

BRAIN ANEURYSM SUPPORT GROUPS

A MANUAL FOR HEALTHCARE PROVIDERS



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FOUNDATION**

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OUR MISSION

Provide information about and raise awareness of the symptoms and risk factors of brain aneurysms to prevent ruptures and subsequent death and disability.

Work with medical communities to provide support networks for patients and families.

Advance research to improve patients' outcomes and save lives.



Founded in 1994, the Brain Aneurysm Foundation is the globally recognized leader in brain aneurysm awareness, education, support, advocacy, and research funding. As part of our mission, the Brain Aneurysm Foundation has several support groups throughout the United States and Canada.

If you are interested in starting a support group at your hospital, this brochure will guide you through the process. We are also available to answer questions and provide one-on-one help and additional resources.

WHY START A BRAIN ANEURYSM FOUNDATION SUPPORT GROUP?

A support group provides a continuum of care for your patients, providing vital support to them, their families, and other loved ones throughout their recovery. Partnering with the Brain Aneurysm Foundation to establish a support group provides you with a wide range of resources that will help ensure that your group successfully meets the needs of your patients.

As you know, a change in health can be extremely stressful, affecting a person's personal, social, and professional life. Support groups help reduce the negative impact of illness by:

- Letting people know they are not alone and that others understand what they are going through.
- Providing a confidential setting where members can share emotions, experiences, and challenges with others in similar circumstances.
- Providing a forum for solving problems and sharing ideas.
- Providing reliable health information, reasonable expectations for recovery, and resources.
- Enabling healthcare professionals to educate patients — and for patients to educate healthcare professionals — about their experiences.
- Helping patients find appropriate resources.

REQUIREMENTS TO ESTABLISH A BRAIN ANEURYSM FOUNDATION SUPPORT GROUP

- Meetings must be led by a healthcare provider, and whenever possible held at a healthcare facility.
- Meetings should be held on a regular basis — ideally monthly.
- Leaders must collaborate with the Brain Aneurysm Foundation to ensure that information provided to patients is current and accurate.



THE ELEMENTS OF A SUCCESSFUL SUPPORT GROUP

Meeting Topics

Each meeting should have a topic. Topics can range from a formal educational component consisting of a guest speaker or audiovisual presentation to an open discussion. As mentioned before, the critical element of every meeting is that it is facilitated by a healthcare provider.

Resources for Topics

The Brain Aneurysm Foundation website, bafound.org, lists a number of important topics related to brain aneurysm diagnosis, treatment, and recovery. Also see page 11 of this brochure for topic ideas. You can recruit guest speakers from your or other healthcare facilities — for example, neurosurgeons, neurologists, interventional radiologists, rehabilitation therapists, nurses, and social workers/counselors — or other local professionals such as attorneys.



We recommend establishing the topics for the calendar year to give guest speakers plenty of notice and members something to look forward to. If there is a last-minute guest speaker cancellation, patients often appreciate an open discussion of their concerns, or you might consider viewing a Brain Aneurysm Foundation webinar followed by a discussion.



Meeting Length/Format

The ideal meeting length is typically 90 minutes, which allows for some socializing at the beginning and end of every meeting. Following is a typical meeting format:

- 15 minutes:** An update by the facilitator with news from the Brain Aneurysm Foundation, including all upcoming webinars and events.
- 30 minutes:** The formal educational session (best to limit this to 30 minutes).
- 30 minutes:** Opportunity for questions and discussion among group members.

Refreshments

Any meeting goes better with some food; consider providing some light refreshments at your meetings. Many hospitals will provide coffee/tea and cookies free-of-charge, or you could ask local merchants for donations, noting that you will acknowledge their generosity at the meeting.

Advice and Help

Keep in mind that facilitating a support group is a learned skill. Please contact office@bafound.org if you would like to talk with an experienced support group leader for advice and help.

Try not to be discouraged if things don't always go perfectly — everyone who has been affected by a brain aneurysm knows that life does not always go according to plan! The most important thing to remember is that the people who attend meetings are very grateful that you are there, that you care about them, and understand what they are struggling with. You will find that this is a personally gratifying experience, and will soon have very loyal and committed participants who will help build and maintain the momentum of your group.

HOW TO START A SUPPORT GROUP

Support Group Leadership Team

You should have a group of two to three individuals committed to running the group for the first year. The model that works best is a neurosurgeon or neurologist and nurses who are familiar with the patients and their families. One person should be designated as the main point of contact with the Brain Aneurysm Foundation. All three should share the responsibility of facilitating the meetings.

Group Type

The optimal model is a long-term group with open membership. Brain aneurysm recovery is a long-term process, and ongoing attendance can be beneficial, as members who are further along in their recovery can help support those who are in earlier stages.





Group Members

Anyone who is affected by a brain aneurysm should be welcomed at any stage of their diagnosis, treatment, and recovery. This includes individuals with ruptured and unruptured brain aneurysms, their family members, friends, and other supporters. You may want to open the meeting to people with vascular malformations, such as arteriovenous malformation (AVM), whose risks are similar to those with a brain aneurysm.

