



# Support Group Guidebook

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Brain Injury Association of New York State

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**THE VOICE OF BRAIN INJURY**

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## INTRODUCTION

### What is a Support Group?

The purpose of a support group is to provide an environment in which attendees can share emotions and experiences and support one another for the mutual benefit of the total group. Some elements of support groups include:

- Sharing feelings
- Listening and responding to the needs of fellow group attendees
- Accepting the needs of fellow group members
- Giving and receiving the opportunity to be understood
- Providing a space where positive and negative views can be expressed without judgment or labels
- An opportunity to understand oneself

A successful support group is one where the individual attendees feel emotionally supported, provide support to other attendees, receive information that helps them manage their situation, and develop ways to cope.

Groups vary widely in size and format. The most important aspects of the support group are: confidentiality, mutual trust, understanding, involvement of attendees helping each other and getting the information and support they need.

### About the Support Group Guidebook

BIANYS created this guidebook as a resource for support groups across New York State and to help facilitate the relationship between BIANYS and BIANYS-affiliated groups. Additional resources are available on the [www.bianys.org](http://www.bianys.org) website. The following information provides details on starting and maintaining a support group and working with BIANYS.

## **WORKING TOGETHER WITH BIANYS**

**BIANYS Mission Statement:** The mission of the Brain Injury Association of New York State is to minimize brain injury through prevention and to support, educate and advocate for individuals with brain injury and their families.

A BIANYS Support Group is a support group that has a valid affiliation agreement (Appendices C & D) with BIANYS and whose leader follows the Job Description (page 7) and Volunteer Code of Conduct (Appendix B) required by BIANYS.

Being a BIANYS support group connects the group with the statewide Association. Each party has responsibilities and benefits through this partnership, which are outlined in this guidebook. Additionally, the list of these responsibilities is provided in Appendix A. A BIANYS support group is eligible for coverage by the insurance company that covers BIANYS. This means that people attending BIANYS support groups are covered in case of any incidents. The insurance policy can also be used, with prior approval, to secure event space for local events. To maintain this coverage, the group must inform BIANYS about meeting locations and times, and make sure to contact the BIANYS Program Coordinator with any changes. Without accurate information on file about the meetings, the group will not be covered.

### **Working together as a team**

Communication is essential! Work with BIANYS staff to establish the best way to communicate with the community. Newsletters, meetings, monthly reporting and conferences can all be effective. Talk with the BIANYS Program Coordinator about what your group needs. Find out about and use whatever resources they can provide. At support group meetings, you can start by reading the BIANYS Preamble:

*The Brain Injury Association of New York State welcomes you to this support group. BIANYS is a statewide non-profit membership organization that advocates on behalf of individuals with brain injury and their families. BIANYS support groups are places of emotional, physical and spiritual safety. What is said here stays here. While these support groups are not forums for clinical treatment, they are forums of mutual support among those facing common challenges.*

- Encourage membership in BIANYS. Individuals need not be members of BIANYS to participate in support groups. However, they should be encouraged to join and should be made aware of other local chapter meetings and other activities.
- Have BIANYS membership information and newsletters on hand at every meeting. Perhaps ask a volunteer who is a member of BIANYS to explain membership to new support group attendees.
- Keep BIANYS informed about the support group activities and progress through photos and articles for the BIANYS newsletter, or letters from support group members.
- Dedicate time at all support group meetings to discuss upcoming BIANYS activities. If possible, attend BIANYS events and conferences to keep up-to-date on brain injury topics.

## **STARTING AND MAINTAINING A BIANYS SUPPORT GROUP**

Support groups may be run by individuals with a brain injury, family members, professionals or friends who volunteer their time. Volunteer support group leaders must go through the process to become a BIANYS volunteer and complete the Affiliation Agreement (see Appendix C). Organizations hosting support groups must sign an Affiliation Agreement (Appendix D) that indicates the responsibilities of the organization and the facilitator information.

