VHL Alliance
VOLUNTEER MANUAL

Version 1.4, Revised July 9, 2019

VHLA is dedicated to research, education, and support to improve awareness, diagnosis, treatment, and quality of life for those affected by VHL.
Curing Cancer through VHL

VHLA is dedicated to research, education, and support to improve awareness, diagnosis, treatment, and quality of life for those affected by VHL.
Dear Faithful Volunteer,

Thank you for being a crucial part of the VHL Alliance (VHLA) by being a volunteer. Without people like you, VHLA’s dedication to those affected by VHL through education, support, and research, could not be accomplished. You are also essential in helping us reach our vision of **Curing Cancer through VHL!**

Your role as a VHL Alliance volunteer is to represent the organization, its mission, its vision, and its policies. This manual is intended as a handy source of information to help ease your task and be successful as a VHLA volunteer.

The expectations of each type of volunteer are outlined on page 1, which also includes a list of many of our volunteer opportunities. The office staff is always available to provide you with any needed information and to answer any questions. Please do not hesitate to contact us!

**After reading this reference manual, please complete and return to us page 5, the signed Agreement to VHLA Policies.**

We want every person and every family affected by VHL to have a long and fulfilling life, #thrivingwithVHL. The VHL Alliance is part of their support network, giving them comfort and hope, and providing real progress toward better diagnosis, treatment, and quality of life.

Thank you very much for sharing yourself – your time, talent, and compassion – to make this possible.

Best Regards,

Heidi A. Leone
Director of Advancement
617.277.5667 ext. 4
Heidi.Leone@vhl.org
# CONTENTS

<table>
<thead>
<tr>
<th>Welcome</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agreement to VHLA Policies</td>
<td>5</td>
</tr>
<tr>
<td>Volunteer Opportunities</td>
<td>6</td>
</tr>
<tr>
<td>Key Volunteers</td>
<td>7</td>
</tr>
<tr>
<td>Ambassadors</td>
<td>7</td>
</tr>
<tr>
<td>CCC Liaison</td>
<td>8</td>
</tr>
<tr>
<td>Hotline Volunteers</td>
<td>8</td>
</tr>
<tr>
<td>Tips and Suggestions</td>
<td>8</td>
</tr>
<tr>
<td>Possible Questions You May Encounter</td>
<td>8</td>
</tr>
<tr>
<td>HLRCC, BHD, and SDH</td>
<td>10</td>
</tr>
<tr>
<td>Your Role</td>
<td>11</td>
</tr>
<tr>
<td><strong>Explanations of VHL Alliance Policies</strong></td>
<td>13</td>
</tr>
<tr>
<td>Confidentiality</td>
<td>13</td>
</tr>
<tr>
<td>Protecting Confidentiality with Email</td>
<td>13</td>
</tr>
<tr>
<td>Mailing Lists</td>
<td>13</td>
</tr>
<tr>
<td>Opinions of Individuals vs. Opinions of the VHL Alliance</td>
<td>14</td>
</tr>
<tr>
<td>Medical Opinions, Your Opinion, and Medical Advice</td>
<td>14</td>
</tr>
<tr>
<td>Expressing Opinions</td>
<td>15</td>
</tr>
<tr>
<td>VHLA and the VHL Clinical Care Centers</td>
<td>15</td>
</tr>
<tr>
<td>Taking care of our Constituents and Ourselves</td>
<td>16</td>
</tr>
<tr>
<td>Dealing with Emotionally Distraught Contacts</td>
<td>17</td>
</tr>
<tr>
<td>Contacting Constituents</td>
<td>17</td>
</tr>
<tr>
<td>Standards for our Online Communities</td>
<td>18</td>
</tr>
<tr>
<td>Fundraising</td>
<td>21</td>
</tr>
<tr>
<td>Local and State Tax Considerations and Regulations</td>
<td>22</td>
</tr>
<tr>
<td>Public Education and Awareness</td>
<td>23</td>
</tr>
<tr>
<td><strong>VHL Talking Points</strong></td>
<td>24</td>
</tr>
<tr>
<td><strong>Information and Resources</strong></td>
<td>26</td>
</tr>
<tr>
<td><strong>Suggested Surveillance</strong></td>
<td>28</td>
</tr>
</tbody>
</table>
AGREEMENT TO VHLA POLICIES

PLEASE COMPLETE AND RETURN VIA MAIL, FAX, OR EMAIL TO THE VHLA OFFICE

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

    Tel: 617.277.5667 x 4
    Fax: 858.712.8712
    vhl.org
    Email: info@vhl.org

DATE: ___________________________

I have read and understand the Policies of the VHL Alliance. I understand my responsibilities under the confidentiality rules of the VHL Alliance.

I agree to be bound in all respects by these Policies and Responsibilities.
(checked box to indicate agreement.)

☐ Expectations
☐ Taking Care of our Constituents and Ourselves
☐ Confidentiality
☐ Contacting Constituents
☐ Mailing Lists
☐ Local or Regional Meetings
☐ Opinions of Individuals vs. Opinions of VHLA
☐ Fundraising
☐ Medical Opinions, Your Opinion, and Medical Advice
☐ Public Education and Awareness

Signature: ___________________________
Print Name: ___________________________
Address: ___________________________
City, State, Zip: ___________________________
Telephone: ___________________________
Email: ___________________________

Volunteer Handbook – [Go to Table of Contents]
Volunteers are the core of the VHL Alliance. Here are some examples of ways to volunteer. Of course, we can work with you to create a unique opportunity for you based on your time commitment, talent, and interest.

Engagement

VHL Partners Mentoring Program
- **Hotline Volunteer**
- **MyVHL**: Patient Natural History Study
- Engaging constituents
  - **CCC Liaison**

Awareness

- **Marketing/Communications**
  - **PR**
  - **Social Media**
- The Mighty LIVE!

