

Navigating Neuroblastoma and this Handbook (Read this First!)

Dear Parents in the NB Family,

This handbook has been prepared for you by parents of children who are or have been in treatment for neuroblastoma. We understand that there is no pain like hearing the word “cancer” used in connection with your child. Each of us has struggled to understand what it means to have our child diagnosed with a disease we had never heard of before, and to obtain the information we needed to manage our child’s treatment. Having been there, we want to offer you hope and tools to make this journey easier.

Although at this time you may feel overwhelmed and even helpless, there **are** things you can do to help your child and your family weather this crisis. Parents almost always express a sense of empowerment when they learn as much as they can about neuroblastoma and its treatment. We have developed this parent handbook to share what we have learned through our experiences fighting neuroblastoma. We have worked together to pool our collective wisdom about things a parent or other primary caregiver needs to know, so you won’t have to spend hours running down resources. We have assembled information that helped us cope and make informed decisions about our children’s treatment--information we hope will help you as well. Our goal is to ease your learning and allow you to spend more time concentrating on what really matters—your child and family.

About Neuroblastoma

Neuroblastoma (NB or NBL) is the most common solid tumor cancer found in infants, but that does not make it a common disease. Although about 1.4 million cases of cancer are diagnosed in the U.S. each year, fewer than 1% are in children. Of approximately 13,000 new cases of childhood cancer in the U.S. each year, only about 650 are neuroblastoma. **See Chapter 1 “What is Neuroblastoma?”**

Understanding that neuroblastoma is a rare disease is important. Some pediatric oncologists see very few neuroblastoma patients in an entire career. You are entitled to ask how many neuroblastoma patients your hospital treats, and to consult with pediatric oncologists and surgeons who specialize in neuroblastoma. You have the right to get all your questions and concerns answered to your satisfaction. **See Chapter 1 “Questions for Your Doctors”; “U.S. Neuroblastoma Specialists”; and “Patients’ Rights and Responsibilities.”** In addition to determining where and by whom your child should be treated, you may be faced with the decision of whether or not to enroll your child in a clinical trial. For many stages of this disease, the most promising treatments are available only through clinical trials. **See Chapter 1 “What is a Clinical Trial?”**

Treatment for neuroblastoma is determined based on a number of indicators that, taken together, determine the degree of risk—low, intermediate or high. In addition, there is a special low-risk category that some infants fall into known as 4s. **See Chapter 1 “What is Neuroblastoma?”** Children with low or intermediate risk neuroblastoma generally have a good prognosis and can be treated successfully by most pediatric oncologists. Treatments for these stages of disease range from “wait-and-see”—monitoring the tumor with periodic scans to see if it regresses on its own—to surgical resection and some chemotherapy. **See Chapter 2 “Overview of Low- and Intermediate-**

Risk Treatment.”

Half of all neuroblastoma diagnoses—about 350 cases per year in the U.S.—are classified as high risk. These children undergo aggressive, multi-agent therapy that includes chemotherapy, surgery, often some form of myeloablative therapy (transplant or targeted radiation treatments requiring stem cell rescue), radiation, differentiation therapy (e.g., Accutane), and often antibody treatments. **See Chapter 2 “Overview of High-Risk Treatment.”**

Neuroblastoma is most commonly diagnosed before age five. Diagnoses at later ages may present unique treatment challenges, because younger children can tolerate more aggressive treatment than teenagers and adults. Because of these differences, we have included a section on issues specific to teenagers and adults undergoing treatment. **See Chapter 3 “Special Issues for Teenagers and Adults.”**

At the current time, at least 20% of children diagnosed as high risk have “refractory” disease that is resistant to initial treatment, and over one third of those who reach remission—also referred to as NED, or “No Evidence of Disease”—will relapse and require additional treatments. Parents of a child with refractory or relapsed neuroblastoma may be faced with difficult and confusing choices. Because refractory or relapsed neuroblastoma tends to respond differently in each child, there is no agreed upon course of treatment, even among NB specialists, so parents must research available treatments and seek advice from many sources. **See Chapter 7 “Treating Refractory NB”; and Chapter 8 “Dealing with Relapse.”**

Because the risk of relapse remains significant after treatment for high-risk disease, additional treatment is important after children have reached NED. Some treatments are geared specifically toward eliminating microscopic disease, often called minimal residual disease (MRD), that standard testing may not be sensitive enough to detect. Some parents also consider the feasibility of alternative medicine. We have provided resources on this topic to help you explore the available options. **See Chapter 5 “Reaching Remission”; and Chapter 11 “Utilizing Complimentary and Alternative Medicine.”**

Children treated successfully for neuroblastoma continue to require medical care and monitoring. We have included information on the more immediate concerns you may have once your child reaches NED, **see Chapter 5 “Reaching Remission,”** and a guide to resources addressing issues related to long-term follow-up care after treatment. **See Chapter 6 “Living with Long-Term Survivorship Issues.”**

Your Role as Caregiver

As you have probably already discovered, the parent or primary caregiver of a child with cancer plays a critical role in the child’s treatment. You are an integral part of the medical team. The doctors are the experts on medical issues, but **you** are the expert on **your child**.

