



**NIEKRO ANEURYSM  
& AVM FOUNDATION**

# NIEKRO ANEURYSM & AVM FOUNDATION

## Support Group Handbook



The Niekro Aneurysm & AVM Foundation was established in 2008 in honor of Joe Niekro who lost his life from a sudden cerebral brain aneurysm on October 27, 2006. The astonishing lack of public awareness and research of such a widespread and often fatal condition led to the launch of a crusade to support research and the treatment of Brain Aneurysms, AVMs (Arteriovenous Malformations) and Hemorrhagic Strokes. Our goal is to raise awareness about the risk factors, causes and treatments of these conditions, while helping support the advancement of neurological research. We provide public education and advocacy, support for patients and families, and develop awareness programs and educational materials for hospitals, clinics and other institutions nationwide.

A strong support network is critical in the adjustment of living as a Brain Aneurysm, AVM or Hemorrhagic Stroke survivor. Niekro Foundation support groups provide a welcome safe haven for patients, families, friends and caregivers to come together and share their fears, challenges, successes and failures in an atmosphere where they are loved and accepted.

I want to personally thank you for your willingness to facilitate a Niekro Foundation Support Group in your area! Social support is essential to the recovery process and social isolation can greatly reduce patient recovery and outcomes after suffering a Brain Aneurysm/AVM/Hemorrhagic Stroke. Many hospitals are not equipped to offer patients and families the ongoing support and rehabilitation post discharge needed in their recovery. It is our goal, with help from volunteers like you, to help bridge the gap and encourage collaboration to provide a comprehensive support program for survivors and their families.

Survivors have the opportunity to meet and learn from other survivors who have experienced similar issues and understand. Survivors, their friends and family learn to deal with the isolation, powerlessness, and alienation and discover how to live again from those who know the journey best.

Thank you,

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## **WHY START A NIEKRO FOUNDATION BRAIN ANEURYSM / AVM / HEMORRHAGIC STROKE SUPPORT GROUP?**

Social support is essential to the recovery process; social isolation can greatly reduce patient recovery and outcomes after suffering a Brain Aneurysm/AVM/Hemorrhagic Stroke. Many hospitals are not equipped to offer patients and families ongoing support and rehabilitation post discharge. It is our goal to help bridge the gap and encourage collaboration to provide a comprehensive support program for survivors and their families.

Our meetings address issues such as depression, social reintegration, coping with disabilities, nutritional brainpower, exercising your brain and much more. The Niekro Foundation empowers members by offering educational information and emotional support; promoting good health and an improved quality of life. Support group members learn what to expect during their healing process and discover new coping strategies through shared personal experiences. Members have access to healthcare professionals and other survivors. The Niekro Aneurysm & AVM Foundation Support Groups help establish social networks that play a vital role for both survivor and family members by providing emotional and moral support. Our mission with these support groups is to help others realize that recovery is possible! The program is designed to motivate members to follow a wellness plan and to make a difference in the community, while creating a forum of mutual acceptance, understanding and self-discovery.

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# **NIEKRO ANEURYSM & AVM FOUNDATION SUPPORT GROUP HANDBOOK**

## **How to Start and Manage a Support Group**

What does it take to start a Niekro Foundation support group?

- One active enthusiast (or more) to facilitate.
- Use your enthusiasm to recruit other interested people.
- Support Group flyers (provided by the Niekro Foundation and customized with your meeting information and contact information: name, phone number, email, etc.).
- A set meeting location, date and time.
- A passion for helping others.

How do you find the right people?

The Niekro Foundation's Brain Aneurysm/AVM/Hemorrhagic Stroke Support Groups are typically started by one or two individuals but can certainly include as many willing enthusiasts as you like to get the ball rolling. Getting the assistance of those who have experienced a Brain Aneurysm/AVM/Hemorrhagic Stroke, family members, physicians, hospital and rehabilitation professionals and counselors will be an invaluable resource.

