Contents

What is VHL and VH LA? .........................................................................................................................2
Why Fundraise? ........................................................................................................................................3
Before You Start .........................................................................................................................................4
Fundraising Ideas ......................................................................................................................................5
Sponsorship ..............................................................................................................................................7
Putting on an Event ...................................................................................................................................9
Publicity and Press ..................................................................................................................................10
Resources ..................................................................................................................................................12
What is VHL and VHLA?

VHL (von Hippel-Lindau) is a genetic condition characterized by blood vessel tumors in up to ten areas of the body. It is caused by a flaw in one gene— the \textit{vhl} gene. With no known cure, active surveillance and surgery are the best options for VHL patients as they battle a series of tumors throughout their life. Some VHL tumors, such as those in the kidney and pancreas, can grow to a stage where they become cancerous. The \textit{vhl} gene is also involved in other more common cancers, such as kidney and breast cancer; discovering a cure for VHL may also lead to a cure for these other related cancers, too.

\textbf{The VHL Alliance (VHLA) is a 501 non-profit organization founded in 1993. Today, VHLA is the world’s leading organization supporting von Hippel-Landau Syndrome. VHLA funds research, increases awareness, and provides education and support to improve the lives of thousands of people living with VHL.}

\begin{table}[ht]
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\textbf{MISSION} & The VHL Alliance is dedicated to research, education, and support to improve awareness, diagnosis, treatment, and quality of life for those affected by VHL. \\
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\textbf{VISION} & The VHL Alliance envisions a cure for VHL. \\
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\textbf{VHLA PATIENT EDUCATION & SUPPORT} \\
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The VHL Alliance strives to help people thrive with VHL, always aiming for better treatments and hopefully one day a cure for this disease. Central to patient care is the \textit{VHL Handbook: What You Need to Know About VHL}, written and published by the VHL Alliance. The Handbook, also available in a children’s version, is the only document in patient-accessible language that offers tips on diagnosis and treatment while providing constructive ways of living with VHL. A free download of the VHL Handbook is available at: \url{vhl.org/handbook}.

VHLA has also established a Clinical Care Center (CCC) program that recognizes teams of specialists around the world who have extensive experience in delivering coordinated, holistic care for people with VHL. See the list of CCCs at \url{vhl.org/ccc}.

VHLA offers many free support resources for patients and caregivers of all ages including:
\begin{itemize}
\item Toll-free hotline
\item Peer-mentor program
\item VHL Alliance website
\item Quarterly newsletters & Wellness E-news
\item Annual Family Weekends, Regional Meetings
\item Teen & young adult programming
\item VHL international affiliate organizations/contacts
\item Facilitated discussion calls for patients/caregivers, caregivers-only, and patients with low/no vision
\item Facilitated online forums
\end{itemize}
\end{table}
RESEARCH

The \textit{vhl} gene, holds the code for the production of the VHL protein. When the normal supply of the VHL protein is interrupted, the normal regulation of cell growth is also disrupted initiating a process known as angiogenesis, the growth of new blood vessels. This is a normal process gone out of control.

The \textit{vhl} gene is also involved in other more common cancers, including kidney cancer and breast cancer. Discovering a cure for VHL may also lead to a cure for these other related cancers, too.

To date, VHLA has awarded over $1.6 million toward research designed to:

1. Increase understanding of how VHL affects the cell.
2. Permit the creation of model systems that better mimic the organ involvement of VHL.
3. Develop improved screening and treatment approaches for people living with VHL.

**The goal is to ultimately find a cure for VHL.**

VHLA partnered with the National Organization for Rare Diseases (NORD) to develop the VHL Patient Natural History Study (also known as the Cancer is in Our Genes International Patient Database – CGIP). This is designed to help researchers better understand VHL and other forms of cancer, hopefully unlocking answers to questions, including:

- Do commonly available over-the-counter medication impact tumor growth rate?
- What about diet or nutrition?
- Is there a correlation between anxiety, stress, or depression and cancer?
- Can exercise help decrease the rate at which tumors develop and grow?
- Does pregnancy or changes in hormone levels put woman at greater risk for tumor progression?
- Does oral health influence cancer severity?
  (Oral hygiene has been tied to cardiac disease; evidence is accumulating for a link to pancreatic disease.)

