

Awareness/Fundraising Event: Guidelines

Thanks so much for choosing to raise awareness about spinal CSF leak, and for planning an event to support the Spinal CSF Leak Foundation! Here are some guidelines and tips for planning your event.

SOME GENERAL GUIDELINES ABOUT THIRD-PARTY EVENTS

A third-party event is any fundraising activity organized and executed by a group or individual where Spinal CSF Leak Foundation has no responsibility for the event but is the beneficiary of the funds raised. The event organizer(s) is/are exclusively responsible for all organizational and administrative details of the event, including but not limited to:

- All expenses, insurance and permits;
- Recruiting volunteers to help out at the event;
- Publicizing the event;
- Selling event tickets and/or finding participants.

The Spinal CSF Leak Foundation policies prevent endorsement of any product, organization, individual, or service unless approved by the Board of Directors. It must be clear that Spinal CSF Leak Foundation is the beneficiary, not the sponsor or host of the event. The Foundation accepts monetary donations only.

Event names or materials may not incorporate or use the name, logo, tagline, or other branding of the Spinal CSF Leak Foundation, with the exception of identifying the Foundation as the beneficiary of the event.

All promotional materials must clearly state that Spinal CSF Leak Foundation will be receiving a portion of the proceeds from the event, such as “Proceeds raised will be donated to Spinal CSF Leak Foundation” or “Donations collected at the event will be donated to Spinal CSF Leak Foundation.”

SUGGESTED LANGUAGE TO DESCRIBE SPINAL CSF LEAK

The following is a simple description of spinal CSF leak, which you can use in your communications:

Spinal cerebrospinal fluid (CSF) leak is an important and under-diagnosed cause of new onset head pain that is treatable. Cerebrospinal fluid (CSF) bathes and supports the brain and spinal cord. This special fluid is held in place by a tough layer of connective tissue called the dura mater. If the dura mater suffers a hole or tear, cerebrospinal fluid is able to leak out. The result is a loss of CSF volume, known as intracranial hypotension. This may result in a range of signs and symptoms, most often positional head pain that is worse when upright and improved when lying down. Many patients are quite disabled by their inability to be functional while upright. Spinal CSF Leak Foundation is working hard to facilitate more timely access to appropriate diagnostics and treatments for those suffering with spinal CSF leak.

Awareness/Fundraising Event: Guidelines

DONATIONS

If you are raising funds, please keep in mind the following:

- The Spinal CSF Leak Foundation is a 501(c)(3) non-profit organization and donations are tax deductible in the USA.
- Online donations can be made through the Foundation website at **<http://spinalcsfleak.org/donate/>**
- Bring a laptop or mobile device to your event and offer to have donors make their donations on the spot.
- Checks should be made out to the Spinal CSF Leak Foundation, with your name in the memo so we can identify it as a donation to your fundraiser. Please provide the donor's mailing address, phone number, and email address, so we can ensure they receive a tax receipt and thank you note. Forward the checks and the donor information to:

Spinal CSF Leak Foundation
707 W. Main Ave, Suite B1 PMB103
Spokane, WA 99201

- For cash donations, keep careful records about the money you collect. Obtain each donor's name, mailing address, phone number, and email address, so we can ensure they receive a tax receipt. *Do not send cash in the mail.* Please mail us a check for the total amount, along with the list of donors and their contact information, so we can ensure that donors are issued tax receipts and thank you notes.
- Thank everyone for their donation. Write personal notes, email, text, or call.

HAVE FUN!

Be sure to take lots of photos, and feel free to tag us on social media!

-  twitter.com/spinalCSFleak
-  facebook.com/Spinal.CSf.Leak.Foundation
-  instagram.com/spinalcsfleakusa
-  youtube.com/c/SpinalCSFLeakFoundation

Awareness/Fundraising Event: Tips

Tips for planning your event

CHOOSE AN APPROACH

Decide what kind of event you'd like to host. We've included some ideas and suggestions in this document, but we encourage you to be creative and come up with something that works for you! Feel free to contact us for help at staff@spinalcsfleak.org.

TELL YOUR STORY

Whatever kind of event you plan, make sure to make it personal by sharing why raising awareness and supporting the Foundation is so important to you.

- **Explain** why you are supporting the Foundation. You might share your own personal story, or you might help someone else affected by a spinal CSF leak share their story.
- **Share** how having a spinal CSF leak has impacted your daily life.
- **Share** how the Spinal CSF Foundation has made a difference for you and others dealing with a spinal CSF leak, and how more research is needed to advance the understanding of the disorder and improve testing and treatment.
- **Help** spread the word so that others suffering from head pain and other neurological symptoms that are worse when upright will consider asking their doctor if they might be suffering from a spinal CSF leak.



AWARENESS ITEMS

You can download and print out informational brochures from our website to share with guests, and you can also purchase t-shirts and other awareness items [online in our SpreadShirt store](https://www.spinalcsfleak.org/online-store).



