; the largest and highest quality application submitted to our Competitive Research Grant Program (see page 3); and a relaunch of the increasingly important MyVHL: Patient Natural History Study. Don’t forget to participate and earn your $50 Amazon Gift Card (learn more at vhl.org/myvhl)!

The excitement doesn’t stop there! We continue to expand our educational and support programs. I urge you to consider joining one of the discussion calls. Call the office or visit vhl.org/support. Come to next year’s VHL Annual Family Weekend in Indianapolis, IN or participate in the Young Adult Retreat. Also, don’t forget to download the VHLApp (vhl.org/vhlapp)! This is a great tool provides all you need to know about VHL at your fingertips and helps you keep track of your doctor appointments.

The connections that we do make are important for us and for them. It’s meeting someone new at the Annual VHL Family Weekend and sharing stories. It’s reading about the PT2977 drug trial (vhl.org/trials) that is giving hope to patients that there could be a pill to help treat their kidney (and maybe other!) tumors. It’s the fun in sharing on social media a video of you and your friends having a laugh, raising awareness and otherwise enjoying life while taking part in the VHL Sucks Lemons Challenge. It is the value in developing friendships with people who share the monthly VHL phone calls with you. It’s the amazing conversations had when someone does answer the phone. It’s even more special when you haven’t talked in a couple of years but both of you still remember your last conversation. So keep trying, keep communicating, and remember that the missed connections only mean you have another opportunity to make a connection.

Stay Connected

by Greg T., VHL patient, VHLA Chapter Leader

It is easier than ever to stay connected with everyone in the age of the computer. Newsletters can be sent via email or snail mail. Social media makes it possible to directly connect with almost anyone. There is even this newfangled idea of using our smartphones to place “a phone call.” The problem is not in the ability to connect but in the ability to be heard. Your mailbox and inbox overflow with advertisements and spam, making it possible for that newsletter to be lost in the fold. With so many social media options available, it is hard to follow which is the popular one of the moment. Even when you do know, there is a lot of “noise” to filter through. Telemarketing scams have become so prominent, that most people don’t even answer their phone if it’s a number they don’t recognize. The question becomes, in a sea of information, why do we still try to reach out to the people of the VHL Alliance and make those connections?

FY18 Financial Report

by Seth Horwitz, VHLA Treasurer

As we enter the giving season, this year, like every year, we ask you to dig as deep as possible. We at the VHL Alliance know that the amount is going to be different for each individual, but we also know that together we can reach our goal of raising $275,000 by the end of the year and $960,000 by June 30, 2019, the end of our fiscal year. We owe this to ourselves, our children, our grandchildren, and generations to come. Together, let us each commit to paying it forward in a meaningful way!

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