Fundraising

- **Peer to Peer Fundraisers**
- **Increase Funding**
  - **Grants**
- Finance
KEY VOLUNTEERS

AMBASSADORS

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

<table>
<thead>
<tr>
<th>Awareness Ambassador</th>
<th>Engagement/Outreach Ambassador</th>
<th>Fundraising Ambassador</th>
</tr>
</thead>
<tbody>
<tr>
<td>Responsibilities:</td>
<td>Responsibilities:</td>
<td>Responsibilities:</td>
</tr>
<tr>
<td>▪ Initiate campaigns</td>
<td>▪ Welcome new constituents</td>
<td>▪ Initiate Regional/national fundraising efforts</td>
</tr>
<tr>
<td>to spread awareness</td>
<td></td>
<td></td>
</tr>
<tr>
<td>▪ Raise regional</td>
<td>▪ Outreach via phone and/or email</td>
<td>▪ Help promote various fundraising efforts</td>
</tr>
<tr>
<td>awareness via news</td>
<td></td>
<td></td>
</tr>
<tr>
<td>outlets and the</td>
<td></td>
<td></td>
</tr>
<tr>
<td>medical community</td>
<td></td>
<td></td>
</tr>
<tr>
<td>▪ Work with Director</td>
<td>▪ Support regional constituents</td>
<td>▪ Investigate fundraising opportunities and share as appropriate</td>
</tr>
<tr>
<td>of Engagement &amp;</td>
<td>and C/CCCs to arrange physician</td>
<td></td>
</tr>
<tr>
<td>Outreach and C/CCCs</td>
<td>education meetings</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>▪ Participate and</td>
<td>▪ Answer questions, provide</td>
<td>▪ Represent VHLA at</td>
</tr>
<tr>
<td>share information</td>
<td>support; inform patients</td>
<td>fundraising events in</td>
</tr>
<tr>
<td>through various</td>
<td>about nearest C/CCC</td>
<td>your area when possible</td>
</tr>
<tr>
<td>platforms and</td>
<td></td>
<td></td>
</tr>
<tr>
<td>communities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>▪ Direct people to</td>
<td></td>
<td></td>
</tr>
<tr>
<td>VHLA Office as needed</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

All Ambassadors:
- Participate in regularly scheduled conference calls (quarterly)
- 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. Work with Liaisons as appropriate.

**CCC Liaison** Connect with the Clinical Care Center where you receive care. Assist and help guide other VHL patients and families who receive care at your CCC. Your experience, insight and knowledge is invaluable to newly diagnosed patients and families, as well as those who are new to your CCC.

**Hotline Volunteers**

Cover 24/7 Hotline number during your assigned days.

Provide support and education to callers.

Inform callers about the nearest VHL Clinical Care Center (listed at vhl.org/ccc).

Direct callers to the VHLA office, as needed.

Provide caller's name and contact information to the VHLA office.

**Tips and Suggestions**

Volunteers often need to be a friendly listening ear: Listen to what the caller is feeling, what they are not saying. Is there a tremble in their voice, a hint of grief, or fear?

The VHL Handbook contains the information you will need. Contact the office (office@vhl.org) if you do not already have a copy, and we will make sure to send it to you. The VHL Handbook is also an excellent resource for all patients, family members, and healthcare providers. Purchasing one or downloading it from the website: vhl.org/handbook is an important suggestion.

Volunteers are not expected to know all the answers. Suggest that the person speak to someone on their medical team, such as their geneticist or genetic counselors – they are equipped to help a patient decipher even the most complex situation. Patients are also welcome to contact the Director of Engagement & Outreach at the office, or at Josh.Mann@vhl.org.

**Possible Questions You May Encounter**

**Q:** *I do not have medical insurance. What do I do?*
A: The website, healthcare.gov provides information options for healthcare insurance by state.

Analogy from VHL Handbook, page 8-9: Getting tested and keeping up with your screenings are a little like not taking care of your house or car — you may get away with it for a while, and then it all catches up with you and it costs you a great deal all at once. There is clear, documented evidence that you will stay healthier longer if you use medical diagnostic techniques wisely and are watchful.

Q: I just moved to a new town. Where can I find a VHL expert who will handle all my needs?

A: The VHL Clinical Care Centers all have experience in VHL care. A list of the Clinical Care Centers throughout the U. S. and abroad can be found at vhl.org/ccc. There is a geographic gap, which means that someone might have to travel to a CCC. It is also recommended that a patient have at least one doctor locally. Suggest that the person bring the VHL Handbook along for their visit with their new doctor. It is important to find a healthcare professional with willingness to learn and to be part of a medical team a team player is important whether they are a general practitioner or a medical specialist.

NIH is another option, but can only see patients who fit their specific experimental protocols.

Q: I live in a small town. Is there a support group meeting near me where I can meet other people with VHL?

A: There is not likely to be a face-to-face meeting for those located in a small town. You may also want to join one of the monthly Telephone Discussion Groups, consider asking for a VHL Partners mentor, or call the VHLA office. Video calls are also a great alternative to meeting in person. The VHLA can help you set up a video call.

National meetings as well as regional gatherings are posted at vhl.org/about/news-events/. In addition, most of VHLA's support efforts are through telephone and internet social media venues

Q: I just found out that I have VHL. Am I going to die?

A: It is important to help the person see that there is hope, and to formulate an action plan that they can implement: screening, nutrition, stress management. When people see what they need to do, they feel more in control.

It sometimes helps to reflect back to them what you hear. “I hear that you are angry – and you have a right to be angry,” or “I hear that this is a scary new journey for you.” You might suggest they join one of the online support groups so they can interact with others on the same path.

You might ask whether they have someone they can talk with about their anxiety: a
friend, member of the clergy, their healthcare provider, etc. might be a good place to start, and the conversation will help you see the options.

People who are diagnosed as adults often have pent-up health maintenance to do that can feel overwhelming. Hopefully the caller will soon be through this catch-up period and on a regular screening schedule and life will feel much more normal.

HLRCC, BHD, AND SDH

VHLA is supporting other genetic kidney cancers HLRCC and BHD. Each has its own support lines, but it is possible that calls from patients with HLRCC or BHD may come to Hotline Volunteers. It is also possible that you may get questions from SDH patients who are participating in MyVHL: Patient Natural History Study. Many of the issues facing VHL patients apply equally well to HLRCC and BHD. Below is a brief overview of these conditions.