Individual groups may be limited in composition to a certain number or population (i.e. a group for survivors of stroke, siblings, individuals with brain injury), but to be affiliated with BIANYS, every support group must be open to the community.

### **FACTORS IMPORTANT TO A SUCCESSFUL SUPPORT GROUP:**

- Organized, dependable leader
- Trust and confidentiality
- Convenient meeting time, comfortable location, & appropriate format
- Balanced program to meet attendee needs
- Continuing publicity
- Handouts and other information distributed at meetings

Keeping a support group going is not easy. The following is a discussion of important factors to keep in mind while planning your support group.

## **ORGANIZED, DEPENDABLE LEADER**

No matter what your support group structure may be, there are certain tasks that are necessary for a successful group. A leader is essential to a support group. A support group leader is a BIANYS volunteer and is expected to follow the BIANYS Volunteer Code of Conduct, the support group leader guidelines, and meet the goals stated in the support group leader job description.

BIANYS envisions that the support group leader will fill the role of facilitator at support groups, but sometimes another person will be brought in to do the job. If the leader brings in another person to facilitate the group, that person must also follow the leader guidelines and volunteer code of conduct and be otherwise qualified to facilitate meetings.

## **FACILITATION**

Facilitate means “to make easier.” In a self-help support group, this means to make it easy for the members to help themselves and each other through a common life experience. Facilitating may entail keeping the group on track to follow an established agenda, or making sure that all voices are heard and one member does not monopolize discussion time, while providing support that is both positive and encouraging. Facilitating is a skill that takes practice, and the BIANYS Program Coordinator can provide information to help support group leaders work on facilitation skills.

In some groups, the facilitator assumes other leadership responsibilities that are administrative in nature. However, if possible, it is best to keep administrative tasks at a minimum and have them handled by someone other than the facilitator.

## **BIANYS Support Group Leader Job Description**

**Objectives:** As an agent of BIANYS, the support group leader will create and facilitate a supportive, empathetic environment for people to discuss issues related to brain injury and provide individuals with information and resources related to brain injury.

**Background:** An identified leader for the group must meet the following requirements:

- The leader will fill out a BIANYS Volunteer application.
- The leader must have a good understanding of brain injury and BIANYS.
- The leader must have good facilitation skills.
- BIANYS can assist with training in many of these areas.

**Training:** Will be provided by BIANYS upon request and supplemented by the BIANYS Support Group Guidebook.

### **Duties:**

- Leader will facilitate or co-facilitate a group on a regular basis and have a backup plan in place if they cannot be at the meeting.
- The leader is required to sign an annual support group agreement with BIANYS.
- The leader will be in regular contact with BIANYS, particularly communicating cancellations, rescheduled meetings, or change of venue to the group.
- The leader will mention BIANYS at meetings, read the BIANYS support group preamble, and make BIANYS materials available to group attendees.
- The leader will, with assistance from BIANYS, develop ways to promote the group to potential new attendees.
- The leader may be responsible for scheduling guest speakers and/or arranging agendas for meetings.

## **BIANYS Support Group Leader Guidelines**

- 1.** Group leaders must complete all required forms and meet standards mentioned in job description.
- 2.** Support group leaders must pass a background check if deemed appropriate.
- 3.** The Volunteer Code of Conduct must be followed at all times.
- 4.** Support group leaders can read the BIANYS Preamble at the beginning of each meeting.
- 5.** Support group leaders will participate in BIANYS trainings when offered.
- 6.** Support group leaders will serve as the time keeper at meetings and facilitate to make sure that all members attending have opportunity to be heard.
- 7.** Support group leaders will consistently hold meetings and notify members as to the date, time and location of meetings. Meeting spaces must be fully accessible.
- 8.** If the leader is unable to facilitate the group, they will call a designated substitute and notify BIANYS of cancellation or substitution.
- 9.** Support group leaders will maintain and distribute information, brochures and materials provided by BIANYS at meetings.
- 10.** Support group leaders will provide statistical information regarding meeting attendance if requested by BIANYS.
- 11.** Membership to BIANYS should be mentioned and encouraged at meetings.
- 12.** The leader will maintain a confidential, safe and supportive environment for attendees.

