VISION STATEMENT
Curing Cancer through VHL

MISSION STATEMENT
The VHL Alliance is dedicated to research, education, and support to improve awareness, diagnosis, treatment, and quality of life for those affected by VHL.
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BACKGROUND

VHL Alliance (VHLA)

Initiated by Joyce Graff, Susan Warnick, and Peggy Marshall (two VHL caregivers and a VHL patient) the VHL Alliance (VHLA) was incorporated (as the VHL Family Alliance) by the Commonwealth of Massachusetts on April 28, 1993. The organization was awarded 501(c)(3) nonprofit status on July 1, 1993, the same year that the VHL gene was identified.

Feelings of isolation among patients and their families, particularly during the pre-Internet era, was the primary motivation for forming the VHL Alliance. Creating a sense of connection helped relieve some of the stress of tumors and the frustration caused by the lack of knowledge of healthcare professionals about this rare condition. As such, the organization made its mission to connect and educate VHL patients and families and provide information to healthcare providers which was important to advance VHL diagnosis, treatment, and quality of life.

Twenty-five years of work has shaped and advanced the VHL Alliance into the pre-eminent resource for patients, caregivers, researchers, and the medical community. In addition, the VHL Alliance is part of an international network serving an estimated 15,000 people worldwide, in 108 countries.

In late 2011, the VHL Alliance initiated its first major leadership transition with the replacement of its Founding Director, Joyce Graff. The change offered the VHL Alliance an opportunity to embark on a strategic planning process that included reviewing the organization's vision, mission, strategies, and tactics. The resulting blueprint was documented as a guide for the VHL Alliance.

Execution of the strategic plan was accompanied by a maturation of the VHL Alliance along with strengthening of the Board of Directors, growing programatic offerings, focus on research, and increased revenue. The success of the VHL Alliance's first strategic plan of 2013-2016 and work accomplished during this time period demonstrated the importance of a defined direction. A second strategic plan was developed and implemented during 2016-2018. With the start of FY2018, the board, volunteers, and staff embarked on its third strategic plan. This plan will utilize the momentum gained from previous years while expanding programs and services in line with 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 with the ultimate vison of finding a cure for VHL.
PROGRAMMATIC INITIATIVES PRIOR TO THE 2013-2015 STRATEGIC PLAN

Since the creation of the organization, there has always been a strong focus on providing educational and support programs for the various VHL stakeholders. These included:

- **Annual Family Meeting:** Geared to educating patients, families, and friends with the goal of empowering attendees to become active partners in clinical care.

- **Handbooks:**
  - The *VHL Handbook: What You Need to Know about VHL*, a reference handbook written in lay terms for people with VHL, their families and friends as well as physicians and members of their healthcare teams.
  - The *VHL Handbook Kid's Edition* written by a team of parents and professionals to help children understand VHL and manage their health with an upbeat and hopeful approach.

- **Newsletter:** Primarily written by VHL staff, published quarterly (including the Annual Report), and designed to educate and empower people with VHL and others impacted by the disease.

- **Website** ([vhl.org](http://vhl.org)): The VHL Alliance's primary source of education and news, providing up-to-date information on VHL clinical care, diagnosis, and research as well as details about upcoming VHL or VHLA-related events.

- **Support:**
  - Hotline: Staffed by volunteers, who through their own personal experience, have learned much about VHL and about living with VHL
  - Regional Chapters: Created to provide support at a local level with the goals of welcoming new constituents, proactively reaching out to existing constituents, and organizing get-togethers for social gatherings, educational programs, and/or fundraisers.
  - Online Support Networks: allowing constituents to communicate across geographic boundaries as well as venue for providing updates about VHL and VHLA. The major social media outlines for the VHL Alliance are:
    - [facebook.com/VHLAlliance](http://facebook.com/VHLAlliance) (Facebook Fan page)
    - [facebook.com/groups/VHLAwareness](http://facebook.com/groups/VHLAwareness) (Facebook discussion page)*
    - [inspire.com](http://inspire.com)
*In 2017, based on input from its members, the VHL Alliance changed the Facebook discussion page to a closed group. This enabled people to feel more comfortable with sharing their struggles while enhancing activity and the types and depths of conversations. In addition, joining the Facebook group is no longer automatic. Prospective members are asked to complete a form which includes indicating their relationship with VHL (see page 15).

- **Clinical Care Centers:** VHL Alliance-approved medical institutions identified for their extensive knowledge and experience in caring for and treating people with VHL with a particular emphasis on comprehensive care.

- **International VHL Medical Symposia:** In collaboration with leading VHL research institutions, the VHL Alliance holds a biennial symposium designed to bring together the leaders in VHL basic, translational, and clinical research, as well as the leading clinicians in VHL clinical diagnosis and treatment. The conference creates a stimulating environment while helping to make connections among these professionals spurring the pace of progress in understanding and treating VHL – and toward finding a cure.

This international symposia program as initiated in 1994 in Freiburg, Germany, under the leadership of Dr. Hartmut Neumann. The Symposium travels from continent to continent allowing participation of researchers, clinicians, and VHLers from around the world.

**SUCCESSES OF 2013-2018**

**VHL Alliance Identity/Branding**

During the course of the 2013-2018 Strategic Plan, evaluation of the organization's identity and branding was initiated. This included:

- Reevaluating the organization’s name
- Updating the logo
- Drafting a tag line
- Reassessing the organization's DBA (“Doing Business As”)
- Revising the Mission Statement

**Re-examining the Organization’s Name:** In 1993, the organization was named VHL Family Alliance symbolizing that everyone, directly or indirectly, impacted by VHL is part of a “Family”. As the organization grew and efforts expanded to include friends, researchers, and healthcare providers, the word “family” seemed less applicable. Could inclusion of “family” result in an
individual concerned about VHL but without family or friends with the disease feel disconnected?

In the summer of 2013, the name of VHL Alliance was registered with the IRS.

**Updating the Logo:** The change to VHL Alliance necessitated a logo update and provided an opportunity to revisit the design and consider a new, fresh look. It was quickly realized it would be impractical to drastically change the logo’s symbol since many constituents have invested in a tattoo to convey their connection to VHL.

The new logo utilizes a more modern font style. The two shades of blue emphasize the word VHL. In addition, the four dots in the symbol are now in the lighter blue shade, helping to emphasize the multiple stakeholders which include: patients/caregivers/friends, healthcare professionals, researchers, and the general public.

**Drafting a Tag Line:** A significant challenge in expanding VHL awareness beyond the immediate constituency is the lack of understanding of the involvement of the VHL gene in many forms of cancer. With this in mind, a tag line of “The Cure for Cancer is in Our Genes” was drafted drawing attention to the fact that finding a cure for VHL will play a vital role in curing cancer.