HLRCC = Hereditary Leiomyomatosis and Renal Cell Cancer. The kidney cancer in HLRCC is more aggressive and can metastasize at the 1 cm level, so that the VHL rules for managing kidney tumors do not apply. HLRCC causes uterine fibroids and some skin bumps. There is an HLRCC Handbook which is available on their website, hlrccinfo.org or from Amazon. Search for “HLRCC”.

VHLA has asked the VHL Clinical Care Centers to also support HLRCC patients. Urologists who deal with VHL are in a good position to support HLRCC patients. Dermatologists and OB/GYN's are being added to the VHL Clinical Care Centers to handle HLRCC skin lesions and uterine fibroids.

Please direct callers to hlrccinfo.org and to their hotline number: 800.767.4845 ext. 709.

BHD = Birt-Hogg-Dubé Syndrome. There is not yet a Handbook for BHD, but there is some high-level information at bhdsyndrome.org. BHD includes lung cysts which can be quite large and when they break can cause the lung to collapse without warning. It also includes skin bumps. The kidney cancer in BHD is a different cell type (oncocytoma, chromophobe, or a mixture) in almost 90% of patients, but also about as non-aggressive as VHL clear cell kidney tumors, making the VHL “3 cm rule” a good starting point for BHD.

VHLA has asked the VHL Clinical Care Centers to also support BHD patients. Urologists who deal with VHL are in a good position to support BHD patients. Pulmonologists are being added to the VHL Clinical Care Centers. Starting with the VHL CCC’s is a good idea (vhl.org/ccc). There is a different extension for the BHD hotline: 800.767.4845 ext. 725.

SDH = Succinate Dehydroginase Syndrome. Mutations in SDH subunits B, C, and D are associated with kidney cancer that is more aggressive than in VHL, so that the VHL “3 cm rule” for tumor removal does not apply. In fact, “wide surgical excision” of kidney tumors is
recommended. SDH is also a genetic cause of both pheochromocytomas and paragangliomas. While the VHL Clinical Care Centers have not been officially asked to support SDH patients, the expertise of the centers in treating both kidney cancer and pheochromocytomas is excellent for SDH patients as well. A patient organization which includes those living with SDH is the Pheo Paratroopers: pheoparatroopers.org/

**Your Role**

**Do not worry, you are not expected to know all the answers.** You are the eyes and ears in the community for VHLA. You are a great resource and can help people find the information they need. There is no one person who knows everything there is to know about VHL. Even the expert centers ask questions! Much of the information you need is provided in the VHL Handbook which has been provided to each of our volunteers as a resource. If you have not received a copy, please contact the office and we will send you one. If you would like an additional copy, they are available for download or purchase at vhl.org/store.

**As research and treatments progress, some information will need to be updated.** While many of these changes will be shared with the VHL Alliance constituency through the quarterly newsletter and on the VHLA website. We also will be sure to update this manual, which will be housed on vhl.org. Our goal is to always keep you up-to-date.

**The most important thing we can impart to callers or online participants is that they are not alone.** Hotline Volunteers and Ambassadors are often in the roles of educator and supporter. That does not mean that you have to solve the problems being presented to you. You are the guide – guiding them to the right places to access the information they need to make an informed decision. In many cases, you will be putting them in touch with resources, either directly if you know them, or with the assistance of the hotline and the office, who can help them see the problem from other angles.

Remember, people need to want to find the answer and take action. Without this internal motivation, action will not happen. Do not take it personally if they decide not to act. You do not need to agree with their decision; they do not need to do what you would have done.

As you connect with the person, please note that parents sometimes feel guilty about "giving" VHL to their children. They did not "give" it, which implies intention; they "passed" it along with no power to choose. We give our children life, love, and strength of character as best we can. Every human on earth has "flaws." Some are in the color of the eyes, or a funny patch of hair, or a quirky twist of the earlobe. Some cause tumors or other medical issues. Those "flaws" do not interfere with their ability to be kind, warm, courteous, or generous.
In addition, there may be times when your conversation is taking place after a treatment has not gone well. Be careful to be supportive, but not overwhelmed by their situation. You might say, "I'm so sorry to hear that you had that experience, but of course the most important thing now is to get the best help we can at this point. How can we move forward, learn as much as possible from what happened to make the path easier for the next person, and provide the best possible care now?"

**It is important to be a good listener.** Generally, throughout the “conversation” you will obtain all the necessary information. Ask the appropriate questions, being careful that you do not sound like you are interrogating. If appropriate, you might ask for information about other family members, and offer to have an information packet about VHL and the VHL Alliance sent to them. Additional packets for others in the family or for physicians can also be sent out. For this purpose, they will need to provide you with names and contact information, which you can pass along to the VHLA office.

When communicating with people, the most important part of responding to people's needs is to be a good listener. We want to establish a friendly rapport with all callers.

Also let them know that the VHL Handbook may be downloaded free or purchased from the [vhl.org/handbook](http://vhl.org/handbook).

**You are a key link in VHLA’s chain of information:** you will hear information that is important learning for all of us. Please let us know if you notice a pattern or if you hear something not already dealt with in our published material – any new twist might be an important clue! We have helped provide this type of information to doctors and it has led to breakthroughs in diagnosis and treatment for a number of aspects of VHL. Please report these to the office: office@vhl.org, or 617.277.5667 ext. 4.

---

**Remember, we could be the first contact a caller has with another VHL patient or VHLA constituent outside of their immediate family. We want the person to feel part of a caring community, and to provide them with as much information as they are ready to hear, focused on enabling them to make informed choices, and manage their own health.**
EXPLANATIONS OF VHL ALLIANCE POLICIES

CONFIDENTIALITY

Our foremost responsibility is to protect the privacy of its constituents. No constituent's name shall be given to another constituent outside of a VHLA's circle of confidentiality without the constituent's express prior written permission. (Email from the individual's own account giving permission is considered sufficient written approval.) Names will not be provided to researchers or reporters. If such a party wishes to reach a constituent, VHLA will give the name of the reporter or researcher to cooperating constituents for them to take action.

Protecting Confidentiality with Email

In a world dependent on email for communication, we ask that the following statements be included at the end of all emails including personal information about our constituents.

