VHL Alliance Events 101

Regional Gathering

The VHL Alliance understands the importance and impact of meeting in person. We encourage you to put together a regional gathering. Some people hold these at their home, a public meeting space (such as a library), or a restaurant. There are a number of restaurants, such as California Pizza Kitchen, Applebee's, or Pizzeria Uno, that are willing to donate part of their proceeds back to the VHL Alliance (see the Dine2Donate 101 document for more information)

Meetings can be a social gathering to get to know one another or an educational program. Often a medical professional – doctor, nurse, genetic counselor, researcher – is happy to join the group and answer questions. Please work with the Director of Engagement & Outreach (josh.mann@vhl.org) to contact the nearest VHL Clinical Care Centers about the meeting.

The VHLA office is happy to assist you in your effort, such as sending out postcards or email notices to people in your region. In addition, meetings can be posted on our website news and events section, can be announced using social media, and, if sufficient time is given, can be included in the quarterly newsletter.

Please also report back to the office after the meeting. This information is important to us.

Steps to Organize a Local or Regional Meeting

Start small and build with strength. Identify a meeting place that is convenient for you, and hopefully others. Announce the meeting with plenty of lead-time, so that people have a chance to make plans that include your meeting. Be sure to include your local VHL Clinical Care Center. Email is the quickest and least expensive way to send invitations, however, some might still opt to send communications via the mail. Remember that the post office takes time to deliver the announcement, so it is good to plan a meeting 8-10 weeks (approximately 2 months) or more in advance of the planned meeting date.

Who - What - Where - Why - When

- Who is invited? Who is inviting them? Who should they call for more information? How can they be reached?
- What is going to happen at the meeting?
- Where will it be? Include driving / parking directions and how to find the room.
- Why should they want to come? Help them imagine the great time they will have, what they will learn, and why they cannot afford to miss this great meeting
- When is the meeting taking place? How long will the meeting last?

As always, please email the VHL Alliance office with any questions! Office@vhl.org
Timeline for Planning a Local or Regional Meeting

- 8-10 weeks – Confirm the place and the speakers (possibly from a local CCC), and talk with the office to get ideas, deadline dates for the newsletter, and other logistics information.
- 6 weeks – Finalize announcement information.
- 5 weeks – Mail/email announcements, begin posting on social media posts.
- 1-2 weeks – Send reminder emails/phone calls.

Day of Event

- Arrive early, to check on the room, unlock doors, and verify the path to the meeting room is clear.
- Post signs to direct people to the room.
- If your meeting is not at a restaurant, bring some modest refreshments (water and cookies and/or fresh fruit).

Prepare your Speakers

If you have invited a speaker, it is wise to have a conversation with him/her prior to the meeting. Ask the person to prepare a talk for a "relatively well-versed lay audience." The audience members are not doctors; they are patients and family members. They will understand some general concepts, but please ask them to explain any technical terms and not assume that the group will understand even the “simplest” medical term.

You might ask them to limit the "raw meat" pictures. This is especially true for kidney surgeons, who have wonderful photos of kidneys covered with VHL tumors. They can be interesting, but most lay people are not prepared to handle more than a few carefully selected shots with a gentle introduction. MRI and CT images are fine, but bright red kidney photos are difficult.

Most speakers appreciate your assistance in pitching their talk correctly for the audience. They will be happier and the audience will appreciate the speaker's care in preparing a presentation that is appropriate for them.

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