

STARTING and SUSTAINING a PEER SUPPORT PROGRAM for NICU PARENTS



 National
Perinatal
Association

Educate. Advocate. Integrate.

INTRODUCTION

The National Perinatal Association (NPA) created the Family Advocacy Network (FAN) to promote the health and well-being of parents and infants by giving a voice to families and their support systems in the multidisciplinary arena of maternal child health. Members of FAN include professionals and parents interested in advocating for families who experience perinatal and neonatal traumas. One of FAN's primary goals is to empower existing parent support programs with information and resources and to help in the creation of new parent support organizations. With this in mind, "Starting and Sustaining a Parent Support Program" was derived from an original manual entitled "Not-for-profits: Solving the Puzzle," written in 2001 by NPA on how to establish, finance, and operate a nonprofit organization.

This document was updated by current members of the NPA Board in 2016 with a more specific focus on starting peer support organizations for NICU parents. Additional content was drawn from the publication by an NPA-convened Workgroup as follows: Hall S, Ryan D, Beatty J, Grubbs L. Recommendations for peer-to-peer support for NICU parents. *J Perinatol* 2015;(35):S9–13

We hope this addendum will empower you to create a stronger parent support program or start a new one.



VISIT OUR WEBSITE

www.support4NICUparents.org

for more resources

ACKNOWLEDGMENTS

UPDATED IN 2016 BY NPA BOARD MEMBERS AND WORKGROUP MEMBERS:

EDITOR

Sue Hall, MD, MSW

CONTRIBUTORS

Becky Hatfield, former Co-Chair FAN

Erika Goyer, Co-Chair FAN

Cheryl Milford, MEd, Co-Chair FAN

Raylene Phillips, MD, ICBLC, NPA President in 2016

Lisa Grubbs, President of NICU Helping Hands

Kelli Kelley, Founder and Executive Director of Hand to Hold

Leelee Klein, President of The Tiny Miracles Foundation

Heather McKinnis, Parent Coordinator at Graham's Foundation

ORIGINAL AUTHORS/CONTRIBUTORS

ADVISOR

Sheila S. Sorkin, MSW

Former Executive Director, National Perinatal Association

EDITOR

Amy E. Tracy, BA

Author, *The Pregnancy Bed Rest Book
& Your Premature Baby & Child*

CONTRIBUTORS:

Sarah Daniels-Campbell

Executive Director, The Preemie Place

Former National Perinatal Association Board Member

Kris Green, BS H ed, MAT, MS

Parent & Community Coordinator

Children's Hospital at Providence

Anchorage, Alaska

Becky Hatfield

Parent Support Coordinator

University of Utah Hospital

Salt Lake City, Utah

Stephanie Lerner-Ernsteen, MSW, LCSW

President ENH Parent to Parent

Evanston Hospital

Evanston, Illinois

WHY START A PARENT SUPPORT PROGRAM?

Families who experience a crisis (for example, a complicated pregnancy, a loss, or the birth of a baby with special needs) are better equipped to handle their situation with the emotional support and aid of other parents who have been through a similar experience. Parent-to-parent support can:

- increase the parents' acceptance of a difficult situation and give them important resources for coping
- provide a safe environment in which to share feelings
- help parents feel less alone
- offer comfort (which family members and friends may not always be able to provide)
- empower parents to problem-solve
- encourage parents to become advocates for their families and for themselves

Peer support organizations for NICU parents can be primarily started and run by parents themselves, or started by hospital staff who identify a need and then recruit parents for the program. **The most successful programs will involve close collaboration between both parents and professionals.** Peer support can be configured in a variety of forms, including:

- one-on-one support
*meeting individually
or communicating via telephone
or e-mail*
- group meetings
- social gatherings
- internet-based support



Because each member within the program can have different needs and wants, and because parents' needs change over time, offering a variety of support options is essential.

If you are considering starting a parent support program, answering the following questions can help you get started:

Why do we want to form a parent support program (the purpose)?

What do we hope to achieve or provide to members (the goals)?

Who are we trying to reach (the membership)?

Is there a local support program that already serves our needs? Consider hospital and community groups. Some larger organizations offer in-house support for their members (for example, a support group for parents of preterm infants within a twins' club).

Is there a regional or national support organization with which we can create an affiliation?

(continued)

What type of leadership do we want? Parents, professionals, or a joint effort by parents and professionals? In general, parent-run organizations are inclined to work for change and education, and the programs offer excellent peer support. Organizations run by a healthcare professional can also facilitate goals and meet the needs of parents, but parents must be intimately involved in their development and ongoing function. Programs that have both parents and professionals leading them can offer a variety of perspectives and tend to have the best longevity.

Do we want to be community-based, hospital-based, or agency-based? Take some time to carefully weigh the costs and the benefits of each option. If your membership will come from more than one source and a large geographic location, a community-based program may be desirable. Creating a parent support program that is not associated with any one organization or hospital can allow the freedom to be creative. These groups may also be better able to achieve accomplishments in a timely manner because there is no chain of command to follow.

If your membership will primarily come from a particular hospital or a community agency (such as your local department of social services or local March of Dimes), you may want your program to become affiliated with that organization. When making this choice, keep in mind that if you will support parents from several hospitals, being affiliated with only one may give the wrong impression that your doors are not open to parents from other hospitals. Consider, too, that such an affiliation may require you to follow established rules and protocol and you may lose some autonomy and independence.

On the other hand, a hospital or other organization can offer support, direction, and resources that may not be available to a small grassroots effort. For example, you may be able to use the organization's nonprofit status to write grants, hold meetings in its office space, or use other resources (such as a print shop, bookkeeper, tax expert, or website designer). **When considering such an affiliation, ask questions about the organization's intentions regarding a partnership and ensure that their goals are compatible with yours.**

Should you decide to create a hospital- or agency-based system, you will need to solicit and gain the enthusiasm and support of the organization's professionals. **Having a clear idea of your program's purpose and goals and the steps you will take to achieve them will get you started on the right foot.**

Connecting with others who have started a support program, especially one that is similar to yours, and asking for advice can be helpful. Ask for materials, such as brochures, job descriptions, volunteer training manuals, and By-laws that the support program created, providing you with ideas and inspiration. If there are likeminded groups in your area, ask if you can attend a meeting or two.



Resources:

American Self-Help Clearinghouse

www.selfhelpgroups.org

Beach Center on Disabilities

www.beachcenter.org

Institute for Family-Centered Care

www.familycenteredcare.org

National Perinatal Association's Family Advocacy Network (FAN)

www.nationalperinatal.org/fan

National Resource Center for Family Support Programs

www.familysupportamerica.org

National Self-Help Clearinghouse

www.selfhelpweb.org

Parent to Parent USA

www.p2pusa.org

Preemie Parent Alliance

www.preemieparentalliance.org

PLANNING A PARENT SUPPORT PROGRAM

The first step when starting a new program is to seek out other likeminded individuals who share your interest and enthusiasm. These individuals may be found through referrals from hospital staff, community healthcare professionals, and other parents (see “Recruiting Parent Volunteers” on page 11). This core group will serve as the planning committee and will most likely be the initial leaders of the organization. (If you cannot find other parents who are interested in starting a grassroots support system, consider joining or starting an online support network, discussed on pages 23-24.)