## **TRUST AND CONFIDENTIALITY**

Trust and confidentiality are critical components for all support groups. As stated in the BIANYS preamble that should be read before each meeting, “What is said here stays here.” This means that any information that might individually identify a group member should not be released outside the group, verbally or in a written or pictorial form, including on social media sites.

The discussion at support groups can often include very personal information about events and feelings. It is imperative that support group attendees feel safe in sharing their experiences and feelings and have a strong sense of trust in other group participants. Keeping discussions confidential ensures that group attendees can share their thoughts and feelings and support each other without concern that it will be repeated elsewhere and in different company.

There are certain situations, such as a person indicating that they are thinking of harming themselves or others, that might require the leader to report some information to other parties. BIANYS can provide information on how to handle these situations in training materials.

## **CONVENIENT MEETING TIME, COMFORTABLE LOCATION, and FORMAT**

Support groups that meet in the community utilize many different types of locations. If you are just starting out, consider local houses of worship, community rooms at banks, libraries, hospitals, rehabilitation centers, fraternal organizations and social service programs as potential meeting locations.

The checklist below can help you decide if your meeting is in a good location. If your answer is “NO” to more than one of these, you might explore the community for a more suitable and convenient place to meet. Also, take a poll of the support group attendees to determine how satisfied people are with the present meeting arrangements.

Checklist for evaluating/choosing a location:

- Central location?
- Accessible by public transportation?
- In a safe neighborhood?
- Wheelchair accessible?
- Not too hot or cold?
- Appropriate lighting for members?
- Near parking?
- At a convenient time for most members?

Consistency in time and meeting place is an important factor. People who have experienced a brain injury often appreciate being able to predict their routine. If you must move the location from meeting to meeting, be sure to let attendees know or give them a written notice containing directions, as far in advance as possible. These changes must also be reported to the BIANYS Program Coordinator.

## **BALANCED PROGRAM TO MEET ATTENDEE NEEDS**

A balanced support group should offer time for group sharing and mutual problem solving, assistance in finding answers and resources to address concerns of attendees, and opportunities to relax and socialize with people who understand.

Remember, losing participants is not a sign of failure. It can mean that people's needs have been met for the time and they have moved on.

Most support groups meet on a monthly basis for one and one-half to two hours, using a regular format that they have found to be effective. Some rotate or combine the formats below within the same meeting. Others use different formats at different meetings. In any case, it's a good idea to establish a pattern to follow for the year, providing a consistent mixture of group **support, education** and **socialization**.

Many groups create an agenda for use at the meetings. An agenda is helpful to keep the meeting on track and ensure that the meeting stays within time limits. An sample agenda follows on the next page. The timing can be adjusted to meet the needs of each group, and specifics related to what is on the agenda should be developed with the group.

## **SAMPLE SUPPORT GROUP MEETING AGENDA**

### **BIANYS Preamble & Introductions (5-10 minutes)**

The BIANYS Preamble can be read at the start of each meeting:

*The Brain Injury Association of New York State welcomes you to this support group. BIANYS is a statewide, non-profit membership organization that advocates on behalf of individuals with brain injury and their families. BIANYS support groups are places of emotional, physical and spiritual safety. What is said here stays here. While these support groups are not forums for clinical treatment, they are forums of mutual support among those facing common challenges.*

In addition, if the group has developed a set of rules that they deem important, this is a good time to read through them. First time attendees should have additional time to tell their story.

### **Information Sharing (20-45 minutes)**

Attendees are encouraged to clip stories from newspapers or health newsletters to share information learned from personal readings and experiences, or to ask questions of professionals who may be present as general resources. If a guest speaker is present, give 20- 30 minutes for their presentation and 10-15 minutes for questions.