During the course of the 2016-2018 Strategic Plan the tag line and its usages was revisited because of a concern that it may not be suitable for all stakeholders. A decision was made that use of the tag line should be limited to addressing the general public.

**Reassessing the Organization’s DBA:** The DBA (“Doing Business As”) is used for national campaigns such as United Way and the Combined Federal Campaign (CFC). With the goal of being earlier in alphabetical listing, in 2011, the VHL Alliance changed its DBA from “Cancer Research Fund VHL Alliance” to “Alliance for Cancer Research and Support – VHL”. Unfortunately, this change did not result in higher revenue, as had been hoped. (Note it takes about 2 years to determine the impact of changes in approach for the CFC.) Thus in the winter of 2013, in time for the 2014 CFC, in consultation with Maguire/Maguire Incorporated, the association management with which the VHL Alliance contracts, the VHL Alliance changed its
DBA to “Cancer Research and Assistance – VHL”. The new DBA seems to have a positive impact on funds raised (see page 26).

**Revising the Mission Statement:** In late 2014, it was noted that the mission statement did not reflect VHL Alliance’s work in increasing awareness about VHL and VHLA. As a result, the word “awareness” was added to the mission statement: “The VHL Alliance is dedicated to research, education, and support to improve awareness, diagnosis, treatment, and quality of life for those affected by VHL.”

The mission statement was reconfirmed by the board during its face-to-face meeting in October 2017 during which the 2018-2020 strategic planning process was initiated.

**Revising the VHLA’s Vision:** As the first step of the 2018-2020 strategic planning, the board revisited the organization's vision, “The VHL Alliance envisions a cure for VHL”. There was a strong feeling that the current vision did not reflect the role that the vhl gene plays in other forms of cancer and the importance of finding a cure for VHL in the general public.

- The vhl gene regulates hypoxia-inducible factor (HIF), one of the main drivers of bad cancer biology. By understanding vhl we learn how to control HIF.
- Loss of the vhl gene impacts DNA repair, one of the linchpins of cancer initiation. By learning how vhl loss affects DNA repair, we will understand this process in other cancers.

With this in mind, VHLA’s mission was updated to “Curing Cancer through VHL”.

**Governance**

Several elements are the building blocks for a well-run organization. These include:

- **Strong Volunteer Leadership**
  - A solid, diverse, and involved board which includes leaders who together provide the expertise for the organization to run smoothly
  - Job descriptions and accountability structure
  - A structure for recruitment of new leadership
  - Orientation process

- **Board Governance Documents**
  - Bylaws
  - Board policies

- **Dedicated and Skilled Staff**
  - Clearly defined job description
Effective, goal oriented review processes aligned with mission and strategic plan

During the period of 2013-2015, the Governance Committee created, updated, and implemented processes and documents needed to strengthen the organization's governance structure. An important outcome was the recruitment of new board members with proficiencies and interests that align with the goals of the organization and the documented strategic plan. In 2017, the board evaluated the board nominating process and officially made the Governance Committee responsible for board nomination and recruitment.

Reviewing and strengthening the organization's governance also provided greater awareness of the need to include fundraising as a staff function; thus resulting in the hiring of VHLA's first Director of Development in July 2015. As the programmatic and fundraising efforts of the organization expands it is incumbent upon VHLA to once again assess its staffing needs within the period of 2018-2020 Strategic Plan.

EDUCATION PROGRAMMATIC EFFORTS

Education is core to the VHL Alliance's mission. It is the heart of empowering people with VHL and their family to make the best medical decision possible for their individual situation. In the medical world, patient outcome goes beyond education of the consumer; provider education is also essential. For this reason, VHLA is committed to developing mechanisms to educate both sectors.

VHL Website: The VHL website (vhl.org) is a major educational resource to all VHL stakeholders, including VHLers, their families and caregivers, VHL researchers, healthcare providers, the general public, and potential donors. Developing one site that serves all is a challenging endeavor.

In the fall of 2015, the site was overhauled in order to modernize its appearance, bring consistency to VHLA branding, and increase accessibility of its valuable resources. Despite the best of efforts, the ease of use remained questionable. In the spring of 2017, the VHLA staff reorganized the website and its sitemap with the soul purpose of making it more user-friendly. Subsections were redefined and content updated.

A “blog” page was added during the website makeover. This page includes stories written by people directly and indirectly impacted by VHL describing how they face, live and thrive with VHL. In some cases, VHLA solicits stories that narrate an important piece of care, along with the considerations and decisions of a particular piece of the VHL journey.
New “blogs” are posted every other week. Together with Facebook announcements, the blogs are driving more traffic to the website page.

**VHL Handbook:** During the 2013-2015 Strategic Plan period, the 5th edition of the VHL Handbook was drafted and sent to press in December 2015. The new edition includes changes to the active surveillance guidelines that were implemented after the publication of the 2012 edition. In addition, there is more in-depth information about Healthy Living for both patients and caregivers. Healthy Living tips, including specific dietary requirements for patients with low or non-existent kidney, pancreatic, or adrenal function, are included.

**Healthy Living:** The VHL Alliance was fortunate to have a genetic counseling student from Boston University intern during her 2014 spring semester. Her work included an extensive literature review on healthy living, including: nutrition/diet, physical activity, and emotional health. Her report included specific tips for living with VHL-related conditions such as low pancreatic, kidney, and adrenal functions. The final summary (along with references) was incorporated into the 5th edition of the VHL Handbook (see above).

**Education of Medical Professionals:** Educating medical professionals about VHL diagnosis and treatment is essential for improving patient outcome. In addition, it is vital that healthcare professionals are up-to-date with the most recent approaches to VHL care. Towards this end, in November 2016, the VHL Alliance initiated a virtual “Journal Club” for VHL Clinical Care Center healthcare professionals. VHLA solicited volunteers to identify a recently published VHL-related manuscript and provide a brief summary/commentary. This was then circulated via email using VHLA’s list serv’s to the CCC team members. Identifying volunteers was a difficult task. In addition, the idea was received with mixed reviews; while some CCC team members greatly appreciated the program, others found it off-putting and protested.