VHLA does not engage in the practice of medicine. It is not a medical authority, nor does it claim to have medical knowledge. In all cases, VHLA recommends that you consult your own physician regarding any course of treatment or medication.

MAILING LISTS

All mailing lists are confidential and will only be used for the specific purpose of carrying out approved programs of VHLA, unless a constituent has specifically requested that his/her name not be distributed for any purpose. The lists may not be rented, sold, nor shared.

Each Ambassador shall send changes to its current mailing list VHLA office. We ask that this information be sent as soon as possible to ensure that the next mailing will go to the right place.

Affiliate groups in nations outside the United States may retain their mailing lists within that nation.
OPINIONS OF INDIVIDUALS VS. OPINIONS OF THE VHL ALLIANCE

Care must be taken by all volunteers, staff and others who may be seen as representatives of the VHL Alliance. Clearly label information when it is your own personal experience or opinion. Any individual is entitled to share his/her own story as long as it is clearly positioned as his/her personal story. Personal opinion should not be advice, and particularly not as the opinion or advice of VHLA.

VHLA offers only information, not opinion, on subjects relating to childbearing, eugenics, and pre-natal testing. Childbearing is a delicate issue. As a group, the VHL Alliance has only one opinion: ultimately the decision whether or not to bear a child is a personal decision on which there are only two votes that count – those of the two individual parents involved. Particularly because of the very strong opinions around the topic of abortion, VHLA wishes to be entirely neutral on this subject.

Issues related to politics and religion also fall into the category of personal opinion. As a representative of the VHL Alliance, please do not share your views about a particular candidate or legislation in a VHLA setting, be it live or virtual.

MEDICAL OPINIONS, YOUR OPINION, AND MEDICAL ADVICE

The VHL Alliance does not recommend any particular type of treatment. That is the job of the individual's medical team. Recommending treatment raises liability issues and puts the VHL Alliance at risk. Information about specific treatment should be offered only as an individual's own experience or opinion, not as the recommendation of VHLA.

VHLA may advise a person of his or her right to a second opinion and may offer names of physicians and medical professionals who are known to be knowledgeable about VHL. Even recommending a medical professional should be clarified as your own personal opinion or as a suggestion from another person with VHL, not a recommendation of VHLA.
**EXPRESSING OPINIONS**

You can always share your own personal experience as you deem relevant to the situation. However, be careful to make clear when you are expressing a personal opinion. As a representative of VHLA, what you are saying might be interpreted as the official position of VHLA. At the same time, you may know from your own experience what might or might not be logical. You might say something like:

- "I cannot really comment on your particular situation, because I am not a doctor or any other type of healthcare professional, and I'm not looking at your scans, but if you would you like, I can share with you what I know about this issue. There are some key questions you might want to ask your clinician to get clear on just what is happening in your case."

- "If you are feeling uncomfortable with the treatment your doctor has recommended, you are always entitled to a second opinion." Most insurance companies will strongly recommend – even require – that you get a second opinion before proceeding with treatment for a serious condition. It is very routine: the doctor shouldn't be offended. In fact, you could even present it as an opportunity for the local doctor to consult with one of the worlds' leading experts on VHL. Through its Clinical Advisory Council, the VHL Alliance is connected with an International team of leading experts on VHL.

**VHLA AND THE VHL CLINICAL CARE CENTERS**

VHLA has a list of physicians and medical professional names who are known to be knowledgeable about VHL, but not necessarily affiliated with a C/CCC. When offering these names, please be very clear that you are not recommending a clinician; you are providing some names from which they may choose. In many cases the lists of physicians are names we have gathered from other VHL patients. **Please be sure to explain that neither you nor the VHL Alliance is endorsing any one doctor, we simply know they have at least one VHL patient.**

When the VHL Alliance recommends a VHL Clinical Care Center, we are saying that this institution has entered into an agreement with VHLA that they will coordinate care and facilitate communication among the physicians who deal with VHL patients. Nonetheless, it is healthcare professionals who deliver care, not "institutions," so it's still no guarantee of "best care" or outcome. As a consumer group, VHLA has the ability to offer feedback with the institution. Feedback should be provided through the VHLA’s Clinical Care Center Coordinator at clinics@vhl.org.
If a representative of the VHL Alliance recommends a healthcare professional or a form of treatment and there is a negative outcome, VHLA could be seen as having pressured the person into the situation. There is a fine line between "recommending" (which is bad) and "educating and sharing" (which is good).

Never recommend or suggest that a doctor should be sued. Healthcare professionals are human beings who try their best, but they are not perfect. Often doctors have so many patients that they cannot take the time to do in-depth research on a rare disease. One of the roles of the VHLA is to provide basic materials in our printed information and resources for patients, family members, loved ones, physicians, and other healthcare professionals. If you are concerned about the advice this person is getting from the physician, then you can certainly ask for a second opinion.

Suing a healthcare professional is never a good idea. It will make it more difficult to get care from any healthcare provider in the future.

**Taking care of our Constituents and Ourselves**

The VHL Alliance wants to make sure that people have all the information they need to be strong and educated consumers. An educated consumer should not feel threatening to a doctor. Educated consumers build rapport with their medical team and work as part of a team in deciding a course of treatment.

Not everyone will make the decision that you would make. Do not ask yourself whether you agree, ask yourself whether you believe this person has all the information they need to make an informed decision.

Not everyone will conscientiously follow a screening program (see Screening Guidelines on page 33). They will sometimes delay screening and wind up with a nasty situation on their hands. *Do not look back; look forward.* No one knows what would have happened if the past had been played differently. Just take it from here and do your best to help them with the present.

Most importantly, *take care of yourself*. There will be highs and lows as you work with other constituents. There are conversations that will warm your heart and make you feel like the champion you are. There are other conversations that will make you want to cry. Let yourself cry, call one of us to share it. Use the VHLA staff for support. **PLEASE HELP US TO TAKE GOOD CARE OF YOU, TOO.**
Dealing with Emotionally Distraught Contacts

In the unlikely event that you are engaged in a real or virtual discussion with a person who raises the topic of suicide or homicide, it is important that help be sought as quickly as possible. Do not try to “talk down” the person. Stay calm as you find out the person's location and telephone number. Use the internet or even your local police department to contact the police in that person's location. Provide the police with as much information as you can and they will take it from there.