You can help ensure that your child gets the best possible care by working closely with the medical team. How to do this appropriately is not always obvious. Cancer centers and hospitals with oncology departments are generally large institutions with complex, sometimes intimidating, bureaucracies. We have provided a brief overview of the typical hospital structure to introduce you to the different professionals you will meet and some common practices. **See Chapter 1 “The World of Hospitals.”**

Understanding the way hospitals work and the responsibilities of the various hospital professionals

will help you cooperate better with your child's medical team. You will also be more effective if you can "speak the language" when you discuss your child's diagnosis, treatment, and daily well-being. The detailed information about neuroblastoma, its diagnosis and treatment in this handbook can help you do this. **See Chapter 1 "What is Neuroblastoma?"; Chapter 2 "Understanding the Basics of Frontline Treatments"; Chapter 14 "Neuroblastoma Terminology."**

You will also need to be familiar with the many different tests and scans used to diagnose your child and measure his or her response to treatment. These tests will be repeated about every 3 months during your child's treatment and periodically for several years thereafter. **See Chapter 4 "Getting Through Tests & Scans."**

You are entitled to copies of test results and other reports for your child. It is important that you keep copies of all test and scan results, and the clinical summary of your child's diagnosis and protocol or clinical trial. **See Chapter 10 "Why Keep Records?"** However, you do not need to keep copies of daily reports such as nursing notes, temperature charts or print outs of blood counts (which eventually may number hundreds of pages), if you maintain records sufficient to allow you to monitor your child's daily progress. Recordkeeping charts that you can download or print out and use for this purpose, along with explanations of common abbreviations and terms used by medical professionals, are included in the "Keeping Records" section of this handbook. **See Chapter 10 "Keeping Records."** Because many different professionals will be responsible, often on a rotating basis, for your child's treatment, such records will be invaluable when updating doctors and nurses (as well as other family caretakers) on your child's status. **You will be the medical team's most important source of information regarding your child's health.**

A crucial part of your role will be finding ways to help your child cope with the rigors of cancer treatment, especially if your child is undergoing the aggressive treatment required for high-risk neuroblastoma. Chemotherapy, radiation, surgery, tests and scans, taking pills or liquid medicines, getting shots – these will be a part of your child's daily life. These invasive measures may cause nausea, fever, infections, hives, pain, or other side effects, as well as anxiety, anger, depression, or fear. Each child's reactions are different. We have drawn upon our collective experiences to provide you with information and tips that have helped parents not only manage their children's medical needs, but also keep their children feeling as safe, comfortable, and happy as possible. **See Chapter 3 "Coping with Treatment: Side Effects, Comfort, and Safety."**

You may also need to help the medical staff perform the delicate balancing act of administering difficult treatments to your child without infringing on his or her dignity. The daily work of an oncology professional is understandably full of time pressure and emotional stress, and pediatric patients can be particularly challenging. Because maintaining your child's emotional well-being and sense of security is essential, we have included some guidance on ways to advocate for your child. **See Chapter 3 "Advocating for your Child."**

Many have observed that when a child has cancer, the entire family has cancer, and we have found this to be true. The struggles of a child in treatment affect siblings, parents and even extended family members in many ways. The issues range from brothers and sisters having problems at school, to difficulties on the job or in the marriage, to insurance and other financial problems. We are not professional counselors, of course, but we have included some tips that helped our respective families weather full-time cancer treatment, **see Chapter 9 "Managing Emotions,"** as well as a list of support resources that have been useful to many of us. **See Chapter 13 "Support Resources."** Most of us have found that one of the most valuable resources for parents is – each other! You can join an on-line support group for parents of children with neuroblastoma by subscribing at <http://www.acor.org/n-blastoma.html>.

Finally, while it is our fervent hope that you will never need to turn to it, we have included

information on hospice, pain management, and other end of life issues, as well as information on support groups for grieving parents and family members. **See Chapter 12 “Turning to End of Life Care.”**

The path your family has embarked on is one that few have to travel. Like childbirth, there is no way out of it but through it. It will test your strength in ways you never imagined, and you will push yourself to do things you never dreamed you could. But along this path you will also find more companionship, understanding, and love than you ever thought possible. Your perspective on life, and its priorities, will never be the same. We know there are many things you must discover on your own, but we hope this handbook will be a useful source of information and support to you during your child’s treatment for neuroblastoma. You are not alone!

Please contact info@cncfhope.org with any comments