WHO WE SERVE

VHL affects approximately one in 32,000 people (approximately 10,000 people in the US and 200,000, worldwide) in every ethnic group. The prevalence of VHL is approximately the same prevalence as muscular dystrophy and one-half that of cystic fibrosis. As a genetic disorder, VHL is primarily inherited from a parent, yet 20% of patients are “new mutations” – an event that occurs randomly to a child in a family with no prior history of VHL. Once this change occurs, a child of an affected person has a 50% chance of having the condition.

Why Fundraise?

Fundraising events and activities are principally about raising much needed funds.

They also raise public awareness.

Fundraising should also be about having \textit{fun}. People go to events to enjoy themselves and this itself will generate new support and awareness.

The best way to ensure a fun fundraising event is for you to enjoy organizing it. The surest way of achieving that is to plan your event effectively.

This toolkit is intended to give you ideas and to take you through the various stages of holding an event from conception to completion. It should help you avoid some of the pitfalls along the way.
This toolkit is by no means comprehensive. The aim is to pack in as much practical information and advice as possible and hopefully encourage experienced fundraisers and newcomers alike to get organizing.

Be Bold. Be imaginative. Above all, enjoy yourself!

Before You Start

The Knowledge

When people are asked to give money to a charity they want to know how it is going to be spent. Therefore, it is important that you know the mission of VHL Alliance and that the money you raise will go towards that mission which is dedicated to research, education, and support to improve awareness, diagnosis, treatment, and quality of life for those affected by VHL.

Enthusiasm and Persistence

Your enthusiasm will encourage people to support you. There will be plenty of ‘No’s’. Be prepared for this and do not let it dampen your eagerness. Remember, there are thousands of charities raising money and people do generally support them. You have to make yours sound the best!

Confidence

You have to be confident and direct. People need to see that you believe in what you are doing. Do not be afraid to follow up if you have not heard back from your contact. Just because you have not heard, does not mean they do not want to give. Also, follow up year after year for annual events. Friends and family members want to support your cause. Remember if you don’t ask you don’t get.

Organization

Draw up a plan of attack. Give yourself plenty of time and set yourself achievable targets.

Contacts and Networking

List everyone you know and how they might help you. You will be surprised how this can help.

Imagination

The more unusual and attractive your fundraising ideas are, the more people support them. Do not just hold out a hat and expect everyone to want to put money into it. Not everyone will donate money, but perhaps they could donate a prize for a drawing or auction.

Legalities

Please be aware of all licenses and permit rules for your state and city, especially for raffles. If you are in doubt call us. Remember you are representing the VHL Alliance and helping convey our key message as well as raising money.
**Fundraising Ideas**

**GENERAL EVENTS**

*Auctions*

For an auction to be successful, items must be of good quality.

A variation on a silent auction is a blind or sealed bid auction in which bidders simultaneously submit bids to the auctioneer without knowledge of the amount bid by other participants. Usually, the highest bidder is declared the winner.

Run an auction of promises: contact your friends and see what they can offer up; babysitting, hairdressing, gardening, photography, decorating, a ride in a special vehicle; the list can go on and on.

*Board Games Evening*

A twist on a card tournament idea. It is something everyone can enjoy, no matter their level. Choose a fun game that most people are familiar with, such as Sorry, Monopoly, Clue, etc.

*Competitions*

Good for schools. Students pay a small fee to enter. (e.g. art, posters, short story)

*Games Night*

An entry fee has to be paid for each game played. (e.g. darts, dominoes, etc.)

*Murder Mystery Evening*

A package is purchased containing the scenario and full instructions. Revenue comes from ticket sales.

*“Sell” Services*

Ironing, cleaning, cooking, dog walking, gift wrapping, and babysitting are a few ideas.

*Sponsored Event*

Swim, run, walk, diet, shave - old fashioned ideas that still work.

*Sports Day*

Organize a volleyball, softball, cornhole, or sports match; charge a team entry fee.

