Ringing in the New Fiscal Year

By Karen Ramsey, VHLA Immediate Past Chair

As the new VHLA board begins its work, the team is hitting the ground running. We have an ambitious 2016–2018 Strategic Plan developed, which supports the organization’s mission and vision. It also specifically outlines how VHLA will move forward over the next three years.

The plan contains five strategies. The first strategy is to Increase Awareness about VHL. Led by board member Barbara Correll and supported by members of her committee along with staff member extraordinaire Heidi Leone, some of the key initiatives for this strategy include creating marketing, social media and public relations plans as well as developing brochures and other informational materials for distribution.

The second strategy is to Improve VHL Clinical Care. Eric Jonasch, MD is championing this strategy with support provided by fellow board member Jessica Everett, MS, CGC, the Clinical Advisory Council, and by our hard-working, committed VHLA Executive Director Ilene Sussman. Some of the key elements of this strategy involve reaching out to VHL Clinical Care Centers (CCCs) to find out their needs. It also includes surveying VHL patients and increasing awareness and usage of CCCs.

The third strategy is to Foster Research, also chaired by Eric Jonasch and, in addition to his top-notch Research Council, he is again supported by Ilene Sussman. Some of the areas of focus for this strategy include reviewing research proposals and selecting recipients of grants provided by the VHL Alliance, fostering collaboration among researchers, and increasing participation in the organization’s patient Databank.

Engage Patients, Family, and Friends is the fourth strategy the board has adopted. Currently chaired by Anna Waller, this strategy is supported by a committee as well as knowledgeable staff members Suzanne Nylander and Heidi Leone. Some of the key initiatives this group are pursuing involve engaging and expanding the number of VHL Chapter Leaders throughout the country and providing additional support to caregivers and teens.

The last but not least important strategy is to Increase Fundraising. Manuel Greco and Bettina Micheli are co-chairing this effort, along with the support of professional fundraiser Heidi Leone and a strong, enthusiastic committee. Some of their work includes connecting with and cultivating current and future donors, identifying potential corporate and foundation grant opportunities (PLEASE let us know if you have any suggestions), and creating a fundraising toolkit to be used by supporters of the organization.

Although executing the strategic plan will not be easy, we are confident we will continue to make headway in our effort to find a cure for VHL! If you would like to get involved, please reach out to the VHL Alliance (info@vhl.org) and we would be delighted to add you to our team of dedicated volunteers!

See page 3 for new board members.

VHL Databank: Your Data at Work

One of the exciting discussions at this year’s International VHL Medical Symposium was a summary of your data provided in the VHL Alliance’s online research project, the Cancer in our Genes International Patient Databank. This Databank is unique since it is based on information obtained directly from VHL experts—you!

Many of the surveys are designed to answer your questions: Does lifestyle impact the development of VHL tumors? Does diet matter? Is there an optimal amount of exercise? What are the risks to the mother of having VHL and carrying a child? Does VHL have any association with other medical conditions? Answers to these questions and more are available for everyone closer to a cure! vhl.org/databank

Top General Health Issues

VHL Patients: General Health Issues

<table>
<thead>
<tr>
<th>Condition</th>
<th>Number of Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diabetes</td>
<td>121</td>
</tr>
<tr>
<td>Digestive</td>
<td>110</td>
</tr>
<tr>
<td>Hypertension</td>
<td>109</td>
</tr>
<tr>
<td>Headaches</td>
<td>108</td>
</tr>
<tr>
<td>Thyroid</td>
<td>107</td>
</tr>
<tr>
<td>Panic Attacks</td>
<td>106</td>
</tr>
<tr>
<td>Headaches</td>
<td>105</td>
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</tbody>
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Continued on next page
questions will help you and your doctors better manage VHL as well as provide researchers essential information to design clinical studies to improve VHL treatments and, ultimately, prevent VHL tumors from forming.