It may take many telephone calls and meetings before finding the future leaders of your support program. **Do not get discouraged; most successful parent programs take time to get off the ground.**

STRUCTURE AND OPERATION

If your program will be small and informal, you may only need one leader (a coordinator, a president, or a chairperson), but **most support programs are run by a group of leaders** (a Board of Directors or a steering committee). Having regular board meetings can help with planning and implementation of activities (and can shorten the business portion of parent support meetings, if you have them). Committees can also be established to help leaders with larger tasks, such as fundraising or planning a special event. Recruitment of volunteers will be ongoing as the program grows.

In the beginning when starting a new organization, it may just be up to you, the person who has the idea. But once you get others to join you **discuss leadership roles and potential jobs, including:**

President (founder, coordinator, or chairperson): Provides general supervision, direction, and control of support activities

Secretary: Records minutes from meetings, sends out agendas, and handles official correspondence

Treasurer: Responsible for care and control of monies and accounting

Historian: Keeps record of program events through various mediums including but not limited to news stories, press releases, photographs, videos, and written accounts

Librarian: Organizes a lending library of books and videos, including developing and maintaining a lending tracking system

Membership Chair: Maintains a list of members with contact information and answers questions from prospective members

Publicity Chair: Announces meetings and events through various avenues, including the media, email applications, and flyers

Outreach Chair: Represents the parent support program to other community and healthcare organizations; may act as a spokesperson to recruit new members or develop programs

Program Chair: Helps to arrange educational and support programs for the membership

Fundraising Chair: Helps raise money for the program and its specific projects

Newsletter Editor: Creates a newsletter to inform and educate the membership and the community

Social Media Chair: Creates and maintains a website, facebook page, twitter account, a presence on LinkedIn, which may include an online communication list and/or support network. Such a chair can be responsible for starting or contributing to discussion threads on all the social media sites, getting your organization's name in front of other people in the community you hope to serve and other organizations with which you might want to collaborate.

Other leaders may be needed according to the support program's focus. For example, a support group for parents of preterm infants may have a bereavement chairperson who provides resources to families coping with a loss.

Many organizations also draft By-laws that define the rules of the parent support program. These can ensure that any issues that may arise within the organization are handled fairly and effectively. For help establishing the structure of By-laws, see *Robert's Rules of Order*.

Many support programs also establish a relationship with professionals in the community who can offer expert advice pertinent to the program. For example, an accountant or tax expert can help with establishing nonprofit status (and writing By-laws) and a healthcare professional can speak to the group on pertinent topics and provide input on accuracy of medical topics you might include in your materials or on your website. You may choose to use these experts informally, or you may establish a formal advisory board with regular meetings.



FINDING YOUR PARTNERS

When starting a support group, it is important to network with professionals in your community. Think about all the agencies and providers who work with the families you support. These are your potential partners and champions. Make a list. Then start sending out information about your program introducing yourself. Be sure to include:

- neonatologists
- pediatricians
- follow-up clinics
- agency directors (WIC, Medicaid)
- social workers
- hospital administrators
- therapists (OT, PT, SLP)
- lactation consultants
- home health providers
- counselors

CREATING A CENTRAL CONTACT

Unless you are affiliated with another organization, your “office” will be located at various leaders’ homes. **It is important to establish a central contact for communication** by using one leader’s address and phone number, and perhaps start off with a specialized email address through one of the major platforms such as gmail. Better yet, open a post office box and establish a business number (remember, leadership will change frequently), forwarding calls to your cell phone or that of another person in your new organization.

NONPROFIT OR NOT

Obtaining nonprofit status will allow donations to your organization to be tax-deductible. Most foundations and corporations that grant monies and gifts require organizations to be nonprofit. Being nonprofit will also allow you an exemption from paying sales tax. If you affiliate with another nonprofit organization, you may fall under their nonprofit umbrella.

If you’re thinking of becoming a charitable organization, you may work with an attorney or tax expert who can help you navigate this sometimes lengthy and complicated process. Ask your membership and advisory board, if you have one, for referrals. Some attorneys will donate their expertise to nonprofits; ask your state’s bar association for referrals.



Resources for Nonprofits:

Independent Sector

www.independentsector.org

The National Center for Charitable Statistics

nccs.urban.org

Guidestar

www.guidestar.org

National Council of Nonprofits

www.councilofnonprofits.org

Idealist

www.idealists.org

Tech Soup

www.techsoup.org



Local Regulations

All nonprofits, even national ones, must incorporate in the state where they are based.

If you are considering nonprofit status, you will want to reach out to your state association of nonprofits for guidance.

See more at:

www.councilofnonprofits.org/tools-resources/how-start-nonprofit

CHOOSING A NAME

Your name should reflect your purpose and membership. For ideas, research the names of groups/programs that are similar to yours. You should also check with your state's Secretary of State to see what names are already in use, and **consider registering your chosen name** to protect its use by others. Some other tips when contemplating a name:

- The term "support group" may imply that your program solely focuses on psychosocial aspects, and for some people, the term has negative connotations. In addition, the word "group" may imply support through meetings, which may not accurately represent your purpose.
- A shorter name or one that can be shortened to an acronym is easy to remember (for example, National Perinatal Association is NPA and Family Advocacy Network is FAN).
- Consider whether or not your name reflects the image you want to project. For example, avoid cute names if you want to project a more serious image.

Once you settle on a name, **you will want to create a fitting logo** which can be used to identify your group on all your materials and social media platforms. Again, draw on a group member with design experience or leverage personal and professional connections to find someone who will help you at little or no cost.

SETTING GOALS

When initially discussing your parent-support concept formulate some clear ideas about what you want to accomplish and what you want to provide members. Then, as you share your vision be open to feedback and new ideas. **Write down what your program would like to achieve in three months, in six months, in one year, and in five years.** For example:

3 to 6 months...

During the first few months, you may plan to recruit members, establish collaborative relationships with the medical team of the NICUs where you hope to provide services, and establish a monthly meeting of your volunteers;

12 months...

Within a year, you may want to become a nonprofit, provide volunteer training and start providing peer support services at your local hospital, and establish a newsletter; a small conference may be in the plans for five years down the road.

