Table of Ten

Overview

The VHL Alliance's Table of Ten is a series of events that will take place all over the world (virtually or socially distant for 2021). Each event will be led by a VHLer who will serve as the host and will put on their own unique, themed, Table of Ten event. They will invite their friends, plan the theme, and integrate a fundraising component. Each host will be asked to create a video telling about themselves and why they are hosting this event. Each host will have a personal fundraising page that they will be able to share via email and on social media. These events will ideally take place in May (VHL Awareness month) and through the summer of 2021. These events will serve as opportunities to share with friends, family members, and colleagues about the VHL Alliance and why it is your charity of choice. Awareness is our main goal in addition to a financial goal of each event raising $5,000 for the VHL Alliance.

Theme ideas:

- Paint N Sip
- Derby Party
- Concert
- Author reading
- Yoga
- Fashion Show
- Outdoor – golf/mini-golf
- Drive-In Movie Night
- Virtual Trivia
- Wine / Beer Tasting
- Cooking Class
- Pottery Painting
- Coffee Talk
- Barbeque
What we need from the Host:

- Set a fundraising goal (we ask that you set a minimum goal of $5,000)
- Select a date
- Put together an invitation list
- Pick a theme and/or type of event
- Event format (virtual or in-person)
- Work with VHLA to put together an invitation (Word Template included in the toolkit)
- Invite your guests
- Coordinate event logistics
- Send out Invite
- Capture RSVPs
- Determine creative ways of fundraising
  - Are you asking each guest to donate a specific amount?
  - Will there be a “ticket” fee?
  - Can you put together a drawing or silent auction?
- Host Event
- Thank your Guests/Donors

Optional:

- Put together a personal video to share why VHL is important to you and pitch your event
- Set up a personal fundraising page (vhl.org/p2p)
Tables of Ten Toolkit

- Fundraising Opportunities Overview
- Auction/Drawing Item Request Template (Letter/Email)
  - Donation Request Form
- Drawing Rules (Select States)
- VHL Infographic Handout
- Event Talking Points
Fundraising Opportunities

- Raffle/drawing – state laws (i.e. unique vacation home, trip, special wine, collection of books, 50/50, etc.)
  o Each state has different laws around raffles. We first recommend that you call your activity a drawing as this has less firm rules.
  o Local businesses are usually willing to help support these types of efforts. We have included a template below that you could use on a letter or send via email.
- Fund-a-need (donation request) see below
- Text to Donate (Give Lively) https://www.givelively.org/
  o Easy, mobile-first method for capturing contributions when donors are on the go. Donors text a custom code (only accessible on U.S. phone carriers) and give via a secure fundraising page.
- Virtual Auction (32 Auctions) https://www.32auctions.com/
  o Amplify your live event with an online auction that can be customized to fit your event and organization.

- $5,000 – Sponsors the purchase of laboratory equipment such as a microscope
- $2,500 – Sponsors 1 year’s tissue storage cost for research
- $1,000 – Sponsors the print of a quarterly educational newsletter
- $500 – Sponsors one month of professionally facilitated telephone support groups for patients and caregivers
- $100 – Sponsors the review data from one patient in MyVHL: Patient Natural History Study

What does your donation do for VHLA?

- Education – VHLA is the clearinghouse for all things VHL for patients, caregivers, AND medical professionals
- Emotional Support for patients and their caregivers – professionally facilitated phone calls
- Online support groups
- Peer mentor program
- Clinical Care Centers - hubs of comprehensive clinical care for people living with VHL
• Face-to-face educational meetings allowing patients and families to meet and learn from each other as well as some of the leading VHL experts in the world.
• Programs specifically focused on Caregivers to support them and prevent caregiver burnout
• State of the art website used worldwide by patients, families, friends, professionals, and researchers
• Highly regarded Competitive Research Grant program
• Biennial International Research Symposium – spurring research and collaborations among researchers
• Support and education by world leaders in VHL care for clinicians less knowledgeable in diagnosing and treating VHL
• FDA recognized Patient History Study called MyVHL to better understand VHL, the impact of lifestyle on tumor development and growth, identify best clinical practices and support clinical trials for VHL
• VHL Hotline providing support 24/7
• Handbook - a compact summary of information essential to managing the health of a person with VHL. Designed to be read by patients, their physicians, and members of their health care teams
Auction/Drawing Item Request Template (Letter/Email)

Dear [COMPANY NAME/CONTACT NAME],

I am writing to you as the event host for an event on [DATE], called [EVENT NAME]. This is our first year hosting the event and I want to ask for your help in making our event a huge success!

The goal of this event is to raise funds for the VHL Alliance, which is a non-profit organization that is dedicated to research, education, and support to improve awareness, diagnosis, treatment, and quality of life for those affected by VHL. Von Hippel-Lindau (VHL) is a genetic form of cancer that causes tumors to grow in up to 10 different parts of the body including the brain, spine, eyes, kidneys, pancreas, adrenal glands, inner ears, reproductive tract, liver, and lungs. It affects 1 in every 36,000 people. Curing VHL is one step closer to curing many other forms of cancer.