*Themed Evenings*

Invite your supporters to a night of Indian, Chinese, Italian or Mexican food - you serve food of that ethnicity. Get people to bring a bottle of wine and charge to cover the cost of the food.
LARGER SCALE EVENTS

If you are feeling a little braver, you could try to organize an even on a larger scale.

Book Fair

It will take time to collect, sort, and price the books. Bookshops, libraries, and publishers may be persuaded to donate books as well as friends and the general public.

Craft Fair

The fair should be planned a year in advance to ensure the availability of artists and you will need to check that other fairs are not going to be taking place in your area on your preferred date. Fire and safety regulations and insurance may also need to be checked. Consider making some handmade items for the fair.

Fashion Show

Clothes might come from a store or from donations (good quality only). Models could be people you know, children or college fashion course students. The event will require refreshments, a PA system, and background music. It is advisable to sell tickets beforehand to assess numbers.

Festival

Ideas include knocking down a stack of tins, sac races, rolling a ball through a hole, roll-a-penny (must land on a playing card), pick a ticket out of a bucket, hook-a-duck, food stand. If all this sounds too daunting, you could have one or more stalls at an event organized by somebody else.

Wine Tasting

The wine and speaker(s) will be provided by local wine merchants and there should be an opportunity to buy at the end of the evening with a percentage going to VHL Alliance.

EVENTS FOR WORKPLACE OR SCHOOL

Not a bad place to try some fund raising ideas, you even have a captive audience to work with! Do not forget to get permission!

Dress Down Day

For fun, add theme e.g. school uniform, pajamas, or bad taste - bad hair, bad tie, the worst shirt.

Cycle or Walk to Work

Put the money you would otherwise spend on transport towards your fund - and reduce pollution at the same time!

Lunch Run

Offer to run out and buy lunch for your busy colleagues. Charge a little extra for a donation.

Bake Sale at Work Every Friday

Make a regular thing of it so people plan ahead.
**Guess the Number**

Have classmates/coworkers donate to guess the number of candy pieces in the jar.

**Night In!**

Persuade colleagues who frequent pubs and clubs not to go out on one Friday or Saturday night and to donate the money they save.

**Workplace Sponsored Charity**

If your company has one of these and the staff have a say in the selection process, nominate VHL Alliance and persuade your colleagues to do the same.

**More Ideas:**

- Plant or Toy Fair
- Pub Crawl
- Barn dance
- Bingo
- Car Wash
- Wine Event
- Gift Wrapping
- Carol Singing
- Karaoke Evening
- Pub Quiz
- Battle of the Bands
- Casino Night
- Dance/Disco
- Garden Party
- Sports Match
- Variety Show

**Sponsorship**

You can get sponsorship for almost anything, a personal challenge, a haircut, or diet. The list is endless. To make the most of sponsorship here are a few tips, especially if you are hoping to raise a large amount.

**Shout about it! Let the World Know!**

- Carry your sponsor form with you at all times, as you never know who you might bump into.
- However you go about obtaining sponsorship, the cardinal rule is to always follow up.
- Call your sponsors. Call again.
- Stop by and see them.
- Ask if they need any more information.

**The Internet**

Set up a fundraising page for VHL Alliance at grouprev.com/vhlalliance. Sponsors can make a tax deductible donation right online that will go directly to VHL Alliance.
APPROACHING AN EMPLOYER

If you are approaching your employer, make sure that you present your ideas in an organized and professional manner detailing:

- The event or activity
- Information on the charity or cause you are supporting
- What benefits there are to the company?
- Your publicity/fundraising plan

Ask to be mentioned on your company website and featured in the newsletter. Staff notice boards and email are two other ways of reaching the workforce.

Remember, aside from contacting the local press to get publicity, you can also contact local businesses - incorporate their company name and logo in any T-shirts, raffle tickets, press releases, and flyers that you might send out. The more organized the plan, the more likely they are to want to support you.