During the early planning stages, it is important to **stay realistic in what you hope to achieve and set obtainable goals**. You do not want to overwhelm the core group with too much work. Something as simple as finding a date and location for regular volunteer meetings can make members feel as though they are spending their time wisely, getting things done, and taking important steps to achieve the program's goals. On the other hand, coming up with some long-term goals and "thinking big" can be energizing.

Be sure to evaluate your short-term and long-term goals every six months. It is common for an organization's membership to change, creating new needs and wants. Be open to revising goals.

Some examples of common goals from established parent support programs include:

- Provide information, resources, and support to families
- Decrease parents' feelings of isolation and loneliness
- Reduce stress on family members
- Increase coping and parenting skills
- Provide opportunities for socializing with people who understand

Some specific programs that can meet these goals include:

Meetings: Monthly, bimonthly, or weekly group meetings can be informal, with both "graduate" and "new" parents gathering together to talk. Or they can be formal, offering information on a topic of interest. Offering both types of meetings can satisfy more NICU parents' needs. **The combination of information presented by a professional, such as a nurse, a social worker, or a psychologist, followed by a discussion that includes veteran parents is often successful.** Professionals may even find parents' insight helps them develop new ideas for supporting parents. Some national groups (such as bereavement organizations or groups for specific disorders) have established standards and protocols for meetings.

A parent-to-parent outreach program: **A good way to support parents is to create a program that connects trained veteran parent volunteers with new NICU parents.** Ideally, these parents can be matched so that they share similar experiences and socioeconomic backgrounds. Peer support may come through one-on-one meetings, telephone calls, and/or email. Training parent support volunteers is discussed on page 16.

Dissemination of information: You can share information through handouts or online resources (downloadable resources and even videos); a lending library of useful articles, books, and videos; a community resource directory; and/or a print or Internet-based newsletter. **Healthcare professionals should review all materials,** and consider adding disclaimers.

Social activities: Some ways parents can interact in a comfortable setting include family picnics, reunions, playgroups, activities such as scrapbooking, and holiday parties. **Some events may be just for families, others for families and healthcare workers together.**

Special projects: These may include in-service sessions to educate the community or other organizations about your support program and the special psychosocial needs of NICU parents, a conference for parents and professionals, or an advocacy campaign to influence local or national legislation.

IMPLEMENTING A PARENT SUPPORT PROGRAM

RECRUITING PARENT VOLUNTEERS

Once your goals have been decided, it is time to recruit members. **How you find parents will depend on the type of support and programs you plan to offer.** For example, if you are working with a small hospital-based support program, potential members may come from doctor and nurse referrals and flyers posted within the hospital. If your organization is a large community-based organization, you may rely on free publicity. Below are some ideas for recruiting veteran parents:

- If your goal is to start a parent mentoring program for your local NICU, you can **join together with other NICU graduate parents to create a nucleus**, and begin recruiting from there. You can also ask your NICU's social worker or members of the medical team to identify past NICU parents that they think might be interested.
- **Create flyers, posters, and/or brochures describing your support program** to be handed out to current NICU parents, and include easy-to-read contact information.
- **Contact other related support programs** (such as twin and multiples clubs, expectant mothers' groups, religious groups) and ask them to share information about your program. Provide them with flyers to hand out, as well as links to your organization's sites on social media.
- **Send a media release** to related local organizations' newsletters (such as the Ronald McDonald House, the March of Dimes, or the American Heart Association), newspapers, local parenting magazines, and local television and radio stations. Some newspapers have listings of community organizations or event calendars. TV and radio stations are required to donate a certain number of spots for public service announcements. It can be helpful to recruit a parent or advisor who has media experience to help write media releases.
- **Attend conferences and presentations related to your program's purpose and goals.** Ask the organizers or presenter if you can make an announcement about your parent support program at the end of the presentation and pass around a sign-up sheet.
- **Create a newsletter** and provide information about the program's need for volunteers; consider sending it to a wider audience that might include potential donors. Do not forget to include contact information.
- **Ask current members for referrals** to new members, either personally or through a "letter of interest."

REGULAR MEETINGS

Where your volunteer and other support staff will meet will depend on the size of your group: How big a room will you need, and how many chairs? Consider, too, how people will get there (by car or public transportation), what parking is needed, and if participants have any special needs (for example, wheelchair accessibility or childcare). **It is a good idea to find a location where you can set up regular meetings, creating a consistent meeting date and time.**

Some places that may offer a free meeting place:

- Hospitals
- Schools
- Places of worship
- Community centers
- Town recreation centers
- Nonprofit organizations
- Libraries
- Parents' houses
- Physicians' offices

When considering the day of the week and time to meet, you will need to know your volunteers' availability. Will most volunteers work during the day and prefer a lunchtime or evening meeting? Do they have young children with early bedtimes? If possible, you may want to host two meetings (one during the day and one at night) to meet all members' needs. Also, ask your members how often they want to meet and for how long (one hour is typical) and evaluate whether such a schedule is reasonable. Keep in mind that as your organization grows and new volunteers step up to the plate, you will need to reevaluate your meeting times and locations.

The First Meeting

The first meeting of volunteers will be an introduction: **The leader and founding members should share their reasons for establishing a parent network and their vision for what the group might accomplish.** Attendees should be encouraged to share their stories (however, some may prefer not to). The leader should then share the program's purpose, goals, and potential plans. Let prospective volunteers know that their input is important and that goals and plans will evolve according to their needs and wants. Encourage attendees to describe what they hope to get from participating as a volunteer and write down all suggestions.

Not all those who attend the first meeting will want to be leaders or active participants of the organization. Be sure to pass around a sheet of paper to gather contact information. Among those willing to be more active, try to determine who is interested in providing direct peer support and who is more interested in performing other volunteer functions, such as hosting craft activities, preparing educational or promotional materials, etc.

FUTURE MEETINGS

During the planning process, you may establish a regular format for meetings or you may decide to offer several different formats. For instance, have a speaker followed by questions and answers at one meeting, ask a trained mental health professional to lead a discussion at another meeting, and watch an educational video at the next one. **Meeting topics will depend on the program's needs and purposes.** For planning and advertising purposes, it is helpful if you can set up a schedule of meetings in advance.

Following is a sample of a typical parent support agenda:

- **Introductions** by the leader. You may want to invite attendees to introduce themselves.
- An **overview** of the program or the purpose of the meeting.
- Presentation by the guest speaker or the leader to start the **topic of discussion**.
- A **question and answer** session.
- A **break** with or without refreshments.
- An **overview of potential plans** and any announcements.