At about that same, Elsevier’s PracticeUpdate offered to develop a von Hippel-Lindau Disease Spotlight. Through this collaboration, journal articles are identified, reviewed for relevancy, when appropriate sent out for commentaries by identified experts, and disseminated to PracticeUpdate subscribers. In this way, PracticeUpdate could replace VHLA’s CCC Journal Club while reaching a broader audience and removing the burden on VHLA staff. The von Hippel-Lindau Disease Spotlight was launched in the spring of 2017 with Eric Jonasch, MD and Ilene Sussman, PhD acting as its Advisory Board. New articles and relevant videos summarizing VHL breakthroughs presented at relevant scientific meetings are uploaded and electronically circulated weekly as “This Week in VHL”. The VHL Alliance shares these emails, via mail merge, with the relevant specialists in the VHL database. The feedback from both clinicians and researchers has been outstanding. The process also serves as an ideal and important touchpoint.
Strategic Plan

The von Hippel-Lindau Disease Spotlight is the first, and currently only, rare disease included in PracticeUpdate's program and puts VHL in the same “catagory” as metatastic breast cancer, renal cell carcinoma, brain cancer, and advanced prostate cancer.

Specialty List Serv's: As a means of facilitating the dissemination of information and maximize learning, the VHL Alliance created email list serv's for each medical specialty. Each list serv includes members of the Clinical Advisory Council as well as medical professionals involved in the Clinical Care Center. In this way, even the most challenging questions related to the most complex VHL cases can be sent to members' CCC teams, the Clinical Advisory Council and experts in the field. The process enhances group learning. Clinicians at all levels of their career are actively providing input into the specific case.

Support Programmatic Efforts

Implementation of the 2013-2015 Strategic Plan uncovered the importance of expanding the VHL Alliance's programmatic efforts to include the emotional toll of living with a life-long medical condition. The emotional impact of VHL goes well beyond the patient and to include family and friends. New programs and/or adaption of existing program and resources have been created that include a more holistic approach to supporting those, directly or indirectly, living with VHL. Efforts to provide programs geared to the psychosocial needs of VHLA constituents continued to expand and mature throughout 2016-2018.

Emotional support programs currently include:

Breakout Discussion Groups at Annual Family Meeting: Separate breakout sessions for patients and caregivers (family and friends) were incorporated into the Annual Family Meeting. The separate discussion groups allow each stakeholder to discuss and to share their individual experiences of the emotional rollercoaster resulting from VHL. Segregating patients from family and friends is key as it allows individuals to speak more honestly and openly about their feelings and needs without feeling responsible for the impact it likely will have on the partners and family members. Another important feature of these discussions is including a professional facilitator who can help direct the conversation, provide insight, and ensure that no one individual dominates the discussion.

Better Together Peer Mentoring: This support program pairs a mentee with a mentor who has experienced first-hand the medical and emotional journey of VHL. The type of pairing is dependent on the needs of the individual(s) involved. For example, pairs are usually caregiver-caregiver or patient-patient. There are also times when someone may benefit from connecting with another person who is concurrently experience a similar situation.
The relationship can be short-term or long-term depending on the connection and needs of the individuals. With modern technology there are no geographic restrictions for either mentors or mentees. The Better Together program is open to minors; however, minors must have permission from a parent/guardian to participate.

In the original version of the program, mentors received training through a collaboration with the 4th Angel program (4thangel.org). After several years of trying to work with 4th Angel, it was decided to terminate the collaboration.

**Monthly Telephone Discussion Group:** A monthly telephone discussion group focusing on the emotional rollercoaster of VHL was initiated in fall 2014. The original group is open to both people with VHL and caregivers (defined as family, friends, and loved ones). While the primary focus of the discussion is the emotional side, medical concerns often creep into the conversations. This group is facilitated by Leona deVinne (http://accendoconsulting.ca/), a trained life coach who also a VHL patient and a VHL caregiver.

Each month a topic is pre-chosen as a starting point. The topic is announced via Facebook and an email list consisting of past participants and indicated interest. For purpose of confidentiality, only those who connect directly with the VHLA office are provided the specific call-in details.

Attendance varies from month-to-month. Those who participate regularly have developed strong and supportive relationships.

Because of the success of the patient/caregiver telephone discussion group, two additional groups are being implemented. The first one is a group specific to VHLers with low/no vision and the second is a caregiver-only group.

The low/no vision group meets monthly. Participants share their feelings and challenges of living a life with minimal, if any, sight. The callers provide each other tips related to mobility, independence, and technology. This group is very successful, with the same participants joining on almost every call. In addition, this group is unique in that people share freely and have incredible “telephone manners”. As a result, there is no need for a paid facilitator. The call is moderated by a member of the VHLA staff.

The caregiver-only call is facilitated by Leona deVinne and meets on an every-other-month basis. Participation is fairly low, an average of 3-5 and is independent of the day or time of day. Feedback from the group demonstrated that the biggest challenge is that people are juggling so many factors in their lives. Taking time for oneself is their lowest priority. Caregivers did express the importance of VHLA continuing to provide the caregiver-only option while also allowing them to participate in the joint patient/caregiver call.
Wellness E-News: Initiated in January 2014 as a monthly communication, the Wellness E-News focuses on wellness or healthy living tips for all stakeholders. Topics have included: risk of too much sun; benefits of exercise; relaxation techniques; healthy eating tips; and rewards of pet ownership. This initiative is highly valued as indicated by the high open rate.

In the summer of 2015, the E-News frequency was modified to every other month in order to balance the number of communications from the VHLA office.

Caregivers: The role and support of caregivers, whether they be a family member or friend, was stressed throughout the course of the 2013-2015 Strategic Plan. As such, in the fall 2015 website update, a new section entitled "For Caregivers" (vhl.org/patients/caregiver-center) was created. Material, resources, programmatic efforts, and information dealing with stress, specifically geared to caregivers, are now available.

Additional offerings for loved ones of VHL patients include a Facebook group (facebook.com/groups/vhlcaregivers) and a caregivers-only discussion group (see page 12).

Young Adult: Young adults with VHL face a unique set of challenges and questions during the time when they are making important life choices and taking on new responsibilities. Questions about where to live, career choice, and the lifestyle about which they dream including committing to a serious relationship and starting a family. For many young adults, it can be the first time in which they are involved in their own medical care which for VHL includes active surveillance and decision on medical procedures. The VHL Alliance understands the importance of creating a young adult community to provide support and a unique opportunity to wrestle with decisions about the future amongst peers.

In June 2017, VHLA launched its first young adult retreat with 7 participants between the ages of 18-30. The group spent the weekend getting to know each other and sharing their stories, concerns, and challenges, and learning about their VHL with the help of members of the Vanderbilt Clinical Care Center team. At the end of the weekend, the participants elected to create a WhatsApp group through which to communicate.

I suppose I shouldn't have been too surprised that it felt comfortable sharing my story with these people. They didn't just listen, they really understood what it is like to live with VHL. As I solved an Escape Room game, played VHL Jeopardy, shared some home-grilled surf and turf, hiked in a state park, listened to live music at a famous local hangout, and even had a little karaoke fun during the car rides, I came to realize that these folks seemed like they were not just surviving, they were thriving with VHL.
Using the success of the retreat, a Young Adult Happy Hour was added to the list of events taking place during the October 2017 Annual Family Weekend. This provided another opportunity for young adults to connect with each other and share and learn how they cope with their VHL.