## **Find a Meeting Place and Time**

Quite a few places have meeting rooms available for nonprofit community events and are very approachable for good causes. Start by contacting local hospitals, libraries, churches, schools, community centers, senior centers and service clubs.

Remember to consider the accessibility of your meeting place—check doorways, aisles in the meeting room and parking for accessibility.

- Set a time and date for the meeting (Survivors prefer to have monthly meetings).
- Host the support meeting on the same night and time every month (i.e - the 1<sup>st</sup> Thursday of every month.)
- Weeknight support groups have the highest attendance for meetings.



## **Publicize the Support Group**

- Contact the local hospitals with neurosurgery or neurology departments to make sure they know about the group and ask them to put your flyer in one of their mailings.
- The Niekro Foundation will provide you with flyers you can post in hospitals, rehabilitation centers and facilities, neurosurgery departments/offices, Psychiatrist and Family doctor's offices. If you can get to the nurse practitioner or the doctor, that would be ideal, but if not, ask the receptionist if they will pass one along to the doctor and keep one on file. And if you happen to spot a bulletin board, stick one on there.
- Local newspapers/community newspapers - most of them have a "good causes" section for freebie announcements. Many community or city papers are free to non-profits to advertise.
- Town/city event calendars - contact city hall and your local Chamber of Commerce.
- Senior Citizen buildings - check with the building manager for in-house newsletters.
- Local TV/Community Cable TV/radio stations - community announcements, talk show hosts, newsroom, PSA's, submit press releases to their community relations team for possible coverage.
- Local TV/Community Cable TV/radio stations - each have community calendars on their websites, which allow visitors to post events.
- Consider doing a public service announcement for radio or television—call them for guidelines.
- Post notices on bulletin boards in supermarkets, at libraries, community centers and convenience stores. Always ask permission from management before posting a notice in a public place.
- Ask group members to take a few flyers to put up around their neighborhood to spread the word. They can give one to their family doctor, dentist, etc. the next time they have an appointment.
- Encourage group members to talk to other people they run into about their Brain Aneurysm/AVM/Hemorrhagic Stroke.

**MOST IMPORTANTLY**, remember to repeat the above list every year (or more frequently) as flyers have a tendency to end up as scratch paper, especially in doctors' offices. It is also nice to remind the medical staff who you are and that the support group is meeting regularly.

On the flyers, list information such as a contact person, email address, and telephone number; the time, date and location of support group meetings, and a description of the group's purpose.



## The First Meeting

- Chairs should be arranged in a circle, avoid a lecture set-up.
- Have a **welcome/sign in table** set up with a greeter to hand out literature or brochures.
- Facilitator introduction. Facilitators should consider withholding their personal story until about the 3<sup>rd</sup> meeting in. Let the meeting be about the other survivors and caregivers.
- Introduction of The Niekro Aneurysm & AVM Foundation™ and background story of the foundation.
- Share Niekro Foundation Newcomer Folders.
- Use icebreakers to help participants become comfortable with each other.
- Ask members to introduce themselves as either a survivor or caregiver.
- Ask members to give their date of surgery or procedure and the name of their doctor.

*Please make sure to maintain control during this time period. It is not unusual for members to want to take over the floor and tell their personal stories. Politely remind members the Break-Out Sessions are reserved for personal experiences.*

- Clarify your guidelines: respect, acceptance, confidentiality, etc. Please read in the beginning of all meetings “The Most Successful Brain Aneurysm/AVM/Hemorrhagic Stroke Support Groups Are Not” (listed below).
- Listen and support group members without criticizing or passing judgment
- Respect each member’s personal situation.
- This is the best time to check and see what the members want from the group and make a list.
- Stick to a schedule - start and end on time to avoid people becoming frustrated or getting up and leaving. Even when the meeting is going great, people need to get home at a reliable time.
- Guest Speakers are normally reserved for the first half of each support group. Please ask members to reserve all questions towards the end and allow the guest speaker the floor.
- The second half of the Niekro Foundation Support Group is reserved for the **Break-Out Sessions (BOS)**. Survivors and caregivers are separated from one another and given distinct discussion periods. This time is reserved for every member of the family to get the much-needed peer to peer support. The BOS are the time periods when members can share their personal experiences and exchange ideas to help learn how to navigate through the recovery period. Encourage members to discuss and share their stories. Encourage the caregivers to discuss their challenges, fears, successes, etc.
- At the end of every meeting please thank all members for taking the time to come to the Niekro Foundation Brain Aneurysm/AVM/Hemorrhagic Stroke Support Group. Go over the line up of scheduled guest speakers for the up and coming months.