CONTACTING CONSTITUENTS

Up-to-date contact information is VHLA’s key for communications to our constituents. It is important that the information remain accurate. Remember that individuals are often somewhat timid and frightened when they first reach out for support. We want them to feel secure that their identity is safe.

It is a good idea to take notes during your conversation. On completion of your interaction, review these notes and send the information to the office. At a minimum, please provide the person's name, address, email, and any actions requested. (Of course, telephone numbers – home, mobile, and work – are greatly appreciated.) Please email the office at office@vhl.org with this information as soon as possible. If you prefer, you can also call the office with this information (617.277.5667 x 4). The sooner we receive this information, the sooner we will respond to any requests, get the person on the VHLA mailing list, and pass the information to the appropriate regional representative.

One of the biggest problems in having a rare disease is the feeling of being alone; no one else can possibly understand what you are going through. When people get into that tailspin, they are less likely to reach out and come to a meeting. It is important to try and connect with each constituent at least once a year. Questions you might ask are:

- How are things going?
- Do they have the information they need for what's going on?
- Do they need to be connected with resources outside their local area, to draw more expertise into the conversation and get a better diagnosis or recommendation for treatment? (If so, contact the office)
- Can they help you with an activity coming up?
- Do they have suggestions for things the local or national group should do?
STANDARDS FOR OUR ONLINE COMMUNITIES

The online discussions groups were founded to spread awareness of von Hippel-Lindau disease throughout the world, and to provide support for people with VHL and their families. All are welcome here – people with VHL, their friends, relations, neighbors, and anyone else who wants to learn about VHL. In order to keep the group a safe and friendly place, we ask everyone to abide by a few ground rules:

<table>
<thead>
<tr>
<th><strong>DO’s</strong></th>
<th><strong>DO NOT’s</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Be nice, supportive, and respectful.</td>
<td>Do not use this group as a substitute for a medical professional or to give medical advice.</td>
</tr>
<tr>
<td>Take your time and be safe.</td>
<td>No commercial use, promotion or solicitation.</td>
</tr>
<tr>
<td>Let us know if something is wrong.</td>
<td>Do not post inappropriate content.</td>
</tr>
<tr>
<td>Take a deep breath.</td>
<td>Do not interfere with the operation of the group.</td>
</tr>
<tr>
<td>Respect the privacy of others.</td>
<td>No scraping or data harvesting.</td>
</tr>
<tr>
<td>Respect the opinions of others, even if you disagree.</td>
<td>Do not use this platform to offer or exchange medication.</td>
</tr>
</tbody>
</table>

**Do’s**

**Be nice, supportive, and respectful.** This group works because we support and care for one another. Be nice and be supportive. Do your best to respect differing points of view.

**Take your time and be safe.** Please take your time getting started with these groups. Remember that your privacy is only as good as your privacy settings. The Facebook group is private and we ask for people to fill out a form before they are accepted. If you have any questions, please write to the Director of Engagement & Outreach (Josh.Mann@vhl.org). We strongly recommend you not post personally identifiable information like your full name, email address, or phone number in the group. If you want to exchange this information with someone with whom you feel comfortable, do so in a private message.

**Let us know if something is wrong.** If you see a member doing something that is contrary to these guidelines or simply feels wrong to you, let us know. If your instinct says something is wrong, it may very well be. We never reveal who reported a problem to us. Every post and member profile has a link to report the item for review by Facebook or Inspire, and you can submit your report anonymously.
Take a deep breath. The Internet makes it easy to forget that we are talking to other human beings, and to misunderstand one another. Email and postings do not carry a tone of voice to let you know whether someone is angry or joking. If a member says something that bothers you, take a deep breath and pause before replying. You are replying to another human. They may be having a bad day or may be upset. You may have misunderstood them, or they may not have expressed themselves clearly. You may simply not see eye-to-eye. This group works because we respect one another. It is rare that we need to shut down a discussion, but when we feel that a discussion is generating “more heat than light,” we will take appropriate action.

Respect the privacy of others. Please respect the privacy of members. Do not post personal information about others in this group unless you are a family member or have been directed to do so by the member or their family. This often comes up when a member is hospitalized or otherwise away from the group for a time. We understand that you want to know how your friend is doing and share that information, but the member’s privacy is primary.

Finally, please do not re-post information about a member from another site, or from a private message. The information may not have been intended for a wider audience. Posting relevant newspaper articles (published information) is encouraged as we all want to learn.

Do Not’s

For the safety of members and to keep the group running smoothly, we ask you please not to do the following:

Do not use this group as a substitute for a medical professional or to give medical advice. This group is not a substitute for professional medical advice or treatment. Always consult your physician and do not rely on the information in this site when making decisions about your health. The content in this group is for information only and is not reviewed by medical professionals. Similarly, do not use this platform to give medical advice. You may share information about your experiences, but do not play the role of health professional.

No commercial use, promotion, or solicitation. VHSA, as the sponsor of these groups, will promote its programs and events through these channels. You may not use this group for any commercial purpose, marketing, promotion, or solicitation. This includes promoting a company, product, service, person, treatment, therapy, website, support group, nonprofit, charity, or fundraiser outside VHSA; recruiting members to participate in market research, clinical studies, or surveys; soliciting donations for charitable causes or for yourself; presenting your resume or using this group to seek employment; or soliciting malpractice clients. Commercial entities are not permitted to join or create profiles in this group. Facebook does post advertising on our group page. We have no control over the advertising posted by Facebook.
**Do not post inappropriate content.** We work hard to keep this group a safe and comfortable place for members. We do not allow content that is inappropriate, hostile towards others, or refers to material that is obscene or violent, vulgar language, contains hate speech or remarks that are disrespectful to any race, religion, gender, sexual orientation, or individual. Content that is potentially libelous, violates an individual's privacy, or violates the legal rights of any individual or entity is not permitted. Links to other sites which contain such material are also not permitted. You may not post information which is false or misleading, or misrepresent yourself. A “reasonable person” standard applies and we reserve the right to remove any content or profile that we feel violates this guideline.