**Teen Event:** In general, the teen years are unique and challenging for both the teens and parents. It is a time marked with the child pulling away from their parents as they seek their own unique identity. Then add the challenge of living with VHL. Creating an opportunity for teens who have VHL or are living with someone who has VHL to meet and, hopefully, create long-term relationships with fellow VHLer is important as they transition from child to young adult.

A program specifically designed for teens was piloted at the 2016 Annual Family Meeting. Following a discussion about how they feel about VHL with Leona deVinne, six teens spent an afternoon participating in a scavenger hunt.

*Next year I am planning on going again. I really enjoyed the trip, and I hope that other people can experience this the same way I have. I can’t wait to meet new people and more VHL Warriors. After all, we have to stick together!*  

Multiple attempts were made to create a mechanism by which the participants could stay in touch. Various options were offered but all failed—although it is suspected that there are private conversations going on.

The 2017 Annual Family Weekend also included a teen program with 6 teens participating. The few teens who had attended the year before were thrilled to see each other and seemed to pick up where they left off.

**Parents of Teens:** In the spring of 2017, a number of people asked the VHL Alliance to create a Facebook group designated for parents of VHL teens. The VHL: Parent to Parent Facebook group was launched in response: [https://www.facebook.com/groups/teenVHLparents2parents](https://www.facebook.com/groups/teenVHLparents2parents).

**Vignette Book:** Living with the unknown is always frightening and is particularly common among newly diagnosed patients and their families and friends. What happens next? Is my reaction to a diagnosis normal? How do I take care of myself (or my loved one)? What type of medical team will help me keep on top of things? What does the future hold? Hearing stories and learning tips from other patients and caregivers who live with VHL is helpful. With this in mind, the VHL Alliance created and published a “VHL Patient Vignettes” book using excerpts from solicited patient/caregiver stories. The book is available through the VHLA store: [vhl.org/store](http://vhl.org/store).
**Connecting to Constituents:** The VHL Alliance database is the main resource by which the organization connects with its constituency. While the database contains a large number of contacts, it is limited to those for whom contact information is provided. In order to better connect to stakeholders, the VHL Alliance updated and created new forms to capture names, contact information, and interest. Forms are now in place for:

- Downloading the VHL Handbook
- Signing up for the quarterly newsletter
- Signing up for the Facebook Awareness Group
- Receiving Well Wishes post surgery

**Research**

Medical research is essential to achieving the VHL Alliance’s vision of discovering a cure for VHL. Much progress has been made since the organization was founded in 1993, the same year that the VHL gene was identified. Nearly two and a half decades of research have resulted in sequencing of the gene and an understanding of the complexity of the biochemical processes regulated by the VHL gene, and several small clinical trials to test potential agents that inhibit blood vessel growth.

The commitment of the VHL Alliance to fostering research is evident from the $1.7 million contributed to research. Since the initiation of the first strategic plan, the importance of funding research is emphasized by the types and size of the grant awards.

**Research Grant Awards:** During the initial stages of the 2013-2015 strategic planning period, donation income was insufficient to disburse funding for research grants at a meaningful level. This period was used to 1) reevaluate the granting and the review processes and 2) develop and launch the VHL Patient Natural History study, see page 16.

Since that time, revenue has grown substantially (see page 27) allowing for an expansion of the grant program. Two types of grants are now available: Pilot Studies - $25,000 for 1 year (geared to position researchers to apply for other funding sources) and Research Grants - $100,000 over 2 years.

During FY17, VHLA received an unbudgeted $100,000 donation directed to research. This gift provided VHLA the opportunity to fund two research grants and two pilot grants for the FY18 cycle. Nineteen proposals were received and reviewed using a process modeled from that used by NIH. Only two grants (one pilot and one research) were highly regarded and considered as “Outstanding” with several grants scoring “Very Good” to “Excellent”. For the first time, the board was faced with deciding whether to only fund the two grants and reserve
the funds for future and better appraised applications, or to use all of the available funds. A unanimous decision was made to reserve the funds for future use. It was also decided that it was time to reassess the grant process, including the specific types of research to be funded and whether to offer a grant larger than the current research grant.

GRANT AWARDEES

FY2015
- **Research Grant Awardee:** Othon Iliopoulos, MD, PhD; Zebrafish Based Discovery of VHL Disease Targeting Drugs
- **Pilot Grant Awardee:** Daniel Segal, PhD; A novel chemical chaperone for treating the VHL cancer Syndrome

FY2016
- **Research Grant Awardee:** Ian Frew, PhD; Using a novel mouse model of ccRCC to investigate Hif-1α and Hif-2α inhibition for cancer prevention and therapy
- **Pilot Grant Awardee:** A.N.A. van der Horst-Schrivers, MD, PhD; Salivary, plasma meTanephRines and anxiEty levelS in pheochromocytomaS (STRESS)

FY2017
- **Research Grant Awardee:** Michael B. Gorin, MD, PhD; iPS model for Retinal Hemangioma Pathogenesis
- **Pilot Grant Awardee:** Raymond Kim, MD, PhD; **VHL IT-Sharing International Consortium (VISlon)**

**VHL Patient Natural History Study (formally called Cancer in Our Genes International Patient Databank):** During the proceedings of the 10th International VHL Medical Symposium (Houston, TX; January 2012), VHLA's Research Council provided the opinion that it was time for the VHL Alliance invest in itself. The Council's message strongly supported the concept that VHLA should devote resources and dollars to create and implement an international patient registry. The registry should be based on patient-driven data and supplement existing clinician-driven studies as well as consolidate patient information from around the world making it independent of geography or specific mutations. Such a comprehensive study would provide important background data required for the approval of any potential medical treatment as well as offer a mechanism for accelerating clinical trials by providing a method to match patients to clinical trials. In addition, the proposed database would be a valuable resource for VHL researchers around the globe. Furthermore, in order to remove any
perception of political favoritism or influence, the Research Council strongly recommended that such an undertaking be performed within the structure of the VHL Alliance.

After an initial collaboration with NIH’s Office of Rare Disease’s GRDR (Global Rare Disease Registry) program, the VHL Alliance chose to transition to a collaboration with the National Office of Rare Disorders (NORD) as their IAMRARE platform was developed. This partnership provided the VHL Alliance a number advantages including input into the platform at the development level as well as the financial benefit of what could be an annual fee of $15,000. Additionally, input from the FDA was being incorporated into the NORD program, meaning that the original surveys created by the VHL Alliance benefitted from review and comment by the regulatory agency.