**Letter and Email**

Companies get lots of requests, so you will need to make yours different. Be clear about the challenge that you have set yourself, who the beneficiaries are and any potential benefits to the person you are writing to. The golden rule with letters is:

**KISS - Keep It Short and Simple**

Tailor your approach to your donor. Try and address each letter individually either to the Managing Director or to the Community Affairs Director, if the company has one. Do not expect a high rate of return from your mailing unless your addressees know you, or you are writing to local organizations. However, it is always worth asking and by following some of the advice here you might improve your chances of success. Often, large companies have very specific processes to follow. Contact the appropriate director for that information as early in the year as possible.

**Face-to-Face**

Ask for a specific amount rather than letting the donor decide - remember that it is easier to trade down than up:

- "Will you sponsor me $100 for my challenge?"
- "No, sorry but I can’t afford that." "How about $50?" "OK"
- Ask your employer to match the money you raise. Some will turn you down but you will be surprised just how many will support you.

**Suggested Key Points**

- Your personal goal.
- Why you are supporting the particular challenge.
- If you have a personal connection discuss how the issue has affected your life and the lives of those around you.
- What the money raised will go towards.
- Website address or copy of the VHL brochure.
- How and where they can send/email their donations - or when you will call them.
- Mail it to friends, family, businesses, work contacts, and local schools.
- As you get closer to your deadline, email or write to all the people you contacted originally. Let them...
know that you are short of your fundraising target, that you still need $X and will they sponsor you in order to take you to the target.

- If you are able to change your email auto-signature at work and/or home, add a line about your challenge to raise awareness of what you are doing. If you have set up a GroupRev page for the challenge, then create a link in the signature (or use vhl.org).

Putting on an Event

HOW TO CHOOSE A SUITABLE EVENT

When considering what kind of event to do, bear in mind:

- The likelihood of success – how popular is the event going to be with the public in your area and is it something you will actually enjoy?
- What skills, interests and talents can you draw on from your family, friends, their families and colleagues?
- How many organizers do you need prior to the event and how many will you need on the day itself?
- Is the venue suitable? Are the facilities sufficient? Consider: parking, access, heating, lighting, catering, toilets, etc.
- Do not bite off more than you can chew! A small well organized event is better than a large chaotic one. You will not have the time or the resources to do everything, so choose one or two things and do them well. It is easier to repeat a past success than to start afresh, so consider past successful ideas.

MONEY

How much money is it likely to cost and how much profit will it make? Minimizing the expenditure and maximizing the income is the key to profitability and should be a constant consideration. To help achieve this, it is essential to:

- Draw up a budget
- Set a realistic target

Deciding on a budget may be difficult, especially at first, but it gets easier with practice. Setting the target focuses your ideas and provides something to strive towards. Together they provide a form of financial control (ensuring, for instance, that expenditure does not surpass your target). They enable you to monitor progress of preparations for the event and help indicate whether you need to consider seeking sponsorship.

Remember, the rule of thumb for fundraising events is to spend less than $.20 of every dollar on expenses.

If you fail to meet your target – don’t worry. Learn from your experiences and ensure future events benefit from what you learn.

Share responsibility for organizing the event among as many people as possible.

Ensure that you choose an appropriate date – take into consideration other national and local events, school holidays, and, even, television attractions.

Allow sufficient time for booking a venue, speakers, catering, etc. Events vary but most will generally need 3-6 months’ preparation time. Confirm the booking in writing.

Reduce costs by getting everything possible donated – we are a charity after all – never forget to tell people. An in-kind donation letter is available upon request.

Maximize income by asking companies to place advertisements in your program or to donate services; charge an entry fee, sell programs, have a collection, sell refreshments (check with the local authority about food hygiene requirements).
Publicity and Press

The most exciting and well planned events can fail miserably without sufficient publicity. It is essential, therefore, that your event is publicized as widely as possible in a manner that will capture attention and encourage people to take part.

The VHL Alliance office would be happy to help you create something that follows our branding guidelines.

 PRESS

The local media serves to provide information to the local community. Tell them about your event. Send a press release (we can help with writing this). Ensure that the heading of the article is interesting and that the date, venue, contact names and numbers and activity are included in the first paragraph. Write on headed paper, use short sentences – make it short and sweet. Stress the local angle and local involvement. Type it double spaced on one side of the paper only, numbering each sheet. Do not underline anything.

