

ELGAN-ECHO

summer/fall 2024 newsletter

ECHO-II UPDATE

Hello from the ELGAN study! We want to update you on our ELGANs who are still taking part in the ECHO Study at the University of North Carolina at Chapel Hill. The study includes two “virtual” visits: one in 2024 and another in 2025 for everyone who is under 21 and still eligible. The goal is to learn more about how changes to your environment affect your health, so we can use that knowledge to improve the health of future children for generations to come. Thanks to all of you, over 200 young adults, parents and

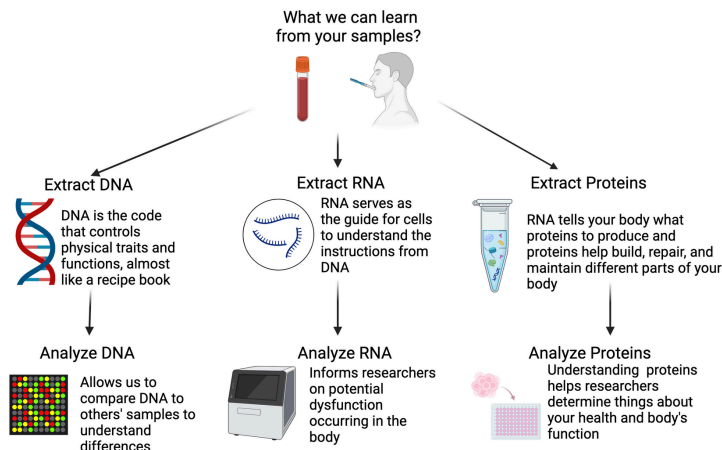
guardians have already joined the study. In this study year, participants are filling out online surveys and having a 1-hour video call with one of our amazing new ELGAN Study Coordinators. In the 2024 visit, participants will also provide physical measurements and blood pressure/heart rate readings. During the 2025 visit, those ELGAN participants born in 2004 will be doing additional surveys and may be asked to contribute a spot of blood. We are looking forward to sharing the findings of this research with all of you!

*If you have not already enrolled, are less than 21 years of age and would like to contribute to this research, please get in touch with **Janice Wereszczak**, Enrollment Specialist, jwerescz@med.unc.edu or phone # **984-974-7869**.*

To learn more about how your past and present ELGAN ECHO study visits are contributing to science, go to <https://echochildren.org/research-summaries/> !!

HOW DOES DNA HELP US LEARN?

Through a special process called DNA extraction, we can examine the DNA in the blood samples you provide. DNA is present in every cell and contains information about our traits, such as eye color and height. This information is organized into sections called genes. Genes can influence how our bodies respond to the environment, and the environment can also affect how our genes function. By studying your samples, we aim to learn how genes and the environment interact to impact a person’s growth, development, and health.



GETTING TO KNOW ELGANS

Help your fellow ELGANS get to know you! Take our fun poll by scanning the QR code or typing the link below into your browser. We'll share the results in the next newsletter!

scan this



or type this in!

bit.ly/elganpoll

PROGRESS IN THE FIELD

When the first ELGANs in this study were born, the earliest a baby could be born and survive was considered to be 23 weeks. Now, babies born as early as 22 weeks often survive. What changed? When the ELGAN study started, the chances of survival were so incredibly low for a baby born at 22 weeks that healthcare providers usually didn't try to give these babies intensive care. But over the past 10 years, a small number of doctors decided to challenge that practice. As they learned more about how to care for these very premature babies, the survival rate went up. They shared their success at medical meetings and in journals, which encouraged other doctors to try the same approach. As more doctors became hopeful about the survival chances for 22-week-old babies, the survival rate increased and, while varied, is now over 60% in at least one U.S. hospital. With more and more babies born at 22 weeks surviving, researchers can now better study their health and development to learn more about how to help future babies born so young. Newer generations of preemies are getting a chance at life because of increased hope and knowledge about babies who are born prematurely.

RESEARCH TEAM PROFILE

Hello, everyone!
My name is Sid
Ratkiewicz, and
I'm the new
participant



engagement coordinator for ELGAN. I'm a psychology researcher in Durham, NC who likes finding ways to help people reach their goals in life and feel more connected to each other. I'll be facilitating the new participant/family advisory board and helping to find ways to turn your ideas for the future of ELGAN into reality. I'm so excited to be a part of this special study and am looking forward to meeting some of you soon!

STAY IN TOUCH!

As ELGANs start to move for school, work and military service, we don't want to lose touch! If you get a new phone number or make a permanent move to a new address, please contact Julie to let us know. Staying current on your contact information helps keep the ELGAN study alive.

Julie Rollins
Project Manager
Julie.rollins@unc.edu
984-974-7869



Art by ELGAN
participant Sierra B.

INTERVIEW RESULTS

We recently interviewed some ELGANs and their families about their experiences with the study. Here are some of the things they said...

ELGANs like to help. ELGANs said they take part in this research because they want to help future generations of premature babies and their families. They also enjoy reconnecting with the coordinators and researchers who have been a part of their lives for so long.



ELGANs want to meet each other. Interviewees brainstormed some exciting ideas for how to connect with other interested ELGANs locally and across the world.

ELGANs are interested in research results. They would like to be able to privately access their own personal results, and want more research highlights publicized in easy-to-understand language so more people can learn about these findings.



ELGANs have great ideas for future research. ELGANs drew on their own experiences to offer exciting ideas for the future of ELGAN and new topics to study.

Thanks to everyone who participated in our interviews!
Stay tuned as we work on developing your great ideas.

PARTICIPANT/FAMILY ADVISORY BOARD

Join our advisory board and get involved in helping shape the future of ELGAN! The participant & family advisory board will meet virtually every month to help develop ideas about how to improve the study experience, how to give ELGANs the opportunity to connect with each other, and what we should study next. The board will start meeting this fall. If you're interested in learning more, please contact Sid Ratkiewicz, Participant Engagement Coordinator, at sratkiew@ad.unc.edu.