In the Spring of 2014, VHLA's study became the first patient registry launched by NORD. The “cost” of being the first organization/disease to use the platform is that VHLA is ahead of the curve and as such is the first to find flaws and limitation in the software. Examples include an 18-24 month delay in updating survey questions and an inability to easily track patient participation, impacting VHLA’s ability to recruit and retain registry users. At the beginning of FY17, NORD hired a new director of IT who spent a year developing a solid team of IT experts. The new team fixed many of the inherent platform issues and allowed VHLA to update its surveys at the end of FY17.

Despite the challenges, the VHLA’s patient registry has demonstrated a number of interesting findings including:

• An association between VHL and oral health
• High levels of digestive complaints and thyroid issues
• High levels of panic attacks amongst VHL patients, particularly in females
• A disparity in time to be diagnosed between male and female, where female diagnosis takes longer than male

As of the fall of 2017, there are over 700 participants of which a small proportion, the number yet to be identified, are actively submitting longitudinal data and medical scans.

The VHL Patient Natural History Study has become a model patient registry. Organizations, particularly those interested in joining NORD’s IAMRARE program, contact VHLA for advice and input into their disease’s study. In the fall of 2016, VHLA staff consulted in the MyKidneyCancer Registry being created by James Brugarolas, MD and Hans Hammers, MD, PhD at UT Southwest. A fee of $10,000 ($5,000 paid in early 2017 and $5,000 to be paid in early 2018) was provided for the work done by the VHL Alliance.
Strategic Plan

Research Council: Historically, the primary role of the VHL Alliance's Research Council (formally Research Committee) was reviewing the competitive research grant proposals. In order to better foster research, it was essential to further engage members of the VHL research committee.

The first action was to include the chair of Research Council on the Board of Directors. Re-evaluating and clearly articulating the role of the Research Council followed. Ultimately, the Council was restructured to include representation from the multiple facets of VHL research including basic, translational, and clinical.

ROLE OF VHLA'S RESEARCH COUNCIL

1. Develop partnerships with other researchers, pharma and diagnostic companies, as appropriate, in order to:
   a. Create road map that takes research from bench through approved therapy including development of any necessary experimental models and reagent development.
   b. Develop improved diagnostic tools for VHL testing and detection of tumors
   c. Direct Clinical Trials Task Force to coordinate and accelerate clinical trials
   d. Expand mutation databank including correlation of genotype and phenotype

2. Generate multiple peer-reviewed positional papers describing vision of VHL research for next 5-10 years

3. Engage in collaborative research including grant submissions

4. Manage VHLA competitive grant program

5. Oversee CGIP in order to maximize data usage

6. Develop agenda and help Fundraise for biennial International VHL Medical Symposium

7. Determine value and future of NDRI Tissue Bank

As part of their role in managing the VHL Alliance's competitive grant program, the Research Council reviewed the process of approving and awarding grants. There is now a rigorous and quantitative review process, modeled after that used by NIH, removing the possibility of partiality.

Under the leadership of Alexander Vortmeyer, MD and through a survey assessing researchers’ tissue needs and usage, it became clear that there was little if any interest in
the NDRI tissue bank. Most research institutes rely almost solely on their own tissue. In addition, the cost of NDRI tissue was too high for most researchers.

**Clinical Trials Task Force:** The organization’s mission includes improving diagnosis, treatment, and quality of life for those affected by VHL. Advances in clinical research and regulatory approval of potential therapies are essential to reach the VHL Alliance’s ultimate vision of finding a cure. In order to accelerate approval by regulatory authorities, it is in the VHL Alliance’s best interest to have a structure in place that could implement a multi-centered clinical trial needed for the approval process.

The Clinical Trials Task Force, established in 2012, collaboratively submitted an NIH Rare Diseases Clinical Research Consortium Grant application in 2013. Unfortunately, this grant was not approved. However, the structure remains in place for further grant submissions and implementing a clinical trial(s), as the need arises.

Since that time, no further work has been done with the Clinical Trials Task Force.

**Clinical Care**

With approximately 7,000 recognized rare diseases, it is impossible for clinicians to have complete knowledge of every rare disease. It is, therefore, incumbent on a patient advocacy group, such as the VHL Alliance, to not only be the preeminent resource and clearinghouse for VHL patients, families, and friends, but also for the medical community. Because of the inevitable knowledge gaps, there is the realization that the best care comes from a medical team with knowledge and experience of caring for VHL patients. Since VHL is a complex disease, it is also important that a mechanism exist for assisting clinicians to provide the best care possible.

**Clinical Advisory Council:** In January 2015, the Clinical Advisory Council (formally Medical Advisory Board) was restructured to include representation from every clinical specialty related to VHL manifestations and care. Three goals of the Council were defined:

1. Develop a network of Clinical Care Centers around the country and the world that provide exemplary care to patients with VHL.
2. Provide education to physicians and patients about state-of-the-art care for VHL.
3. Move the field forward with collaborative efforts to drive innovations in VHL treatment strategies.

The first task of the Clinical Advisory Council was the generation of a set of articles that describe, in an organ-specific fashion, state-of-the-art care for VHL. These manuscripts will serve as a key references for the community, as well as be the foundation for a comprehensive
review article on the latest standards in medical treatment for VHL. In cases where reviews have recently been published, an additional manuscript is unnecessary.

A major challenge with this concept is volunteering people with already too much on their plate to take on one more task. For this reason a number of manuscripts have still not been written or submitted.

The list of published articles is below:


Manuscripts still to be written and submitted are: Retina, CNS, Kidney, and Adrenal.

In 2014, a manuscript on Genetic Kidney Cancer Syndromes by Tai Ho and Eric Jonasch, had been published in Journal of the National Comprehensive Cancer Network eliminating a need for an additional review.

**ROLE OF VHLA’S RESEARCH COUNCIL**

- Generate and publish VHL specific state-of-the-art management guidelines for:
  - Kidney
  - Retina
  - Genetics
  - Adrenal
  - CNS
  - Oncology
  - Pancreas

- Enable other healthcare providers through VHLA list serves

- Create web-based resources for clinicians on the VHLA website Present VHL-specific Grand Rounds topics at academic centers

- Advocate for and speak at VHL specific sessions in Society meetings – ASCO, AUA, etc.

- Approve and guide Clinical Care Centers

- Review and improve the VHL Handbook

**Clinical Care Centers:** From its beginning, the VHL Alliance created a Clinical Care Center (CCC) program. CCC’s were identified as hubs of VHL care that included a team of specialists (including all organs involved in VHL) experienced in diagnosis and treating VHL patients.
Expansion in the number of CCCs was also accompanied by steps to strengthen individual centers. With the input of the Clinical Advisory Council, the CCC program was reevaluated in order to improve patient satisfaction. The result was the creation of two different designated types of centers: Clinical Care Centers (CCC) and Comprehensive Clinical Care Centers (CCCC) with supplementary responsibilities for communication between CCCC team members and inclusion of additional medical specialties (Endocrine Surgeon, Nephrologist, Neurootologist, Oncologist, and Radiologist).