POPULAR DISCUSSION TOPICS AND PRESENTERS

- Breastmilk Pumping and Feeding - lactation consultant or nurse
- Understanding Your Baby's Behavioral Cues - NICU therapist
- Tips for Successfully Feeding Your Baby - NICU therapist
- Infant Massage - trained professional
- Safe Sleep - neonatologist, NNP, or nurse
- What You Need to Know about Protecting Your Baby from RSV - neonatologist or NNP
- Understanding PPD and PTSD - social worker or psychologist
- How to Become Your Baby's Best Advocate - peer support leaders
- Your NICU Baby's Development - neonatal NICU and Early Intervention specialist
- Getting Ready to Bring Baby Home - NICU nurse or discharge planner/coordinator
- What to Expect When You Go Home - Community Visiting Nurses or Early Intervention

More suggestions at: www.support4nicuparents.org/wp-content/uploads/2016/02/List-of-Parent-Activities-and-Lunch-Learn-Topics.pdf

COMMUNICATING WITH YOUR COMMUNITY

By Text: Sending a group text is a useful way to notify volunteers about meetings, cancellations, or special events.

Newsletter (Print and Online): For those who are unable to attend meetings, a newsletter, often sent through Mail Chimp, Constant Contact, or some other email application, can be a valuable source of information and support for the work they are doing. A newsletter is also an important tool for membership communication. It can be helpful to look at samples of other newsletters from organizations that are similar to yours.

Some ideas for newsletter content:

- Summaries of new medical studies applicable to NICU babies and their families
- Reviews of pertinent books, including memoirs by NICU parents
- Resources on the Web
- Description of new apps that are available for parents of NICU babies
- Articles by parents and professionals
- Parent celebrations and photographs
- Volunteer recognition
- Community resources
- Information about pertinent workshops and conferences
- A calendar of upcoming events



REQUESTS FOR DONATIONS

Whether you are requesting a meeting space or a meal donation for your support group, a successful donation request includes these key components:

WHO YOU ARE, and WHAT YOU DO

Introduce them to your group.
Tell them why what you do is important
to NICU parents and their families.

WHY YOU CHOSE THEM

Tell them why you asked them, and
not someone else.
Explain how their mission and vision
align with yours.

HOW THEIR DONATION WILL BE USED

Be specific.
Explain how their donation will
help families in need of support.

THANK THEM

Be sure to follow up with a note
letting them know what their
generosity meant to your group.
Share pictures when appropriate.

FINDING FINANCIAL SUPPORT

The larger your organization is and the bigger your goals, the more money you will need for sustaining your support program. **It is important to determine your needs and budget for reasonable expenses.** Some budget considerations include:

- Distributing a **newsletter**: Either through printing and mailing or through the use of a platform such as Mail Chimp or Constant Contact.
- Developing and maintaining a **website** and/or online support group
- Developing and distributing **printed materials** to new NICU parents
- Providing **gifts** for new NICU parents
- Providing **meals** and **refreshments**
- Hosting **social events**
- Hosting **educational webinars** for parents and/or volunteers, professionals
- Funding a **lending library**
- Reimbursing volunteers and NICU parents for **babysitting** and **transportation**
- Planning and hosting a **conference**
- **Exhibiting** at professional conferences to raise your organization's profile
- **Telephone** expenses
- Office and storage **space**
- **Paid staff**

FUNDING SOURCES

Sponsorships You may be able to create a relationship with a hospital's foundation, a national parent support group, a nonprofit agency, or a local business that can provide seed money and/or larger grants to your organization.

Donations Nonprofit support programs that have parent graduates can solicit donations through a letter-writing or email campaign, and through donation buttons on their websites.

Fundraisers Events that raise money include bake sales, raffles, car washes, and fundraising dinners (but you can be more creative!). Again, partnering with local businesses can be a win both for the business and for your organization. Some money-raising events require a permit; check with your local government.

Grant writing Ultimately, you may choose to write a grant for foundation money. There are many foundations, corporations, and government agencies that offer grants (check the Internet and library for local guides). Most require nonprofit status.



Online Fundraising Tools and Resources for Nonprofits:

Nonprofit Tech for Good
Facebook for Nonprofits
PayPal Donations
Network for Good

www.nptechforgood.com
nonprofits.fb.com/topic/fundraising-tools
www.paypal.com
www.networkforgood.com

TRAINING PARENT SUPPORT VOLUNTEERS

As discussed earlier, parent support comes in a variety of forms: through group meetings, social activities, and by pairing veteran parent support volunteers with new NICU parents. Knowing the right thing to say to parents coping with a crisis is not always easy. A training workshop can help by:

- educating parent support volunteers on **appropriate volunteer procedures**, both for your organization and for the hospital(s) in which you will be providing services
- teaching **active listening** techniques
- helping parent support volunteers to recognize and to cope with potential **difficult situations**
- familiarizing volunteers with community referral **resources**
- allowing parent support volunteers to **process their own experiences**, helping them to recognize how past experiences may impact their volunteer abilities
- minimizing **liability and confidentiality** issues

Who Should Volunteer?

Many parents choose to volunteer as a way to give back to an organization that helped them, or to provide understanding to parents going through a similar experience as they did. Parents who are ready to help others are those who have resolved their issues by integrating the trauma into a learning experience, and they have matured and grown from the experience. **Potential peer support volunteers should:**

- be emotionally **ready to talk** about their own crises
- be **good listeners**, allowing others to talk
- be **open-minded**, allowing others to have different opinions
- exhibit **emotionally stable** characteristics (for instance, they do not lie, exaggerate, or “take sides”)
- **accept people** with different cultural, ethnic, religious, or socioeconomic backgrounds
- **do not have a history** of contention, discord, or dissatisfaction with the support program or the organization with which the program is affiliated



SHARING YOUR STORY

Never underestimate the power of sharing stories. When parents share their stories they:

- Acknowledge their traumatic experience
- Understand their feelings and reactions better
- Find meaning in what has happened
- Feel more capable and resilient

Additionally, they should meet the following criteria (Adapted from The Tiny Miracles Foundation):

- Must be out of the NICU for at least **2 years**
- Have been in the NICU for at least **one month**, or longer with their baby
- Have a **recommendation from a NICU nurse or doctor**
- Have personal/professional/volunteer **recommendations**
- **Pass all background checks**, criminal and professional, and educational
- Have a **relationship** with someone who is familiar with them, within the organization
- **Be able to pass all health screenings** for becoming a parent support mentor and hospital volunteer (usually requires a negative test for tuberculosis and record of required immunizations)
- Be able to provide **consistent volunteer service** (suggested bi-weekly), and have proper communication skills (both written and oral) to coordinate with staff and other volunteers
- Be able to **complete formal mentor training** conducted by the parent support organization for 2 hours, and shadow an experienced parent mentor for 2-3 onsite mentoring sessions
- Be able to **complete training to become a volunteer at the hospital** where the volunteer will be a NICU mentor
- Be able to attend **follow up mentor training sessions** each year



Every support group has different needs. Organizations will have to review the above criteria and adapt them to their own specific requirements.