**Do not interfere with the operation of the group.** We reserve the right to remove posts and block access by individuals which interfere with the normal operation and use of the group, at our discretion. Examples include off-topic posting, bumping posts, posts that excessively advance a personal agenda or make it difficult for other members to be heard, creating multiple accounts or aliases, and abusing the Friend or Private Message features.

**No copyright infringement.** If you find an article or other information online that you think will interest members, post a short description, with an explanation as to why you think it is important and include a link to the original document if possible. That will allow your fellow members to retrieve the source document. Do not post the entire item or significant portions of it. If we think a post violates someone's copyright, we will remove it.

**No scraping or data harvesting.** You may not scrape, harvest, or otherwise collect information in bulk from this list. You may not copy content from this list for another site, or for any other purpose.

**Do not use this platform to offer or exchange medication.** No part of this group may be used to facilitate the donation, exchange, or receipt of medication, as it is against the law to do so. If you are interested in donating unused medication to help those in need, you will need to determine how the laws of your country and locality govern such donations. In the U.S., many states have programs through which unused medication can be donated for distribution to those in need. Good starting points for learning about these programs are your state’s web site, your physician, and your pharmacist. You are welcome to share information about such programs here, but you may not use this site to engage in or facilitate the exchange of medication.
FUNDRAISING

Funds shall be raised in the name of the VHL Alliance, Inc. The Board of Directors shall determine the use of VHLA's revenue. Restrictions on the money raised beyond education, support, or research require a discussion and approval from the Executive Director in advance of the fundraiser. In such circumstances, fundraising efforts shall be coordinated with the VHLA staff.

Fundraising is an essential component of what we do. Volunteers play an important role in funding at the local level.

VHLA is almost entirely supported by private donations. Fundraising dollars are used to support the small office staff responsible for running VHLA and providing patient, caregiver, and healthcare professional support and educational programs. These include: quarterly newsletters, VHL Handbook, VHL website, Annual Family Meeting, Clinical Care Centers, patient support, and more.

Dollars are needed to fund VHL research so that the cure can be found. VHLA funds research grants – totaling $2 million to date. In addition, MyVHL (formerly known as CGIP) vhl.org/MyVHL is an important effort in the quest for a cure. It will not only provide data on the natural history of the disease, but will also provide information about factors which may contribute to tumor growth. Best practices for diagnosis and treatment will be gathered from MyVHL, allowing VHLA and its Clinical Advisory Council to update screening guidelines. In addition, the information collected by the Databank will prove to be the basis for multi-centered clinical trials of potential new therapies; trials initiated by the VHLA Clinical Trial Task Force.

Yes, it is about the money! Basic research, drug discovery, and clinical trials are needed and they do not come cheaply.

Funding VHL research is not only about the 10,000 people in the United States who have VHL or even about the 200,000 people with VHL worldwide. Research on the VHL gene has already resulted in multiple drugs on the market now for advanced kidney cancer, colon cancer, and pancreatic cancer, and these new drugs and strategies are helping people with breast, prostate, and skin cancer, as well. The VHL gene performs a very basic function in the cell which is common to all cancers.

We need all our friends and family members to help us support research. Your efforts, be they local, regional, or national, are essential. Every contribution helps, including: Casual Day at the office, a bake sale at a sporting event, a school penny drive, a personal fundraising page, or a letter/email campaign. Anything you do will not only raise some money to help with VHLA’s educational, support, and research efforts, it will also raise awareness of VHL.
Before you launch into a fundraising effort, please touch base with the office. The VHLA staff is there to help you in any way possible. We can help you with ideas, help advertise your effort, and make sure you have copies of all the relevant state registration documents in case you are asked. (Fundraising ideas, Event 101 documents, talking points, and templates are available from the office upon request).

The VHL Alliance is a registered 501(c)3 non-profit organization (IRS tax ID: 04-3180414). We are responsible to the IRS for properly accounting for all monies handled by representatives using our name. All checks should be made out to the VHL Alliance, and sent to the office. Acknowledgement of donations, with tax receipt, will be sent out from the office. Of course, we encourage you to send personal thank-you notes to your donors. If you would like, the office can provide you with VHLA notecards.

Please help us keep careful accounts and meet our accounting obligations to our donors and to the IRS.

Every dollar we raise for VHL is important! Nearly $.90 of every dollar goes directly to research, support, and education.

NO DONATION IS TOO SMALL! EVERY DOLLAR COUNTS IN THE FIGHT!!!

Local and State Tax Considerations and Regulations

The VHL Alliance is registered in all states where it is required. Nonetheless, in each state there are certain activities that are regulated more closely, especially raffles, Bingo, or anything that might be considered gambling. Be sure to check with the office to see if our registration covers the activity you have in mind. Do this before the event, to avoid any fines from the local government. Walks or runs on city streets or parks may require permission from the local authorities (police, parks commission) and potentially others. Be sure to ask well in advance.

In order for donors to get tax deductions, the donation must be received by the VHLA office, and a tax receipt written to the donor by the office. The VHLA is responsible to the IRS for reporting all those donations and accounting for any money handled by VHLA and its regional volunteers. Please help us meet our reporting obligations to the IRS and to your state government. If you have any questions, do not hesitate to check with the office.

In many states, exemption from state sales tax can be obtained for items you purchase to use for regional activities. This is not automatic, but requires special registration. If you are planning an event or a large purchase, please check with the office to see if we already have state sales tax exemption in your state, or if we might be able to obtain it in time to meet your need. We are glad to assist with the paperwork.
PUBLIC EDUCATION AND AWARENESS

Each individual can help enormously to raise awareness of VHL in its own community. Talking points about VHL and about the VHL Alliance are provided on the next page. These points are also useful in your fundraising effort.

Consider writing an article or a letter to your local newspaper, or contact your local radio or television stations about a VHL get-together or fundraising effort. Local news outlets love to feature people and events in their region – they often give preferential treatment to local news. **May is VHL Awareness Month!** This is a great time to raise awareness of VHL.