There was much enthusiasm by symposium attendees for the results reported from the Databank. One interesting result was that many people living with VHL are also living with other health concerns. The most commonly reported health problem is digestive issues—this is not surprising as it can be a symptom of VHL lesions in the pancreas (2/3 of the participants reported that they had cysts or tumors in their pancreas). Endocrine conditions are also a concern for up to 1/3 of the contributors: pheochromocytomas, followed by obesity, vitamin D deficiency, diabetes, and hypothyroid.

There are a number of unanswered questions about VHL and pregnancy. The Databank already has more information from women with VHL who have been pregnant (134 women and 228 pregnancies) than any published study. These numbers will allow VHL researchers to determine which VHL tumors are present in women before and after pregnancy, look at tumor growth over time and compare it with women who have never been pregnant.

### Oral Health Finding

<table>
<thead>
<tr>
<th>Number of participants = 170</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Dry mouth</strong> (32.3%): Normal for age 70+; very high for average age 43</td>
</tr>
<tr>
<td><strong>Mouth sores</strong> (47.1%): Very high; possibly due to digestive issues</td>
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<tr>
<td><strong>Root canal(s)</strong> (40.2%): High; typical is 20%</td>
</tr>
<tr>
<td><strong>Crown(s)</strong> (44.5%): Consistent with high percentage of root canals</td>
</tr>
</tbody>
</table>

A surprising finding from the Databank is the relationship between VHL and poor oral health. Most everyone is brushing, flossing, and getting dental care (and virtually no one smokes), but dry mouth and related problems with gum disease and tooth decay are more typical of an older group of people than Databank participants. More studies are needed to fully understand the cause of and relationship between VHL and these problems. Could they be related to digestive issues, number of surgeries, changes in the immune system, or medications? In the meantime, this information is good to share with your dentist so that you can quickly address any problems and choose solutions that work well.

There are several common treatment concerns addressed in the Databank. One of these questions is the debate between radiosurgery versus open surgery for hemangioblastomas in the brain and spinal cord. Early data shows a wide range of short and long-term outcomes with these procedures, from completely dissatisfied to completely satisfied. Sharing your experience in the Databank will help provide a more scientific answer!

The VHLA office can also learn from your answers to Databank surveys. For example, 25% of you regularly go to one of the VHL Clinical Care Centers, but over 40% choose to see doctors near their home. We need to establish additional VHL Clinical Care Centers, especially where there is a long distance between centers.

At this point, the Databank has more data about women than men as 2/3 of participants are female. Men—your participation is needed!

More information from children with VHL is crucial to improving pediatric treatments for VHL as well as understanding what happens during the teen years. The average age of those in the Databank is 43 years old (the range is from 13 to 81). Parents of those under the age of 18 are encouraged to answer surveys on behalf of your children.

The Databank has already provided new, interesting information that is not part of current clinical knowledge. We want to thank everyone who has contributed their data and experiences.

### Reproductive Strategies: Ethical deliberations with the VHL-positive young adult

This is a summary of original research that Andrea conducted for her Bioethics dissertation at King's College London. It was presented at the International VHL Symposium for Young Adults (Utrecht, Netherlands, 2015) and the International VHL Medical Symposium (Boston, 2016). Andrea's personal VHL diagnosis uniquely positioned her to conduct this research. She is very grateful to the courageous participants for sharing how their VHL diagnosis continually shapes their lives. While this research does uncover emotionally charged experiences, it also generates hope that, together, we may help inform practices for improving care for future members of the VHL community.

Written by Andrea Berkemeier, BSE Biomedical Engineering, University of Michigan; MA Bioethics & Society, King's College London; VHL patient

To conduct this research, I reviewed published papers on the science (medicine), social impact, ethics, and philosophy regarding reproductive counseling. I then interviewed eight VHL-positive adults from five different countries about their experience of being diagnosed with VHL, receiving reproductive counseling, and processing ethical considerations related to VHL and reproduction. Using standard research techniques, I coded and analyzed the interviews. The common themes from the interviews are discussed below.

Participants often described their reproductive counseling experiences as overwhelming. The most common entry-point into reproductive counseling was learning that their future biological children will have a 50% chance of inheriting VHL. After learning this fact, participants felt obligated to act responsibly by ‘strategizing reproduction’ with the same responsibility they use when managing this complex disease in other areas of the body.