Carefully screening potential volunteers is essential. The volunteer trainer or coordinator should be chosen carefully in advance and demonstrate the ability to screen, train, and place peer support volunteers. The volunteer trainer or coordinator could be a hospital employee and/or a parent; but if a parent, the selection and training of volunteers should have the input of NICU professionals.

Not all parents are suited to give direct support, and these parents should be encouraged to find alternative volunteer activities. **To help identify those who may not be ready to offer peer support, consider the following:**

- Does the potential volunteer often talk about **unresolved issues** regarding care, negative feelings toward caregivers, or any other ongoing issues?
- Does the potential volunteer **get easily irritated over certain issues** (in other words, exhibit 'hot buttons')? Does the potential volunteer talk about possible litigation?
- Is the potential volunteer capable of **understanding different points of view**?
- Is the volunteer comfortable supporting parents with **different cultural, religious, or political views** than their own?
- How does the potential volunteer **manage stress**? For example, excessive use of alcohol may be an indicator of poor stress management.

Conducting a Training Workshop

While formats for training programs can vary, **there are some key topics that should be addressed** through sharing stories, role-playing, reading case scenarios, and discussion. Developing a training manual with relevant information and community resources can be helpful. **Ask other organizations similar to yours if they have a training manual you can review.**

Most training sessions begin with prospective volunteers sharing their unique stories – the personal experience that motivated them to volunteer. **Sharing these stories can help:**

- the volunteer trainer to **get to know the volunteers and evaluate** their readiness to volunteer
- the volunteer trainer to **pair volunteer parents with new parents** (if one-one-one support will be offered)
- the **volunteers to begin feeling more comfortable** with reliving the details of their crisis (and perhaps self-evaluate their readiness to offer support to others)
- the volunteers to **recognize that they are not alone** and that while every parent's experience is unique, experiences often share similar elements and parents often share similar feelings

Providing a volunteer job description – **what is expected and not expected of a parent support person** – can be helpful. Ensure that volunteers understand that they are laypeople offering support. The main roles of a parent volunteer are to be a **good listener, to offer resources, and to encourage families to become advocates.** Volunteers should never give medical advice.

Content of training may include:

- Defining the **roles** of a parent mentor:
 - To actively and empathetically listen and encourage the NICU parent without trying to solve their problems or give them advice
 - To assist parents in identifying and utilizing their current support systems
 - To offer emotional and informational support
 - To encourage advocacy for their baby
 - To empower parents to step into their parental role as an essential member of their NICU baby's care team
 - To identify when to ask for help and where help is available for parents they are supporting
- Defining **expectations** of a parent mentor:
 - To maintain confidentiality: the manner in which each hospital handles the sharing of patient information should be communicated
 - To treat all parents with respect, regardless of their cultural, racial and ethnic backgrounds, socio-economic status and religion
 - To make a time commitment for the program
- Development of essential **skill set**:
 - Basic communication and reflective listening skills
 - Understanding of expected and normal emotional responses of NICU parents and responses which indicate parents might be at-risk for more serious mental health issues, including signs of depression

- Criteria for when volunteers should contact a volunteer supervisor about any concerns, so that the supervisor can then contact a professional
- Knowledge of hospital and community resources

Parent mentor training should be offered to groups of 8-12 parents at a time whenever practical, allowing for **a group that is small enough to result in intimacy but large enough to stimulate conversation** and facilitate role-playing and other training methods as necessary.

Demonstrations and observations, role-play, practice interviews and videotaped interviews can be utilized as training methods.

Mentors should be encouraged to reflect on their own NICU experience and consider how it may affect their provision of support to NICU parents.

Ongoing supervision of peer mentors is recommended to ensure that both group facilitators and individual mentors are supported and provided guidance when needed.

[Extracted from: Hall S, Ryan D, Beatty J, Grubbs L. Recommendations for peer-to-peer support for NICU parents. *J Perinatol* 2015;(35):S9–13.]

THE ROLE OF PEER MENTORS

A volunteer trainer must also stress that **the volunteer's role is not to solve every family problem**. Oftentimes families enter volunteer relationships with many problems that have nothing to do with the reason they are seeking support. Volunteers should not get caught up in complicated family needs. **Support program leaders can develop a resource list** including helpful organizations, health and human service agencies, and a list of professional consultants. In addition, **volunteers should not feel obligated to give more of a commitment than they feel comfortable**.

Reading and discussing case scenarios should be an important part of a training workshop. This allows the trainees to “test” their handling of certain situations and the trainer to provide feedback. **Following are some difficult situations that can be discussed.**

Medical procedures: What should you do if a parent asks about a controversial medical procedure? (Provide resources and literature and tell the family that it is okay to ask health professionals many questions, including asking about possible complications and side effects.)

Extreme anger: What would you say to a family who was extremely angry and talking about taking legal action? (Tell them that you understand their anger and frustration, and then refer them to a professional trained to deal with these types of issues, such as a social worker or a crisis counselor.)

Depression: What would you do if you had a parent who was very depressed and possibly suicidal? (Immediately refer that person to your volunteer supervisor who will in turn contact a professional.)

Attention seeking: What would you do if you had a parent who exaggerated his/her story and seemed to not be telling the truth? (Do not get distracted by the exaggerations and continue to offer support. Report your concerns with your volunteer supervisor, a social worker, or a crisis worker.)

Death: How would you deal with a death of an infant? (Let the family know that you are sorry and that you are still there for them. Provide them with a list of bereavement resources, including books, articles, support programs, websites, and trained professionals who have experience in bereavement counseling. Do not stop supporting the family.)

Matching Veteran Parent Volunteers with Current NICU Parents

The volunteer coordinator should consider many factors when connecting a new NICU family with a peer volunteer. **Matches may be most effective when the families share similar characteristics and experiences.** Some people recommend that facilitators should attempt to match veteran parents with new NICU parents based on the similarity of:

- baby's gestational age and diagnosis
- parents' ages
- family size, structure and lifestyle
- education and income level
- culture, language, and ethnic background
- geographic location

All parent matches should be followed up to determine their suitability, and the opportunity to change mentor/buddies should be available.

Tips for Peer Support Volunteers

Below are some helpful points for parent support volunteers to remember. Add these to training discussions and/or your training manual.

