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 the unknown as well as the frustration caused, in part, 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 their families while providing information to healthcare providers to advance VHL diagnosis, treatment, and quality of life.

More than 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 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 programmatic offerings, focus on research, and increasing revenue. The success of the VHL Alliance’s first strategic plan of 2013-2016 demonstrated the importance of a defined direction. Subsequent strategic plans (2016-2018, 2018-2020) were developed and successfully implemented. With the start of FY2020, the board, volunteers, and staff are once again embarking on a new strategic plan process. This plan will build on the work accomplished and utilize the momentum gained from previous years. Program and service expansion will be 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 vision of Curing Cancer through VHL.

2021 will include a new leadership transition as the retirement of VHL Alliance’s current Executive Director, who has served nearly 10 years. This is an opportunity to identify a leader with the skills and experienced needed to launch the VHL Alliance from “adolescence” into “adulthood”.

VHL RESEARCH
“When you are studying about von Hippel-Lindau disease you are not just studying about [the] .... disease. ... you are also now touching other diseases as well where we can use the VHL gene to understand what is happening.”

William G. Kaelin, Jr., MD
2019 Nobel Prize Awardee for Medicine


Today, thanks to these researchers and others, we know the VHL gene to be the tumor suppressor gene. Its protein product, pVHL, binds to multiple proteins forming the VHL complex. Under normal circumstances this complex binds with the transcription factor, HIF (Hypoxia-Inducible Factor). HIF levels regulate various cellular growth factors (VEGF, PGDF) and proteins involved in the ways cells utilize glucose and generate energy.
The increased levels of growth factors are, in turn, responsible for the regulation of blood vessel production.

When the VHL gene is malfunctioning, the perceived lack of oxygen (hypoxia) prevent HIF to bind to the VHL complex, thereby preventing HIF from degradation. Accumulation of HIF results in the overexpression of various cellular growth factors (such as VEGF and PGDF) and a change in cellular metabolism. These changes lead to an overproduction of blood vessels which ultimately leads to tumor production.

This cascade of events is not only critical to von Hippel-Lindau Disease, but also to other cancers such as bladder, brain, breast, colon, ovarian, kidney, and pancreatic.

The impact of Dr. Kaelin’s, Sir Ratcliffe’s, and Dr. Semenza’s research on elucidating the role of the VHL gene in the perception of cellular oxygen levels was globally acknowledged when they were selected as the 2019 Nobel Laureates for Medicine.

The work of these esteemed researchers provides the context of the VHL Alliance’s vision of **Curing Cancer through VHL**.
PROGRAMMATIC INITIATIVES

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, important that the VHL Alliance not only be the preeminent resource and clearinghouse for VHL patients, families, and friends, but for the medical community as well. Because of inevitable knowledge gaps, the best care comes from a medical team with knowledge and experience of caring for VHL patients. Because VHL is a complex disease, it is also important that a mechanism exist for assisting clinicians to provide the best care possible.

- Clinical Care Centers (CCCs) and Comprehensive Clinical Care Centers (CCCCCs): The goal of the VHL Alliance’s Clinical Care Center Program is to provide coordination of care across medical specialties and thereby to improve diagnosis and treatment of VHL; resource centers for patients and physicians who are new to VHL; a ready channel for communicating advances to these centers of expertise; and a model that can be replicated elsewhere.

Medical institutions apply to be part of the program. Acceptance is based on a thorough review by VHL Alliance’s Clinical Advisory Council. Approval is dependent upon demonstration of extensive knowledge and experience in caring for and treating people with VHL, with an emphasis on comprehensive care including identified specialists necessary to meet both VHL surveillance and treatment needs. In addition, C/CCCs have agreed to provide outstanding holistic, coordinated care for VHL patients.

A separate designation of a Comprehensive Clinical Care Centers (CCCC) exists for those institutions that have been in existence for 2 or more years, have demonstrated exemplary patient satisfaction, established supplementary responsibilities for communication between CCCC team members and included additional medical specialties (such as Endocrine Surgeon, Nephrologist, Neurootologist, Oncologist, and Radiologist).

In order to assist patients, all C/CCCs are required to have designated team members to act as the point of contact and patient navigator.

1. Sponsoring Physician: Plays a crucial role in patient contact and management
   - Ensures organization and coordination at the C/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 MyVHL: Patient Natural History Study
   - Ensures team members notify Patient Navigator when VHL patients are seen in their specialty departments
   - Conducts / facilitates regular communication with entire C/CCC team in addition to communicating with Electronic Medical Record System (EMR; VHLA suggests supplemental communication methods, such as internal list-serve for sharing
observations about VHL, directs specialists toward VHL Alliance specialty list-serves, encourages specialists to educate their department about VHL, etc.; manages an internal list-serve for sharing observations about VHL; directs specialists toward VHL Alliance specialty list-serves and Virtual Tumor Board; encourages specialists to educate their department about VHL, etc.

- Promotes inclusion of VHL patients in patient meetings (i.e.: cancer support groups) when appropriate
- Arranges / participates in medical education meetings to teach physicians outside of C/CCC team about VHL
- Serves as a member of “C/CCC Lead Team”; meets with VHL Alliance C/CCC Liaison at least once per year

2. **Patient Navigator:** Helps patient navigate the hospital system working with them to make sure they are compliant with surveillance and are seen by the necessary specialists
   - Personally, welcomes each VHL C/CCC patient; introducing them to the concept of comprehensive, coordinated care within the C/CCC team; Flags patients' EMR records as VHL and has oversight of each VHL patient's care
   - Works at the patient and institutional level to ensure that each C/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
   - Reviews each VHL patient’s care; follows up with patients that have missed any C/CCC appointments
   - Monitors the patient’s psychosocial needs such as through HADS (Hospital Anxiety and Depression Scale); works with specialists to establish relevant care close to the patient’s home, as needed
   - Shares genetic testing / surveillance results with patient; ensures patient’s PCP receives report after each C/CCC visit
   - Reminds / encourages patients after every clinical encounter to participate in MyVHL: Patient Natural History Study; provides each patient with a patient package including information sheets and opportunities provided by VHL Alliance
   - 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 “C/CCC Lead Team”; meets with VHL Alliance C/CCC Liaison at least once per year
3. **Point of Contact:** Serves as initial contact for patients, families, and physicians
   - Contact info is listed on VHL Alliance website and given to our hotline volunteers; Uses VHL Surveillance Guidelines to connect patients with relevant C/CCC specialists. This person should have a basic understanding of VHL, but is not expected to answer any medical questions that require the patient to see a specialist.
   - Ensures each C/CCC Specialist has patient resource package to provide patients information sheets and patient brochures.
   - Serves a member of “C/CCC Lead Team”; meets with VHL Alliance C/CCC Liaison at least once per year.
   - Hold at least one patient-facing event annually.

