

The VHL Alliance

Strategic Plan

2016-2018

VISION STATEMENT

The VHL Alliance envisions a cure for 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.

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 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 have 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 was important to advance VHL diagnosis, treatment, and quality of life.

Twenty-three 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 without strengthening of the Board of Directors, growing program offerings, focus on research, and increased revenue.

The success of the VHL Alliance's Strategic Plan demonstrated the importance of a defined direction. The plan documented here cumulates multiple discussions and input by the VHL Alliance's Board, volunteers, and staff. The goal of the 2016-2018 Strategic Plan is to utilize the momentum gained over the past three years and execute the organization mission, which is *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 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 patients and others impacted by VHL.
- **Website (vhl.org):** The VHL Alliance's primary source of education and updates 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 organize 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/VHLA](https://www.facebook.com/VHLA) (Facebook Fan page)



[facebook.com/groups/VHLAwareness](https://www.facebook.com/groups/VHLAwareness) (Facebook discussion page)



inspire.com

- **Clinical Care Centers:** VHL Alliance approved medical institutions identified for their extensive knowledge and experience in caring for and treating VHL patients 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 was 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 patients from around the world.

SUCCESSSES OF 2013-2015

VHL ALLIANCE IDENTITY/BRANDING

During the course of the 2013-2015 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

Reexamining the Organization's Name: In 1993, the organization was named VHL Family Alliance as a way that everyone, directly or indirectly impacted by VHL, was symbolically part of a Family. As the organization grew and efforts expanded beyond patients and their families 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.

Old Logo



New Logo



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. Note that the 2016-2018 strategic plan revisits the tag line asking the question of whether it is suitable for all stakeholders.

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 the 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 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 13).

Revising the Mission Statement: In late 2014, it was noted that the mission statement did not reflect VHL Alliance’s work to increase awareness about VHL and VHLA. As such, 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.”

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 process 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 recruiting new board members with proficiencies and interests that align with the goals of the organization and the documented strategic plan. 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 a Director of Development in July 2015.

EDUCATION/SUPPORT PROGRAMMATIC EFFORTS

Through the 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 ensued to include a more holistic approach to supporting those, directly or indirectly, living with VHL. Addition and modifications included:

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 caused by VHL. Segregating patients from family and friends is key as it allowed individuals to speak more honestly and openly about their feelings and needs without feeling responsible for the impact it could 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.

VHL Partners: This support program pairs a mentee with a mentor who has experienced first-hand the medical and emotional journey of VHL. The relationship can be short-term or long-term depending on the connection and needs of the individuals. Mentors are trained through a collaboration with the 4th Angel program (4thangel.org). With modern technology

there are no geographic restrictions for either mentors or mentees. The program is also open to minors provided that written consent is given by their parent or guardian.

Monthly Telephone Discussion Group: In the fall of 2014, the VHL Alliance hired a licensed social worker to facilitate a monthly telephone discussion group focused on the emotional rollercoaster of VHL. While dealing with specific medical concerns is inevitable, the primary focus of the discussion is the emotional side. Attendance varies from month-to-month. Attendees who participate regularly have developed strong and supportive relationships. The long-term goal is to hold separate discussion groups for patients and caregivers (family members and friends) to encourage a more open flow of conversation.

Because of some concerns about commitment by the initial facilitator, at the beginning in the fall 2015, a new person was hired to guide the calls. This person is a life coach who has VHL and, thus, has first-hand experience on what it means to live with this life-long medical condition.

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.

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 posted on the VHL Alliance's website. In addition, it was later incorporated into the 5th edition of the VHL Handbook (see page 61).

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 of 2015 website update, a new section entitled "Caregiver's Center" (vhl.org/patients/caregiver-center) was created. Material, resources, and information dealing with stress, specifically geared to caregivers, are now available.

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 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.

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 VHL Handbook provides updates on screening standards which took place since 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.

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. Two 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.

The commitment of the VHL Alliance to fostering research is evident from the \$1.3 million contributed to research during the years preceding the 2013-2015 Strategic Plan. The plan reemphasized the VHL Alliance commitment to finding a cure.

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. Reevaluation and clearly articulating the role of the Research Council was followed. Ultimately, the Council was restructured to include representation from the multiple facets of research including basic, translational, and clinical researcher of all aspects of VHL research.

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 which removes the possibility of partiality.

Thanks to increased fundraising, there has been 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.

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.

Cancer in Our Genes International Patient (CGIP) Databank: The VHL Alliance Research Council met during the proceedings of the 10th International VHL Medical Symposium (Houston, TX; January 2012). The overarching opinion was “It is time that the VHL Alliance invest in itself.” The Council’s message was that the VHL Alliance should invest research funds to create and implement an international patient registry which would consolidate patient information from around the world, providing a comprehensive natural history study that was independent of geography or specific mutations. Such a database 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 was strongly recommended that such an undertaking be performed within the structure of the VHL Alliance itself.

