



Questions for Your Child's Doctors

You have the right to have all questions about your child's diagnosis, treatment, prognosis, and other available treatments answered to your satisfaction, keeping in mind that many questions about neuroblastoma have no definitive answer. The questions below are some that we *wish* we had asked at the time of our child's diagnosis, so that we would have been better informed in facing the situation. We hope these questions will help you get the information you need to understand better your child's diagnosis and the treatment options.

Understanding Your Child's Diagnosis

How long will it take you to determine my child's diagnosis?

What tests will be done to diagnose my child?

Will all tests be performed at this facility?

Are there tests to determine neuroblastoma diagnosis and prognosis that are not available at this center?

What are the results of my child's tests and scans?

Where is my child's cancer? Has my child's cancer metastasized? To what extent?

What stage of disease does my child have and what risk assignment?

How do I get copies of my child's test results?

Understanding Your Child's Prognosis

What is the survival rate for children with my child's stage of disease and risk assignment?

What are the prognostic factors for NB and how are they determined?

Which prognostic factors affect my child and what is their significance?

What is my child's chance of surviving cancer-free for five years? For ten years?

Exploring Your Hospital's Experience with Neuroblastoma

How many children have you/this hospital treated with my child's stage of disease and risk

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assignment in the past year? In the past five years?

What cancer does each doctor in the department specialize in? What other cancers besides NB do they treat?

Which specific doctors at this center will treat my child? Which doctor is primarily responsible for my child's care?

Do the same doctors care for my child in both the day clinic and the hospital?

Who will perform my child's surgery? What types of surgery does this doctor perform? How many NB surgeries does this doctor perform per year?

Getting a Second Opinion

Are there NB experts in the country that I might consult? Who would you recommend?

Which centers in the country treat the most patients with NB?

Who are the leading NB surgeons in the country?

Exploring Treatment Options

What is the treatment for my child's disease stage and risk assignment?

What are the realistic goals of this treatment?

How many children have been treated on this protocol?

How long has this treatment protocol been in use?

Is this treatment a clinical trial (open or closed)? What are the purposes of this trial? Is randomization involved? What specific rules or limitations do I need to know about this trial?

What is the survival rate of children treated on this protocol?

Are there other treatment options for neuroblastoma and where are they available?

How do the survival rates vary for the different treatments?

Will my child undergo a stem cell transplant? What type?

What transplant alternatives are offered elsewhere?

Will my child be eligible to receive antibodies after transplant at this institution?

How does the regimen offered here differ from regimens at other centers? What are the risks and benefits of each?

Handbook for Parents of Children with Neuroblastoma

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Will stem cells be collected? When?

When will surgery be performed? How does this compare with other centers?

Do we have any choices about the treatment?

If this were your own child, what would you do and why?

Understanding the Demands of NB Treatment

How long does this treatment regimen generally take to complete?

Can you give me a detailed outline and schedule for my child's treatment?

Realistically speaking, what are the caretaking demands of this treatment on parents?

How often will my child be hospitalized? How many days per week will we be in clinic?

Can we do any parts of this treatment at our local hospital? What are the risks of doing so?

How will my child feel during treatment?

Which treatments are done on an out-patient basis, and which on an in-patient basis?

How do I keep my child safe during treatment?

Learning About the Risks of Treatment

What are the risks and short-term side effects of this treatment?

What are the long-term side effects of this treatment?

Understanding Tests to Determine Response to Treatment

How often will my child's response to treatment be evaluated?

Which tests will be used?

Where will these tests be done?

Do other cancer centers use different tests to determine a child's response to NB treatment?

Finding Information and Support

Where can I find information to learn about NB?

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Where can I find the results of studies about this treatment?

Have you published any studies about this treatment?

Where can I find studies about other available NB treatments?

What support services are available at this center for my child? For my family?

Who do I contact about insurance and payment issues?

Could I speak with the parent of a child who has completed this treatment?

Please contact info@cncfhope.org with any comments