4. **CCC Specialist:** Expert in the treatment of given VHL manifestation
   - Adheres to VHL Surveillance Guidelines; monitors the patient's psychosocial needs at every clinical encounter such as through HADS; works with Patient Navigator to establish relevant care close to the patient’s home, as needed.
   - Encourages patients to participate longitudinally in MyVHL: Patient Natural History Study at each appointment / procedure; distributes patient resource package to patients.
   - 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 C/CCC system.
     - Educates department on need for coordinated care between multiple specialists to properly manage VHL.

In 2019, VHL Alliance’s Clinical Care Center Process Improvement Committee developed requirements for the C/CCC (see page 11). These requirements were designed to help assure that C/CCC’s were meeting the specified program goals while being engaged in patient and healthcare provider education and advancing research. Demonstration of meeting the defined requirements is part of the application (new or renewal) and review process. Existing C/CCC’s are given a maximum of 2 years to include these requirements into their program.
Strategic Plan 2020-2022

C/CCC Process Matrix

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

- Patient contacts CCC via Point of Contact
- VHL Navigator assists patient in making CCC Specialist Appointments
- VHL Navigator notifies patient of appointments
- VHL Navigator notifies patient of next steps
- VHL Navigator introduces Patient to Liaison
- 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
- Patient contacts CCC Specialist / Department

Lead Team meets with Liaison annually to develop plans for strengthening CCC. Liaison shares plan with VHLA; helps identify best practices to share with other CCCs.
C/CCC Requirements

Core (Mandatory) Requirements:
- Provide coordinated care for VHL patients
- Hold at least one team meeting of VHL C/CCC specialists annually
- Encourage patients to provide feedback (positive or negative) to VHL Alliance
- Implement mechanism for CCC team communication
- Distribute Patient Resource Packet
- Assess patient and caregiver emotional health

For CCCs only:
- Work with VHL Alliance to identify patient ambassador (if one isn’t already in place)
- Participation in/completion of at least 3 of the additional programs/initiatives listed below (dispersed across all 3 categories)

For CCCCs only:
- Additional specialists added to care team (compared to previous applications)
- Meet with Patient Liaison at least once per year.
- Participation in/completion of at least 6 of the additional programs/initiatives listed below (dispersed across all 4 categories)

Additional Programmatic Opportunities

Research
- Participate in at least one VHL research initiative or author at least one VHL peer reviewed publication in the past 2 years
- Submit proposal for VHL specific discussion/talk/presentation at specialty society meeting
- Increase and/or maintain MyVHL participation at 50% among C/CCC patients

Education
- Host one internal, organizational Grand Rounds program related to VHL, or other internal-facing educational program, formal or otherwise
- Send at least one care team member to the Biennial International VHL Medical/Research Symposium
- Provide C/CCC feedback related to areas of improvement for the CCC program to VHL Alliance at least once per year either via form and/or call with VHL Alliance staff/leadership
- Submit at least one case to Virtual Tumor Board per year

Patient Care
- Internal VHL-specific tumor board mechanism and process

For CCCCs only:
- Participate, commit to participate, or have effectively participated, in the Wellness Coaching Program

General
- Create/maintain webpage on hospital website about C/CCC team, with link to vhl.org
- Expand CCC team to include hospital/practice administrative leader
- Understands C/CCC structure; Knows, works with, and communicates with other team members
- Becomes a member of VHL Alliance list-serve
• **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.

### Role of VHL Alliance’s Clinical Advisory Council

1. Generate and publish VHL specific state-of-the-art management guidelines for:
   - Kidney
   - Retina
   - Reproductive/GYN
   - Adrenal
   - CNS
   - Genetics
   - Pancreas
   - ELST
   - Oncology
   - Psychosocial (including “wellness”, counseling, and hospice)

2. Enable other healthcare providers through VHL Alliance list-serves
3. Create web-based resources for clinicians on the VHL Alliance website
4. Present VHL-specific Grand Rounds topics at academic centers
5. Advocate for and speak at VHL specific sessions in Society meetings – ASCO, AUA, etc.
6. Approve and guide Clinical Care Centers
7. Review and improve the VHL Handbook

The first task of the Clinical Advisory Council was the generation of a set of articles that describe, in an organ-specific process, state-of-the-art care for VHL. These manuscripts were to serve as 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 had recently been published, an additional manuscript is deemed redundant and 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, only a few manuscripts were written or submitted for publications.

The list of published articles are below:


Manuscripts for the Retina, CNS, Kidney, and Adrenal were either never written or not submitted.

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.

- **Medical Education:** Educating current and upcoming 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.

  - **Von Hippel-Lindau Disease Spotlight:** In November 2016, the VHL Alliance initiated a virtual “Journal Club” for VHL Clinical Care Center healthcare professionals. VHL Alliance solicited volunteers to identify a recently published VHL-related manuscript and provide a brief summary/commentary. This was then circulated via email to the C/CCC team members. Identifying volunteers was difficult. In addition, the idea was received with mixed reviews: while some C/CCC team members greatly appreciated the program, others found it off-putting and protested.

  At about the 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 replaced VHL Alliance's C/CCC Journal Club while reaching a broader audience and removing the burden on VHL Alliance 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”. On a monthly basis, VHL Alliance shares this list of new articles, via email with the researchers and healthcare professions VHL Alliance's database.

  Feedback from both clinicians and researchers has been outstanding. The process also serves as an ideal and important touchpoint.

  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 “category” as metastatic breast cancer, renal cell carcinoma, brain cancer, and advanced prostate cancer.

  - **Virtual Tumor Board:** Incorporated into the PracticeUpdate is a Virtual Tumor Board feature. Launched in the Spring of 2018, the Virtual Tumor Board has had a slow start. Changing the person in charge of pre-reviewing and editing submitted cases to Amit Tirosh, MD, (CCC sponsor at Sheba Medical Center), has helped to encourage new cases.
While the Virtual Tumor Board is not widely used, it is a valuable resource for clinicians, those who are less knowledgeable about VHL diagnosis or treatment or are treating a difficult case.