*Here's how you can keep it **SIMPLE** during the Niekro Foundation Support Group:*

**Supportive** - Ask caring questions; listen attentively to the answers.

**Inspirational** - Reassure others that life gets better.

**Motivational** - Encourage action and acknowledge improvement.

**Practical** - Offer options, helpful tips and resource information.

**Life-affirming** - Avoid comparing Brain Aneurysm/AVM/Hemorrhagic Stroke stories; don't deny, judge, or devalue the feelings of others. This creates a safe environment for members to disclose their problems.

**Educational** - Talk about what's worked for you and others; make suggestions, don't give medical advice

## **Maintaining the Group**

- Rotate tasks and responsibilities among group members.
- Develop a network of peers and professionals for support.
- Stick to a schedule - start and end on time to avoid people becoming frustrated or getting up and leaving. Even when the meeting is going great, people need to get home at a reliable time.

Keeping a support group going is challenging but rewarding. The group dynamic is between people, who may be very different, but all share similar hurdles and other obstacles to overcome. Patients will be at various stages of recovery (or lack thereof), and these differences can make it difficult to meet everyone's needs. But these differences are what make the group richer by providing diverse perspectives.

The general attitude should be one of mutual support. That may sound obvious, but it is very common to feel a need to justify our pain by minimizing that of others. Often patients come to NIEKRO FOUNDATION Support Groups after years of trying to navigate through the recovery system by themselves, and their suffering may not have been taken very seriously in the past. Many want to say, "My pain is so much worse than yours!" It is important to remember that we can't measure the pain of a Brain Aneurysm/AVM/Hemorrhagic Stroke or the quantity of damage. Everyone at a support group meeting has chosen to give up his or her free time to be there; which says a great deal about what they have all been through and their continued struggles. As a facilitator, make sure all attendees have the opportunity to be heard and share.



## What Makes a Good Support Group?

- The sharing of up-to-date, reliable information.
- Prompt response to contacts.
- Regular meetings.
- Access to appropriate professional advisors (i.e., doctors, physical therapists, nurses, etc.).
- Links to healthcare providers and financial assistance.

## The Most Successful Brain Aneurysm/AVM/Hemorrhagic Stroke Support Groups Are Not:

**They're not a pity party.** It's a place where survivors and caregivers can offer and share honest feelings and frustrations and work toward solutions.

**They're not a place to lash out.** Don't allow an upset or angry person to disrupt or dominate the group discussion. The leader or facilitator could pre-arrange to have an assistant present to help diffuse these situations. He or she could quietly ask the disruptive person to come with them into the next room, or outside, so they can calm down.

**They're not just social events.** A group that focuses only on social activities limits its opportunity to better the lives of its members.

**They're not a church or synagogue.** A group that brings any type of religious beliefs or practice into their meetings will ostracize current and potential members. The support groups are not a place for any type of practice or expressed views of religious beliefs.

**They're not a soap-box for political views.** The meetings are not a place for views on politics to be expressed or literature to be shared.

**They're not free clinics.** It's not uncommon in a medical-based support group to have a member who is very attention-seeking, using their personal story to keep the group attention focused on them. These types of situations are very prevalent when a medical staff member is the guest speaker. Redirect conversations from a personal agenda to the group agenda by politely interrupting with something like "I'm glad you brought vasospasms up. Anyone else have vasospasms?" Simply to explain that it is a NIEKRO FOUNDATION Policy that all comments or questions pertaining to personal cases are not allowed while a guest speaker has the floor.