Before sending it, show your press release to a friend who knows nothing about the event and see what they say. Telephone beforehand to find the right person to send it to. Also telephone afterwards to check that the release has been received and to see if any further information is needed.

Copy deadlines vary from paper to paper – check these.

Build up a mailing list of local newspapers, public service announcements, magazines, local TV and radio stations, relevant newsletters (churches, schools, clubs, colleges, etc.), and get contact names if possible.

Inform the media of photo opportunities. The more original and interesting these are, the more likely the press is to attend. If they do not attend, take your own photographs and send them in, complete with captions and names, with your press release.

If you can arrange a pre-event photo call (e.g. a celebrity in a t-shirt publicizing the event) you can gain extra publicity for the event and encourage the media to use the story.

 OTHER FORMS OF PUBLICITY

Tell everyone you know! Word of mouth is the best form of publicity!

Make posters and distribute them in public places (e.g. work notice boards, supermarkets, community centers) approximately three weeks before the event. This provides people with enough notice but ensures the posters will not have time to be covered up with other things.

Never underestimate the value of friends and relations: they have another set of contacts to you and different skills. Where possible, delegate. Give them copies of your sponsorship form (or links to your fundraising site) to give to their friends and workmates.

Consider using banners or sandwich boards.

Do not forget social media. Sites like Facebook, Instagram, and Twitter are a great place to spread the word to your friends and acquaintances.

 INVOLVING THE LOCAL COMMUNITY

Members of the community are a resource that is very near at hand and may prove invaluable. Groups from your area can help you at events for you.

You will probably find that many groups in your local community are already heavily involved in other charitable projects. It is, however, always worth asking – in the end you may rise to the top of their priority list!
Possible Avenues You Could Try

- Schools
- Youth groups
- Churches
- Sports Centers and clubs
- Amateur dramatic clubs
- Youth/social clubs
- Shops/supermarkets
- Hotels/restaurants
- Pubs
- Service organizations e.g. Rotary, Lions, etc.

Writing Approach Letters

Approaches to local businesses, service clubs, grant making trusts, and other potential donors can be a very successful way of fundraising.

This type of fundraising can be highly competitive so you need to make sure that your application stands out from the crowd. Here are a few guidelines to ensure that your application is noticed.

You will get a better response by writing to local organizations, companies, and trusts rather than national headquarters.

If is always better to write to a specific individual in an organization, rather than ‘to whom it may concern.’ This way you can follow up the letter and be sure someone has read it.

Try to assess the appropriate amount to ask for. It is a common mistake to ask for too little.

Personalize your letters, maybe using the name of a neighbor who suggested you write to this donor or refer to your volunteer work in the local area.

Events Checklist:

- Keep a list of everyone who is approached for support and their response.
- Review expenditure at regular intervals in the planning stages.
- Use publicity material and advice from VHL Alliance.
- Inform your local police for larger events.
- Have contingency plans for bad weather and mishaps.

On the day:

- Allocate one person to run point and monitor the running of the event.
- Make two people responsible for collecting the money.

After the event:

- Thank everyone who helped and tell them, and the media, how much you raised. Personal, hand written thank you notes are key. We can provide notecards if desired.
- Always, always, always remember to thank everyone who gives you a donation, no matter how small.
- Evaluate the event and record any successes and areas for improvement.
Resources

To help you with fundraising, VHL Alliance can provide you with:

- Newsletters & Annual Reports
- Information Brochures
- Note cards for ‘thank you’ notes
- Letter template for solicitation letters
- Letter template for in-kind donations
- T-shirts are available to purchase
- Event sponsorship proposal template
- Donation Request form/letter

Your efforts to fundraise for VHL Alliance are much appreciated.

We will help you as much as we can – just let us know what you need.

THANK YOU & GOOD LUCK!
VHL Alliance is dedicated to research, education, and support to improve awareness, diagnosis, treatment, and quality of life for those affected by VHL.

The VHL Alliance is a 501(c)3 non-profit organization – Tax ID: 04-3180414

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