- **Specialty List-Serves:** An additional resource to healthcare professionals is VHL Alliance’s specialty list-serves. Each list-serve includes members of the Clinical Advisory Council as well as medical professionals involved in the Clinical Care Center.

- **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 a patient of 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.

In 2017, VHL Alliance piloted a Health Wellness Coaching Training program for team members at a select few CCCs. Leona deVinne ([http://accendoconsulting.ca/](http://accendoconsulting.ca/)), a trained life coach, who is also a VHL patient and a VHL caregiver, was hired as a contractor 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 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.
Wellness Coaching Program Content

The program content aligns with the eleven core coaching competencies:

1. Meeting Ethical Guidelines and Professional Standards
2. Establishing the Coaching Agreement
3. Establishing Trust and Intimacy with the Patient
4. Coaching Presence
5. Active Listening
6. Powerful Questioning
7. Direct Communication
8. Creating Awareness
9. Designing Actions
10. Planning and Goal Setting
11. Managing Progress and Accountability

Identifying a specific day and time where all participate could be available over a 28-week period and the inability for any one participant to participate in every session given their patient load and other responsibilities were the largest barriers to the pilot training program.

The feedback from the pilot program was phenomenal, encouraging VHL Alliance to expand the program to more CCCs.

Preliminary results demonstrate the program’s effectiveness:

1. A 70% improvement in participants’ understanding of the three parts of empathy
2. A 30% improvement in participants’ belief they had the tools to help others create change in their lives
3. 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. One participant responded:

“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.”

In order to accommodate the challenging and variable schedules of healthcare professionals, the program was adapted so that videos were provided online as a substitute for the group sessions. The sponsors of two CCCs (MD Anderson and Vanderbilt University) asked to have their teams participate in the program.
Strategic Plan

Despite all good intentions, participation remained a challenge. As a result, it was decided that the program would remain available, but participation would be on request.

Education

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 (healthcare) education is also essential. For this reason, the VHL Alliance is committed to developing mechanisms to educate both sectors.

Over the years, the VHL Alliance has expanded the breadth and depth of programmatic offerings to support its mission of research, education, and support to improve awareness, diagnosis, treatment, and quality of life for those affected by VHL with the ultimate vision of Curing Cancer through VHL.

CONNECTING WITH CONSTITUENTS AND PROGRAMS

- **Ambassadors**: Early in its existence the VHL Alliance created a Chapter Leader program to provide support at a local and regional level in order to welcome new constituents, proactively reach out to existing constituents, and build community by organizing get-togethers for social gatherings, educational programs, and/or fundraisers. The goal was to have a Chapter Leader in each state/region of the country.

  This model presented multiple challenges including: 1) the difficulty of finding Chapter leaders in less populated areas and 2) the challenge of finding one person who would have the desire, interest, and/or capacity to fulfill the vast “job description”.

  In 2019, the Chapter Leader model was transitioned into the “Ambassador” model which defined three separate roles for volunteers: Awareness, Clinical Care Centers, Engagement/Outreach, Fundraising.

  An Ambassador Job description was created (see page 17) and personal telephone calls were made to each of the Chapter Leaders. After describing the program, each volunteer was asked whether they wanted to recommit as an Ambassador and to identify their strengths and interests. In order to support these volunteers and to demonstrate VHL Alliance’s commitment to them, each Ambassador was provided with a copy of the book *StrengthsFinder* by Tom Rath.

  An additional feature was the creation of a volunteer mentorship program. A Mentor with the role of supporting and encouraging volunteers was designated for each type of Ambassador.
Mentors work individually with Ambassadors in order to support them in achieving their defined goals. The Director of Advancement holds quarterly calls with all the Ambassadors as well as regular calls with the Mentors. Note that in 2020 C/CCC Liaisons are being transitioned into the Ambassador program.

### VHL Alliance

#### Ambassador Roles & Goals

The VHL Alliance Ambassador plays a crucial part in the work of the VHL Alliance, dedicated to those affected by VHL through education, support, and research. The work is essential in helping reach our overarching vision of Curing Cancer through VHL.

VHL Alliance Ambassadors represent the organization, its mission, its vision, and its policies. The role of the Ambassador falls into four main focus areas: Awareness, Engagement/Outreach, Fundraising, and C/CCC Liaison. Please check the box(es) below that lies within your area(s) of interest.

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<td>Initiate campaigns to spread awareness</td>
<td>Welcome new/support regional constituents. Provide VHLA Office with updated contact info</td>
<td>Initiate regional/national fundraising efforts</td>
<td>Act as a connection between the VHLA, local patients, and the C/CCC; meet annually with the Lead Team to develop patient engagement opportunities and be a resource for educating medical professionals</td>
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<td>Raise regional awareness via news outlets and the medical community</td>
<td>Outreach via phone and/or email</td>
<td>Help promote various fundraising efforts</td>
<td>Communicate with patient/families; make sure they know about the C/CCC</td>
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<td>Social Media influencer – help create, post, and share pertinent information</td>
<td>Work with Director of Engagement &amp; Outreach and C/CCCs to arrange patient education meetings</td>
<td>Investigate fundraising opportunities and share as appropriate</td>
<td>Work with Director of Engagement &amp; Outreach and C/CCCs to arrange patient education meetings; make yourself available to the C/CCC as a resource including for education opportunities</td>
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<td>Participate and share information through various platforms and communities</td>
<td>Answer questions, provide support; inform patients about nearest C/CCC</td>
<td>Represent VHLA at fundraising events in your area when possible</td>
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**All Ambassadors:**

- Participate in regularly scheduled conference calls (quarterly) and keep in contact with Mentor between calls
- Make best effort to attend the Annual Family Meeting each year
- Represent VHLA in your community
- Communicate with the VHLA office on a regular basis; sharing feedback as able
- Arrange a regional get-together, which can be a social gathering to get to know one another, an educational program, or an awareness activity where others can be included
• **Annual Family Weekend:** The Weekend is hosted in the fall and brings patients, families, and clinicians together for a weekend packed with clinical education and lively discussions. It provides patients and their loved ones the opportunity to meet and develop long-term relationships with others living with VHL. This may often be the first time that an attendee will meet, or even speak, to someone else with VHL, outside their family. The weekend includes a Friday evening fundraising event, the Saturday **Annual Family Meeting**, Saturday afternoon Teen Event, and a Sunday morning **Team VHL** walk/run.