A new role added to the CCC program is that of Patient Navigator. This person, often the same as the CCC Point of Contact or CCC Sponsoring Physician, plays a crucial role in patient contact and management. See job descriptions below.

Additional modifications to the CCC program are:

The VHL Alliance has also introduced the CCC Liaison, a volunteer position for VHL patients or caregivers. As the role evolves, the liaison’s primary responsibility is to connect with the leadership team of the CCC, making sure that everyone’s needs are met; those of the CCC, the patients and VHLA.

1. “Job descriptions” and expectations of each member of the team have been clearly defined and included in the CCC application.
2. Ability for patients to provide important feedback about their experience through an online form sent directly to VHLA: (https://docs.google.com/forms/d/1x35igCRZFvcYmY_d5M2xYW1KMUCmLvjjuSQ4ZTbc/viewform?edit_requested=true). In this way, feedback can be relayed anonymously, eliminating any concerns a patient may have about doing so directly.
3. A more thorough and meaningful review process by the Clinical Advisory Council for all applications and biennial renewals.

At conclusion of the 2016 strategic planning period, there are 12 CCCCs and 19 CCCs in the U.S. with an additional 19 international centers.

**CCC Requirements**

Each Clinical Care Center application (both new centers and renewals) are required to:

- Submit institutional surveillance protocol to be approved by Clinical Advisory Council.
- Provide surveillance protocol, a list of participating team members and their contact information, and referral standards to the specified Point of Contact for that Center. (This will help them in the referral process as they help the patient navigate the system.)
Identify and implement system to assess psychosocial needs of each patient. (Addressing ongoing psychosocial needs may be better achieved at a clinic closer to the patient's home, but the patient navigator and referring specialists at the CCC should work with the patient/family to establish this care.)

Agree to communicate medical updates, including psychosocial needs, with patient's primary care clinician.

Identified team members must be Board certified in specified area. Retinal specialists are required to have completed a retina fellowship.

Agree to turn in complete, updated applications every other year to keep contacts current.

Encourage patients to participate longitudinally in the Cancer in Our Genes International Patient Databank (CGIP, www.vhl.org/databank).

Roles of CCC(C) Team Members

CCC Sponsoring Physician

- Ensures organization and coordination at the CCC. Designates Point of Contact and VHL Navigator and assembles team of VHL specialists. Shares VHL Surveillance Guidelines within team, ensures team members know each other, and educates team on the importance of patient participation in the CGIP Databank.
- Ensures team members notify Patient Navigator when VHL patients are seen in their specialty departments.
- Conducts / facilitates regular communication with entire CCC team in addition to communicating with EMR. Suggestions: manages an internal list-serve for sharing observations about VHL, directs specialists toward VHLA specialty list-serves, encourages specialists to educate their department about VHL, etc.
- Promotes inclusion of VHL patients in patient meetings, (ie: cancer support groups) when appropriate.
- Arranges / participates in medical education meetings to teach physicians outside of CCC team about VHL.
- Member of “CCC Lead Team”; meets with VHLA CCC Liaison at least once per year.

CCC Point of Contact

Best practice is to designate a genetic counselor or nurse in the sponsoring physician’s department. Consider multiple contacts with a common email address to ensure coverage at all times.

- Serves as initial contact for patients, families, and physicians. Contact info is listed on VHLA website and given to our hotline volunteers. Uses VHL Surveillance Guidelines to connect patients with relevant CCC specialists. This person should have a basic understanding of VHL (and hopefully HLRCC and BHD), but is not expected to answer any medical questions that require the patient to see a specialist.
Strategic Plan

- Ensures each CCC Specialists have CGIP Databank physician information sheets and patient brochures. Frequently encourages patients to participate longitudinally in CGIP.
- Member of “CCC Lead Team”; meets with VHLA CCC Liaison at least once per year.

CCC PROCESS MATRIX

Below is a process matrix that demonstrates how patients contact a CCC, how CCC team members work together to provide coordinated care, and how the Liaison works with the CCC.

- Patient contacts CCC via Point of Contact
- VHL Navigator assists patient in making CCC Specialist Appointments
- VHL Navigator notifies patient of next steps
- CCC Specialist shares the patient’s medical result(s) and psychosocial needs with VHL Navigator and Point of Contact
- CCC Specialist(s) care for patients includes: tests, treatments, and psychosocial monitoring
- VHL Navigator introduces Patient to Liaison
- Patient contacts CCC Specialist / Department
- VHL Navigator notifies patient of appointments
- Patient provides feedback to liaison at least annually
- Lead Team meets with Liaison annually to review patient feedback and develop plans for strengthening CCC. Liaison shares plan with VHLA; helps identify best practices to share with other CCCs.
CCC Patient Navigator
- Personally welcomes each VHL CCC patient, introducing them to the concept of comprehensive, coordinated care within the CCC team. Flags patients’ EMR records as VHL and has overview of each VHL patient’s care.
- Works at the patient and institutional level to ensure that each CCC patient is adhering to the VHL Surveillance Guidelines and receiving all recommended tests and treatments.
- When feasible, works with appointment scheduling to expedite and coordinate VHL appointments.
- Has overview of each VHL patient’s care. Follows up with patients that have missed any CCC appointments.
- Monitors the patient’s psychosocial needs using ie: HADS. As needed, works with Specialists to establish relevant care close to the patient’s home.
- Shares genetic testing / surveillance results with patient; ensures patient’s PCP receives report after each CCC visit.
- Reminds / encourages patients after every clinical encounter to participate in CGIP.
- Determines if patients are facing insurance / financial barriers; utilizes the hospital’s Patient Financial Services Department to assist patients in overcoming these barriers.
- Member of “CCC Lead Team”; meets with VHLA CCC Liaison at least once per year.

CCC Specialist
- Adheres to VHL Surveillance Guidelines. Monitors the patient’s psychosocial needs at every clinical encounter using ie: HADS; as needed, works with Patient Navigator to establish relevant care close to the patient’s home.
- Encourages patients to participate longitudinally in CGIP after each appointment / procedure.
- Serves as department expert on VHL:
  - Receives notification from departmental colleagues each time a VHL patient is seen.
  - Ensures VHL Patient Navigator incorporates these patients into the CCC system.
  - Educates department on need for coordinated care between multiple specialists to properly manage VHL.
- Understands CCC structure. Knows, works with, and communicates with other team members.
- Becomes a member of VHLA list serve. Posts questions/responses to clinicians at other CCCs.
- Willing to give VHL presentations at physician and/or patient meetings when requested by the Sponsor.
Medical Wellness Coaching: With increasing demands put upon healthcare professionals by hospital administration and insurance companies, it is increasingly more difficult for holistic medical care to be provided. The stressful environment impacts one's capacity to assess, discuss, and meet the psychosocial needs of the patient of anyone living with a life-long, chronic ailment, such as VHL.