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 they developed their Natural History Studies Program. 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 \$20,000, or more. Additionally, since working with and getting input from the FDA was being incorporated into the NORD program, the surveys created by the VHL Alliance were reviewed and input provided by the regulatory agency.

In the Spring of 2014, CGIP became the first patient registry launched by NORD. As of the spring of 2015, there were 467 GCIP users.

Clinical Care

With approximately 7,000 recognized rare diseases, it is impossible for clinicians to have complete knowledge of every one. 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. Because of the complexity of VHL, it is also important that a mechanism exist for assisting clinicians 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 key references for the community, as well as be the foundation for a comprehensive review article on the state-of-the-art medical treatment for VHL.

ROLE OF VHLA'S RESEARCH COUNCIL

- Generate and publish VHL specific state-of-the-art management guidelines for:
 - Kidney
 - Adrenal
 - Pancreas
 - Eye
 - CNS
 - Psychosocial (including "wellness", counseling, and even hospice)
 - ELST
 - Reproductive/GYN
 - Genetics
 - Oncology
- 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's) program. CCC's were identified as hubs of VHL care that included a team of specialists (including all organs involved in VHL) with experience in diagnosis and treating VHL patients. During the course of the 2013-2015 Strategic Plan, the number of CCC's expanded (25 to 29 in U.S.; 13 to 15, Internationally).

Expansion in number was also accompanied by steps to strengthen individual centers. With the input of the Clinical Advisory Council, the Clinical Care Center program was reevaluated in order to improve patient satisfaction. The result was the creation of 3 different designated types of centers: 1) Clinical Care Centers (CCC); 2) Comprehensive Clinical Care Centers (CCCC) with supplementary responsibilities for communication between CCCC team members and inclusion of additional medical specialties (Endocrine Surgeon, Nephrologist, Neurotologist, Oncologist, and Radiologist;) and 3) Specialty Centers (SC) designed for institutions that do not fit the CCC criteria but have expertise in a given medical specialty. Currently, in the U.S., there are 10 CCCC's; 19 CCC's; and no SC's.

All centers are required to submit an initial application and a biennial renewal to be reviewed and approved by the Clinical Advisory Council. Centers are also now asked to:

1. Ensure that the center's point of contact be equipped with the protocol for annual screening, a list of participating team members and their contact information, and referral standards must be provided to the specified Point of Contact for that Center
2. Assess of the psychosocial needs of patients and to communicate any needs, along with a medical update, to the patient's primary care clinician

VHLA Specialty List Serves: As a means of facilitating the dissemination of information and maximize learning, the VHL Alliance creates email list serves for each medical specialty. Each list serve 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 as well as the Clinical Advisory Council to learn from the experts in the field while enhancing group learning.

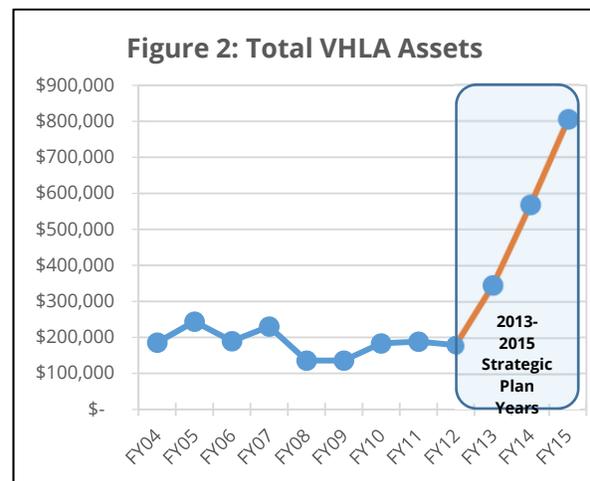
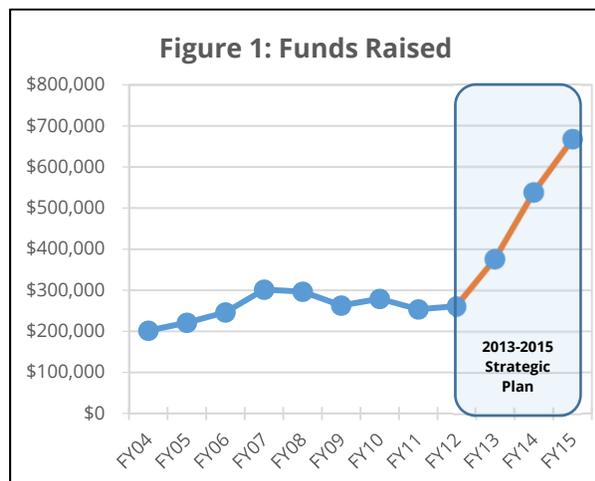
Fiduciary Responsibility