Meeting Times and Locations

Decide on a time and place for your meetings that works well for the support group leadership team, especially the lead facilitator. We recommend a regular schedule: for example, the first Monday afternoon of each month. Monthly meetings work best, as groups that meet less frequently tend to have lower attendance. Meetings should take place at the same time of day, and in the same location. Select a location that is handicapped accessible, and preferably at a hospital or other healthcare facility. Be sure there is adequate parking and/or access to public transportation.

SUGGESTED TOPICS FOR MEETINGS

The following are suggested topics for group meetings; visit our website, bafound.org, for detailed information.

When a speaker with expertise in a specific topic is not available or you have a last-minute cancellation, our many informative webinars are a great resource. You can access them from our website, and facilitate a discussion following the presentation.



Scan the QR code to view webinars on the Brain Aneurysm Foundation website

Brain Aneurysm Basics

- Definitions of aneurysms, differentiate between cerebral and extracranial (i.e., AAA), risk factors, family history information, some general brain aneurysm statistics (incidence, gender, age, cost, size, multiple BAs)
- Diagnostics (CT, MR, conventional angio), risks/benefits and rationale for each
- Treatment options (coil, clip, flow diversion, observation), risks/benefits and rationale or indications for each
- Risk of untreated or undiagnosed aneurysm (SAH, stroke, cranial nerve impairments)

Treatments for Brain Aneurysms

- Detailed discussion of coiling, clipping, stenting, bypass/occlusion (to a lesser degree), and observation
- Information on pre-procedure prep, any medications specific to procedure (i.e., Plavix), typical hospital stay and recovery period
- Follow-up surveillance methods (MR, CT) and typical time frames



Subarachnoid Hemorrhage (SAH)

- Definition
- Aneurysmal, spontaneous, traumatic SAH
- Signs and symptoms
- Urgency of treatment
- Mortality/morbidity
- Sequelae: vasospasm, re-bleed, seizure, hydrocephalus, headache syndromes, cognitive impairments

Recovery: Symptoms and Management

- Memory/attention
- Fatigue
- Motor/sensory/perceptual impairments
- Depression (patients and caregivers)
- Post-SAH medications: anti-seizure meds, antiplatelet therapies — rationale and side effects/management
- Post-SAH headaches
- Time frame of recovery

Recovery/Rehabilitation

- Rehabilitation therapies
- Length of rehabilitation, rehabilitation activities, adaptive equipment
- Community resources for adaptive equipment
- Selection of rehabilitation providers
- Vocational rehabilitation
- Returning to work; advocating for work alternatives, etc.

Finances/Legal

We recommend inviting a social worker and/or an estate/employment law professional to present this discussion.

- Family and Medical Leave Act (FMLA) and its role in employment protection
- Accessing short- or long-term disability (STD/LTD) through an employer
- Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI)
- Inpatient/outpatient coverages and policies
- Respite care, community supports
- Long Term Care (LTC) insurance
- Advance directives/Durable Power of Attorney for Health Care (DPOA-HC) and their importance

Psychosocial Aspects of Recovery

You may want to consider breakout sessions for caregivers and patients to meet and support each other separately.

- Depression, anxiety: symptoms and treatment options (counseling, peer support, medication)
- Caregiver support; how to arrange for caregiving
- Learning to ask for and receive help
- Resuming social roles: communication, compensatory techniques in social situations

GETTING THE WORD OUT

There are many ways to get the word out about your support group, and we will help.

What You Can Do

- Contact the Brain Aneurysm Foundation at: office@bafound.org.
- Provide the meeting dates, locations, and contact person for meetings in an e-form that we will provide to you.
- Ask nurses, physicians, and practice managers in your healthcare facility to encourage patients and families to attend.
- From your website, create a link to our website (bafound.org) and to your support group's page on our website.
- Send flyers and postcards (see "How We Can Help") to healthcare providers in your area. Neurosurgery and neurology practices, hospitals, and medical practices may be willing to post this information.
- Some hospitals list support group meetings on their website – contact your facility's Communications Department and provide them with the details.
- Share the information with your own healthcare providers, as they may post flyers in their offices.
- Send a short press release or a Public Service Announcement (PSA) to the calendar or health editor of community newspapers and local radio and TV stations.
- At each meeting, encourage members to talk about meetings and invite others who may benefit. Be sure to have a few flyers available for members to take with them/share with others.

How We Can Help

- We will post the information about your group on our website, bafound.org, and will create a page specifically for your group.
- We will announce and promote the group through social media ([Facebook](#), [Instagram](#), [Twitter](#), and [LinkedIn](#)) and our online support community, as well as send an e-mail from our database to people who live in your area.
- We will provide you with a flyer and postcard template to promote your group.





BRAIN ANEURYSM FOUNDATION

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