Literature is mounting demonstrating and expressing concern about healthcare professional burnout caused by growing pressure on healthcare providers. The combination of emotionally distraught patients and overworked healthcare professionals is likely to impact the important partnership essential for optimal diagnosis and continued care of patients with diseases such as VHL.

With this in mind in 2017, VHLA piloted a Health Wellness Coaching Training program for team members at a select few CCCs. Leona deVinne (http://accendoconsulting.ca/), a trained life coach, who also a VHL patient and a VHL caregiver, was hired to create and implement the program. The program itself was designed to be 14 sessions with a virtual meeting every other week via Zoom. In addition to the sessions, participants had the option of 4 individual coaching sessions with Leona during the course of the program. Pre, mid, and post-program surveys assessing participation and program content/format were incorporated.

Note that the VHL Alliance staff was provided the opportunity to participate in the video sessions.

The program content aligns with the eleven core coaching competencies:

- Meeting Ethical Guidelines and Professional Standards
- Establishing the Coaching Agreement
- Establishing Trust and Intimacy with the Patient
- Coaching Presence
- Active Listening
- Powerful Questioning
- Direct Communication
- Creating Awareness
- Designing Actions
- Planning and Goal Setting
- Managing Progress and Accountability

Planning and implementing the pilot training program demonstrated that the greatest barriers were 1) identifying a specific day and time where all participate could be available over a 28-week period and 2) it was impossible for any one participant to participate in every session given their patient load and other responsibilities. With this in mind, VHLA is moving to a series of online recorded video sessions.
The feedback from the pilot program is phenomenal, encouraging VHLA to expand the program to more CCCs.

Preliminary results demonstrate the program's effectiveness:
- A 70% improvement in participants' understanding of the three parts of empathy
- A 30% improvement in participants' belief they had the tools to help others create change in their lives
- A 54% improvement in participants' being able to identify success markers with VHL patients

Most participants also stated that they strongly agree or agreed that they could use and apply the tools they acquired.

“I think one of the most useful things about this course thus far has been the insight into what individuals and their families experience with a VHL diagnosis. Not only have I learned far more about their experience, but we are learning ways in which to effectively help families navigate a diagnosis.”

**Fiduciary Responsibility**

The Board of Directors of any non-profit plays a major role in assuring and implementing fiduciary responsibility. Fiduciary responsibility and fundraising go hand-in-hand when discussing budget and net funds. As such, board members are tasked with budget and spending oversight as well as playing a significant role in fundraising. Best practice in non-profits is to have 100% of the board financially contribute on an annual basis. This is clearly stated in VHLA’s job description for board members, an outcome of the 2013-2015 Strategic Plan.

*Make a personal financial contribution to the organization that is personally significant and support generating contributions from other sources.*

At the outset of the 2013-2015 Strategic Plan, VHL financial stability was somewhat shaky with funds to only cover several months of operations. Since that time, thanks to a culture and practice of frugality and increased fundraising awareness and activities, VHLA currently benefits from strong financial stability with sufficient funds to expand programmatic opportunities.

The income boost has also enabled the competitive research grant program to stabilize and grow. In addition, the growth of income has also allowed the organization to demonstrate its appreciation of the staff and the desire to maintain low turn-over. As such in the spring of 2015, the board elected to create a bonus structure based on surplus net income above that fiscal year’s budget. At the board’s discretion the bonus was implemented for the first time at the end of FY16.
As a non-profit organization it is important to understand that there is need to spend money in order to raise money. It is also important to keep management and fundraising costs at a minimal. The VHL Alliance is very cognizant of the industry's rule of thumb of maintaining overhead costs (management plus fundraising costs) to below 20% of revenue.

**FUNDRAISING**

During the period of implementing the previous strategic plans there has been a greater emphasis on raising funds to support and expand the VHL Alliance's efforts.

New fundraising efforts included:

1. Annual Fundraising Dinner and Team VHL Annual 5K in conjunction with the Annual Family Meeting. Note that with the addition of other events the Annual Family Weekend was created.
2. Creation and implementation of Team VHL under the leadership of Suellen Lindquist. The team raises funds while participating in exiting Marathons such as the Hatfield and McCoy Marathon (June 2015), Baltimore Running Festival (October 2016), ET Marathon (August 2017)
3. Annual NYC Gala which began as a 3rd party event
4. Growth in 3rd party constituent events
5. Increase in individual fundraising effort
6. Application for a Global Genes Impact Grant for $15,000, which was unfortunately not funded due to unwarranted concerns of liability.
7. Addition of “Double your Donation” software onto the vhl.org website through which donors can determine if their workplace offers a matching gift. This did not result in an increase in matching donations so was discontinued.

Workplace Payroll Deduction Donations
As far back as 2007, the VHL Alliance joined the federated group CancerCure of America, administered through the management firm Maguire/Maguire Incorporated. As a member of this “umbrella organization,” the VHL Alliance received donations through various workplace payroll deduction fund drives organized and managed by the federal government, various state and municipal governments, local United Ways, and businesses. These drives outreach to more than 10 million employees annually.

The largest and most successful annual workplace charity campaign is the Combined Federal Campaign (CFC). Pledges made by Federal civilian, postal and military donors during the campaign season (September 1st to December 15th) support eligible non-profit organizations that provide health and human service benefits throughout the world.

The VHL Alliance has no influence over the execution of the CFC or other workplace campaigns. Furthermore, the overarching outcome of these campaigns is more dependent on external factors such as workplace environments and national political concerns. Unease around workplace giving, particularly towards the CFC, itself, is also a major influencer. Unfortunately, there has been growing discomfort about the CFC, including some of its administrative processes.

Factors, that may slightly influence outcome for which the VHL Alliance can have control are the organization’s DBA (“Doing Business As”), percent overhead, and marketing website found at (cancercureamerica.org). Since the outcome of a given year’s campaign takes nearly a full calendar year to determine, changes for the following year must be made prior to learning the outcome of the current year’s campaign.