Fiduciary responsibility and fundraising go hand-in-hand when discussing budget and net funds. The VHL Alliance considered both aspects while working to grow its assets. As such, during the course of the 2013-2015 Strategic Plan, a thorough budget review was performed to determine if and where expenditures could be reduced. With a culture and practice of frugality, it is not surprising that opportunities for cost-saving were at a minimum. Replacing a couple of vendors, reducing printing quantities, and ensuring that there was not a net loss from the Annual Meeting were the only opportunities identified for decreasing expenditures.

There is a balancing of keeping management and fundraising costs at a minimal with the concept that there is a need to spend money in order to raise money. 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. In the years of the 2013-2015 Strategic Plan, costs have been closer to 10%.

Fundraising

The 2013-2015 Strategic Plan spurred a greater emphasis on raising funds to support and expand the VHL Alliance's efforts. The increased revenue, (Figure 1) stabilized the organization from one with minimal assets; the VHL Alliance now has sufficient reserves to cover costs for at least one year (Figure 2). The income boost has also enabled the competitive research grant program to stabilize and grow.



New fundraising efforts included:

1. Annual Fundraising Dinner, in conjunction with the Annual Family Meeting
2. Creation and implementation of Team VHL with an Annual 5K in conjunction with the Annual Family Meeting and participation in exiting Marathons such as the Hatfield and McCoy Marathon
3. Growth in 3rd party constituent events, such as the Annual NYC Gala
4. Increase in individual fundraising effort

Workplace Payroll Deduction Donations

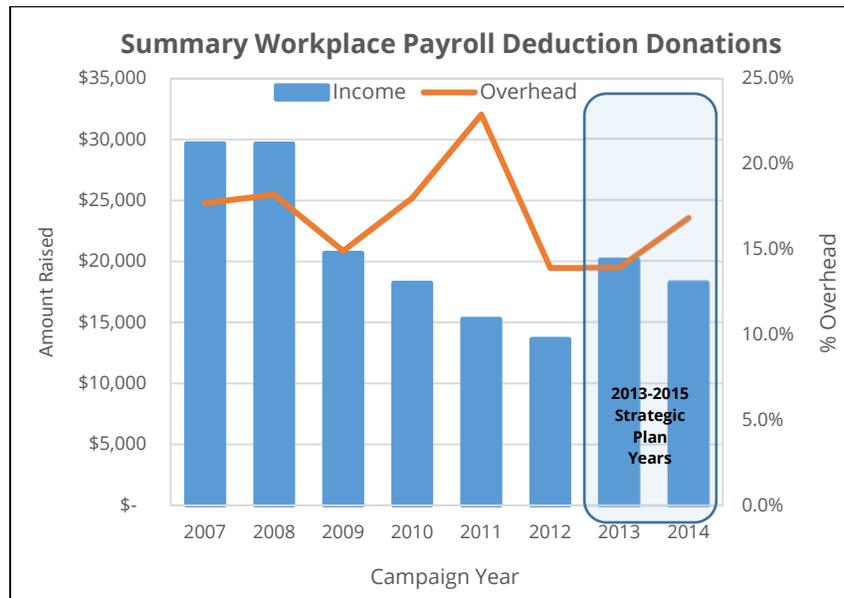
As far back as 2007, the VHL Alliance joined the federated group CancerCure of America, administered through the management firm Maguire/Maguire Incorporated. As a member of this “umbrella organization,” the VHL Alliance received donations through in various workplace payroll deduction fund drives organized 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.

During implementation of the 2013-2015 Strategic Plan income from workplace giving, such as the United Way and CFC, or has exceeded the results of the national campaign.



2016-2018 Strategic Plan

BOARD STRUCTURE

Based on the defined Goals, the FY16 Board of Directors restructured the organization’s committees to best achieve the goals of the 2016-2018 Strategic plan. 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. A 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
- Research Council

WORK OF COMMITTEES, COUNCILS, AND STAFF

STRATEGY: INCREASE AWARENESS

Measurable Goals: 5% gain on website hits; posting on social media 2 times a week to increase followers by 5%; increase media presence by sending out 8-10 press releases per year

Process Owner: Barbara Correll

Staff: Heidi Leone

- Review and refine (if necessary and for target segments) positioning and messaging
- Revisit tagline
- Discuss how to best reach each of these segments
- Create marketing/awareness plan including each segment
- Develop and execute social media plan including awareness activities utilizing Hootsuite free software
- Develop complete style guidelines, including format for documents, brochures, etc.
- Revisit newsletter length and format
- Develop and execute PR plan including developing a press release template
- Fine Tune Website
- Optimize SEO (Search Engine Optimizing) for web searches
- Determine and create awareness and fundraising collateral needs
- Advocacy on the State and Federal level
- Identify spokesperson

