



[Date]

Dear [parent name] and [child name],

Thanks to your involvement in the ELGAN-ECHO study, ELGAN is influencing how to care for prematurely born children and their families, from the newborn period onward. And ELGAN is extending its scientific influence by teaming up with ECHO's over 70 research groups (see more at <https://www.nih.gov/echo>).

ECHO is particularly interested in our ELGAN group because you started in the study at birth. The early information and biospecimens we collected are like rings in a tree, a virtual story-book of your beginnings of becoming you! Being an "ELGAN" means you have a remarkable life story and we're so grateful to all of you for sharing this health history and helping us learn from it.

ELGAN is continuing to learn from you! Right now, we are recruiting for the next study visit. The 17-year visit is just a little bit different from previous visits. For starters, there is no academic testing or MRI. The study activities are listed below, and we hope you participate in as many parts as you are comfortable. Please ask us your questions about these items at any time.

- **Measurements of growth:** height, weight, skin fold thickness, head and waist circumference.
- **Physical well-being:** We'll measure your heart rate, blood pressure, and lung functioning.
- **Personal well-being:** Questionnaires about your health and well-being as a teen. Parents/caregivers will have their own set of questionnaires.
- **iPad puzzles & games:** This is a repeat from the 15 year visit for teens, but we'll ask the parent/caregiver to do this as well.
- **iPad strength and movement games:** a pegboard game, a grip-strength game, a balance game, and two walking games for teens
- **Biospecimens:** For teens who are willing to contribute, we will do everything possible to make this easy, fun, and not embarrassing. You can ask as many questions as you want about each of these, and "opt-out" of anything you absolutely do not want to do. Each of these samples helps us learn about important parts of our individual and social environments:
 - **Baby teeth:** we ask if you'd like to contribute 1-2 baby teeth only if you did not provide them at the 15-year visit.
 - **Toenails:** We ask that you do not polish or cut your toenails 2 weeks before your study visit. We will supply clippers for toenails from each toe. You get to keep the clippers!
 - **Hair:** We'd like to take 100 pieces of hair (that's about the amount of hair that people usually shed naturally per day). We've received training on how to do this so it is not noticeable. If you keep your hair very short, we might ask if you could let it grow a bit for the visit.

- **Cheek swab:** Most teens have done this at the 15-year visit but if you have not, we'll ask for this at the 17-year visit. The swab is rubbed like a tiny toothbrush on the inside of your mouth.
- **Saliva:** We ask teens to spit into a tube if they did not do this at 15-year visit. We'll ask all biological moms and dads to provide this as well.
- **Urine:** We ask for a sample, just like at the 15-year visit.
- **Stool:** Our guts contain trillions of bacteria, viruses, fungi and other microbes including those that end up in our poop. Researchers are learning how the gut "microbiome" influences how we grow, develop, fight illness, and more. Other than researchers, most people would rather not think about poop. We feel that studying stool samples may be one of the most incredible opportunities of the entire ELGAN-ECHO study! We will do whatever we can to make this contribution as easy for you as possible.
- **Blood:** We know blood draws are not among a teen's favorite activities, but for those of you who are willing to provide a sample, we'll make it as easy as possible.

In summary, this letter is your invitation to participate in the 17-year ELGAN-ECHO evaluation. We anticipate this visit taking about 4-6 hours. We can schedule a visit on any day of the week and/or most weekends. It can also take place over two days if that is better for you. If traveling to the study site is not an option, talk with your study coordinator about other arrangements. As a thank you for your time and effort, **[child's name]** would receive \$ ___ for the evaluation, plus additional amounts for biospecimens, depending upon what they provide. [Parent's name] will receive \$ ___ to compensate for travel, completing questionnaires and iPad puzzles & games, and providing a saliva sample.

We hope you will participate in the 17-year ELGAN-ECHO research study. Each of you holds an important piece to the puzzle for improving our knowledge about prematurity, our environment, and having the healthiest and most satisfying lives possible.

I look forward to speaking with you more about the study.

Sincerely yours,

ELGAN ECHO Study Coordinator