Medical centers and hospitals provide educational programs, Grand Rounds, for their medical staff. Work with your doctor, a doctor at one of these institutions, or the department head (urology, neurology, ophthalmology, endocrinology, etc.) at your local hospital to explore the possibility of a VHL-focused Grand Rounds presentation. If you have a VHL Clinical Care Center in your region, please contact the Director of Engagement & Outreach Josh.Mann@vhl.org to involve the VHL Clinical Care Center. Hearing your story is also educational and impactful for medical professionals – it helps bring VHL into “reality.”

Educational and other materials are available from the VHLA office and are part of our overall branding package. Local brochures should be sent to info@vhl.org for review and to make sure they meet with our branding guidelines. Our branding guidelines are also available upon request.
What is von Hippel-Lindau or VHL?

VHL or von Hippel-Lindau is a disease caused by a genetic mutation of the VHL gene.

The VHL gene is involved in many other forms of cancer, including breast, kidney, and pancreatic cancers.

The disease causes the development of multiple tumors in as many as 10 sites throughout a patient's lifetime, from early childhood through adulthood.

Sites at risk include: kidney, retina (eye), spinal cord, brain, pancreas, adrenal gland, inner ear, reproductive tract, liver, and lungs.

Studies of the VHL gene have resulted in approval of multiple cancer drugs.

In the case of the kidney and pancreas, if not treated correctly, tumors can advance to malignant forms of cancer.

VHL follows a dominant inheritance pattern: children have a 50% chance of inheriting the mutated VHL gene.

20% of people with VHL are the first person in their families with this disease.

VHL affects people of all ethnicities in every country of the world.

The prevalence of VHL is approximately one-half of that of cystic fibrosis (1 in 36,000).

Approximately 200,000 people worldwide are affected by VHL.

*The VHL gene controls the major feeding pipeline of every tumor. Curing von Hippel-Lindau brings us one step closer to curing many forms of cancer!*
What is the VHL Alliance (VHLA)?

VHLA is the preeminent resource or clearing house for patients, caregivers, researchers, and the medical community. VHLA is about:

Education Support
Diagnosis Treatment
Research Awareness

VHLA was founded in 1993.

VHLA provides support through a toll-free hotline as well as online support communities.

VHLA is an educational and support resource through personal conversations, the internet (vhl.org), quarterly newsletters, regular email bulletins, annual family meetings, regional meetings, VHLA Handbooks: What You Need to Know About VHL and the VHL Handbook Kids’ Edition.

VHLA has Regional Ambassadors throughout the United States and there are affiliated organizations in 28 countries of the world.

The Work of the VHL Alliance has led to:

- Awarding $2 million for VHL research by VHLA
- Development of guidelines for screening and treatment
- Improved diagnosis and treatment of VHL patients
- Increased life expectancy and enhanced quality of life
- Development of a strong international community to combat feelings of isolation
- Organization and recognition of VHL Clinical Care Centers, worldwide
- Development of MyVHL: Patient Natural History Study (formerly known as CGIP)
- Establishment of the VHL Clinical Advisory Council and the VHL Research Council
- Understanding of the underlying biological mechanism responsible for many other forms of cancer
- Multiple approved medicines for several forms of cancer, including kidney cancer
INFORMATION AND RESOURCES

Clinical Care Centers

A description of the Clinical Care Centers program is maintained on the VHL Website, along with a list of the participating centers, worldwide, at vhl.org/ccc

Social Networking

Current VHLA online venues for discussions:
Facebook private discussion group: https://www.facebook.com/groups/VHLawareness/
Inspire: vhl.inspire.com
Multi-lingual community rareconnect.org/en/community/von-hippel-lindau

Social Media Accounts:
Twitter twitter.com/VHLA
VHLA Facebook Fan Page: facebook.com/VHLAlliance/
LinkedIn https://www.linkedin.com/groups/4652845
YouTube https://www.youtube.com/user/vhlfa
Instagram https://www.instagram.com/vhl_alliance/
Pinterest https://www.pinterest.com/vhlalliance/
Caregiver Group: facebook.com/groups/vhlcaregivers/
VHL: Parents to Parents: facebook.com/groups/VHLparents2parents/
VHL Low/No Vision Facebook Group: facebook.com/groups/vhlvision/
And other regional groups

Note that to help users of our social networking sites to remain polite and stay on topic; “Standards for our Online Community” have been created. The “Standards for our Online Communities” (page 29) are that people be polite and stay on topic. Re-sending jokes or heart-warming stories from the internet, and posting specific religious images or references are not permitted. As a protection against viruses, attachments are not allowed; of course, we are always open to a discussion about posting such attachments on the website.

The VHL Alliance staff monitors these sites and will move a conversation offline, if necessary.
**Fundraising**

You can create your own fundraising page to support the VHLA at [vhl.org/p2p](http://vhl.org/p2p)

See more on page 21 of this document.

**Support Groups**

The VHL Alliance offers monthly facilitated discussion calls. One-on-one support is also available from a mentor through the VHL Partners program. For more information, contact VHLA ([vhl.org/support](http://vhl.org/support)).

**Monthly Telephone Discussion Groups:** Request more information, including call-in info, at each site below:

- Patient/Caregivers Group – [vhl.org/ptcgcall](http://vhl.org/ptcgcall)
- Parents of VHLers Group – [vhl.org/parentscall](http://vhl.org/parentscall)
- Low/No Vision Group – [vhl.org/lownovisioncall](http://vhl.org/lownovisioncall)

Mentor Program: Call 617.277.5667 x4 or e-mail [info@vhl.org](mailto:info@vhl.org) for more information.

**Toll-Free Hotline: 800.767.4845, x1 or hotline@vhl.org**

The VHLA Toll-Free Hotline Committee is available 8 AM to 10 PM ET, 7 days a week. Each Hotline volunteer has personal experience with VHL – totaling hundreds of years of experience with VHL!