  - **Annual Family Meeting:** Geared to educating patients, families, and friends with the goal of empowering attendees to become active partners in clinical care. The meeting is hosted by a hospital participating in the VHL Alliance’s **Clinical Care Center** program and is held in a different part of the country providing accessibility to constituents residing in different geographic areas. It also provides an opportunity to feature the Clinical Care Center and its team of VHL experts.

    Presentations include: an overview of VHL; the most up-to-date information on VHL diagnosis and treatment of all involved parts of the body; and advances in VHL research. A highlight of the meeting is the separate breakout sessions for patients and caregivers (family and friends), allowing attendees to discuss and to share their individual experiences of the emotional rollercoaster resulting from VHL (**Breakout Discussion Groups** -see below).

  - **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 distinct discussion groups allow each stakeholder to discuss and to share their individual experiences of the emotional rollercoaster resulting from VHL. Separating 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.

• **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 19).
• **Connecting to Constituents**: The VHL Alliance database is (CRM: Customer relationship management) the main resource by which the organization connects with its constituency. While the database contains many 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:
  1. Downloading the VHL Handbook
  2. Signing up for the quarterly newsletter
  3. Signing up for the Facebook Awareness Group
  4. Receiving Well Wishes post-surgery
  5. Birthday Club
  6. Research Grants

• **Support**: VHL Alliance offers a wide-array of support programs primarily focus on 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. VHL Alliance programs and resources have been created to include a more comprehensive approach to supporting those, directly or indirectly, living with VHL.
  - **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 experiencing 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.
    While not used widely, availability of the program is invaluable.
  - **Online Support Networks**: allows constituents to communicate across geographic boundaries as well as being a venue for providing updates about VHL and VHL Alliance. The major social media outlines for VHL Alliance are:
    1. Facebook Fan Page: [facebook.com/VHLAlliance](http://facebook.com/VHLAlliance)
    2. Private Facebook Discussion Group*: [facebook.com/groups/VHLAwareness](http://facebook.com/groups/VHLAwareness)
    3. Inspire: [inspire.com](http://inspire.com) (less active than VHL Awareness group)
**Special focus online discussion groups**

1. For Caregivers: [facebook.com/groups/vhlcaregivers](facebook.com/groups/vhlcaregivers)
2. For Parents of Children with VHL: [facebook.com/groups/VHLparents2parents](facebook.com/groups/VHLparents2parents)
3. For VHL constituents with Low/No vision: [facebook.com/groups/vhlvision](facebook.com/groups/vhlvision)
4. For VHL constituents who are first in their family: [facebook.com/groups/VHLdenovo](facebook.com/groups/VHLdenovo)

* In 2017, based on input from its members, VHL 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.

- **Parents of Teens**: In the spring of 2017, several 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: [facebook.com/groups/VHLparents2parents](facebook.com/groups/VHLparents2parents) (see above).

- **Teen Event (13-18)**: 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 VHL constituents 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!”

In 2017 and 2018, a teen event was successfully included in the Annual Family Weekend. The few teens who had attended the year before were thrilled to see each other and seemed to pick up where they left off. However, in 2019, there were insufficient teens registered to include the event.

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.
• **Telephone Discussion Groups:** A monthly telephone discussion group focusing on the emotional rollercoaster of VHL was initiated in fall 2014. The original group was 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.

The success of the discussion group led to programmatic expansion. Currently there are 5 monthly or semi-monthly calls:

1. Low/No Vision Call: monthly
2. Patients / Caregivers Call: monthly
3. Parents of VHL Patients Call: every other month
4. Patients Without Caregivers: every other month (experimental)
5. Men’s Call: every other month (experimental) – not found successful

Given the nature of the calls, a facilitator is assigned for each group. Josh Mann, VHL Alliance's Director of Engagement and Outreach facilitates the Low/No Vision and the Men's calls, while Leona DeVinne ([accendoconsulting.ca](http://accendoconsulting.ca)), a trained life coach who is also a VHL patient and a VHL caregiver, facilitates the other calls.

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

Attendance varies from month-to-month. Introducing a VHL discussion group calendar into the website that allows for automatic reminders has improved attendance. Those who participate regularly have developed strong and supportive relationships.

• **Young Adults (18-32):** 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 they are involved in their own medical care including making difficult decisions about active surveillance and medical procedures.

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, VHL Alliance 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.”

The Young Adult Retreat has become an annual event. In June 2018, it moved to Boston making it much easier for the staff, particularly important as attendance continues to grow (2018 – 11 participants; 2019 – 20 participants). The program has evolved to include a lot of fun activities, time to connect, and education programming:

1. Discussion with a psychologist on the emotional impact of VHL
2. VHL overview and research with a clinical researcher
3. Leadership training

From three years of experience it has been determined that the ideal participation number is 20-24 with an age range of 18 (post high school graduation) to 32.

In 2019, the young adult retreat was renamed as the Julie Flynn Hope Retreat for Young Adults. Julie Flynn was a patient who passed away in 2018. Julie was a school counselor whose outlook toward VHL was the importance of hope. Naming the retreat after Julie is fitting on many levels and reflects the source of funding: friends and family of Julie Flynn.

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. However, future years proved less successful for this get-together, so it is no longer included in the Annual Family Weekend activities.

- **Wellness Coaching Program:** Having a chronic illness and navigating the complex needs associated with that can be very challenging. There are proven tools and techniques that can create ease, reduce stress, and help increase the feeling of control. The VHL Alliance adapted its Medical Coaching Program (page 14) to be relevant to patients and their caregivers.

  Leona DeVinne created and implements the program. Leona is experienced in working with VHL patients and caregivers and is also a patient and caregiver.

  The Wellness Coaching program provides the tools and techniques to help reduce stress, create ease, boost resilience and help increase the feeling of control. The virtual (online) program includes:

- 1. 11 modules of the VHL Wellness Coaching program consisting of videos and practical tools to use along with supplemental learning suggestions
- 2. 4 1-hr coaching calls a with a certified coach
Perspective participants are interviewed during which the program is thoroughly explained. In order to ensure commitment by participants, each is asked to pay a nominal fee of $50.

“Learning about myself, my values and how I react to certain situations, the good and the tough, has been truly enlightening. This recognition, together with some really useful tools, have certainly left me feeling less stressed, more resilient and better equipped for whatever the future may bring.”