### **Support Groups (50-60 minutes)**

Proceed with group sharing and problem solving around topics of interest. Professionals and friends who attend may want to go to a “family group” at this time. This time may also be used for a general “round robin” where group attendees go around the room and share their experiences to get support.

### **Wrap-up (5-10 minutes)**

The group re-convenes for last minute questions or announcements.

The evening ends with an informal “meet-and-greet” time when attendees can exchange phone numbers, make dates to get together or ask specific questions of leaders, professionals or each other.

## **PUBLICITY**

If you want your group to be a community resource open to new participants, information about the group should be shared continuously. The following are suggestions for publicizing meetings. Additional assistance can be provided by BIANYS staff.

Make an effort to publicize special speakers or occasions to the larger community (i.e. Brain Injury Awareness Month in March).

Work with BIANYS staff to send a press release to local radio and TV stations about your meetings. Non-profit groups can often submit 30 to 60 second announcements at no charge.

Take advantage of your partnership with BIANYS and coordinate listings for the BIANYS Brain Power quarterly newsletter, website, social media and other ongoing outreach efforts.

Regularly place announcements in as many locations as possible. Press releases and flyers are created by BIANYS staff and will include the name of the group, contact person and phone number, meeting time and place, who is invited (i.e. professionals and agency personnel as well as individuals with a brain injury and/or family members). Some suggestions of places to post meeting notices include:

- Local hospitals, rehabilitation facilities, VA Hospitals
- Online and print newspapers and events calendars
- Local cable TV bulletin boards
- Bulletin boards at local stores, coffee shops, etc.
- Local professionals who work with the brain injury community
- Independent Living Centers

## **DISTRIBUTING INFORMATION AT MEETINGS**

Getting needed and desired information to support group attendees is one of the major goals of a support group. In most successful groups, it is an area that receives attention at each meeting. Information about BIANYS and membership should be provided. The BIANYS Program Coordinator can help with your specific information needs or provide resources for further information. In addition, the leader and group participants can work together to:

- Seek accurate sources for information through guest speakers, videos or printed materials.
- Encourage attendees to share what they have learned or what printed material they have obtained.
- Supply resources for obtaining more in-depth information about problems that group members face.
- Display informative materials at each meeting. BIANYS may be able to provide handouts on the evening topic, newsletters or other general information.
- Bring any special materials such as videos, manuals, books, etc. which participants may use or borrow.

Support group attendees need to be encouraged to become involved in this important component of the program. Have the group discuss topics and information needs, so that a few people do not need to guess what the others want.

On occasion, questions arise in support group meetings that can't be answered at that time. The leader or an appointed person should be responsible for writing down the question and the name of the person requesting the information. The answer may be found through help from the BIANYS Program Coordinator.

For more information: Contact BIANYS at 518-459-7911 and ask to speak with the Program Coordinator in charge of overseeing Support Groups.

# **APPENDIX A**

## **LIST OF RESPONSIBILITIES**

### **BIANYS Responsibilities**

- BIANYS will maintain and disseminate a current listing of all affiliated support group meetings and contact people on the BIANYS website.
- BIANYS will facilitate communications among support group leaders across New York State.
- BIANYS will provide technical assistance and support as needed.
- BIANYS will keep support group leaders apprised of the latest information regarding brain injury.
- BIANYS will offer trainings and information sessions related to support groups for leaders and facilitators.
- BIANYS will provide insurance coverage for the support group meeting and events organized by the support group, with prior approval.

### **Responsibilities of the Support Group**

The sections above explain the relationship between BIANYS and affiliated support groups. Below is a list of the major responsibilities for the support groups:

- Support Groups affiliated with BIANYS must file the Support Group Affiliation Agreement (Appendix C for individuals creating a community group; Appendix D for organizations affiliating their groups with BIANYS).
- Support Groups must keep the BIANYS Program Coordinator updated on meeting times and locations. If a group is covered by the BIANYS insurance policy, BIANYS must have advance notice of dates and times, or the meetings will not be covered.
- The Support Group Leader Job Description (page 7) outlines the responsibilities of the leaders.
- The Volunteer Code of Conduct (Appendix B) outlines the expectations that BIANYS has for all volunteers.

