



ELGAN-ECHO

Study Newsletter

In this newsletter, we would like to address the timely theme of “**transitioning to adulthood**” and how it feels as a parent whose child has grown in so many ways. Dr. Crisma Emmanuel, a UNC researcher, submitted an essay on this topic that we hope you will enjoy. We are also including resources you might find helpful.

Parent Perspective: Reaching Adulthood

At our University of North Carolina-Chapel Hill ELGAN-ECHO site, several parent/guardian study participants were asked if they would be willing to talk about their experience raising their extremely preterm child, with an emphasis on their child’s current health and well-being now that they are transitioning into adulthood.

Throughout the interviews most parents/caregivers emphasized how much their child had physically blossomed—going from spending weeks, if not months, in the NICU to healthy, to thriving teenagers.

Even for children with a physical diagnosis, participants mentioned how their child was able to incorporate these differences into their new normal to achieve happiness — often finding hobbies and interests that were unique, including cooking, basketball, dancing on the step team, and learning Korean.

For many families, transitioning to adulthood is seen as a rocky time- with parents voicing the uncertainty that comes with these changes. However, both parents and ELGAN youth showed their strength once again by emphasizing how they adapted to these changes- whether what followed was “normal,” or required them to forge their own path.

We would like to thank all those who participated and emphasize that while raising a premature child has never been easy, you have “ridden the rollercoaster” that is called prematurity with strength and love.

17/18 Year Visits Underway!

All ELGAN sites are currently conducting remote and in-person visits and all ELGANs are eligible to participate in this visit even if they’ve turned 19 years of age. The 17/18 year study visits will continue until August 2022. Please reach out to your SC for more information!

Be on the lookout for more information about our NEW third study “visit”! Beginning in February 2022 SCs will contact teen participants about participating in a third, remote-only study visit!



After Graduation

Many of our ELGAN teens have completed or will soon be completing high school. Some will start jobs, some will decide to continue their education, and some will do a bit of both. Some will move away and for some, residing in the family home makes more sense. As parents of children born extremely preterm, the trajectories of parenting bring a wide range of emotions. We wish to honor the amazing job you have done raising such great people and we look forward to a future with your ELGANs leading by example.

Transitioning to Adulthood Resources

ELGAN website :

elgan.fpg.unc.edu/resources

The National Resource Center for Supported Decision Making :

www.supporteddecisionmaking.org/states

Turning 18: What it Means for Your Health :

www.gottransition.org/resource/?turning-18-english

www.gottransition.org/resource/?turning-18-spanish

Legally Authorized Representation

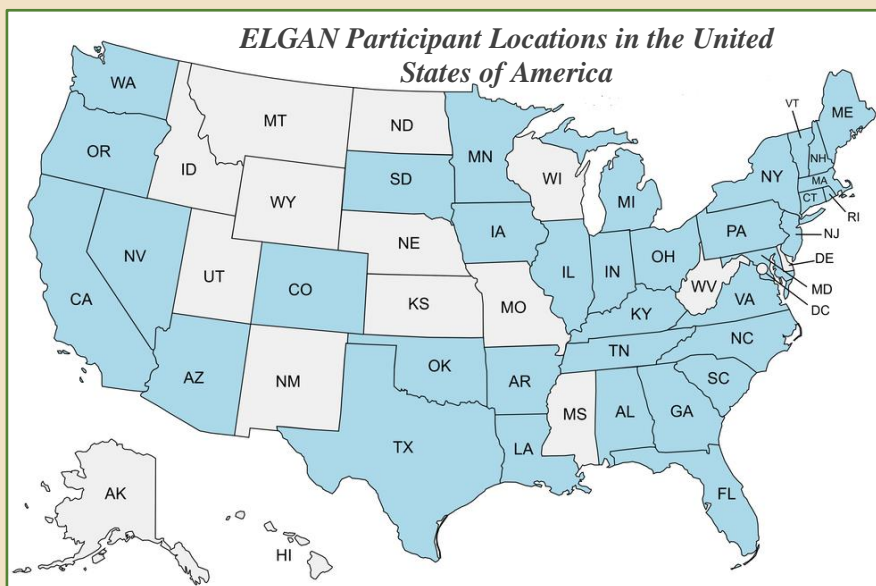
In caring for your child or loved one, you may want to make use of the Legally Authorized Representative (LAR) designation for situations in which informed consent is required. Many members of our ELGAN cohort may need a guardian to represent them because of difficulties with decision-making or understanding benefits and risks, confidentiality, voluntariness, and other factors associated with research. These difficulties could be due to autism, developmental delays, trauma, or general challenges related to being born extremely prematurely.

This designation is becoming especially relevant as the participants in our study reach age 18 and no longer depend upon parents or other guardians based on minor status. The requirements for LARs vary by state and research institution, but in most cases close family members or groups of family members, those with healthcare power of attorney, and legal guardians qualify to provide consent for participation in non-therapeutic research settings. Refer to the list of resources on this newsletter or on our website for more information.



ELGAN-ECHO on the Road

A study team members' visit to upstate New York this summer allowed for an impromptu 17-year ELGAN ECHO home visit. A special thanks to Petey McPuff for checking that the biospecimens were packaged properly!



Preparing for ELGAN 20th Anniversary

It's hard to believe, but 2022 rings in the 20th anniversary of the ELGAN Study! There is so much to celebrate and its success is because of you - our amazing ELGAN families! We would love to hear about any ideas you may have on how we can make this milestone special. Feel free to pass along your ideas to your Study Coordinator.

Staying in Touch

ELGANs on the Move

Near and far, our ELGANs have been moving around quite a bit since their days in NICUs in Connecticut, Illinois, Massachusetts, Michigan, and North Carolina. We thought you might like to see where they are living — for now! Locations are shown on the map in blue.

Additional Locations: Australia, Bermuda, Canada, England, Israel, and Puerto Rico

This past spring, we sent out **ELGAN ECHO Contact Information Forms**. The form arrived in a padded envelope along with a small container of hand sanitizer with our ELGAN ECHO logo on it. Hopefully, you received these. As our teens (and families) often relocate, we want to make sure to not lose touch. Please let your Study Coordinator know if your contact information changes. As we have mentioned previously, each and every one of our ELGAN ECHO participants is important to the success of the study so we do not want to lose even one of you if we can help it! Please stay in touch as we hope this project continues for many years.

**Your Study Coordinator:
Phone:
Email:**