**RESOURCES**

- **Handbooks**: The VHL Handbooks are an important reference handbook for people living with VHL, their families, loved ones, and their medical team.
  - **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 handbook is updated every few years in order to contain the most up-to-date information about diagnosing and treating VHL. It is an essential guidebook for living and thriving with VHL.

  The VHL Handbook is available in a downloadable format ([vhl.org/handbook](http://vhl.org/handbook)) at no cost. It can also be purchased through VHL Alliance or ordered through Amazon in both a hard copy and Kindle format.

  - **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. This handbook was published in 2009. Given the content level, there has not yet been a need for an update.

    The VHL Handbook Kid’s Edition can also be purchased through the VHL Alliance or ordered through Amazon.

- **Hotline**: Staffed by volunteers, who through their own personal experience, have learned much about VHL and about living with VHL. These volunteers are available for people in need of an immediate response; they are often the first interaction with the VHL Alliance. If a Hotline volunteer is faced with a question that they cannot answer, it is escalated to the Director of Engagement and Outreach.

- **Newsletter**: The quarterly newsletter (including the Annual Report) is designed to educate and empower people with VHL and others impacted by the disease. Material is written by a mix of board members and other volunteers, researchers, healthcare providers, and staff.

  Articles include patient stories and experiences, programmatic updates, and educational material relevant to VHL diagnosis, treatment, and care. Standard features include VHL Happenings and a CCC Corner. In 2019, based on constituent feedback, a section entitled “Recent Developments in VHL-Related Research” was introduced. This section is written by
Amit Tirosh, MD (CCC sponsor at Sheba Medical Center) using articles recently featured on Elsevier’s Practice Update.

In addition to mailing newsletters to constituents, the text and audio versions are posted online at vhl.org/newsletter.

- **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 VHL Alliance store: vhl.org/store, however, limited copies are available since it was only printed once.

- **Website (vhl.org)**: VHL Alliance’s website is the primary source of education and news for the multiple categories comprising the VHL Alliance constituency, including: patients, family and friends, researchers, healthcare providers, current and potential donors. The site provides up-to-date information on VHL clinical care, diagnosis, treatment, research, clinical trials, audio version of quarterly newsletter, as well as details about upcoming VHL or VHL Alliance-related events and programs. Patient stories are also available in both text (blogs) and video formats. The website is also the portal to MyVHL: Patient Natural History Study.

Realizing that it is challenging to create one site that serves all, in the fall of 2015, the site was overhauled in order to modernize its appearance, bring consistency to VHL Alliance 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 VHL Alliance staff reorganized the website and its sitemap with the sole purpose of making it more user-friendly. Subsections were redefined and content updated.

At the same time, a “blog” was introduced into the site. While not a blog in a traditional sense, as it does not allow for interactive conversation, this section allows patient stories to be shared.

**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 together 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 VHL Alliance’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, VHL Alliance 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 increased revenue allows 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 minimum. 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

The 2013-2019 Strategic Plans emphasized raising funds to support and expand the VHL Alliance’s efforts.

- **Fundraising Efforts:**
  1. The Annual Family Weekend was created around the Annual Family Meeting. A Friday evening fundraising event along with a Sunday morning Team VHL Walk/Run have been added. The success of these events is highly variable since they are totally dependent on the volunteer involvement in that particular region.
  2. Creation and implementation of Team VHL under the leadership of Suellen Lindquist. The center of Suellen’s effort is her Mom’s Day Run which takes place on Mother’s Day each year in Ventura, CA. An event that started small and initially raised only a few thousand dollars, continues to grow with revenue in the range of $30,000 - $50,000. The 10th anniversary of this event will take place in May 2020.
    In addition to the Mom’s Day event, Team VHL usually participates in exiting Marathons.
  3. In 2014, a patient living in NYC and working in the financial sector initiated an Annual NYC Gala. This began as a 3rd party event and later became a VHL Alliance initiated event. The event was highly successful, raising a total of $1,000,000 over the course of 5 years. However, by year 5, it was evident that the event had run its course and was discontinued due to low return on investment.
  4. Growth in 3rd party constituent events. Third party events are essential for the growth of VHL Alliance revenue.
    A 3rd party event that has great potential of growing is the **Coffee Against Cancer** during May Awareness month. With little time to spread the word, this was piloted at the last minute in May 2019 as an awareness campaign.
  5. Encouragement of peer to peer fundraising through online platforms such as Facebook and the software incorporated into the CRM platform used by VHL Alliance.
  6. Increase in individual fundraising efforts and identification of Major Gift donors with improved stewardship.
  7. **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 receives 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, resulting in reduced workplace giving. As a result, a revamped CFC program was piloted for the 2017 campaign. The new system continues to shake out.

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.

8. Testing of “Double your Donation” software on the vhl.org website was tested, but did not result in an increase in matching donations. It, therefore, was discontinued.

**Governance**

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

1. **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
2. **Board Governance Documents**
   - Bylaws
   - Board policies
3. **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 (and continues to refine) 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 separate staff function. This resulted in the hiring of VHL Alliance’s first Director of Development in July 2015. As the programmatic and fundraising efforts of the organization expands it is incumbent upon VHL Alliance to regular assess its staffing needs.

For the in person board meeting in October 2018, VHL Alliance hired a consultant to provide board training and lead a discussion on next steps. This highly successful meeting led to the identification of the following action items (status included):

**Governance/Board Development Related**
1. Confirm board committees for 2019/ realign as needed – completed
2. Refine job description/roles for individual board members, board as whole and each committee – completed
3. Develop annual process for board member accountability (annual check in conversations) – still in creation
4. Review board & committee membership and recruit as needed – in process
5. Explore succession planning for ALL VHL Alliance leadership roles– still in creation
6. Confirm staff role for each committee – completed
7. Create template for committee chairs to document best practices – completed
8. Document policy and process where there are governance gaps – in process
9. Continued conversation/take steps for board and committee members to plan meetings/share info (to relieve staff burden) – in process
10. Develop refined meeting agenda and minutes templates to support strategic discussion, exchange of information and follow up – complete
11. Annual calendar planning - scheduling main topics for board meeting discussion, aligning VHL Alliance operations/decision making process, and activities/events – complete
12. Document (and implement) guideline/policy for board member removal – not yet initiated
13. Develop comprehensive yet concise VHL Alliance Board Handbook – not yet initiated

**Fundraising Related**
1. Develop Strategic Fund Development Plan – not yet initiated
2. Develop VHL Alliance Gift Acceptance Policy – complete
3. Document vision & knowledge of current VHL research champions – complete
4. Major donor prospect research/identify potential major gift donors – ongoing
Strategic Plan

Clinical Care Related
1. CCC Feedback Process – completed, ongoing
2. Expanded liaison program – in process
3. Continue connection with MyVHL registrants and potential participants/Engagement – ongoing

Communications/Marketing Related
1. Develop VHL Alliance Strategic Communications Plan – in process
2. Each committee to define goals, key measures (2-3), timeline – process with 2020-2022 SMART goals

Other Action Steps
1. Create joint budgeting effort for board and staff – not yet initiated
2. Schedule time for board/gather information relative to recent tax law changes and impact on nonprofits – complete
3. Develop policy for cash on hand/reserve guideline – complete
4. Review Retreat Survey feedback for additional updates/action steps – complete
5. Explore cross-training/back up throughout VHL Alliance including volunteers, board, projects, officers and staff – not yet initiated

Identity/Branding
During the 2013-2018 Strategic Plans, 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

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”.