# **APPENDIX B**

## **BIANYS VOLUNTEER CODE OF CONDUCT**

All volunteers for the Brain Injury Association of New York State, in delivering BIANYS services and in all other activities, shall meet the following standards of conduct:

- A. Treat all persons with respect and courtesy, all personal information as confidential, and have a personal commitment to being non-judgmental.
- B. Present themselves in a manner that reflects positively on themselves and BIANYS.
- C. Be punctual for scheduled activities.
- D. Comply with decisions made by BIANYS executive staff.
- E. Not authorize the use of the name, logo, endorsement, services or property of BIANYS for the benefit or advantage of any person except in conformance with BIANYS policy.
- F. Not accept or seek on behalf of any person, any financial advantage or gain offered as a result of the volunteer's affiliation with BIANYS.
- G. Not disclose any confidential BIANYS information that is available solely as a result of the volunteer's affiliation with BIANYS without the express authorization of BIANYS.
- H. Not publicly use any BIANYS affiliation in connection with the promotion of partisan politics, religious matters or positions on any issue not in conformity with the official position of BIANYS.
- I. Not knowingly take any action or make any statement intended to influence the conduct of BIANYS in such a way as to confer any financial benefit on any person, corporation, or entity in which the individual has significant interest or affiliation.
- J. Not operate or act in any manner that is contrary to the best interests of BIANYS.

## APPENDIX C



### Support Group Affiliation Agreement (for individuals starting a community group)

I \_\_\_\_\_ agree to facilitate a brain injury support group in \_\_\_\_\_ . I shall strive at all times to support BIANYS and their goals in my endeavors to reach out and help persons with brain injury and their families. I will provide supportive, empathetic environment for people to discuss issues related to brain injury. I have read the BIANYS Support Group Guidelines. You may share my name, telephone number and meeting date and times with individuals and the groups that contact BIANYS. I will not share names or addresses of support group members with anyone outside of BIANYS (within the confines of current law) and understand that confidentiality is of utmost importance and will convey this to the group at each meeting. I agree with the BIANYS Volunteer Code of Conduct and agree to keep support group meetings open to the public.

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_

Email: \_\_\_\_\_

Will the support group be affiliated with a BIANYS Chapter?

 Yes No

Proposed Meeting Times and Location\*: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

\*If a location is not yet determined, please let the BIANYS Program Coordinator know when that information is available. This form will be updated annually or if there is a change in Leader/Facilitator.

## APPENDIX D



### Support Group Organizational Affiliation Agreement

\_\_\_\_\_ agrees to maintain a brain injury support group in \_\_\_\_\_ (name of organization) agrees to identify and provide support and training to the support group leader we designate. We shall strive at all times to support the goals of BIANYS as we reach out and help people with brain injury and their families. We will provide a supportive, empathetic environment for people to discuss issues related to brain injury. We have read the BIANYS Support Group Guidelines. You may share our name, telephone number and meeting date and times with individuals and the groups that contact BIANYS. We will not share names or addresses of support group members with anyone outside of BIANYS or our organization (within the confines of current law) and understand that confidentiality is of utmost importance and will convey this to the group at each meeting. We agree with the BIANYS Volunteer Code of Conduct, accept liability during support group meetings, and agree to keep the support group meetings open to the public.

Name of Organization: \_\_\_\_\_

Organization Contact: \_\_\_\_\_

Facilitator of Group: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_

Email: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Proposed Meeting Times and Location: \_\_\_\_\_

\_\_\_\_\_  
\*If a location is not yet determined, please let the BIANYS Program Coordinator know when that information is available. This form will be updated annually or if there is a change in Leader/Facilitator.