Although I defined reproductive counseling broadly when I conducted the interviews, participants seemed to discount informal reproductive counseling conversations with family and friends. Rather, they emphasized information provided in a professional/clinical setting.
This ‘official reproductive counseling’ is reportedly ‘non-directive’—the counselor discusses options without directing the patient toward a specific option. That being said, there appears to be a predictable message which guides patients to want IVF+PGD*, settle for PnGT**, view surrogacy as a last resort, ignore the possibilities of adoption or sperm/egg donation, and try to avoid ‘irresponsibly’ leaving the chance of having a VHL-positive child open to ‘fate’. While the end result (ie: IVF+PGD) may be what some patients ultimately choose, the means by which it is accomplished (ie: directive, biased reproductive counseling) does not respect every patient’s ability to make a personal, informed reproductive choice.

This IVF+PGD guided routine is made possible, in part, by censorship. That is because while some ethical considerations, including the health/wellbeing of the parents and the future child, were openly discussed, many of the other important factors were either unmentioned or were only briefly discussed before the participant became visibly uncomfortable. The specific topics that were discussed seemed to be determined 1) by questions from the patient or 2) by topics which a counselor is legally required to address. Both of these situations, however, are inherently flawed, because they place the counselor as a barrier between an anxious patient and the desired outcome of a healthy child. The counselor’s personal bias may also influence the direction of the conversation. In this way, the patient is put into a situation where they have to ‘consent’ to a particular option without having all the knowledge needed to make a well-informed decision.

Informal reproductive counseling sessions with family/caregivers may also be contributing to a VHL-positive individual’s sense of obligation to strategize reproduction. Participants frequently shared that they would feel guilty if their future children inherited VHL. Some went so far as to say they would feel even guiltier than their own parents did because they now have access to reproductive options that were not previously available. Participants also spoke about their VHL-negative family members who feel ‘helpless’ when watching them (or their other VHL-positive family members) cope with VHL-related complications. A VHL-positive individual who ‘gambles’ with creating more VHL-positive individuals may somehow lose support from family and friends. If patients can openly discuss their reproductive choices, they may be able to better express their own views and why their choice may differ from those of other family members. When ethical considerations are excluded from discussions, the patient may feel more anxious about making reproductive decisions.

The current process of reproductive counseling requires restructuring to be more holistic and individualized for each patient. To best serve the patient, reproductive counseling in both formal and informal settings should be more inclusive of ethical considerations. Adding emotional counseling may also help patients feel less overwhelmed. Thinking through tough ethical questions can provoke emotionally challenging conversations, but informed deliberation is necessary for patients to be able to make an informed decision. Without inclusion of ethical considerations, patients are made vulnerable and, thus, are more likely to be directed to choose a particular reproductive option.

Questions or comments about this research may be sent to: andrea.berkemeier@kcl.ac.uk

* IVF+PGD: In vitro fertilization with pre-implantation genetic diagnosis, implantation of VHL-negative embryos, and donation (to research) or termination of VHL-positive embryos
** PnGT: Prenatal genetic testing (ie: amniocentesis) with termination of VHL-positive fetuses

Welcome New Board Members

It is with great enthusiasm that we introduce our Fiscal Year 2017 VHL Alliance board members and officers. We have a wonderful team this year that will provide the organization with a variety of diverse talents and perspectives. Our new board members include:

**Gordon Cooke**: VHL patient from San Diego, California. Gordon will serve on the Fundraising Committee

**Jessica Everett**: Genetic counselor who provides support to VHL patients. She is from Ann Arbor, Michigan and will serve on the Clinical Advisory Council.

**Doug Karle**: VHLA Chapter leader from Mahtomedi, Minnesota. Doug will serve on the Engagement and Awareness Committees.