With the 2018 identification of the tag line, VHL Alliance's DBA was changed to “Curing Cancer through VHL”.

- **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.

- **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 VHL Alliance. 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.

- **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.

- **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. 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 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.

At the beginning of the 2018-2020 Strategic Plan process VHL Alliance's tag line was once again revisited. This led to the development of the existing tag line “Curing Cancer through VHL”. The new tag line is particularly applicable give the work of the 2019 Nobel Laureates in Medicine (page 5).

• **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.

  1. The *VHL* gene regulates hypoxia-inducible factor (HIF), one of the main drivers of cancer biology. By understanding *VHL* we learn how to control HIF.
  2. 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.

VHL Alliance’s vision was updated to “Curing Cancer through VHL.”

**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 $2.3 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.

• **Clinical Trials:** In the summer of 2018, Peloton Therapeutics, a small company out of Dallas Texas, launched an open-label Phase II multi-centered clinical trial using a HIF2α inhibitor, PT2977. The study was designed to evaluate the efficacy and safety of PT2977 in patients with VHL disease who have at least one measurable renal cell carcinoma (RCC) tumor. Changes in VHL disease associated non-RCC tumors was defined as the trial's endpoint. Following lesions in all VHL-impacted organs are also being followed.
The strong relationship between VHL Alliance and Peloton paid off with a recorded breaking recruitment rate of more than the 50 patients specified in the study design. In addition, the anectodal data reported by patients on VHL Alliance's Awareness Facebook group are extremely positive, even beyond the kidney.

During the summer of 2019, Merck purchased Peloton making it necessary to forge new relationships with those at Merck involved in the study.

The study is ongoing with no true indication of when the data will be revealed, future studies, or when, and if, there will be an FDA submission.

**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.

- **International VHL Medical/Research Symposia:** In collaboration with leading VHL research institutions, 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 symposium 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 VHL constituents from around the world.

- **MyVHL: 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), VHL Alliance'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 VHL Alliance 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 Global Rare Disease Registry (GRDR) 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 of 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, VHL Alliance’s study became the first patient registry launched by NORD. The “cost” of being the first organization/disease to use the platform is that VHL Alliance 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 VHL Alliance’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 VHL Alliance to update its surveys at the end of FY17.

An ongoing issue with the platform is the fact that with the upload of new data dictionary previous responses are not automatically populated into the surveys forcing participants to begin from scratch. Ironically, this was not because of a technical issue but rather the time involvement by NORD staff to update the existing data dictionary. This is a major deterrent to making any changes, no matter how small or large, to the current surveys.

Feedback from VHL Alliance’s constituents has identified several barriers to participation. These include:
1. Lack of knowledge about MyVHL
2. Time commitment
3. Anxiety about security issues of online data
4. Mistrust of data usage

Paying it forward and helping others is a major motivator for participation. Learning more about how they fit into with others with VHL is also reason that people want to participate in MyVHL.
Marketing material is continuously being created and shared that addresses the barriers and the motivators of patients.

Most of the organizations involved in NORD’s IAMRARE registry program experienced the problem of participation, especially longitudinal participation. One organization reported great success with offering a $50 Amazon gift card for all those that participated.

In the fall of 2018, VHL Alliance instituted a similar incentive program to any MyVHL participant who completed all the surveys and submitted a medical records request form. Initially 11 people qualified in November – December 2019. However, during the subsequent 14-month period only an additional 8 people have qualified.

In the summer of 2019, VHL Alliance created a system to systematically remind existing participants to update their MyVHL data. Up until that point, annual notifications were done using the reminder system integrated into the IAMRARE program. In addition to being cumbersome, when activated the program sent multiple reminders to each participant. As a result, it was often deemed necessary to inactive the option. The new system has proven to be much better received and more effective.

Despite the many challenges, participation continues to grow slowly, but surely. As of January 2020, there are about:
1. 900 people who have consented
2. 650 participants who have completed at least one survey
3. 11,050 surveys completed
4. 70 record release forms collected

Obtaining medical records from the specified institutions is an additional hurdle to recruitment. Many hospitals require completion of their own individual request forms, even though the form used by VHL Alliance is IRB approved and HIPAA compliant. There is often a long response time from form submission to receiving the requested records making it a long and somewhat tedious task.
The fact that MyVHL is only available in English is inconsistent with its assertion of being an international patient registry. Given the large Hispanic speaking community in the U.S., translation into Spanish was the obvious choice for experimenting with different languages.

The IRB requires that all language translations be performed using a certified translation process. Thus, VHL Alliance invested approximately $6,000 (a relatively low market price due to relationships with the company) into translating the MyVHL data dictionary, all supporting material (consent forms, etc.), and all marketing material.

After much discussion and coaxing, NORD’s IAMRARE group uploaded the Spanish MyVHL version in the Fall of 2018. (Something that they had promised prior to arranging for the translation.) Because NORD never developed the technology, despite the promise to do so when the platform was originally launched, the Spanish edition is not fully integrated. In addition, the instructions to registry and access the surveys are in English.
Not surprisingly, there has been minimal use of the Spanish version. This is in part due to the implementation of the European GDPR rules that went into effect in May 2018. The IAMRARE platform does not have GDPR certification and, because NORD does not want to include multiple languages, there has and will not be any attempt for it to be obtained.
• **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.