Please consider donating an item to be [auctioned off at the event or to include in our drawing]. A donation, no matter the size will help add to the success of our event. You will be recognized as a [auction or drawing] partner.

Attached to this letter I have included some additional information about the VHL Alliance as well as a contribution form should you choose to make a donation. Thank you in advance for your consideration of supporting this event.

With appreciation,

Name
Event Committee Member
Email Address
Phone Number
**Donation Request Form**

**EVENT DATE**  **EVENT LOCATION**

Thank you for your making a contribution to our [silent auction/virtual auction/drawing].

<table>
<thead>
<tr>
<th>Donor Name</th>
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<tbody>
<tr>
<td>Organization</td>
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<td>Mailing Address</td>
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<td>Email</td>
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<td>Retail Value</td>
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</tbody>
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**Description of item:**

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**Restrictions:**

- 
- 

Donor Signature: ________________________________ (required)

All items must be received by **DATE**

Please check all that apply:

- [ ] Delivery by donor
- [ ] Please contact us to arrange donation pick up
- [ ] Gift certificate/donation enclosed
- [ ] Donor will provide promotional materials (photos, brochures, menus) via .jpg or .eps format

We appreciate your support! Thank you!
Texas: CREA (charitable raffle enabling act), permits “qualified organizations” to hold up to two raffles per calendar year with certain restrictions.


Massachusetts: The short answer is yes, and there is no restriction on how many. There are some specific protocol that needs to be followed

http://massnonprofit.org/expert-advice/fundraising/regulations-on-raffles-are-complex
https://www.mass.gov/guides/guidance-on-raffles

Michigan: Yes - but a license is needed

https://www.michigan.gov/cg/0,9673,7-403-95973---,00.html

New York: Yes. Must obtain a license. Cannot do online raffles - tickets must be sold on-premises

https://gaming.ny.gov/pdf/REVISED%20Raffle%20Guidelines%208%2023%202018.pdf

New Jersey: Yes, must obtain a license. No online raffle ticket sales; https://legalbeagle.com/12717851-non-profit-rules-for-a-raffle-in-new-jersey.html

Virginia: Yes, a permit may be required depending on prize amounts

http://law.lis.virginia.gov/admincode/title11/agency15/chapter40
https://www.raffleticketsoftware.com/virginia-state-raffle-regulations/

Florida: Yes, but see specific rules


Illinois

VHL Infographic

Curing Cancer Through VHL

Von Hippel-Lindau Disease (VHL) is a genetic form of cancer that causes tumors to grow in up to 10 different parts of the body including the brain, spine, eyes, kidneys, pancreas, adrenal glands, inner ears, reproductive tract, liver, and lungs.

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

955
number of participants in MyVHL: Patient Natural History Study

$2.6m
committed to VHL research through the VHLA Competitive Research Grant

1,167
number of free patient handbook downloads since July 2017

24 U.S. CLINICAL CARE CENTERS

12
U.S. comprehensive clinical care centers

20
international clinical care centers

WHERE YOUR VHL ALLIANCE DONATIONS GO

99% of every dollar donated to the VH Alliance is used to further the VH Alliance mission!

91%
Research

8%
Fundraising

1%
Management

TO MAKE A DONATION AND TO LEARN MORE ABOUT OUR PROGRAMS AND RESOURCES

visit us at vhl.org

1208 VFW Parkway, Suite 303, Boston, MA 02132 / 617.277.5667 x 4 / vhl.org
The VH Alliance is a 501(c)3 non-profit organization - Tax ID # 04-3160414
VHL Talking Points

What is VHL?
- Von-Hippel-Lindau, or VHL, is a genetic disorder that causes tumor growth.
- VHL is caused by changes in the VHL gene, which normally prevents tumor growth.
- VHL tumors affect up to 10 parts of the body, including the eyes, brain, and kidneys.
- These tumors can be benign or cancerous.
- VHL can cause cancer, especially kidney cancer.

Why does VHL happen?
- Every cell in our bodies has two VHL genes, which prevents tumor growth.
- However, people with VHL (disease or syndrome) have a mutation to one of those VHL genes.

Who has VHL?
- VHL affects approximately 1 in 36,000 people.
- Parents who have VHL have a 50% chance of passing it on to their children.
- 20% of people who have VHL are de novo cases which means the VHL gene mutated spontaneously and was not passed down from the parents.

How does VHL get treated?
- Although there is no cure for VHL, the associated tumors can be treated.
- Early detection and treatment of tumors significantly improves a patient's diagnosis.
- Doctors remove tumors through traditional surgeries except for eye tumors.
- These are typically treated with laser surgery. Some drugs are in clinical trials to treat VHL tumors.