

Choose an Approach

We have listed some ideas, but we encourage you to be creative and come up with something different. Feel free to contact us for help at staff@spinalcsfleak.org

Tell Your Story

Explain why you are supporting the Foundation. It might be your own personal story, or the story of a friend or family member who is suffering from a spinal CSF leak. Share how having a spinal CSF leak has impacted your daily life. Share how the Spinal CSF Foundation has made a positive impact for you and others dealing with a spinal CSF leak and how more research is needed to advance the understanding of the condition and improve testing and treatments.

Help spread the word so that others suffering from headaches that are worse when upright will consider asking their doctor if they might be suffering from a spinal CSF leak.

Spinal CSF leak is treatable and often curable with the right diagnosis and treatment.

Awareness Items

Ask us about awareness wristbands and temporary tattoos. Brochures can be downloaded for printing.

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:

- *Facebook, Twitter, Instagram etc.*
Social media 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 the Spinal CSF Leak Foundation Facebook page.
Use: #spinalCSFleak #uprightheadache
- *Email*
Although social media is very effective, a more personal approach via email can often be more 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, wristbands and/or temporary tattoos, if using.
- 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.
- Plan for photos - Ask your volunteers to take lots of photos. Ask participants to wear purple, take pictures and selfies and share them on social media and post on Facebook. Post your photos on our Spinal CSF Leak Foundation Facebook page.

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:
Lisa Perryman, Treasurer
Spinal CSF Leak Foundation
8840 North 7th Avenue
Phoenix, AZ 85021
- Cash Donations - Keep careful records about the money you collect. Obtain each donor's 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!

Use your imagination to make your event fun. Think outside the box. Help spread awareness about spinal CSF leak by letting people know your story and why raising awareness and/or funds is important to you.

Awareness and Fundraising Event Suggestions

We have included a list of ideas below, but we encourage you to be creative and come up with something different. To help raise awareness, take lots of photos, share them on social media and post them on the Spinal CSF Leak Foundation Facebook page. Email us at staff@spinalcsfleak.org for detailed guidance and a toolkit (talking points, brochures, wristbands, temporary tattoos).

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. Spinal CSF leak is curable for many patients with the right diagnosis and treatment. As a volunteer, 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 is 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 leakers get temporary relief from consuming caffeinated beverages. If you are not well enough to host, consider asking a friend to host one for you. Invite your friends and contacts. Tell them your story and distribute informational brochures and awareness wristbands. Think about using a purple theme. Ask your guests to wear purple and serve treats with purple icing. Ask them to post selfies and 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

This simple campaign is not really an event at all but a great way to raise funds and awareness with your friends and contacts without them having to fit another event into their busy schedules. Did you know that many spinal CSF leakers get temporary relief from caffeine? Use postal mail to send invitations to your family, friends and contacts. Include one of your favorite instant coffee packets or tea bags. Include your story and explain why you are raising awareness and fundraising for the Spinal CSF Leak Foundation. Ask your contacts to enjoy a cup of tea or coffee at their own convenience, read your story and consider making a donation to the Foundation.

Cups4Cures

Plan a hot chocolate and popcorn based event at home or in a high traffic area. Be creative and organize some fun activities. Provide information about spinal CSF leak to raise awareness and sell hot chocolate to raise funds.

5K Walk, Bike, or Run or 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 leak 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 and spinal CSF leak wristbands in your honor. Include brochures as part of the run package for every participant to raise awareness.

Talent Show

Host a Talent Show in honor of the Spinal CSF Leak Foundation. There is plenty of local talent out there and people just love to perform. Advertise in print and social media and explain that the entrance fees and donations will go to the Spinal CSF Leak Foundation.

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 or provide inexpensive purple Hawaiian leis. Serve purple cocktails, take lots of pictures and post on social media and our Spinal CSF Leak Foundation Facebook page. Explain how debilitating a spinal CSF leak can be and ask them to spread awareness about the condition. Explain how donations are needed to help raise awareness, advance research and improve testing and treatments.

Cupcakes for a Cure / 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.

Other ideas:

Cyclebar

Zumbathon

Skating party

Auction

Harvest Festival

Tournament (Golf, Bowling, Ping Pong etc., local or celebrity)

Movie Night (Outside or inside)

Battle of the Bands

Coupon Books

Challenge Collection (ex. Auburn vs Alabama)

At Home Fund Drive (watch movies, sports events and collect \$ at door)

Car Wash

Lemonade Stand

Paper Mobiles

Donation Drive Clothes Collection

Volley for a Cure (competition between school or work place)

Workplace or School Events: (Dress Down Day, Color Day, Sports Team Day)

Share Your Ideas

We would love to hear from you about your ideas and/or your events!

staff@spinalcsfleak.org