**Key Contact Information**

**VHLA Office**
617.277.5667 ext. 4  
info@vhl.org  
1208 VFW Parkway, Suite 303, Boston, MA 02132

**MyVHL: Patient Natural History Study**

**Contact:** MyVHL@vhl.org

**Web page:** [vhl.org/MyVHL](http://vhl.org/MyVHL)

Patients can enter their own information by completing the online surveys

Medical records and scans may be uploaded or mailed to the VHLA office for inclusion in the Databank

Additional “participants” can be created in order to include information for minor children and deceased relatives.
SUGGESTED SURVEILLANCE

Until a cure is found, screening is a patient’s strongest defense to prevent severe VHL complications.

Screening is the testing of individuals at risk for von Hippel-Lindau disease (VHL) who do not yet have symptoms, or who are known to have VHL but do not yet have symptoms in a particular area. The unaffected organs should still be screened.

Modifications of screening schedules may sometimes be done by physicians familiar with individual patients and with their family history. Once a person has a known manifestation of VHL, or develops a symptom, the follow-up plan should be determined with the medical team. More frequent testing may be needed to track the growth of known lesions.

People who have had a DNA test and do not carry the altered VHL gene may be excused from testing. Even with the VHL gene, once an individual has reached the age of sixty and still has no evidence of VHL on these screening tests, imaging tests may be reduced to every two years for MRI.

Revisions in this version of the screening guidelines for VHL include a change in recommendations from CT to MRI, in order to reduce exposure to radiation for all people. CT should be avoided for all pre-symptomatic people, and should be reserved for occasions when it is truly needed to answer a diagnostic question.

In order to monitor the most critical areas of the brain and spinal cord in the most efficient and cost-effective manner, CNS MRIs should include the brain, cervical, thoracic, and lumbar spine. Scans should be ordered as no less than a 1.5T MRI with and without contrast, with thin cuts through the posterior fossa, and attention to inner ear/petrous temporal bone to rule out both ELST and hemangioblastomas of the neuraxis.

Regular audiometric tests are included in the screening protocol to provide a reference point in case of sign or symptom of hearing loss, tinnitus (ringing in the ears), and/or vertigo (dizziness, loss of balance). If hearing drops, swift action may be required to save hearing.

MRI is the preferred screening method for the abdomen. Quality ultrasound may be substituted for MRI of the abdomen no more than once every two years. “Quality” is defined as a machine that produces good quality pictures, with an operator experienced in imaging the organs being studied. The objective is to find even small tumors, which are difficult to identify on ultrasound.
**Any Age**

Inform families that, if they choose, they and their geneticist may contact one of the clinical DNA testing laboratories familiar with VHL for DNA testing. If the family marker is detectable, DNA testing can identify those family members who are not at risk and may discontinue surveillance. Testing may also be useful in calculating risks for family members who do carry the altered gene and require periodic surveillance. Risk factors are not definitive indicators of what will happen, but only highlight areas at higher or lower risk probability. Early detection and appropriate treatment are the best defenses.

**From Conception**

Inform obstetrician of family history of VHL. If the mother has VHL, also refer to the discussion of pregnancy in the VHL handbook and in the surveillance protocol. A woman who is having any genetic testing done may request a VHL test be included in that series of tests.

**From Birth**

Inform pediatrician of family history of VHL. Pediatrician should look for signs of neurological disturbance, nystagmus, strabismus, white pupil, and other signs which might indicate a referral to a retinal specialist. Obtain routine newborn hearing screening.

**Ages 1-4**

**ANNUALLY**

- Eye/retinal examination with indirect ophthalmoscope by an ophthalmologist skilled in diagnosis and management of retinal disease, especially for children known to carry the VHL mutation.
- Pediatrician should look for signs of neurological disturbance, nystagmus, strabismus, white pupil, and abnormalities in blood pressure, vision, or hearing

**Ages 5-15**

**ANNUALLY**

- Physical examination and neurological assessment by pediatrician informed about VHL, with particular attention to blood pressure (taken both while lying and standing), hearing impairment, neurological disturbance, nystagmus, strabismus, white pupil, and other signs indicating retinal problems.
- Dilated eye/retinal examination with indirect ophthalmoscope by ophthalmologist informed about VHL.
- Test for fractionated metanephrines, especially normetanephrine in a “plasma free metanephrine” blood test or in a 24-hour urine test. Obtain abdominal ultrasonography annually from 8 years or earlier if indicated. Obtain abdominal MRI or MIBG scan only if biochemical abnormalities found.
EVERY 2-3 YEARS

- Audiology assessment by an audiologist. Annually if any hearing loss, tinnitus, or vertigo is found
- In the case of repeated ear infections, MRI with contrast of the internal auditory canal using thin slices, to check for a possible ELST.
- Test for fractionated metanephrines, especially normetanephrine in a “plasma free metanephrine” blood test or in a 24-hour urine test. Obtain abdominal ultrasonography annually from 8 years or earlier if indicated. Obtain abdominal MRI or MIBG scan only if biochemical abnormalities found.

**Age 16 and Beyond**

**ANNUALLY**

- Physical examination by physician informed about VHL.
- Dilated eye/retinal exam with indirect ophthalmoscope by ophthalmologist informed about VHL.
- Quality ultrasound, and at least every other year when not pregnant, MRI scan of abdomen with and without contrast to assess kidneys, pancreas, and adrenals.
- Test for fractionated metanephrines, especially normetanephrine in “plasma free metanephrines” blood test or 24-hour urine test. Abdominal MRI or MIBG scan if biochemical abnormalities found.

EVERY 2-3 YEARS

- MRI scans should be ordered as no less than a 1.5T MRI with and without contrast of brain, cervical, thoracic, and lumbar spine, with thin cuts through the posterior fossa, and attention to inner ear/petrous temporal bone to rule out both ELST and hemangioblastomas of the neuraxis.
- Audiology assessment by an audiologist.

**During Pregnancy**

**For women with VHL**

- Regular retinal checkup to anticipate potentially more rapid progression of lesions.
- Test for pheo early, mid, and again late pregnancy to ensure no active pheo during pregnancy or especially labor and delivery.
- During the 4th month of pregnancy, MRI—without contrast—to check on any known lesions of the brain and spine. If known retinal, brain, or spinal lesions, consider C-section.

*Updated: 11/1/2018*