

ELGAN ECHO STUDY NEWSLETTER

Teens <u>Teach</u> about <u>ELGAN</u> and the <u>EN</u>vironment <u>S</u>tudy (<u>TEENS</u>)

The ELGAN ECHO Study has begun!

We first met when your teens were the tiniest babies, so it's very exciting to be able to welcome you back for our third follow-up visit fifteen years later. This visit is made possible by funding from the National Institutes of Health and a special NIH program called ECHO - Environmental Influences on Child Health. ELGAN and ECHO studies have combined together to increase our knowledge about health issues and outcomes in children all across the country. ECHO is especially designed to learn about environmental elements - such as those found in air, water or food, as well as bacteria or viruses in childhood illnesses, and also genetic and social environments - that may influence growth and development.

A Study Coordinator from the hospital where you were born (or the research center you visited when you were 10 years old) will soon be in touch with parents or caregivers about scheduling your 15 year study visit. Study visits began July 2017 at our lead site, the University of North Carolina at Chapel Hill. All other sites will begin study visits now (Fall 2017) and will continue through December 2019. We look forward to seeing you again very soon!

Meet your ELGAN ECHO Study site Team Members!

{Add Study Coordinator(s) and Principal Investigator name and photos here. Also, if appropriate provide any special information you'd like your teens to have that is particular to your site.

History of ELGAN: A Note from the ELGAN Study Creators

We thought you might like to know a bit about the background of the ELGAN Study. Our ELGAN subjects are teenagers now but the notion of studying the outcomes of premature infants goes back much further. We have been privileged to work with some incredible researchers who made ELGAN possible. The ELGAN Study began as a study of brain development in extremely preterm infants. Later, follow-up of premature lungs and eyes were added. As Alan Leviton and Liz Allred approach retirement, we asked them to provide for you with some insight into how it all began and where we are today. This is their story:

ELGAN began as a study of brain development in extremely preterm infants. Later, we focused on the premature development of the lung and the back layer of the eye called the retina.

In the early 1970s, it first became clear that some brain injuries in newborns were linked to infection and inflammation in the blood. During the next 15 years, it was not possible to find out if this applied to extremely preterm infants. Then in the early 1990s, ultrasound scans of the brain were improved enough to identify the type of brain injuries we were looking for.

However, we needed another research tool: the ability to measure the concentrations of many different proteins. When this technology became possible in the mid-1990s, we could really begin to plan the ELGAN Study.

ELGAN had to enroll a large number of babies in order to have this research accepted by other physicians and scientists. We needed the participation of almost all families whose

extremely preterm infant was born at more than a dozen university-affiliation hospitals during a two-year interval. Your family is one of more than 1,240 families who agreed to enroll their newborn in the ELGAN Study. To achieve our goal, we obtained cooperation from neonatologists, high-risk obstetricians, and administrators at 14 hospitals. Only then could we seek funds from the federal government (NIH) to carry-out the study.

The dream of identifying some of the events and exposures responsible for developmental problems in the brain and other organs is still unfolding. At each assessment, we have learned so much that will help reduce the occurrence of such serious medical problems, and the later consequences. For example, we have shown that high concentrations of inflammation-related proteins in the blood are indeed associated with injury to the brain, lung, bowel, and retina. We are just now showing that elevated concentrations of other proteins in the blood can prevent or minimize such injury, and might even enhance repair, thus minimizing the late consequences of the injury.

Thanks so much for your help in making this possible. We very much value your willingness to continue making the world better for future generations of extremely preterm newborns.

Publications

We have published more than 100 peer-reviewed professional articles based on information from ELGAN children during 2002-2007 (birth and 2-year assessments). So far, we have published 20 articles based on the assessments at age 10 years.

ELGAN ECHO Website and Facebook Page

Please visit our website, www.elganstudy.org. The ELGAN ECHO Family Website may be a useful resource for you, includes current publications, and may serve as a way for you to stay connected with people at your ELGAN ECHO Study location. Please check it out! You can also find and "like"

us on Facebook at www.facebook.com/elganstudy. This page has study updates, contact information and other ELGAN ECHO news, which may be helpful for you.

Teen Corner

Fall Word Search

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