**Mark Pallansch**: VHL patient from Minneapolis, Minnesota. Mark will serve on the Awareness Committee.

The board leadership for Fiscal Year 2017 is:

- **Manuel Greco**, Chair
- **Barbara Correll**, Vice Chair
- **Andrea Rafael**, Treasurer
- **Soniya Sapre**, Secretary
- **Karen Ramsey**, Past Chair

Returning board members are:

- **Eric Jonasch**, **Anoop Mangat**, **Bettina Micheli**, **Anna Waller**

It is also important to acknowledge the fabulous members who have rolled off the board including Past Chair, Jane McMahon; former Secretary Sarah Nielsen; and board members Heidi Larson, and Patricia Tang. Thank you all for your support of the VHL Alliance!

To see complete board bios, visit vhl.org/about/people/board-of-directors
CCC Corner

The VHL Clinical Care Centers (CCCs) are your resource for care from a team of specialists with experience treating VHL. Because of the importance of the CCC program in helping you to effectively manage your VHL, CCCs will be a regular feature in our newsletters. Several CCCs will be highlighted in future newsletter editions.

University of Virginia—Charlottesville
VHL Comprehensive Clinical Care Center
Physician Sponsor: Ashok Asthagiri, MD
(Associate Professor, Neurosurgery)
Contacts: Nancy Staton, RN and Vicki Aylor

The University of Virginia became one of the VHL Clinical Care Centers in 2013, and was approved as a Comprehensive Clinical Care Center in January, 2015. Dr. Asthagiri believes in a personal approach, meeting with each patient coming to see a specialist at the CCC, even if the patient does not have an appointment with him. He makes sure that each patient and their family knows that a team of doctors is managing their VHL. The patient does not need to figure out which specialist and test are needed—the team is there to do that for them. Every effort is made to coordinate appointments over one or two days with the different specialists.

State University of New York, Upstate Medical University—Syracuse
VHL Clinical Care Center
Physician Sponsor: Gennady Bratslavsky, MD
(Professor and Chair of Urology)
Contact: Jennifer Lee

SUNY Upstate Medical University is the newest VHL Clinical Care Center in the U.S. joining the program in October, 2015. Dr. Bratslavsky kicked off their CCC with a two hour physician education meeting. Topics included: Overview of VHL, Genetic Testing, Pancreatic Tumors, CNS Tumors, Retinal Hemangiomas, Renal Cell Carcinoma, Endolymphatic Sac Tumors, Pheochromocytomas, and Related Rare Genetic Syndromes. A local VHLA volunteer also attended and shared VHL Alliance materials. This meeting was a great way to let doctors know about the expertise available at their own VHL Clinical Care Center. We look forward to similar meetings at SUNY and other VHL CCCs.

12th International VHL Medical Symposium

April 7–9, 2016, Boston, MA

The 12th International VHL Medical Symposium held in Boston, April 7th–9th, brought together VHL researchers, clinicians, and patients from around the world. The symposium was a great way for researchers to have the opportunity to meet and interact with physicians treating VHL and with VHL patients and families. Most importantly, it was a venue to discuss the tremendous advances that have been made in research that is bringing us closer to effective treatments for VHL.

An entire day was devoted to presentations and discussions directed to VHL patients, their families and friends. Several patients and caregivers presented their unique experiences with VHL, giving a picture of the effects of VHL on self-perception, career path, family dynamics, and the transition of medical decisions from child to adult. Discussions involving the audience covered ways to work together to reduce feelings of isolation with VHL, and how to best meet the needs of caregivers and teens.

The interaction between patients and researchers is invaluable. In fact, two researchers were so inspired that they volunteered to help the VHLA outside of their laboratory research.

Targeting VHL tumor pathways:

In contrast to many genetic diseases that affect a single organ or metabolic pathway, VHL is very complicated as up to ten organs can be affected. The gene’s product, VHL protein (pVHL), produced by normal, non-mutated VHL genes regulates multiple metabolic (energy) pathways:

- Targeting blood vessels
- Targeting cell metabolism
- Targeting HIF
- Repairing the VHL gene, or VHL protein
- Activating the immune system
- Decreasing inflammation

Link for complete summary on website: vhl.org/about/resources/international-vhl-medical-symposium/

Sign up for the Annual Meeting: vhl.org/weekend2016
**The VHL Alliance Office is Moving!**

Our new address is:

VHL Alliance  
1208 VFW Parkway, Suite 303  
Boston, MA 02132

The phone number will be the same at 617.277.5667 x4.

