



ELGAN-ECHO

Study Newsletter Spring - Summer 2023

ELGAN-ECHO Highlights

Enrollment to date:

- 767 (95% of target)
- 7th highest in ECHO
(out of 31 cohorts)

Completeness of data:

- 97% of participants have submitted data the ECHO program.

Biospecimens:

- 331 blood specimens
- 454 saliva specimens
 - 64 - Child only
 - 238 - Child & 1 parent
 - 152 - Child & both parents
- 189 stool specimens
- 468 urine specimens
- 426 hair specimens
- 430 toenail specimens
- 154 shed teeth

Publications:

- 28 ECHO-wide papers
- 105 ELGAN-only papers

Seven years ago, our ELGAN cohort joined the ECHO project, a national study looking at environmental influences on child health outcomes. The joint effort allowed us to continue our important work of improving the care of people born extremely preterm but also to contribute to the health and well-being of all children. We present here some of the highlights from these past 7 years.

We are excited about the future direction of ELGAN and ELGAN/ECHO however much will depend upon your ongoing participation as well as funding. Our study leaders have applied for grants, and we are hopeful that we will receive good news. In the meantime, we are laying the groundwork for both ELGAN Study and ELGAN ECHO projects.

Sharing these updates and opportunities with you depends on us having up-to-date contact information for you and/or your parent/guardian. Please fill out and return the enclosed "Contact Information Form" to your local study site so that we can stay connected!

Getting Involved with the Future Direction of ELGAN:

ELGAN Interviews: Are you willing to be interviewed? We are looking for 8-10 volunteers who will help us understand what topics of study are most important to young adults born extremely preterm.

ELGAN Future Direction Surveys: Would you be willing to complete a brief survey ranking topics of study in order of importance to you? We are asking for volunteers. You will be entered into a drawing for a \$25 gift card.

ELGAN Advisory Board: The above interviews and surveys will help us with creating an ELGAN advisory board. This board of interested ELGANs will guide the direction of ELGAN research. More information on this opportunity will be available soon.

Return of Results Workshop in Bethesda, MD

In March 2023, one of our Wake Forest ELGAN participants was invited to discuss with study leaders the importance of receiving individual results from the ECHO Study. Our ELGAN served on a 4-member panel and was superb! Of course, there was a bit of pizzazz!



Nails done with **ELGAN** spelled out on the left hand and **ECHO** on the right.

For a full list of our publications, please refer to www.elganstudy.org

ELGAN ECHO on the Road

Many participants were able to travel to their study sites over the past 7 years to participate in an ELGAN-ECHO visit. States outside of our ELGAN-sites include CO, FL, GA, HI, IA, LA, MD, ND, NV, NY, OH, OR, SD, TX and VA - plus Australia, Bermuda, Israel, and Puerto Rico!

Additionally, study coordinators conducted over 30 home visits.



Hummingbird,

-ELGAN Study participant, Jadine B

We Want to Hear from YOU!

We would love to feature updates from you in our ELGAN newsletters and study website.

Ideas:

- Update on school
- A new job
- A special relationship
- A book or song that you love
- A drawing or other artwork
- An amazing event you attended
- A baby in your life
- A cool device you are using

Contact: elganstudy@unc.edu or **984-974-7869** with your updates.

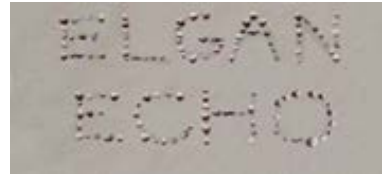
[SITE TO ENTER LOCAL SC CONTACT INFO HERE PRIOR TO MAILING]

ELGANs are VOTING!

ELGANs are voting on issues that are important to them. For help understanding your right to vote in your state, contact your local *Protection and Advocacy Agency*.



**Every
vote
matters.**



Seashell Art - Florida Home Visit

The Gift

*To Know
That You were capable
Of light
All along*

*Is a precious strength
That ignites
Within your soul*

*Oh, the gift
Of healing*



From **Follow My Light**, a collection of poems by ELGAN Study participant, Zaniyah Victorious

A Message from Julie Rollins, ELGAN ECHO Program Manager



Since September 2011, it has been heartening and humbling for me to be a part of your journey in the world of pediatric research. Those of you who have participated in the ECHO Program over the last 7 years, each in your own unique way, have overcome barriers and demonstrated your commitment to current and future ELGANs and more broadly now through ECHO, all fellow children and teenagers in the United States! It is our hope that the ELGAN Study will continue to participate in the ECHO Program, and you will come along with us on this second part of the journey. If we receive funding, the ECHO portion of ELGAN will transition from your hospital birth site to the University of North Carolina at Chapel Hill, and study activities will be done from a distance (online, phone, Zoom and by mail).

What can you expect? You will be contacted in the coming months either by your study site or a UNC Chapel Hill Study Coordinator to make this communication transition possible. We hope you will be interested in learning more about ECHO Phase 2!! Please keep an eye out for more detailed information from your home study site heading to your inbox or mailbox very soon.