LEAD INVESTIGATOR

Andrew F. Olshan, PhD
Chair, Department of Epidemiology
Gillings School of Global Public Health
University of North Carolina - Chapel Hill

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

Kathryn Carrier, MPH
Project Director
Phone: 919-966-3000
Fax: 919-966-6650
Email: kathryn_carrier@unc.edu

Elyssa Trani, MS
Research Assistant
Phone: 919-966-1635
Fax: 919-966-6650
Email: elyssa_trani@unc.edu

Toll-Free Phone Number
1-877-658-1623

Mailing Address
137 East Franklin Street
Suite 32, CB 8050
Chapel Hill, NC 27599-8050
WHAT IS NENA?

NENA (Neuroblastoma Epidemiology in North America) is one of the largest epidemiologic research studies to date that investigates relationships between genetic susceptibilities, in-utero exposures, and neuroblastoma.

- Neuroblastoma is the most common malignancy of infancy. This cancer primarily occurs in very young children.
- It is thought that genetics may be associated with the development of this disease.
- The early age of diagnosis indicates that exposures occurring during the prenatal period may also play a role in the etiology of neuroblastoma.

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

COG & CCRN

- NENA is approved by the Children’s Oncology Group (COG) - Protocol AEP107N1.
- IRB for NENA has been obtained from COG as well as through the University of North Carolina - Chapel Hill.
- The study recruits cases via the Childhood Cancer Research Network (CCRN) – Protocol ACCRN07 and does not require IRB approval from each institution.

WHAT NENA COLLECTS

Participants complete all pieces of the NENA Study from their homes and via mail.

Study staff recruit and assist participants by phone and email from the research office.

MATERNAL QUESTIONNAIRE

Biological mothers complete a pen and paper questionnaire about their pregnancy history, vitamin and medication use, and diet history.

ADULT SALIVA SAMPLE

Biological mothers and fathers collect their own saliva samples using special spit tube kits.

CHILD SALIVA SAMPLE

Parents/guardians use a child-friendly kit in order to collect a sample of their living child’s saliva.

STORED TISSUE SAMPLE

Parents/guardians of deceased children sign a parental consent form allowing NENA to obtain a tissue sample collected and stored through COG – Protocol ANBLOOB1.

ELIGIBILITY FOR NENA

NENA seeks to enroll 600 children (both living and deceased) who have been diagnosed with neuroblastoma, along with their biological mothers. Biological fathers, when available, are strongly encouraged to participate as well. When both biological parents participate, NENA can analyze genes from family triads. This increases the potential for understanding genetic susceptibilities related to neuroblastoma.

In order to be eligible:

- Children must be diagnosed with neuroblastoma between 12/24/2007 and 7/31/2013 at a COG institution.
- Children must have been under 6 years old at the time of diagnosis.
- The biological mother of each eligible child must be living and available for participation. Biological mothers must have carried their child during pregnancy.
- Biological mothers and fathers must speak either English or Spanish, reside in the United States, Canada or Puerto Rico, and be at least 18 years old when agreeing to enroll in the study.

- NENA collaborates with Principal Investigators and Clinical Research Associates at COG institutions. However, NENA staff members are the only ones responsible for recruiting study participants.
- Only families that have registered with the CCRN and consented to being contacted for future, non-therapeutic research are approached for NENA.