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**VHL Volunteer Opportunity:**  
**App Developer**

Do you or someone you know have the skills to develop an App? If so, please e-mail or call the office at office@vhl.org / 617.277.5667 x4. We would love you to create an App to help people keep track of their medical appointments!

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**Call for Auction Items**

If you have an auction item to donate to VHLA's Fundraising Dinner and Auction in Los Angeles, CA, please contact us at office@vhl.org or call us at 617.277.5667 x4.

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**Do Not Miss Out!!**  
**Annual Family Meeting**

Mark your calendars, purchase your tickets, reserve your spot! This year’s Annual Family Weekend, September 23–25 in Southern California, is going to be the best yet with several new activities and gatherings. The Fundraising Dinner and Auction will be honoring two people who are both important to the VHL community—Dr. Michael Gorin and Suellen Lindquist. The Annual Meeting will feature talks from various VHL experts as well as breakout sessions for patients and caregivers. For the first time this year, we will be having a separate Teen Activity for those ages 13–17 who are directly or indirectly impacted by VHL. They will be enjoying a fun day of adventures that is not to be missed! Saturday evening will have two more first time events: a Concert Event with Emily B and Friends as well as Young Adult Meet & Greet Happy Hour for young adults! Finally, don't forget the annual Team VHL 5K Walk/Run on Sunday morning! This is a great way to get your friends and family members to support you and the VHL Alliance! Please visit vhl.org/weekend2016 to find out more details, purchase tickets, and reserve your spots at all the above mentioned activities. Do not miss out!

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**Save the Date!**

**January 26, 2017**  
The fourth annual New York City Benefit Dinner in support of the VHL Alliance at The Harvard Club of NYC. More information to follow.

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**HAPPENINGS**

**UPCOMING**

**VCTC Race to Benefit VHLA**

The Van Cortlandt Track Club X-C Summer Series (Bronx, NY) will host a race to benefit the VHL Alliance on August 4, 2016. For more info, visit, vhl.org/about/news-events/vctc

**San Diego VHL Alliance Benefit**

Julie & Gordon Cooke will be hosting a fundraiser at their home in San Diego, CA, on Thursday evening, September 22, 2016. Email info@vhl.org if you are interested in attending.

**Team VHL Baltimore Marathon**

Join Team VHL on October 15, 2016 as they participate in the Baltimore Marathon. There are 18 participants so far! For more details or to donate visit grouprev.com/teamvhlbaltimore or write to team_vhl@vhl.org

**RECENT**

**Shawn Runs the Boston Marathon**

On Monday, April 18th, Shawn M crossed the finish line in Boston, MA as he completed the running of the 120th Boston Marathon. The VHLA staff were on hand to cheer him on. Great job Shawn!

**May Awareness Month**

On May 25th in Boston, MA, the The Leonard P. Zakim Bunker Hill Memorial Bridge was lit up in blue for VHL May Awareness Month.

**Davis Family Golf Tournament**

Big thanks to Altimate Electric who hosted a golf tournament on Monday, May 2, to benefit the VHL Alliance. The events raised $7,500 for VHL, was great fun, and raised awareness about VHL.
You can double or triple your giving to VHLA!

Many employers will match charitable contributions made by their employees. Click here to see if your company participates:

doublethedonation.com/vhla

Our Sincerest Thank Yous

Donations are seen on the printed version only.

Your help is greatly needed

DONATE
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JULY 2016 VHL Alliance Newsletter
Join us for the VHL Alliance Annual Family Weekend

September 23–25, 2016
Los Angeles, CA

Fundraising Dinner & Auction
Annual Family Meeting
Teen Event
Concert by Emily B and Friends
Young Adult Meet & Greet Happy Hour
2016 Team VHL 5K Run/Walk

For details on all events, lodging, and registration, go to vhl.org/weekend2016
Call the office with any questions: 617.277.5667 x4 or e-mail office@vhl.org