- Ask the family **how much contact** they think they would like. Some families will be satisfied with one conversation; others will want ongoing contact. Ask the family when you should call or visit.
- Discuss with the family whether they prefer to have contact in person, over the phone, or by text or email. **Volunteers should determine their personal limits as well**, such as whether they want to allow parents to contact them at any time, or within specified limits.
- Remember to listen for context, not just content, during a conversation. People react in many different ways when facing fear and stress. Try to think of the feelings, not just the words. **Ask questions and do not judge.**

- **Maintain confidentiality.** Never discuss a family’s situation with others (unless it is to report a concern to the volunteer supervisor). If you are supporting parents in a healthcare environment, you may be required to sign a confidentiality agreement.
- **Let the family tell their story** and ask questions. Refrain from offering too much information, which may be overwhelming.
- It is natural for parents to be curious about your experience, which may offer great hope to them. Keep in mind, however, that every experience is unique and every person is an individual. **Emphasize that every situation and family will follow its own course.** However, you can talk about specific things that helped (or did not help) you.
- While offering support, **it is not uncommon for volunteers to revisit difficult feelings** that were and continue to be extremely painful. Even those who are many years away from the experience can be caught off guard with an overwhelming sense of sadness and anxiety. Try not to discuss these feelings with the family as it may provoke added anxiety. Instead, talk to a supportive person, such as a friend, family member, support peer, or a counselor.

Sample of a Volunteer Training Agreement

I understand that after attending the volunteer training that I am required to: (fill in the blank of what is expected).

As a volunteer, I understand that I will have access to patient information. As a condition of my volunteering, I will treat all information as strictly confidential and will not disclose such information without prior authorization. When authorized, I will disclose confidential authorization only on a need-to-know basis. I agree that I will not share confidential information at any time with any person not authorized to receive such information. If I need to talk about a patient or parent, I may speak to my supervisor. I may also ask for help for myself if I begin to experience discomfort with my own personal issues evoked by the volunteer experience. This information will be kept confidential as well. I will not share my personal issues with the patient or parent that I am visiting.

Print Name

Signature

Date



Am I a mandated reporter? Peer-to-peer organizations have unique obligations to the families they serve. If volunteers have concerns, it is critical that they respect confidentiality and do not share a families’ personal information - or the content of their conversations - with anyone other than the volunteer program director. To find more guidance on this sensitive subject visit the U.S. Department of Health & Human Services’ Child Welfare Information Gateway at www.childwelfare.gov.

TYPES OF PARENT SUPPORT

A parent support organization can provide one-on-one individual support from veteran NICU parents to new NICU parents, either in person or by phone; support through group meetings; or web-based support.

ONE-ON-ONE SUPPORT IN PERSON

This is probably the best model for the provision of peer support because the support is personal and is **tailored to what the individual NICU parent needs and desires**. Volunteers can reach out to new NICU parents individually by introducing themselves while making informal rounds in the NICU, or they can be matched with new parents who have requested support from the organization.

Providing support at a baby's bedside relieves the new NICU parent of the responsibility to leave the NICU to access support, and gives volunteers the chance to be helpful "in real time," as events may be unfolding in the NICU. Volunteers can check in with parents about how often they may desire contact, and contact can even continue via other methods such as phone, email, text, group meetings, etc. Drawbacks are that **some parents may not want to take time away from their baby** at the bedside to talk, preferring to access support from the privacy of their home at a later time. Also, some matches may not be successful; **parents should always have the opportunity to request a new match**.

ONE-ON-ONE SUPPORT BY PHONE

Telephone support is a good option when current NICU parents don't want their time with baby interrupted. Again, receiving support over the phone while at home may be preferable to some. This is an excellent option, too, for parents who have difficulty with transportation or other responsibilities (such as caring for siblings in the home or going to work) that may prevent them from spending time in the NICU, especially during the day when veteran parents are most likely to be able to visit the NICU themselves. Telephone support can be more spontaneous, especially if veteran parents are flexible and willing to be contacted throughout the day and evening. One drawback might be finding a time for parents to connect that is mutually convenient.

An especially useful feature of telephone support is that **it can be made available to parents anywhere** in any geographical area, so if a family's baby is hospitalized in a NICU that itself doesn't have any peer support programs, parents can still avail themselves of support. Parents may find this type of support either through referrals from NICU staff, especially social workers, from promotional materials that national support organizations may send to various NICUs, or from their own online searches. If your parent support organization plans to provide telephone support, you will need to decide whether it will do so only for parents at specific NICUs to which you will be providing services, or to any parents upon request. **Again, if parent matches don't work for whatever reason, it should be made clear to every parent that they have the opportunity to request a new match.**

PARENT SUPPORT GROUPS

Parent support groups can be primarily supportive in nature, or primarily educational in nature, but most groups will provide both at the same time. Some parents will shy away from coming to groups advertised as “support groups,” thinking they don’t need support; they may be more receptive to sessions that are advertised as being educational in nature. A typical model is for such group meetings to be held at the hospital and jointly run by a NICU staff person and a member of a parent support organization.

This model of parent-professional collaboration leads to the best group longevity, because both NICU staff and volunteer parents are committed to its success. The frequency of group meetings is determined by the size of the NICU’s parent population and the need, as well as by availability of staff and volunteer parents.

Many programs will have monthly offerings to which **both current NICU parents and recent NICU graduate parents are invited.** These may be hosted over lunch (“Lunch and Learn” sessions) or in the evening, sometimes with an informal dinner provided by the support organization.

It is necessary to both advertise the group meetings and to actively recruit current NICU parents through personal invitations at the bedside. For some parents who come to group meetings, **this may be the only type of support they access.**

Group moderators can even provide some feedback to NICU staff based on feedback they receive from parents in the group. **Having both NICU professionals and parents participate in the group can lead to improved understanding and relationships on both sides.**

WEB-BASED PARENT SUPPORT

An online community can add to, perhaps even improve, the support services of your traditional support program by offering **another support source for members** (or you may decide to start an online community in lieu of a traditional support program). Online groups can:

- help parents learn that their experiences are not so different and there is a **community of other parents** feeling the same way they are
- offer **flexibility** in time, location, accessibility, and level of involvement
- give a **sense of anonymity** that some parents find comforting (some people prefer not to talk face to face)
- provide **opportunities to learn** about special services or medical treatment outside of their geographic boundary

SHOULD YOU JOIN AN EXISTING ONLINE COMMUNITY?

Learning about how other online parent groups work can be helpful if you are considering starting an online community for your traditional support program's membership. **If you are thinking about starting a broader-based support network, you should investigate whether an existing group can fulfill your (or your organization's) goals.** If there are many similar groups that serve the needs of the population that you seek to support, recreating yet another one may be unnecessary and counterproductive.

Your contribution to an existing group could be uniquely valuable. If you have an area of expertise and join an online community, you may have the opportunity to become a group leader. In order for online support groups to fulfill their goals, individuals who have leadership skills must emerge from within the group. Much of the burden of facilitating a group typically falls on the shoulders of the person who started the group, the group owner. It is helpful to have trusted members that can take on some of the workload and aid in the development and advancement of the group.