<table>
<thead>
<tr>
<th>Role of VHL Alliance’s Research Council</th>
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<tbody>
<tr>
<td>1. Develop partnerships with other researchers, pharma and diagnostic companies, as appropriate, in order to:</td>
</tr>
<tr>
<td>a. Create a road map that takes research from bench through approved therapy including development of any necessary experimental models and reagent development.</td>
</tr>
<tr>
<td>b. Develop improved diagnostic tools for VHL testing and detection of tumors</td>
</tr>
<tr>
<td>c. Direct Clinical Trials Task Force to coordinate and accelerate clinical trials</td>
</tr>
<tr>
<td>d. Expand mutation databank including correlation of genotype and phenotype</td>
</tr>
<tr>
<td>2. Generate multiple peer-reviewed position papers describing a vision of VHL research for the next 5-10 years</td>
</tr>
<tr>
<td>3. Engage in collaborative research including grant submissions</td>
</tr>
<tr>
<td>4. Manage VHL Alliance competitive grant program</td>
</tr>
<tr>
<td>5. Oversee MyVHL in order to maximize data usage</td>
</tr>
<tr>
<td>6. Develop agenda and help fundraise for Biennial International VHL Medical/Research Symposium</td>
</tr>
<tr>
<td>7. Determine the value and future of NDRI Tissue Bank</td>
</tr>
</tbody>
</table>

The first action was to include the chair of the 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.

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.
• **Research Grants:** 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 MyVHL: Patient Natural History study (see page 32).

Since that time, revenue has grown substantially (see page 24) 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, in 2018 raised to $150,000 over 2 years.

During FY17, VHL Alliance received an unbudgeted $100,000 donation directed to research. This gift provided the VHL Alliance 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.

Over the years, interest in and quality of grants submitted has greatly increased. As a result, in part using the funds reserved during the 2017 grant cycle, in 2018 two research grants (one at $150,000 over 3 years and one at $100,000 over 2 years) and one pilot grant were awarded. Momentum in grant funding was continued in 2020 when, again, two research grants (each at $150,000 over 2 years) and one pilot grants were awarded.

During the years, VHL Alliance has become much more stringent in terms of requiring final reports prior to sending the last grant payments as well as requiring mid-term reports prior to allowing research grants to go into the 2nd year.

It is important to realize while there is a thorough grant review process in place, it is not realistic to believe that all research proposals will result in productive data. There is always risk involved in the grant making process.
2020-2022 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. This was further refined as an outcome of the FY19 Board retreat.

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.

Job descriptions for each committee, along with board position and roles, have been developed and approved.

Committees and Councils

- Audit Committee
- Clinical Advisory Council
- Clinical Care Center Process Improvement Committee
- Finance Committee
- Governance Committee
- Fundraising Committee
- Marketing and Communications Committee
- Major Gifts Committee
- Nominating Committee
- Patient and Caregiver Education Committee
- Research Council
Strategic Plan

Organization Chart

Board of Directors
  - Executive Director
  - Staff

Clinical Advisory Council
  - Ilene Sussman

Surveillance Task Force
  - Ilene Sussman

Research Council
  - Ilene Sussman

Committees
  - Awareness Education
    - Heidi Leone
    - Josh Man
  - Marketing Communications
    - Heidi Leone
  - Fundraising
    - Heidi Leone
  - Clinical Care
    - Josh Mann
    - Ilene Sussman
  - Organization
    - Ilene Sussman
  - Ambassadors
    - Heidi Leone

VHLA Staff
- Executive Director: Ilene Sussman
- Director of Advancement: Heidi Leone
- Director of Engagement and Outreach: Josh Mann
- Administrative Assistant: Samantha Robinson
WORK OF COMMITTEES, COUNCILS, AND STAFF

**Strategy:** Executive and Finance

**Measurable Goal:**
- Maintain Good Governance and Best Practices – 100%

**Process Owner:** Doug Karle/Seth Horwitz

**Staff Support:** Ilene Sussman

1. Create joint (Board/staff) budgeting effort

**Strategy:** Audit

**Measurable Goal:**
- Annual Audit
- Submission of IRS Compliant Federal and State Tax Forms

**Process Owner:** Prashant Kudva

**Staff Support:** Ilene Sussman

1. Identify and hire new auditor
2. Annual audit
3. Annual submission of Federal and State tax forms

**Strategy:** Executive and Finance

**Measurable Goal:**
- Maintain Good Governance and Best Practices – 100%

**Process Owner:** Doug Karle/Seth Horwitz

**Staff Support:** Ilene Sussman

2. Create joint (Board/staff) budgeting effort
**Strategic Plan**

**Strategy:** Governance

**Measurable Goal:**
- Maintain Good Governance and Best Practices – 100%

**Process Owner:** Camron King/Julie Woodruff

**Staff Support:** Ilene Sussman

1. Hire New Executive Director*
2. Set Committee Matrix
3. Add new board members with specific talents
4. Create Audit Committee
5. Create joint budgeting effort (Board and staff)
6. Review and update bylaws and board policies (as relevant), annually
7. Document policies where there are gaps
8. Develop comprehensive yet concise VHLA Board Handbook
9. Review succession planning for all VHLA leadership roles

* In the second fiscal quarter of FY21, the VHL Alliance will hire a new executive director. Their onboarding process will span six months with the assistance of an onboarding committee. A detailed onboarding checklist is being developed and will be tailored to the person. Key components will include:

- Directors’ fiduciary duties and responsibilities
- VHLA code of business conduct and ethics
- VHLA history, mission, vision, and goals
- Culture of the VHLA and the board
- Short- and long-term strategy, priorities, and challenges
- Financial reports, including annual report, budgets, and projections
- VHLA industry, competitive landscape, and risk
- Board structure, administration, and policies
- Communicating the transition and meeting key stakeholders
- Introduction to major components of the organization: compiling documents and resources and meeting with informants on staff
- Relationship building – who are the players who deserve early attention.
- Regulatory, compliance, and related matters
- Study public disclosures, including website, regulatory filings and governance documents (committee charters, corporate governance principles)
- Become familiar with industry and competitor trends and risks
- The Leadership Agenda
- Understand key governance issues in general
• Identify programs to supplement understanding of governance issues, director responsibilities, industry considerations
• Gap analysis
• Board profiles and contact information
• Committee assignments
• Board and committee calendars
• Prior 12 months’ board materials and minutes
• Strategic plans
• Organization chart
• Calendar one-on-one meetings with external advisers such as accountants, compensation consultants, outside counsel to the board

