

LEAD INVESTIGATOR

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We are available to answer your questions or provide additional information anytime.

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Neuroblastoma Epidemiology in North America

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The logo for Neuroblastoma Epidemiology in North America (NENA) features the word "NENA" in a large, bold, blue sans-serif font. The letters are slightly shadowed to the right, creating a 3D effect.

Neuroblastoma Epidemiology In North America

**A Guide for
Participants**



THE UNIVERSITY
of NORTH CAROLINA
at CHAPEL HILL

WHAT IS NENA?

NENA (Neuroblastoma Epidemiology in North America) is one of the largest research studies to date focusing on genetics, exposures during pregnancy, and the development of neuroblastoma.

- ◆ Neuroblastoma is the most common malignancy of infancy. This cancer primarily occurs in very young children.
- ◆ It is thought that genetics may play a role in the development of this disease. By analyzing genes from children with neuroblastoma, as well as genes from their parents, risk factors related to heredity may be uncovered.
- ◆ Because neuroblastoma is typically diagnosed at a very young age, researchers believe that studying a mother's diet, vitamin and medication use during pregnancy may reveal important clues about the disease.

Findings from the NENA Study will contribute to scientific knowledge about neuroblastoma. This, in turn, benefits children and families affected by the disease.

HOW DOES NENA FIND PARTICIPANTS?

- ◆ NENA is approved by the Children's Oncology Group (COG).
- ◆ The study receives family names, addresses, and phone numbers from COG's Childhood Cancer Research Network (CCRN). Only families that are registered with the CCRN and have already consented to being contacted for non-therapeutic research will be approached.

ELIGIBILITY FOR NENA

NENA seeks to enroll **600** children (both living and deceased) who have been diagnosed with neuroblastoma before 6 years of age, along with their biological mothers. Biological fathers are strongly encouraged to participate as well.

In order to be eligible:

- ◆ The biological mother of each eligible child must be living and available for participation.
- ◆ Biological mothers must have carried and given birth to their child with neuroblastoma.
- ◆ Biological mothers and fathers must:
 - Speak either English or Spanish.
 - Reside in the United States, Canada or Puerto Rico.
 - Be at least 18 years old when agreeing to enroll in the study.

How participation works:

- ◆ Everything needed to complete the study is provided by NENA and mailed directly to the home. Participants do not need to purchase any materials, pay for any postage, or travel anywhere.
- ◆ NENA staff based at the University of North Carolina - Chapel Hill are available by phone and email to assist with all aspects of participation.
- ◆ Adult consent forms and parental consent forms (for children) are provided by NENA for each person participating in the study. These forms describe the study in more detail and explain the rights of research participants.

WHAT PARTICIPATION INVOLVES

Participants complete ALL pieces of the study from their own homes. NENA provides prepaid mailers that participants use to return each item listed below.

Biological Mothers

Complete a paper/pen questionnaire that asks about health, pregnancy and medical history, family cancer history, intake of certain foods, drinks, and vitamins, and the child's early feeding habits. This takes about one hour to complete.



Biological Mothers and Fathers

Use a special spit-tube kit to self-collect a saliva sample. This takes about 20 minutes to complete.



Children

Parents or guardians of living children collect a sample of their child's saliva using a sponge kit specifically designed for use with young children. This takes about 15 minutes to complete.



Parents or guardians of deceased children are provided with a parental consent form. When signed, this form allows NENA to obtain a sample of tissue already stored through COG.