## Stay in Touch

- Communicate regularly with your group members via the telephone or email.
- Consider calling or emailing members to remind them a few days before the meeting. If needed, the Niekro Foundation can provide an email template for you to send out monthly with the upcoming meeting information.
- Maintaining a Facebook page is an excellent way to communicate with group members.





## Ways to Keep Your Support Group Strong

- Meet on a regular basis in a central location.
- Offer topics that are appropriate for a wide variety of ages.
- Structure the group's responsibilities so that they are divided among a group of people.
- Remember to send out email blasts to remind all members about the meeting. Reminders should be sent out one week ahead of the meeting.

## Things to Expect at Meetings

- People might be uncomfortable being there, uncomfortable because they don't want anyone to know they're there. Suggest they talk to their spouse or significant others and share their difficulties. Doing it alone is not the most efficient path to recovery.
- Meeting others with a Brain Aneurysm/AVM/Hemorrhagic Stroke face-to-face can be a powerful and emotional experience and it is not uncommon for newcomers to get emotional during their first meeting.
- Marketers. There are people who go from support group to support group to hustle health items: pills, supplements and all kinds of wonderful junk they stand to make money on. They could be selling it themselves, for someone else, or handing out business cards. The Niekro Aneurysm & AVM Foundation does not welcome marketers.
- People monopolizing the floor with their personal story. Facilitators need to be sure that there is an opportunity for everyone to speak at some point throughout the meeting.
- "People only show up for one or two meetings and you'll never see them again..." Two ways of looking at it: 1) you're doing a terrible job, or 2) you're doing a fabulous job! With support groups it is not uncommon for attendance to go up and down. Some people find that after attending a couple of meetings they are no longer in need of a support group. Think of this as a pat on the back for a job well done; a person has graduated from the group and moved on with life.

## Guest Speakers

It's always a treat to have someone attend and run the show. Who might you approach to invite to be a guest speaker?

- Doctors, especially neurosurgeons/neurologists - they can explain the latest developments
- Endovascular Doctors - have them showcase the devices
- Psychologists - they can teach relaxation, talk about cognitive therapy, etc.
- Relaxation specialists - A hypnotist, Yoga instructor, chiropractor, Feng Shui or reflexology expert: any of these experts can show you how to properly relax



- Stroke Coordinators
- Surgical nurse or research nurse
- Neuro-psychiatrist to discuss survivor depression or anxiety
- Ask doctors to do a “field trip” through the operating room or endovascular suite
- Chefs can give cooking demos on brain food

## **Motivational Speakers**

Be careful about inviting people who have something to sell, whether products or services. Make it clear they are not invited to harvest new customers. If they have something to offer that you, or your group, find interesting or beneficial discuss beforehand a possible donation to The Niekro Aneurysm & AVM Foundation™.

## **Sample Discussion Topics for Caregivers**

- Responsibilities and rewards of caregiving
- How to handle day-to-day problems
- Information on community and support services
- Self-advocacy
- Effects of change and loss on marital and family relationships
- Learning about health boundaries
- Warning signs of caregiver stress
- Ways to relieve caregiver stress
- Taking care of yourself
- What to say and do when you can no longer be a full-time or part-time caregiver
- Long distance caregiving
- Coping with your feelings
- Dealing with grief and moving on
- Facing the day when placement in long-term care is a necessity

## **Sample Discussion Topics for Survivors**

- Goal setting
- How to handle the day-to-day problems of deficits
- Effects of change and loss of friendships
- Learning to set up boundaries
- Taking care of yourself
- Coping with your feelings
- Anxiety
- Depression
- Spreading the Word: Brain Aneurysm/AVM/Hemorrhagic Stroke Awareness



## **Frustrations**

After having done all the work for the support group and only 2 or 3 people show up to the meeting you will find yourself feeling frustrated. Positive spin: since there are only a few members it gives you a chance to really talk to them and reach a little deeper than in a sold-out house. You can also utilize the low turnout by focusing more on the few that are there. Can they help to promote the group? Do they have suggestions? It could be that low turnouts are common for your area. Besides, even if you reach only one person, you've reached one more than had you not tried at all - pat yourself on the back for doing a great job!

