

CSF Chapter Agreement

This Chapter Agreement (the “Agreement”) is made on the _____ day of _____, 20_____ (the “Effective Date”) by the Chiari & Syringomyelia Foundation, Inc. (the “CSF”), a non-profit corporation organized in accordance with the laws of the State of New York, with national offices located at 29 Crest Loop, Staten Island, NY 10312 and the group located in the city and state of _____, _____ (the “Chapter”).

What This Agreement Means

When this Agreement is signed, CSF recognizes the Chapter as an **official CSF chapter**. Both CSF and the Chapter agree to raise awareness about Chiari malformation, syringomyelia and related disorders, as well as raise important funds to find better diagnosis, management and treatment options for patients. This signed contract grants the Chapter a license to use the CSF logo and brand, only under the stipulation that the Chapter agrees to follow the **terms and conditions** set forth below. **Thank you for becoming a leader and a beacon of support for the over one million families who are affected by these disorders!**

Terms & Conditions of Chapter Status

We (the Chapter representatives) understand and agree to the following terms and conditions:

The Chapter becomes an official CSF Chapter only **after a CSF representative (Board Member, Executive Director, Chapter Coordinator, etc.) has approved the Chapter’s status**. At that point the Chapter is considered an **official CSF Chapter**.

CSF claims ownership of its exclusive right, title and interest in its own **Intellectual Property and reputation**. The Chapter must acknowledge and agree to protect this right from its own members and from third parties. If you learn of any activity that may constitute unauthorized use or infringement, please notify CSF’s national offices immediately.

Use of CSF Logo(s), Names and Trademarks

- You may use, reproduce, distribute and display CSF Logo(s) to promote local events, services and activities in your local area
- You may NOT use CSF Logo(s) or name if it appears that CSF is endorsing any product, enterprise, project etc. (personal or public) without the *explicit written consent* of CSF

- When CSF Logo(s) are used in advertising, promotional and educational materials produced, you must include ® or ™ to indicate CSF's Intellectual Property over its trademark.
- The official Chapter Representative is entitled to receive CSF business cards *only after raising \$100 for the organization*; these cards will specifically state that you are a uncompensated volunteer

Any membership list or information provided by CSF National offices to the Chapter is deemed strictly confidential, is not for distribution and can only be used with the express consent of CSF. Violation of this is subject to termination of Chapter status and possible legal action.

The Chapter must operate in compliance with the laws and regulations of the state of incorporation (New York); the Chapter's activities will be monitored by CSF. CSF will handle all state status filings required of the Chapter.

To accept the position of Chapter Representative the CSF Board of Directors (BOD) asks that this person organize events exclusively for CSF. This does not prohibit Chapter members from attending other organizations' events, however, it is strongly recommended that CSF events are given priority.

CSF can terminate the Chapter's status at *any time* if the Chapter or members of the Chapter have been found to disregard the terms and conditions of this Agreement. Please see the section below ("What the Chapter Can NOT Do") to take steps and avoid any unnecessary termination.

Chiari & Syringomyelia Foundation

Chapter's Roles & Responsibilities

** - Indicates the minimum requirement for the Chapter in order to have an active status.

* - Indicates the minimum that each Chapter can choose to work on

SUPPORT

1. Obtain contact information (NAME, ADDRESS, PHONE & EMAIL) of local members and send to national office via email to info@csfinfo.org. This information must be sent **immediately upon receipt of the phone call/email. **This is **identifiable information** and must therefore be treated with extreme care and confidentiality.

2. You must establish and maintain a positive organizational image and identity at all times. These disorders are tough... so we need to be tougher!

3. Designate 2-3 representative(s) as the local contact person(s) to provide emotional support for the Chapter and surrounding areas. The representative(s) must agree to have his/her/their phone and email available on the CSF website and local Chapter materials. They should also encourage them to participate in group activities to help grow the local community and increase support.

4. **Host three or more support group meetings and/or social gatherings per year.** A good rule of thumb is to start by hosting a support group meeting at the library, a local restaurant, a coffee shop, etc. and you will begin to build a community of friends. Once the community starts to grow, more social events can be planned. Some examples include: bowling, movie nights, dinner at a local restaurant, etc. By having more fun, Chapter members will become closer emotionally, which can help each individual begin to feel better, too!

FUNDRAISING

- *1. **Participate in a fundraiser for CSF.** These fundraisers can be as few as one or two, or as many as 50 or more! CSF hosts several fundraising campaigns throughout the year (i.e. – every September CSF hosts the Crush Chiari/Smash Syringomyelia campaign). You can work with CSF’s national offices to come up with your own fun ideas.
2. **Participate in the unite@night walks,** either through a group walk or a solo walk. Contact Cathy Poznik for more information on how to participate.
3. **Plan a fun community fundraiser—** set up a lemonade stand, a restaurant fundraiser, or anything else you may think of! You can find some fun ideas to spark your creativity under “Other Fundraising Ideas” at the end of this packet.
4. **Get sponsored as a runner or athlete!** If you’re training to run a marathon or compete in a race, triathlon, Cross-Fit competition, Tough Mudder, etc., you can set up your own personal fundraiser by contacting info@csfinfo.org to help make a difference!
5. **Consider also participating in CSF-sponsored fundraising events.** CSF hosts a few special events annually, including the Bobby Jones Classic for CSF in Atlanta, GA, the Dinner Dance for a Cure in Twinsburg, OH and several others. Tickets are available for attendance online, or by contacting info@csfinfo.org for more information.