With a failing in workplace giving, the government agencies have mandated a change in CFC’s structure. This change is being piloted during the 2017 campaign.
Summary Workplace Payroll Deduction Donations

2013-2018 Strategic Plan Years

Income
Overhead


Campaign Year

Amount Raised ($)

VHLA Overhead (%)

Incomplete
2018-2020 Strategic Plan

BOARD STRUCTURE

At the start of the 2016-2018 Strategic Plan the Board of Directors restructured the organization’s committees in order to best achieve the defined goals. Goal setting for the 2018-2020 Strategic Plan resulted in the addition of one more committee: Improve Clinical Care Committee. This committee is unique since the nature of its work requires that the lay committee work closely with the Clinical Advisory Council.

Each committee is chaired by at least one Board member. Committees also include non-Board members in order to expand input, ease the work of the Board, and develop new leadership. At least one staff member is assigned to each committee to provide support.

Each committee chair (also known as the process owner) reports back to the Board on the committee’s progress.

COMMITTEES AND COUNCILS

- Clinical Advisory Council
- Engage Patients, Family, and Friends Committee
- Finance Committee
- Governance Committee
- Increase Awareness Committee
- Increase Fundraising Committee
- Improve Clinical Outcomes Committee
- Research Council

WORK OF COMMITTEES, COUNCILS, AND STAFF

STRATEGY: INCREASE AWARENESS

Measurable Goals:

- By 2020, have 1,000 Active (longitudinal) participants in MY VHL
- Increase website usage by 5% usage year over year

Process Owner: Barbara Correll

Staff: Heidi Leone

1. Share VHL Information with the general public
   - Curing Cancer through VHL
Strategic Plan

- “Super Cancer”
- Explore value of changing DBA to “Curing Cancer through VHL” – currently “Cancer Research and Assistance – VHL”
- Press Releases
- Paid advertisement and collateral material
- Translate research into broad-based knowledge communication
- Use informatics as way to get message across
- Maximizing viewing of Suellen video (one-minute and longer formats)
- More earned media and partnerships with other organizations (such as the Mighty, PracticeUpdate)
- Global but local awareness activities – Scavenger Hunt
- Explore working with international affiliates to determine if there are ways to work together such as for May Awareness
- Internet presence, Explore Google ad words
- Secure celebrity spokesperson

2. Improve participation in MY VHL among VHL warriors
- Logo/Tag Line?
- Campaign for patients
- Tracking and following up on participation/medical scans
- Curating records – everything but radiology data
- Translate into Spanish and other languages

3. Improve understanding of MY VHL among medical professionals at CCCs as well as researchers
- Campaign for researchers/healthcare professionals including those at CCCs

**STRATEGY: IMPROVE CLINICAL CARE**

**Measurable Goals:**
- By 2020, have 1,000 active (longitudinal) participants in MY VHL
- Increase number of VHL patients being seen at CCCs by 50% by 2020

**Process Owners:** Doug Karle

**Staff:** Josh Mann, Ilene Sussman

1. Enhance quality of care among CCCs
   - Hold CCCs more accountable
   - Form Committee
   - Get more CCCs to follow all the guidelines such as promoting participation in MY VHL and assessing emotional health
   - Increase number of CCC liaisons
   - Engage patient liaison at CCCs
   - Update VHL Handbook including revisiting format
Strategic Plan

1. Launch Virtual Tumor Board to supplement list servs
   - Revise guidelines for surveillance of pancreatic neuroendocrine tumors
   - Survey CCCs on number of patients
   - Increase awareness and usage of CCC’s through newsletters and social media

2. Expand network of CCCs across USA
   - Ensure at least one CCCC in every region of the US

3. Educate non-CCC healthcare professionals about treating VHL
   - Videos VHL 101 of all the specialties
   - New physician package
   - Reach out to Genetic Counselor
   - Educate healthcare providers about VHL and available resources through VHLA: Develop and send collateral material
   - Be a present at society meetings
   - Increase medical access to VHL information
   - Clinical Advisory Council to complete specialty manuscripts and VHL review article
   - Explore and develop program(s) to involve clinical fellows and possibly med students
   - Outreach to/education of health insurers around Annual Surveillance Guidelines

4. Expand Wellness Coaching training programs to more CCCs and throughout CCC teams

**STRATEGY: FOSTER RESEARCH**

**Measurable Goals:** Submission of multi-institutional grants by 2020

**Process Owners:** Eric Jonasch

**Staff:** Ilene Sussman

1. Reassess and document VHLA competitive grant process
   - Determine amount and types of research to fund
   - Identify top researchers and budget needed to hit a “breakthrough” cure
   - Attract more researchers and increase number grant applicants

2. Explore tissue usage and creating a tissue bank
   - Identify lead institution for tissue bank
   - Explore The Rare Cancer Research Foundation and Board Institute as a source for converting tissue samples into cell culture

3. Facilitate promising research-related relationships
   - Multi-centered Peloton Trial
   - Encourage Novartis submission of pazobanib to FDA

4. Grow MY VHL data usage
   - Write manuscripts for publication of current CGIP data

**STRATEGY: ENGAGE PATIENTS, FAMILY, AND FRIENDS**
Strategic Plan

Measurable Goals:
• 100% outreach of database contacts annually
• Chapters in 90% of states by 2020

Process Owners: Anna Waller
Staff: Heidi Leone, Josh Mann

1. Create additional volunteer opportunities
   • Increase volunteer opportunities
   • Facilitated leadership opportunities and training program

2. Increase annual “touches” with stakeholders
   • One-on-one outreach to 100% contacts in database
   • Explore, identify, and initiate methods of engaging teens
   • Increase use of Parents of Teens Facebook page
   • Explore, identify, and initiate methods of engaging young adults beyond and between Young Adult Retreat and Annual Meeting gathering
   • Connect patients with similar conditions to share best practices and medical specialists – VHL Partners Program
   • Annual Meeting Saturday evening schmooze and pizza

3. Use App and other technologies to enhance engagement
   • Launch and maintain app
   • Expand utilization of app
   • Identify and open new channels of communication with patients and their families including pushing messages through app
   • Expand App capabilities and usage to provide information to healthcare professionals

4. Expand chapters
   • Work with Chapter Leaders and CCC liaisons to create VHL constituent get-togethers

Strategy: Increase Fundraising

Measurable Goals: Increase net revenue by 15% annually

Process Owners: Manuel Greco, Board Members, Chapter Leaders
Staff: Heidi Leone

1. Expand grassroots/chapter/board fundraising activities
   • Increase third party fundraising
   • Expand larger regional fundraisers to additional 3-4 regions
   • National Mom’s Day Event
   • Fundraise outside of patients & families
2. Steward existing donors
   • Grow and implement donor pipeline with Individual Engagement Plans
   • Connect with and cultivate donors: big and small

3. Pursue grant opportunities
   • Work with grant writer to submit grants to foundations