



ECHO
Environmental influences
on Child Health Outcomes

Fall 2019

ELGAN-ECHO Study Newsletter

What's next?

"I genuinely enjoy participating in the ELGAN-ECHO study knowing that being a part of testing for research, I'm helping current premature babies, future premature babies, and families in their unique journeys. It warms my heart to know I'm helping others."

-UNC participant

"I participate in the ELGAN-ECHO study because it gives me an opportunity to contribute to the science that helped save my life after I was born, and can help others who find themselves in similar situations. As someone who has received many blessings in my life, I like to give back in the ways that I can, and participating in this study is one of those ways because it gives me an opportunity to help people who are just like me."

-BCH participant

ELGAN-ECHO 17/18 Year Study Visit

Our next ELGAN-ECHO study visits will start around age 17. We'll be contacting you in the months before your 17th birthday, so we appreciate your updated contact information so we can let you know more about these visits! The focus will be on general health, and unlike the 15 year visit, there will be no MRI and no school achievement tests.

Here are a few items that we plan to do at the 17/18 year visit:

Lung function: All ELGANs require some degree of pulmonary support in the NICU and sometimes throughout their early years. We'll be assessing the power of your lungs through lung tests as you blow into a spirometer. Some teens may be familiar with this task if they have asthma or reactive airway disease.

Exercise, nutrition & sleep: In addition to surveys on these topics, at select Study sites we'll be asking teens to wear a take-home accelerometer (or actimeter). This is a small device that measures motion (like a fitbit) and can teach us about physical activity and sleep habits.



iPad games & puzzles: For those who participated in the 15-year visit, you probably recall the iPad games: shape sorting, pointing arrows, word pronunciation, memory sequence. For the 17/18-year visit, we plan to repeat those items but add a few movement items. We'll have a balance activity with iPod and a grip strength activity using a dynamometer – you will see how strong you are. Lots of fun gadgets - pretty cool!

Biospecimens: Placentas – blood – urine – saliva – teeth – what next? Our ELGANs have provided researchers with a gold mine of bio-specimens over the years starting on the day they were born! These biospecimens continue to advance our knowledge about health and human development of not only ELGANs but of all children. **Our partnership with ECHO extends the benefits of this research to all humans.**

A Poem from a fellow participant family

This is a sweet, sentimental poem written by the brother of one of our ELGAN subjects. Will was 11 when his sister was born prematurely. She spent a solid year in the NICU – let that sink in. This ELGAN subject's name and hospital are not identified here but you can probably tell from the pronunciation of Will's name, that the subject is a Southerner!

Growing

She was born way too early
Real tiny and very small
She weighed only a pound and a half
Her head was like a tennis ball

The hospital was her home
She stayed there for a year
There was lots of growing to do
And the doctors had to be near.

She almost died many times
Once it was Christmas Day
They called a code blue to save her
It was a really weird holiday

She always did smile a lot
Even when she was in pain
She needed to grow new lungs
And had lots of weight to gain.

She tried to do it by herself
But she couldn't keep the pace
So she got a trach in her neck
And a ventilator helped her win the
race

Finally, she's out of the hospital
She's two and can really squeal
She loves to run around a lot
And now she calls me "Wee-ill"

I feel like a lucky big brother
That sounds kind of funny I know
She came way too early
But I got to watch her grow

Will (age 13) 2006

Why Collect Bio-specimens?



Everyone is exposed to various chemicals in our daily lives, from our food and water to the air we breathe, and these exposures may affect our health. Your blood, hair, nails, urine, saliva, and teeth can be used to look for the presence of both toxic *and* beneficial substances that may play a role in your health.

They will also allow us to look at nucleic acids (DNA and RNA) that may influence health.

Contributing bio-specimens helps us understand the role your environment plays in influencing your health & development!

ELGAN-ECHO on the Road



ELGAN - ECHO field trips are sometimes necessary, as was this visit to one of our mountain states in May of this year. Two ELGAN

- ECHO study visits were completed - the families were incredibly welcoming and the teens were simply amazing. Here is some snowball art from that trip. If you are interested in continuing with ELGAN-ECHO but feel you cannot return to your study site, please reach out to your Study Coordinator. We are happy to come to you!

Staying in touch

The teenage years zip by. People move and phone numbers change. Please remember to update your Study Site Coordinator of any upcoming changes to your contact information. Simply sending an e-mail or a text message (if cell# listed) would suffice! **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