EDUCATION

- *1. **Provide local members with CSF approved materials for patient education, advocacy information, etc.** This can be as simple as directing members to CSF’s website. Most, if not all, of these materials can be found on the CSF website at csfinfo.org. You can also have members contact the Chapter Coordinator, directly.
- *2. **If an educational lecture is scheduled, ensure all speakers and attendees at local educational lectures sign release agreements that acknowledge that the lecture will be videotaped** so that every single lecture CSF hosts can be made available for people around the world to share.

3. **The Chapter should host local educational lectures arranged by CSF national offices.** These lectures should be attended by as many Chapter members as possible; but other non-members should be invited as well to spread awareness!
4. **Become more involved in community programs to spread the reach of awareness.** For example, you can attend and participate in local health fairs, community events, etc. to educate more people who may have never heard of these disorders.

ADVOCACY

1. **Host an “advocacy day” with your Chapter’s local members.** Get together to write letters and make phone calls to your local representatives and share your own personal stories with one another. CSF will be able to provide sample letters, scripts for phone calls, etc.
2. **Participate in CSF’s unite@thehill.** Use the letters written during the advocacy day(s) you have hosted, or simply collect letters and CSF representatives will walk these letters to Capitol Hill. You can also physically attend the unite@thehill by contacting the Chapter Coordinator for more information.

ADMINISTRATION

- *1. **Protect the Intellectual Property and reputation of CSF from third parties or even Chapter members who are infringing on CSF’s rights and/or name.** By agreeing to respect the CSF name and image, you support the hard work that is done by CSF board members, staff-persons and extremely dedicated volunteers who seek to advance the Mission and improve education, awareness, and health outcomes for patients.
2. **If you so choose, the Chapter can set up a formal Chapter committee** to help organize and implement any Chapter activities and events. This will help you work better together, as a community!

Basic Rules & Regulations

WHAT THE CHAPTER CAN NOT DO.

In order to avoid unnecessary termination of your Chapter status, please refrain from the following activities. If you are ever unsure whether or not your Chapter or your Chapter members’ activities are outside the rules set forth in this Agreement, please call the Chapter Coordinator (Cathy Poznik) at 330-998-6195 or email at cpoznik@csfinfo.org.

You may not share any information or membership list. While you are required to capture contact information for CSF’s national offices, you may *never* distribute any person’s contact information to *anyone or any group*. Any addresses, phone numbers, emails, etc. that individuals provide to CSF through you is considered highly identifiable information and therefore must be protected as confidential information.

While at CSF-sanctioned events or posting about CSF-sanctioned events on social media or in print, you may not distribute any awareness, education or advocacy materials that are not created by CSF. However, you may distribute materials not created by CSF at other events or online for other purposes or organizations, if you would like.

You may not set up checking accounts in CSF's name. All banking *must* go through CSF's national offices. Should you need small amounts of financing for CSF-related activities (i.e. – unite@night walk expenses) or reimbursement, please fill out the **Request for Payment Form** available at the end of this Agreement and online and submit to the Chapter Coordinator.

You may not provide patients with any medical advice. CSF must remain a neutral body for informational purposes, only. Any advice you give to members of your Chapter or your support group must be based on your personal opinion. By recommending doctors, medical procedures, surgeries, etc., you will put your own legal status, as well as CSF's legal status, at-risk and your Chapter will be immediately terminated.

You may not recommend any particular physician to patients. CSF must not endorse one physician and his/her practice over another's. By recommending one particular physician, you will have endorsed their practice using CSF's name and will have directly violated this Agreement ("Use of CSF Logo(s), Names & Trademarks").

You may not deter patients from seeing any particular physician, either. While CSF does not endorse one physician over another, it also may not legally impede that physician's practice. By recommending that a patient not see one particular physician, you pose a great psychological danger to the patient or his/her loved one who is seeking medical guidance. Such fear mongering will not be tolerated.

Chapter Agreement & Non-Disclosure Agreement

Any membership lists or personal information provided by CSF National or private individuals to the Chapter is deemed *confidential*, is *not* for distribution and can only be used with the express consent of CSF, Inc. By signing this form, I understand that **violation of the privacy of CSF membership lists may subject me to legal action.**

Chiari & Syringomyelia Foundation _____ Chapter
Please provide *at least (1)* Chapter Representatives' contact information.

*Print Name: _____

*Signature: _____ *Date: _____

*Address: _____

*City: _____ *State: _____ *Zip: _____

*Phone Number: _____

*Email: _____

By signing this Agreement on behalf of the Chapter, I acknowledge that I have read and understood the terms of this Agreement and the relationship contemplated by this Agreement, and I sign the Agreement with the intent to legally bind the Chapter by this Agreement.
