



ECHO
Environmental influences
on Child Health Outcomes

Summer/Fall 2020

ELGAN ECHO Study Newsletter

With the spread of COVID-19, families are facing serious concerns about illness, jobs, schooling and more, and our first thoughts are for your health and well-being in these difficult times. We want to take this moment to send caring and “keep-well” wishes your way. Alongside personal worries, people are often asking how they can help. As part of ELGAN-ECHO, **you have an opportunity to contribute valuable information to our knowledge about COVID-19** as well as prematurity! We’ve added a survey on COVID for both parents and children. With your help and the help of thousands of other families participating in ECHO, we can gain critical knowledge about the effects of the pandemic in both children and adults. Thank you in advance!

Pediatric to Adult Transition

ELGAN ECHO participants are now 16-18 years of age, and some are high school graduates! Over the years, we’ve heard about your journeys after the NICU - of being terrified at times but also overjoyed at your and your children’s accomplishments. It’s been an honor to see you during these years of growth and development. We cannot thank you and your families enough for your dedication to ELGAN ECHO and this “team of vulnerable babies” blazing a trail for preemies for generations to come. For some of our ELGAN families, the NICU days are distant memories, faded by years of well-being. This road however has not been the same for all. Many of our ELGAN teens need assistance with everyday decision making and planning. Some have physical and/or developmental challenges that require on-going support. Parents worry about how to protect and care for their children as they themselves are aging. How does one select an adult health care provider once children age out of pediatric practice? What are options for post-high school education and job training? Will my child need full guardianship or are there other “steppingstones” for independent living? To help with these questions, we’ve listed some resources recommended by specialists in transitional care at: <https://elgan.fpg.unc.edu/resources>. If you know of other helpful resources, please relay that information to your Study Coordinator so we can add to our list.

ELGAN ECHO on the Road

Our last field trip for ELGAN ECHO before the COVID-19 pandemic was a visit in January 2020 to central Texas. Here is some branch & stone art from that trip. We are grateful to you all.



17-18 Year Visits are Underway!

Age 17-18 study visits started in-person in January 2020, then quickly switched to remote/online visits due to COVID-19. If your teen is 17 or soon to be, you and your teen are eligible to enroll. Some study activities can be done from your home at this time. When your study site is allowed to resume in-person visits, they will schedule a time for you to come in for an in-person visit and complete physical measurements, iPad puzzles, movement - strength - balance items, and collect bio-specimens. Please contact your study coordinator, xxx at (xxx) or email (xxx) with any questions.

What Questions are we Trying to Answer with ELGAN ECHO?

Many families have asked “what are the big questions we hope to answer with ELGAN ECHO”. We posed that question to our investigators. As their lists were long, we decided to choose 2-3 per newsletter along with a brief explanation on why these questions are of interest. You can also refer to our website elganstudy.org for our most updated list of publications.

A Focus on Epigenetics

Some of the science of the ELGAN researchers includes an assessment of the “epigenome.” The term epigenome literally means “on top” of genes. All of our cells contain genes. These genes can be turned “on” or “off”. We are learning that there are ways that the environment can modify our genes by adding “tags” onto our genes. These tags can come from many environmental sources including diet and stress and can serve like a light switch, turning our genes on or off.

We are very interested in finding out the following questions:

- Is a mothers’ socioeconomic status (and stress level) at the time that her baby is born associated with the addition of tags on the genome of the infant?
- What tags on the genome early in life around the time of pregnancy help infants with severe neonatal illnesses to go on to have favorable health and development later in life?
- What tags on the genome early in childhood (e.g. at age 2 or 10) help infants with severe neonatal illnesses to go on to have favorable health and development later in life?

Biospecimens

In our last newsletter, we described the many biospecimens that we are hoping to collect at the next ELGAN ECHO visit, one of which is stool. Studying the microbiome may be one of the most important aspects of the 17-year visit. Each of us have a unique microbiome that was established early in our lives - starting possibly even before we were born! Knowing all of this, we wonder if the microbiomes of ELGANs may be affected by prematurity. Although teens may find it awkward to provide a stool sample, please remember that our ELGAN ECHO investigators feel that this may lead to groundbreaking discoveries in the ways our bodies work!



Pictured above are the Study Coordinators from all 12 ELGAN sites and the UNC Study Lead Team attending a 17-year visit training session in December 2019.

Staying in touch

The teenage years zip by. People move and phone numbers change. Please remember to update your Study Coordinator of any upcoming changes to you (or your child’s) contact information. Please remember that there is no substitute for you and your child in this study. Long-term studies such as ELGAN ECHO depend upon the ongoing participation of ALL original enrollees.

Coordinator Name
Research Coordinator
Phone Number
Email Address

Check out the new publications & updates on our website: www.elganstudy.org: Family Recruitment Letter/ Covid Letter to Families / Microbiome video & storyboard.