Finding out what online groups are out there is as easy as typing keywords (for example, "preterm infant" or "antepartum bedrest") into a search engine, such as Google. Numerous websites, including support groups, will result from this search. **People who do not have the time to devote to starting a traditional support program, but who feel motivated to help others, often find an outlet for their energy on the internet.**

TYPES OF WEB-BASED SUPPORT GROUPS

Internet support groups vary, and the mission of a support group will dictate which form it will take. **There are three main types of online groups:**

Bulletin or message boards: These are spaces on the Web where individuals can write (or post) messages for others to discuss and comment on. Some bulletin boards offer users the ability to read archived posts and search for specific topics.

Mailing lists: Also called listservs, these lists allow individuals to write e-mails that are shared to the entire subscription member list.

Chats: Chats are gatherings of people where questions and commentary are posted in "real time."

These Internet-based support groups operate in different ways. A busy or large mailing list can generate hundreds of e-mails per day, while a smaller group may only have a few messages a week. Before joining or starting a Web-based support group, it is imperative that you determine how you feel about receiving messages that might not be relevant or helpful to the group's purpose. Bulletin boards offer more flexibility because members have the option to go to the bulletin board and read or not; the drawback is that members may be less likely to fully participate in the group. You should also consider safety issues, which will be addressed later.

There are also groups that operate like a mailing list and a bulletin board, such as **Yahoo Groups** (www.yahogroups.com). Members have the option of receiving the messages that the group generates via e-mail or going to the group's webpage to read the messages. Generally, these types of groups also offer a daily digest, which is a compilation of the messages sent. This is a good option if you are uneasy about the number of messages that will appear in members' inboxes and would like the ease of replying to messages from e-mail programs.

To supplement a support group's existing bulletin board or mailing list, chats are helpful. Group owners schedule a day and a time for everyone to "meet" in a chat room or on **a facebook page, or a chat room can be open all of the time to allow people to come in and out as they choose**. Chats can also be scheduled at a particular time, on a particular topic, and can be moderated by a healthcare professional. The support from chats may be sporadic, but participants have the opportunity to connect with people on a more personal level through typing to each other in real time. A disadvantage to chat groups is that participants are unable to watch and get a feel for the group before jumping in. Support organizations' facebook pages can serve as both bulletin boards and places where chats are held. Additionally, chats can even be held on twitter using specific hashtags identified in advance.

When evaluating the different types of online support groups, you may be able to browse to get a feel for the dynamics of the group as well as its operation. To ensure your good intentions, some group owners may request a written explanation for why you want to browse the group. **If the group members have expressed concern over privacy and security, the group may be restricted**, preventing your browsing.

After a short time, the owner may require you to write an introduction, so if you decide not to join the group, thank the owner and unsubscribe immediately. If you decide to join a group, carefully read any messages that you receive from the group owner; **many groups send "welcome" messages that contain important information about the rules of the group** and the expectations that the group has of its membership.

SHOULD YOU START AN ONLINE PARENT SUPPORT GROUP?

The creation and maintenance of an online group requires effort and time. You must research the various types of Internet support, discussed earlier, and choose appropriately. **The kind of group that you decide on will determine the leaders' responsibilities**. If your online group will supplement an existing traditional support group, evaluate whether you have the necessary manpower to maintain an Internet group.

A high level of commitment by the leader is necessary for the group to succeed and flourish. **Message boards and mailing lists often need maintenance, archiving, and, most importantly, direction**. Chats need setting up, and then **moderating** to ensure that they are meeting the needs of parents and that the discussion stays appropriate. It is not uncommon for a group leader to have to start conversations and work hard at keeping them going, especially in the early days of a group. Eventually, the group will take on its own life. Until then, you need to anticipate being an active participant, a pursuit that can be time-consuming and, at times, emotionally arduous.

It is important to realize that because of the nature of the internet, online support groups have frequent ups and downs. **You cannot expect the group to remain a hub of activity at all times, and members will**

come and go frequently. These aspects of online groups can be frustrating, especially if you have invested a lot of time into the creation and facilitation of the group. Group owners must develop a tough skin and learn to accept that this is part of the Internet. It is unlikely that someone's leaving is a personal affront, but rather that the participant has gotten what or he or she came for or simply has become too busy to be an active contributor. If you are particularly close to the issue in your own life, or actively seeking support yourself, you may find it difficult to accept these realities. If so, consider joining an established group as a member until you are emotionally ready to develop your own.

KNOW YOUR TOPIC AND YOUR MEMBERS

Most likely you have personal or professional experience with the issue that has influenced you to want to offer support to parents. **Successful online groups are led by those who have knowledge of a family crisis and who understand what the family is experiencing.**

Be prepared to stay informed. Your members may turn to you for help in finding services, guidance in searching for information, and help in coping. The people that you encounter within your community will come from a wide range of ethnic, religious, and socioeconomic backgrounds. It is vital to the success of your group that you are willing and able to **accept diverse points of view.**



CONTINUING YOUR EDUCATION

If parents are going to make informed decisions about their children's care they need reliable and accurate information. In your role as a parent support specialist, families may come to you for information and resources. You are more likely to be able to help them if stay current. You may want to:

- Subscribe to professional newsletters (AAP, NANN, MedPage, PPA, AWHONN, NPA)
- Take online educational webinars (CDC, DSHS, FAN+PPA)
- Attend conferences and workshops (especially NPA's and PPA's)
- Join your local perinatal association or quality collaborative

REMEMBER: Every family will need to make the choice that is right for them, but if you can direct them to reliable sources of information you are modeling good decision-making skills.



The National Perinatal Association's Family Advocacy Network and the Premie Parent Alliance are two excellent resources you should know. They partner to offer professional development and technical support for community leaders. Visit their websites to learn more: www.nationalperinatal.org/fan and www.premieparentalliance.org

STARTING AN ONLINE PARENT SUPPORT GROUP

GROUP SETUP

It is easy to set up a mailing list, bulletin board, or a chat. There are many free mailing list servers, bulletin boards, and chat servers available. **These services will give you step-by-step instruction on how to start and maintain your group.** Many of these services have advertisements on them, but they generally offer you the option of purchasing ad-free service. Most of these services offer “help files” and e-mail support for questions. Naturally, if you choose to purchase the service, you are going to be offered more support.

If you are interested in starting a group that is more personalized, or you have specific ideas in mind about how you want your community structured, **you can use one of the many web design tools available online**, like Wix or Wordpress, that offer tutorials and customer support. If you need to learn more you can take a class on HTML (hypertext markup language), web design, and other programming languages at your local university or community college. Certain campuses even offer online classes.

There are also many books available on these subjects and if you are really self-motivated, you can teach yourself. The Internet itself is also a wonderful resource for material on this subject. Lastly, if you do not have a computer expert volunteer, you can hire a programmer/website designer to design a site that is specific to your needs. This can be quite costly, but you will get exactly what you want.