## **Literature/Handouts**

Try to keep up a supply of pamphlets, copies of articles, etc. for people to take home. The Niekro Aneurysm & AVM Foundation will supply you with Newcomer Folders and inserts to give to every new group member at each meeting.

## **Personal Sanity**

- Avoid burnout
- Ask for help within the group. It helps to have more than one person sharing the work of publicity, facilitation, problem solving, outreach, etc.

## **Continuity**

Many times when someone learns about your group, from one of your flyers or by word of mouth, the contact info gets put in a wallet and can stay there for many months before it gets rediscovered. It might get tucked away until someone gathers up the courage to call you, or until a more convenient time. It is best to keep the meetings at the same time and at the same place, and try NOT to change your contact phone number or email.

## **After the Group Grows How Can Volunteers Help?**

- Timekeeper
- Contact person
- Refreshment coordinator
- Greeter
- Information/publicity
- “Reminders” - volunteers to phone and email participants of meeting dates and activities
- Meeting leaders #1 and #2



**Quarterly Survey for The Niekro Aneurysm & AVM Foundation  
Brain Aneurysm/AVM/Hemorrhagic Stroke Support Group**

**YOUR OPINION COUNTS!**

We are interested in knowing what you think. All responses are entirely anonymous. Thank you for taking the time to complete this survey.

Location: \_\_\_\_\_ Date: \_\_\_\_\_

- 1) What brought you to this support group?
- 2) How did you hear about this support group?
- 3) Is this the right group for you? Does it address your concerns?
- 4) Are you deriving benefit from the group?
- 5) What has contributed to making the meeting better?
- 6) Is the meeting content relevant to your needs?
- 7) Have your needs changed?
- 8) Do you feel comfortable sharing your feelings within the group?
- 9) Does the facilitator maintain control of the meeting or do meetings lose focus, leaving you frustrated?
- 10) Are you satisfied with the facilitator's level of participation in the group?
- 11) Are you satisfied with the conduct of the group?
- 12) Is the meeting schedule adequate for you?



- 13) Is the meeting location convenient and accessible?
- 14) Would you like to see activities planned outside of these meetings?
- 15) Do you need to meet face to face with others?
- 16) Would telephone or online support suffice?
- 17) How will the group publicize its availability to potential new members?
- 18) Please give 3 suggestions on the type of guest speakers you would like to hear.

**Suggestions:**

**Comments:**



**The Niekro Aneurysm & AVM Foundation  
Brain Aneurysm/AVM/Hemorrhagic Stroke Support Group  
Sign In Sheet**

**Location** \_\_\_\_\_ **Date** \_\_\_\_\_

\*Please Print Clearly

Name \_\_\_\_\_

Telephone Number- (H) \_\_\_\_\_ (Cell) \_\_\_\_\_

Address \_\_\_\_\_ First Visit- Y/N

\_\_\_\_\_ Date of Birth- \_\_\_\_\_

Email \_\_\_\_\_

Name \_\_\_\_\_

Telephone Number- (H) \_\_\_\_\_ (Cell) \_\_\_\_\_

Address \_\_\_\_\_ First Visit- Y/N

\_\_\_\_\_ Date of Birth- \_\_\_\_\_

Email \_\_\_\_\_

Name \_\_\_\_\_

Telephone Number- (H) \_\_\_\_\_ (Cell) \_\_\_\_\_

Address \_\_\_\_\_

\_\_\_\_\_ First Visit- Y/N

\_\_\_\_\_ Date of Birth- \_\_\_\_\_

Email \_\_\_\_\_