Spring 2019

ELGAN-ECHO Study

You are Unique!

Even identical twins have non-identical bodies and minds, with different experiences and environments helping each one become the individuals she or he is.

Your unique personal development means you bring a unique piece of the prematurity puzzle to ELGAN research. Your participation ensures that we can learn from you about the many different ways ELGANs develop and mature over time.

We've seen well over half ELGAN teens for their first ELGAN3-ECHO visit. If you have not yet had a teen study visit, please consider scheduling one this spring or summer. For those who have already visited with us, *a heartfelt thank you! And we look forward to seeing you again when you're 18!*

What's New for you?

Did you receive your ELGAN-ECHO card holder? Cardholders were sent out recently and we hope you like them. If you did not receive yours, please contact your study coordinator.

How old is the ELGAN cohort now?

Born 2002
age 17 : 259 (29.1%)

Born 2003
age 16: 390 (43.9%)

Born 2004
age 15: 240 (27.0%)

Letter from a Fellow ELGAN Parent

You may recall in our last newsletter, we featured an essay written by a family from the Michigan State study site. We are happy to offer another essay written by a different parent from that same site.

The first few days and weeks were scary. She was so small and there was nothing I could do to help her. Every little "gain" was a huge victory, and every setback was pure fear of losing her. I remember one day very clearly. The doc in the NICU said "We are concerned about her weight," then walked away. I spent the next few hours stewing over that, thinking "What does that mean?" I ended up going back to the NICU very upset and asked for details. From birth to about five years, I don't think I've ever had a solid night's sleep since she was born, every breath, turn, or cry would wake me and I would listen to see if it was something to be alarmed over. She had about five febrile seizures and every one stressed me out. Her last one was at four years and for that I'm very thankful. School has been stressful, not for health reasons, but because I wanted her to do well and love it. From 2nd until 5th grade, I enrolled her in tutoring sessions which helped her tremendously . . . money well spent. For many years, she was my #1 priority, almost to the detriment of my health. I have learned that in order to truly take care of her, I must take care of myself. I am so thankful for her in my life and the time I've been given with her.

What have we learned so far?

Going on for over 17 years, ELGAN is an unusually long study, made possible because of your continued interest and effort to help us learn about the effects of prematurity throughout childhood. We can now compare information from birth, preschool and school ages, and present a few of our recent findings below:

- Despite the very stressful circumstances that ELGAN babies encounter early in life, two thirds of the ELGAN group did not have a serious developmental problem at 10 years of age.
- Average test scores for thinking and learning skills (cognitive development) were higher at age 10 than at age 2, suggesting improvement in these skills between ages 2-10.
- Children who had chronic lung disease (CLD) in infancy were NOT more likely than those without CLD to have asthma at age 10.
- Proteins in baby's blood were identified as increasing or decreasing inflammation. ELGANs who sustained higher levels of proteins that decrease inflammation had fewer problems related to their prematurity.
- In addition to studying proteins in baby's blood, we have recently been studying molecules in the placenta that influence gene expression – the process in which genes in the cells are turned OFF or ON. Cells figure out what jobs they must do depending on which genes are turned on. Our research showed that genetic expression in the placenta was different for boys and girls, and that it was associated with children's cognitive development at age 10.

For more findings, check our website at https://elgan.fpg.unc.edu/. We have links to over 150 publications generated by this study. Publications are color-coded based on topic, including: medical, neurodevelopment, ROP & vision, lung, brain imaging, pregnancy, inflammation, growth factors, endocrine, genes and epigenetics.

Where are we headed?

Why Baby Teeth?

Your study coordinator will be asking if you have any baby teeth stored at home. Here's why:

Baby teeth can be used to identify a child's exposure to environmental toxins. Baby teeth start to develop toward the end of the first trimester of pregnancy and form a new layer each day. These layers contain a record of exposures during fetal development.

ECHO's goal is to understand relationships between early life exposure to environmental pollutants and later-in-life child health outcomes, so that programs, policies, and practices can be designed to improve child health in future generations.

If you are interested in learning more about this topic, check out this article in Discover Magazine: http://discovermagazine.com/2018/jun/long-in-the-tooth

Additional questionnaires

For families who have already completed the 15 year visit, your study coordinator will be contacting you regarding additional parent-only questionnaires.

18 year visits

It is hard to believe but we are starting to gear-up for the 18 year-old visits. Our study coordinators are busy completing online training and preparing for our first 18 year visit due in spring of 2020!

Staying in touch

The teenage years zip by. People move and phone numbers change. Please remember to update your site coordinator of any upcoming changes to your 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 the original enrollees.

Coordinator Name
Research Coordinator
Phone Number
Email Address