**Strategy: Fundraising** (overlaps with Marketing)

**Measurable Goal:**
- Increase annual revenue by 15%
- Increase donor number by 20%
- 100% Board member participation in donor cultivation plan
- 100% Board member participation in development of Board Network

**Process Owner:** Mark Pallansch

**Staff Support:** Heidi Leone

1. Make website donate button more prominent
2. Add tagline to all events: “Can’t attend but want to contribute donate now!”
3. Add donate option on store, if possible, through PayPal
4. Get Charity Navigator to update ruling (not done since 1993)
5. Learn from other organizations
6. Board members acting as gift officers
7. Put silent auction online – for Family Weekend
8. Text to donate
9. Create a “hungry child” campaign (for $x, x can be accomplished) from Thriving Tuesday stories
10. Survey constituency
11. Coffee Against Cancer
12. Advertise reoccurring donation opportunities – and possibly tie to Giving Tuesday
13. Build additional board expertise
14. Regional fundraisers (Board/Ambassadors/Others)
15. Create 3-yr Strategic Fundraising Plan with targeted revenue
16. Expand/make more prominent online “fundraisers in a box”
17. Pursue fundraising grant opportunities
18. Host some fundraising event honoring Bill Kaelin in NYC

**Strategy: Marketing (General Awareness) (overlaps with Fundraising)**

**Measurable Goals:**
- Increase website usage by 5% (# of unique visitors, page visited, time on site)
- Send out 2-3 press releases with the goal of one placement of a feature article
- Double monthly touchpoints to stakeholders through eblasts
- Increase social media posts by three times and followers by 10%, improve participation in MyVHL to 1,000 users

**Process Owner:** Barbara Correll

**Staff Support:** Heidi Leone

1. Update donor acknowledgement letter to talk about Nobel Prize
2. Utilize increased public awareness of importance *VHL* gene/Dr. Kaelin & Nobel Prize
3. Host a Jeffersonian Dinner
4. Strategize on using Dr. Kaelin to increase awareness, etc.
5. Create video or documentary from patient stories
6. Educate members Federal legislators through strategic partnerships
7. News/Media Outlets include press releases/PSA
8. Create Communication Plan
9. Refresh website
10. Impact of VHLA: Grants; number of CCC’s, number of patients VHLA has connected to VHLA CCC, etc.
11. Add board members with current and relevant marketing experience
12. Expand Coffee Against Cancer
13. Encourage the CCC’s to have someone from their marketing department be represented on the team
14. Expand and increase collaborations
15. SEO for website and YouTube
16. DMV license plates: Curing Cancer through VHL – Mark is looking into this
17. Prepare big 30th anniversary event of gene discovery and VHLA (2023)
18. Find and connect with other story sites (such as The Mighty) to share with that are “outside” our community
19. Create strategic quarterly/semi-annual social media plan
20. Develop and implement federal advocacy plan for research funding

**Strategy: Education & Outreach**

**Measurable Goals:**
- Add 100 active participants to MyVHL
- Increase Facebook members by 200
- Execute one Live Facebook through The Mighty each month
- Increase Ambassadors by 10

**Process Owner:** Connie Rath

**Staff Support:** Heidi Leone & Josh Mann

1. Create audio version of Handbook and put online
2. Better engage new patients
3. Text to communicate with constituents
4. Reach out to younger crowd
5. Survey (on a regular basis) to better understand patient and caregiver needs.
6. Personal reach out to patients, families, and caregivers to bring them back and continue their relationship with VHL (text, phone, email, letters)
7. Develop & provide more education resources (i.e. how to get involved, C/CCC support packets, etc.)
8. Monthly Podcast – with VHL-related news and info, plus clinician interviews
9. Continue and expand reach through expanded collaborations (with The Mighty, C/CCCs, etc.)
10. Tweak/Redo VHLApp and better utilize message notification feature
11. Research on where VHL patients are geographically
Strategic Plan

**Strategy: Clinical Care** (Awareness & C/CCCs)

**Measurable Goals:**
- Actively track use of newly created/existing resources to gauge usefulness (via Google Analytics & qualitative feedback) and identify opportunities for improvement around content and dissemination.
- Launch 3 initiatives focused on engaging patient and care team stakeholders to further identify needs, issues, concerns, and best practices.
- Identify 10 C/CCC achievements related to new requirements launched in 2019.
- Complete at least 12 interviews of various C/CCC care team members from across the country to highlight their commitment to the VHL community.

**Process Owner:** Stacy Lloyd with input from Clinical Advisory Council

**Staff Support:** Josh Mann & Ilene Sussman

1. Update donor acknowledgement letter to talk about Nobel Prize
2. On the website, create a button to enter geographic region to show the closest CCC’s
3. Track patient use of online resources
4. Convert liaisons to Ambassadors
5. Increase # of C/CCC Ambassadors
6. Mini medical symposiums for professionals and patients at CCC’s – keynote speakers from CCC’s at regional meetings
7. Utilize updated guidelines to engage medical societies
8. Publish updated guidelines in appropriate medical journals
9. Increase # of C/CCCs – and hold existing CCCs accountable and remove them if they are not performing
10. Physician education (through medical societies, etc.)
11. Demonstrate through data better clinical outcomes through C/CCC’s
12. Survey patients and CCC’s to better understand gaps and needs
13. Engage C/CCC more regularly
14. Work with International Affiliates to translate updated handbook into as many languages as possible
15. Creating a “residency training program/mentorship” for each relevant specialty (see research point #5)
16. Create online specialty-specific continuing education courses for CME credit
17. Initiate a quality improvement tool in order to improve care group
18. Revisit Clinical Advisory Council

**Strategy: Research**

**Measurable Goals:**
- Increase research dollars by 10% annually
- Increase collaborations and success for outside funding
- Engage early career researchers
- Help to get PT2977/MK6428 approved and accessible to patients

**Process Owner:** Research Council (Eric Jonasch/Othon Iliopoulos)

**Staff Support:** Ilene Sussman

1. VHLA facilitated medical symposiums
2. Prioritize research focus of grant to be awarded based on greatest impact to patients– currently included in decision making discussion
3. Development partnership with Ciitizen to streamline getting patient records and scans, and facilitating 2nd opinions
4. Researcher utilize patient data (MyVHL) to further research
5. Encourage more VHL research
6. Make sure research dollars get on brag sheet
7. Stay on top of PT2977/MK6482 study and work on issues of accessibility
8. Revisit Clinical Advisory and Research Councils
9. Continue to increase research dollars each year and promote that fact – brag sheet