

Finding Other Families: Listservs and On-line Communities

After our children were diagnosed with neuroblastoma, most of the parent authors of this Handbook felt alone in a way never known before. Family and friends circled around us in support, many of them with stories of family members and friends who had been cured of cancer. But it didn't always help. What we wanted was to connect with other neuroblastoma parents, and know that their kids were okay. We wanted to hear success stories from people who had experienced exactly what we were facing.

One parent recalls the day she finally met another stage 4 neuroblastoma family at her hospital -- the child was close in age to hers and had responded successfully to treatment. She recalls needing to meet them like needing to eat that day. It gave her the first real sense of hope she had felt since her child's diagnosis.

If you are reading this, chances are you're a parent, family member, or close friend of a child with neuroblastoma. Whether you're right at the beginning of the journey or several months into it, you may have few or no acquaintances in the neuroblastoma community. If you wish to reach out and connect with other neuroblastoma families (and not every parent does), know that it can easily be done. After reading this short section of the Handbook, you will have the ability to connect with hundreds of neuroblastoma families -- online, by phone, or even in person. Support, hope, and neuroblastoma success stories from those who have walked the walk are definitely out there.

The largest support group of NB parents can be found online -- on the N-BLASTOMA listserv sponsored by the Association of Online Cancer Resources, or "ACOR." For many of us, finding this group was like finally glimpsing a lighthouse from a stormy sea. You can subscribe to the group on the ACOR website. Click on "MAILING LISTS" at www.acor.org and look under "N" or go to <http://listserv.acor.org/archives/n-blastoma.html>. You will see N-BLASTOMA listed. Click on "join or leave the group" and you can join the group immediately.

N-BLASTOMA is an active online group of parents from hospitals across the country and around the world. Its members offer general support as well as information and personal insights about any and all aspects of neuroblastoma treatment (including frontline and relapse). Currently there are over 650 subscribers, all of them families and friends of children with neuroblastoma. Posting a question or a "hello" on the N-BLASTOMA listserv will get you responses within hours, or sometimes even minutes, depending on the urgency of your message. You will find lasting, valuable connections with parents who have experienced in the past or are facing now exactly what you're going through.

Once you join, posts can be sent directly to your e-mail. Some parents have found it helpful to create a filter using N-BLAST as the filtering keyword, and a separate folder for this mail to be sent to, like "NB" or "N-BLAST". This way, any e-mail from the forum will be sent to a separate folder and will not take over your Inbox. The emails can also be received in a daily or weekly digest.

Keep in mind that there is no requirement to "post." The N-BLASTOMA listserv is in effect an online bulletin board and, if desired, you can monitor and benefit from it without ever revealing your presence.

Another online support group (newer and currently less active) can be found on the Children's Neuroblastoma Cancer Foundation website. Go to www.cncfhope.org, and at the top of the home page, under "Community," select "Forums." Here you can join the forum, and posts can be viewed on the website or sent to your e-mail.

Many neuroblastoma parents have found it invaluable to become friendly with the other pediatric cancer families at their hospital. Even if you connect with a family whose child does not have neuroblastoma, chances are they know someone who does. They can connect you with other families, and so on. It often evolves into a network of local parents that you can talk with, meet for coffee, or even schedule time together with your children. No one understands your child's weakened immune system like another family who's been there, and issues such as special accommodations or last minute cancellations won't bother a parent who has had to cope with a sick child of their own. Many parents form close relationships that continue long after their children's treatments have ended.

You could also mention to the nursing staff and social worker of your hospital that you would like to meet other neuroblastoma families. Although privacy laws prohibit them from giving you names, phone numbers, room numbers, or any other information, once you tell the hospital staff that you'd like to be contacted, they will pass your contact information along to someone else with your permission.

If you have a local cancer resource center, it may offer the opportunity to connect personally with local cancer families. Many such centers, primarily those in urban areas, offer programs, networks, and support groups for families. Even if support groups are not available, your local center may be able to connect you with other families in the area just by taking down your contact information and spreading the word.

You can also network with parents of children with neuroblastoma at annual conferences and other events held by various pediatric cancer foundations. The Children's Neuroblastoma Cancer Foundation has an annual conference for neuroblastoma families, offering presentations by neuroblastoma specialists and social events for the families. Many of the parents on the N-BLASTOMA listserv attend this annual conference in order to connect in person with each other. Events for families are also sponsored by Curesearch, Alex's Lemonade Stand, the Rally Foundation, etc. (although these are foundations focusing on funding research for all pediatric cancers). By registering on the websites of such foundations you can receive updates of their events.

If you haven't done so already, consider starting a [CaringBridge](#) or [Care Pages](#) website for your child (see "Keeping Friends and Family Informed"). Not only will such a website help you communicate updates to people without being bombarded by e-mail and phone calls, but you will be surprised at how quickly word of your website spreads. Through friends of friends of friends, you will receive messages from other cancer families, and eventually from neuroblastoma families, in the online "guestbook" these free website services provide. For example, one parent learned her sister-in-law's best friend worked with a neuroblastoma mom living about an hour away. She posted in the parent's guestbook and that parent then visited her son's website. This simple connection created a lasting friendship, yet they would never have found each other on their own. When visitors leave contact information in your online guestbook, you can then visit their websites and in this way gradually become part of a network.

Ultimately, whether and how you wish to connect with others in the neuroblastoma community is a very personal decision. You may learn that connecting in person with other neuroblastoma parents is an invaluable source of support and hope for you – or you may decide to be a "silent" member of an online support group and absorb the available information privately at your own pace. Each parent copes in a different way. Our purpose in setting forth these various suggestions is to merely to make sure that you know that these various sources of support and information are available. Neuroblastoma treatment can be long and arduous, and we wish you to know there is a uniquely caring community of neuroblastoma parents available for any who feel it would be helpful.

Please contact info@cncfhope.org with any comments