

ELGAN-ECHO

Fall/Winter 2025



STUDY UPDATE

Hello from ELGAN-ECHO! We have reached a big milestone in the study: this summer, the last (and youngest) ELGAN-ECHO participants completed their final study visits. All ELGAN-ECHO participants have now graduated from this phase of the study, and our data collection period for this phase of ELGAN is complete. It has been a pleasure and a privilege to watch ELGANs reach adulthood through the past 8 years of ELGAN's partnership with the national ECHO study. Thank you for our time, effort, support, and

continued dedication to this research project. Because of your engagement year after year, this is the one of the biggest and longest running studies of people born prematurely. For the next few years, we will stay busy analyzing the data from ELGAN-ECHO and writing research papers on our findings. We hope to share the results with you as we learn more. Stay tuned! We hope the future will bring another phase of the ELGAN study to learn more about how being born prematurely affects experiences in adulthood.

RESEARCH TEAM SPOTLIGHT

After 14 years of service to the ELGAN Study, Julie Rollins will be shifting roles from Program Manager to study consultant to allow her to pursue an exciting career opportunity closer to home in Massachusetts. Julie is now the Clinical Research Director in the Department of Neurology at Boston Children's Hospital (BCH). Fortunately, this new position allows Julie to remain close to ELGAN as BCH is home to one of our largest study sites.



Julie has been an integral part of the ELGAN Study since 2011, working to make sure everything about the study runs smoothly. While she won't be managing ELGAN on a day-to-day basis anymore, she will be contributing her expertise to the project from time to time. We thank her for her incredible service over the last 14 years and wish her all the best in her new role at Boston Children's!

SEASONAL SPOTLIGHT

November is Prematurity Awareness Month! Here's some ideas on how to observe the month:

- Spread awareness about prematurity by sharing your story with others.
- If you're an ELGAN parent, provide support to new parents by volunteering with an organization like Hand to Hold (handtohold.org, a national non-profit).
- See if your local NICU accepts volunteers or donations of needed items for new families.
- Give to non-profit organizations that support premature babies and their families, for example: March of Dimes (marchofdimes.org), or Graham's Foundation (grahamsfoundation.org).

Want to learn more about Prematurity Awareness Month? Scan this QR code or

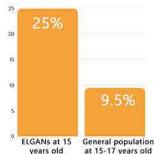


marchofdimes.org/prematurity-awareness-month

RESEARCH RESULTS

Children born extremely preterm face higher asthma risks, but ELGAN research suggests the link is more complex than once thought.

As teenagers, ELGANS had higher rates of asthma than their full-term peers.



We looked at factors we thought might contribute to asthma and were surprised by what we found.

What *doesn't* make a difference?

Having a lot of **inflammation** in infancy is related to many other conditions later in life. But babies who had higher rates of inflammation weren't more likely to have asthma as kids and teenagers.

Nearly half of ELGANS had **chronic lung disease** as babies, a condition that often requires extra breathing support. These ELGANS often had breathing troubles as toddlers. But as teenagers, these ELGANS weren't more likely to have asthma.

Sources: Emmanuel C, et al.: Neonatal inflammation and its association with asthma and obesity in late childhood among individuals born extremely preterm. *Pediatr Res*. 2024; Jackson WH, et al.: Risk factors for chronic lung disease and asthma differ among children born extremely preterm. *Pediatr Pulmonol*. 2018 ; National asthma data. CDC website, https://www.cdc.gov/asthma/most_recent_national_asthma_data.htm

So what contributes to a higher risk of asthma?

Environmental and Social/Economic Factors

While some ELGANS from all backgrounds developed asthma, we found the risk of asthma increased for kids who...

- Grew up in a lower-income family, with less access to helpful resources
- Gained weight more quickly in childhood

Why does this research matter?

These findings suggest that asthma in preterm children is not just a persistence of lung problems that began in the NICU. Being born very early does raise risk, but it seems childhood environment matters more than the baby's health at birth.

This helps focus effort and interventions to the right time and place. To prevent asthma, helping kids have a healthy childhood, reducing environmental risks, and addressing social challenges can make a difference.

ELGAN BY THE NUMBERS

Since 2017, ELGANS have generously offered their time and effort to the ELGAN-ECHO project. Here's a look at how all your contributions add up!

8 YEARS of data collection
1,541 study visits completed
3,114 bio-samples contributed

68,707 questions answered
19,644 variables studied

CONTACT US!

Want to update your home address or contact information? Have an update you'd like to share in a newsletter, or a question for the study team? Please reach out to Sid Ratkiewicz, our Study Engagement Co-ordinator, at: sratkiew@ad.unc.edu