STRATEGY: IMPROVE CLINICAL CARE

Measurable Goals: 20% increase in number of patients being taken care of at CCC's

Process Owners: Eric Jonasch, Sarah Nielsen

Staff: Ilene Sussman

- Survey CCC's on number of patients
- Develop system in database of storing clinician information provided by patients
- Survey patients about their healthcare team
- Increase awareness and usage of CCC's
- Connect patient to each CCC
- Increase number of CCC's, particularly in barren regions
- Identify what CCC clinicians want/need from VHLA

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- Develop and implement plan to address needs of CCC clinicians
 - Create and implement quality matrix for CCC review
 - Foster relationships between Clinical Care Centers
 - Clinical Advisory Council to complete specialty manuscripts and VHL review article
 - Mailings: Email lists and communications with of specialist/PCP's
 - Education of PCP's
 - Outreach to/education of health insurers around Annual Screening
 - Develop and incorporate integrating plan for Integrative Health at CCC's
 - Identify improved diagnostic tools for VHL testing and tumor detection by each specialty
 - Coaching program for genetic counselors
 - Explore and possibly create training program for non-CCC clinicians

STRATEGY: FOSTER RESEARCH

Measurable Goals: One federally funded grant or one new clinical trial and > 1000 CGIP participants

Process Owners: Eric Jonasch, Sarah Nielsen

Staff: Ilene Sussman

- Foster and articulate collaboration between researchers
- Create road map or org chart that takes research from bench through approved therapy including development of any necessary models and reagents (components)
- Identify venue, develop agenda, and build support for biennial International VHL Medical Symposium
- Increase CGIP participation and obtain medical records
- Curate CGIP data
- Expand buy-in of CGIP among researchers, including internationally
- Develop committee to review research proposal based on usage of CGIP data
- Write manuscripts for publication of current CGIP data
- Explore the possibility of expanding CGIP to other diseases as a revenue stream
- Expand usage of Tissue Bank (NDRI)
- VHLA grant program
- Engage CCC's in CGIP
- Reach out to relevant CME venues to include VHL as an example in their presentations
- Circulate CGIP material among medical societies
- Explore and possibly identify funding for Clinical Trials Task Force to run a multi-centered Axitibnib trial

STRATEGY: ENGAGE PATIENTS, FAMILY, AND FRIENDS

Measurable Goals: Functioning Chapter in 75% of States; 2 Programs for younger generation(s) and family and friends; Connect one-third of CCCs with volunteers and local events

Process Owners: Andrea Rafael, Anna Waller

Staff: Heidi Leone, Suzanne Nylander

- Update Volunteer Handbook to include Guidelines for Fundraising and Awareness events (May as VHL Awareness Month) and confidentiality agreements
- Work with Chapter Leaders to Increase Awareness and Fundraising events on regional level
- Events in collaboration with CCC's
- Provide greater support to caregivers

- Create support system for teens
- Engage Chapter Leaders
- Get chapter leaders on website conversation
- Chapters in every state
- Ensure access to visually impaired
- Ensure Annual Meeting is welcoming to “newbies”
- Provide complete list of volunteering categories (including those related individual connection, outreach, regional, fundraising)

STRATEGY: INCREASE FUNDRAISING

Measurable Goals: Raise income by 50% based on FY16 budgeted income (\$947,000 to \$1,400,000)

Process Owners: Manuel Greco, Bettina Micheli

Staff: Heidi Leone

- Identify software or mechanism for researching and evaluating prospective donors and grants
- Connect with and cultivate donors: big and small
- Develop donor pipeline with Individual Engagement Plans
- Expand larger regional fundraisers to additional three-four regions (Chicago, California)
- Utilize VHL Awareness Month (May) for mingling events by volunteers, including by Chapter Leaders
- Quantify, research, and promote corporate matching gifts – possibly providing a link on our website for donors to search matching companies – research companies that provide this link
- Explore and identify grants/foundations
- Promote iGive and Amazon Smile (through twitter, Facebook and Instagram)
- Fundraising tool kit
- Identify if Crowdrise is best vendor of teams and personal fundraising pages
- Expand individual fundraising pages and fundraisers
- Create collateral material
- Provide option to donate with VHL Handbook download
- Ask for extra donation through PayPal and in all situation when people are purchasing or registering for an event or item)
- Option to cover the 3% credit card fee processing on Network for Good
- Document comprehensive, multi-faceted fundraising strategy
- Explore Patient-Centered Outcomes Research (PCORI) grants