Awareness/Fundraising Event: Tips

SPREAD THE WORD / PUBLICIZE THE EVENT

Explain what you are doing, where, when, and why. Remember to tell your story and why it is important to you to spread awareness and fundraise for Spinal CSF Leak Foundation. Here are some ways you can reach people:

- **Social media.** Social media, including Facebook, Twitter, Instagram, YouTube, TikTok, and more, is a great way to share information with a large number of people. Consider sharing photos, videos, and links from the Spinal CSF Leak Foundation website or social media pages. For hashtags, use: #spinalCSFleak and #becauseyourduramaters
- **Email.** Although social media is very effective, a more personal approach via email can often be compelling. Include a digital flyer. Tell your story and ask your contacts to forward the email to their friends and contacts.
- **Postal Mail.** People love to get mail. Send a handwritten note, letter, or flyer.
- **Calls and Texts.** You may be more likely to reach some of your contacts by giving them a call or sending a text. You can always follow up with an email.
- **Flyers, Banners, and News Outlets.** Print flyers about your event and ask businesses, stores, and organizations to post one. If your event is at a church, school or other location, ask for permission to include a write-up in their bulletin. Write a short press release and send it to a local newspaper.

TIPS FOR A SUCCESSFUL EVENT

- Choose a location that will work well for your event. Get permission to use the location.
- Identify a contact person at the venue, explain what the event is and what your needs are. Ask if there are any specific requirements to use their facility.
- Schedule a date and time.
- Recruit volunteers. Share your story and tell them about spinal CSF leak. Suggest they look at the Spinal CSF Leak Foundation website for more information. Thank them for their help.
- Gather all the supplies and other items you will need for your event.
- Arrive early for your event so you have time to set up and train volunteers.
- Distribute brochures and other awareness items.
- Clean up. Make sure you know where to place trash, or take it home with you. Ensure the area is tidy when you leave.
- Thank all volunteers and your venue contact person.
- Ask your volunteers to take lots of photos. Ask participants to wear purple, and to take pictures and selfies. Have people share them on social media.
- Send thank-you notes to all of your volunteers and donors.

Awareness/Fundraising Event: Ideas

EVENT IDEAS

The following are just a few suggestions for awareness or fundraising events you might consider—but these are just starting points! We encourage you to get creative!

MEDICAL OFFICE AWARENESS

Awareness of spinal CSF leak remains low among health professionals and the general public. As a result, many patients are misdiagnosed, which can add months or even years to their suffering. You can help raise awareness among staff and patients at the offices of healthcare providers you already visit by providing information about spinal CSF leak and the Foundation. It's simple and easy—just print our series of documents and bring them with you on your next visit.

<http://spinalcsfleak.org/resources/>

COFFEE / TEA PARTY

Many people with spinal CSF leak experience temporary relief by consuming caffeinated beverages. If you are not well enough to host a party, consider asking a friend to host one for you. Invite your friends and contacts. Tell them your story and distribute informational brochures. Think about using a purple theme. Ask your guests to wear purple and serve treats with purple icing. Ask them to post selfies and share information about spinal CSF leak on social media. Consider asking them to make donations to the Spinal CSF Leak Foundation to fund more education and research.

STAY-AT-HOME TEA / COFFEE CAMPAIGN

Use postal mail to send one of your favorite instant coffee packets or tea bags to family and friends. Include your story and explain why you are raising awareness and fundraising for the Spinal CSF Leak Foundation. Suggest your contacts enjoy a cup of tea or coffee at their own convenience, read your story, and consider making a donation to the Foundation.

5K WALK, BIKE, OR RUN / CHARITY SPORTS GAME

With the popularity of weekend walk/run events, it would be great to get a group of friends to sponsor you or a family member for a spinal CSF leak team at a running event. As a patient, you may not be able to participate, but you can definitely get the word out. Collect donations and ask your friends and family to wear purple shirts. Include brochures as part of the run package for every participant to raise awareness.

Awareness/Fundraising Event: Ideas

TALENT SHOW

Host a talent show in honor of the Spinal CSF Leak Foundation. Advertise on social media and explain that the entrance fees and donations will go to the Spinal CSF Leak Foundation. If your participants are okay with it, stream it online for an even bigger audience!

DINE FOR DOLLARS

Approach a local restaurant or coffee shop and ask if they would be willing to donate a portion of the proceeds during the event period to the Foundation. Set up a spinal CSF leak information booth and ask your friends and contacts to attend.

COCKTAIL PARTY

Host a purple themed cocktail party! Ask your guests to wear purple. Serve purple cocktails. Take lots of pictures and post on social media. Explain how debilitating a spinal CSF leak can be and ask guests to spread awareness about the condition. Explain how donations are needed to help raise awareness, advance research, and improve testing and treatments.

BAKE SALE

Ask friends and family to provide baked goods for a bake sale to promote awareness of spinal CSF leak and to raise funds for the Spinal CSF Leak Foundation. Find a location at a community event, local store, or in conjunction with another event. Once you get permission for the event, be sure to publicize through print and social media and ask folks to donate baked goods. Explain how donations are needed to advance research and to help educate the medical community as well as the community at large.

SHARE YOUR IDEAS!

We'd love to hear from you about your event ideas! And once you host an event, of course we'd love to know how it event went. Feel free to contact us at staff@spinalcsfleak.org.