THE IMPORTANCE OF WORD OF MOUTH

This is the most informal method of recruiting people for support groups, and it's the most effective. But it takes time. Don't get discouraged if you have very low levels of interest and attendance at first. As you build a reputation for being a safe and supportive place for families, membership will follow. Tell everyone you can about the group, and ask them to tell others. When your group meets, ask for their feedback. Be open to suggestions. Then encourage members to tell others about the support group. People are more likely to join if someone they trust recommends you.

PUBLICITY

Once you have a finished online community, you will need to publicize your group. The most effective way to bring traffic to your site is to submit it to search engines and to use “key words” that will bring interested people to your site.

Asking for links on websites that are relevant to your topic can be a very effective way to promote your group. Simply e-mail the web master of the site and ask them to list your link. Many site owners are happy to do this, as it makes their site more comprehensive, but they may ask that you reciprocate. It is good “netiquette” (proper behavior on the web) to agree to do so.

MODERATING THE GROUP

Initially, you (or a member within your organization) will be the sole moderator of your support group. If you want your group to thrive, you will need to have several important elements in place: **volunteer moderators, training for those volunteers, a disclaimer, and a set of rules for your community.**

Choosing moderators should be done carefully. Individuals that stand out as leaders do not necessarily make good moderators. You need to look for people who have the ability to keep control without pushing their personal opinions. Moderators should have welcoming and pleasant personalities, providing a comfortable atmosphere for all participants. Good moderators must be able to deal effectively with members who violate rules, and they should not take such encounters personally. It is not always clear who will make good moderators, so take your time in selecting them.

Training for moderators is as important to online support groups as it is to traditional support programs. Moderators will need a familiarity with the management tools of your group as well as a clear understanding of the organization's policies. A training packet can be useful; include guidelines for dealing with disruptions, a copy of the group's rules and regulations, a confidentiality agreement, and any other helpful documents.

PROTECTING MEMBERS

Online support groups can fulfill many important and valid needs, but they are not without a downside. Humans need contact with other people internet groups should not replace that very real need. **It can be easy to get caught up in the online world and lose touch with the support systems that exist in the real world.** If you notice that a member is spending a great deal of time posting messages, you might consider e-mailing them privately and encouraging them to seek support from family, friends, or a professional. **Members should seek help through a variety of sources, and they should use what they learn from support groups to develop new and varied coping skills.**

Another drawback of web-based communication is the lack of intonation and visual cues. **It is easier to misinterpret a post or email than a conversation.** A hastily written response may prompt a negative response and divert the group from their role of supporting each other. **Even posts written with good intentions may be taken the wrong way.** While in crisis, members may have difficulty expressing their feelings and be misunderstood. In addition, members may become worried when another member stops posting.

Be prepared to remind your group of these possible difficulties and continue to support your membership. A written explanation of what is expected of members when they participate in your group can be particularly helpful. **Clear guidelines and expectations promote a sense of community,** and users should be informed of what can happen if they do not adhere to the rules of the group. **If your topic is especially sensitive, your group members will appreciate that you are striving to offer them protection and a comfortable place within which they can post about personal issues.**

The following are some steps you can take to protect your online group:

- **Implement a confidentiality agreement** for volunteers to sign to help limit the disclosure of personal information.
- When deciding on the type of support group (e-mail list, bulletin board, or chat), look for a service that encrypts user information and **does not allow other members access to identifying information**, such as e-mail addresses.
- **Do not make it a requirement for membership that participants supply information** that could help locate them. If you do not have or store that information, it is unlikely that your group can become a target.
- **Write a privacy policy** (look for examples on websites similar to yours) and post this policy in an easy-to-see place. Your privacy policy will also serve to remind your membership that the information exchanged within your group should stay within your group.
- **Include a disclaimer** on your website. Look at disclaimer on websites similar to yours. Consulting a legal professional is a good idea.

Helping your online community (and your volunteers) feel safe and comfortable within your group is one of the major factors in guaranteeing its success. **If you are careful in the setup and maintenance of your group, you will create a positive and supportive community.**

EXAMPLE OF A GENERAL DISCLAIMER:

This is a community support forum - run by parents, for parents. We are not medical professionals, and only speak from our personal experience as parents of children born prematurely or who have had a stay in the NICU.

Resources mentioned on or by NICU Family Forum are listed for educational and support purposes only. Any comments or advice posted on our site or our Facebook page by our community, or the views and opinions of the resources shared do not necessarily reflect the opinions of NICU Family Forum or Hand to Hold.

Endorsement, recommendation, or favor by NICU Family Forum is not implied or constituted by being listed as a resource or shared on our site or the Facebook page. Any such mention shall not be used for advertising or product endorsement purposes.

Thank you to Hand to Hold for sharing this example. www.handtohold.org
Visit their facebook page at www.facebook.com/HANDtoHOLD

SUSTAINING A PARENT SUPPORT PROGRAM

All support programs (online and off) can be tremendous supplements to parents' experiences, but they need good direction in order to achieve their goals. **The purpose of any support program is to help individuals deal with a difficult time in their lives, move on to productive and healthy outlooks, and become powerful advocates and voices for change.** If you plan carefully and spend time with the details, you can provide people with the opportunity to build relationships that can be positive and life-affirming.

The following are some suggestions from successful parent support organizations for maintaining and growing your program:

- If you are working closely with a hospital or with healthcare professionals, it is important to **establish a trusting relationship**. Medical professionals have an obligation to serve families. You will gain support by demonstrating that your support program has the parents' best interests in mind.
- **Evaluate your program's progress** (or lack of progress) at least once a year. Have your goals been met? Were your goals realistic? Are additional goals needed? Do you need to change priorities? Ask the membership and the people you serve for feedback.
- **Avoid burnout** by recruiting new members, dividing and delegating the work, and frequently shifting the workload.
- **Let your volunteers know they are appreciated**. A simple thank you is all that is needed, but you can also host volunteer appreciation lunches and write notes of thanks.
- **Network** with other programs similar to yours and share ideas by setting up brainstorming sessions and hosting informational nights.
- **Welcome criticism** and agree to disagree. Members should feel comfortable about sharing feelings and expressing their ideas; however, no one should ever "attack" another member's feelings or ideas. Have training sessions on conflict resolution and skills for active listening.
- **Avoid having the same people lead for too long**. Having leaders serve for two years gives that person time to get into the organizational leadership, but avoids having one person's ideas dictate the activities of the support program. However, continue to utilize the skills of the seasoned leaders.
- **Encourage the development of leaders** through trainings, by joining organizational memberships, and by attending conferences (such as NPA's annual conference). Networking with other parent support leaders throughout the country can give members a real lift and help them to realize that what they are doing is truly important. Ideas from other organizations are often a way of creating excitement, and renewing the energy necessary to keep a parent support program going.

