

ELGAN-ECHO Study Newsletter

Autumn 2018



Study Progress

It's been one year since we kicked-off the **ELGAN-ECHO Study!** Study Coordinators from all 12 sites have been busy contacting families, scheduling appointments, and conducting the visits with study teens. We are proud to say that so far we have enrolled nearly **300** of our ELGAN participants who were born between 2002 and 2003. On August 30, 2018, we learned that our efforts paid off when the National Institutes of Health (NIH) announced that we will receive on-going funding.

There are many challenges to long term follow-up, and we fully recognize that the on-going success of ELGAN-ECHO can only be explained by the dedication of our families. For this, we wish to express our deepest thanks to all of you.

Study Coordinator's Update

The ELGAN-ECHO visits for 15 year olds will run until March of 2020. If participants have turned 15 (or will soon turn 15), and you have **not** been contacted to schedule your study visit, please reach out to your coordinator (contact info below).

For families whose teens have **already** had their 15-year visit, we have some new, additional surveys that we are now asking teens and parent/ guardian to complete as part of the larger ECHO Study. Your Study Coordinator will contact you with more information about these surveys and additional stipends.

Plans to update the elganstudy.org website, Facebook page, and create a new Instagram page, are underway. If you have ideas on how to make these sites more useful and appealing to ELGAN-ECHO families and teens, please let us know!

[Study Coordinator Name]

[Email]

[phone number]

[Please add site specific institutional logo here]

Fall Activities List

- Get a flu shot
- Go apple picking
- Get lost in a corn maze
- Go for a hike
- Go for a hayride
- Collect colorful fall leaves
- Bake an apple pie
- Carve a pumpkin
- Take a fall foliage drive
- Host a bonfire
- Attend a fall festival
- Decorate a fall themed wreath
- Visit a pumpkin patch

Flu season is here!

Visit your local doctor's office clinic, pharmacy, or school to get your influenza vaccine this year.



Letter from a Fellow ELGAN Parent

At our Michigan State University ELGAN-ECHO site, study participants were asked if they would be willing to write about their experiences having or being a preemie. We are sharing one of the essays with you here.



“Having a child that was born severely prematurely is very frightening and scary. In the beginning, you worry about everything and if you will make a mistake. You worry that you will miss something that will cause them to get sick, or worse. As time goes by, you develop a routine and a comfort zone. You begin to relax and feel more confident and secure in your ‘gut feelings.’ You realize that your child’s day to day routines are different than other children their age, that they have limitations other children may not have. But you also have a joy and love that only that child can give. You learn that despite your need to protect them from harm, illness, and cruelty of others who perhaps don’t understand, you can’t smother them. For us, our child had severe lung disease. She could do what others did, she just did it more slowly. Never hold them back; rather support and nurture them in their growth. Premature children are a blessing. Hold them close to your heart—always.”

Helping Premies & Their Families Everywhere

September was Neonatal Intensive Care Awareness month, a time dedicated to honoring NICU patients, families, as well as the staff who take care of them. There are many great ways to support NICUs throughout the year. Here are a few suggestions:

Project Sweet Peas: PSP is a national non-profit led by volunteers who provide resources to patients and families in the NICU. The organization provides an array of different services such as family care packages, informational literature, and peer-to-peer support. <https://www.projectsweetpeas.com>

March of Dimes: Many of you are avid advocates for this agency whose mission is “Healthy Moms. Healthy Babies”. Check out their website for local events. Add the March for Babies Walk-a-Thon on your 2019 calendar.

<https://www.marchofdimes.org>



Reach Out and Read: Many NICUs are encouraging families and staff to read to babies every day starting soon after admission. A few NICUs have joined forces with Reach Out & Read to formalize the process. Your teen might consider organizing a book drive at their school for their local NICU. Good choices would be books with brightly contrasted pictures, soft, cloth, textured, or board books, and of course, nursery rhymes. Books should be new. Here is a lovely article written by a mom who read to her baby in the NICU. <https://www.dallasnews.com/life/family/2018/03/12/why-reading-preemies-makes-difference>

How about a walk down memory lane with this song by Frank Maroney, written about his sister born at 26 weeks gestation? <https://www.youtube.com/watch?v=e-UAV6mGX20>

Do you know of any Young Adult literature that features teens who were born extremely prematurely? Nope, we don’t either. Perhaps you or your teen can give it a go. Take a look at Dallas Woodhouse who has this to say about being born so prematurely. Hint: Her motto is P.A.S.T. (Premies Are So Tough!) <https://composejournal.com/articles/premature-birth-writing/>