



ELGAN Study Newsletter

20th Anniversary Edition



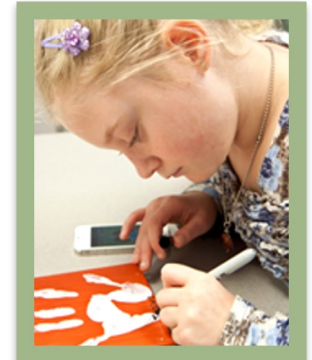
ECHO
Environmental influences
on Child Health Outcomes

The tiniest babies making the biggest difference.



Twenty years ago, the first ELGAN study participants were born. In-person visits, hundreds of questionnaires, multiple measurements, brain scans, biospecimen samples and so much more have influenced how premature infants are cared for and what we know about health outcomes. We are so grateful for your contributions and hope we continue to move mountains together.

In this anniversary edition of the newsletter, you will find study updates and hear from past and present ELGAN Study principal investigators. One of our study participants contributed a poignant essay on stress, coping, and resilience. And lastly, an ELGAN Mom shares her experiences and trouble-shooting tips for adolescents who wear glasses.



Stress, Coping, and Resilience

Many of you have described adversity you have faced and how you have coped with those challenges. One study participant put her experience into words. We appreciate her sharing this with ELGANs through our newsletter. By the way, did you know that writing is a great way to deal with stress? Let us know if you are interested in submitting a column for our newsletter. We would like to feature your story!

In March, my high school shut down for what was going to be a 2-week break while the pandemic unfolded. Needless to say, this was expanded exponentially. Thankfully, my school has not had many issues staying open since we came back, but I will feel the effects until I graduate and likely further.

My family was extremely lucky, none of us ever tested positive, and we were able to work from home with the exception of my mom. We did our best, masks becoming a staple in our wardrobes. I occupied myself cleaning our basement. This was a good coping mechanism - productive. I also embarked on a massive book project, completely unassigned. And when the year began again, I got a job in town. Little did I realize that this “piling on” of activities would overwhelm me. Not to mention the constant anxiety of watching my peers ignore the rules we’d lived by so religiously for months, i.e. masking and social distancing. My incessant badgering in class about correctly wearing masks earned me a reputation. (Not a good one either.) I was coughed on and teased by people who were annoyed with my caution. It seemed the problem was for me to monitor, not for my teachers or coworkers. Or was I overreacting? This is a question I still struggle with. As businesses and routines open again, I can’t help but feel that old anxiety. I love the freedom of being around people, seeing people’s faces, but I also like the security of the mask, the precaution.

This all came at the same time as an eating dilemma. While we were at home quarantined, I found myself eating when I was bored, which was a lot. To combat this, I started to count calories. I was also running every day. Over that spring and summer, I would essentially eat for comfort, feel worse, and skip meals or binge eat. I was self-aware enough of the problem to think, “I just miss not thinking about it.” Finally, I started to break the cycle, ending the limitation.

Some days are harder than others, and I’ve gained a little weight and lost a lot of my endurance as I’ve stopped exercising. With school, work, chores, and about a hundred extracurriculars, I can barely fit in my usual hours of sleep a night. Having the pandemic hasn’t helped- though I appreciate my friends and family more than ever now, as well as social activities, being outside, good health and free time. Slowing down for those months was good for my relationship with my siblings. It’s hard to accept the loss of so many experiences and memories, but I can’t say it wasn’t without its benefits. I will look back on this as a catalyst in my life, when I was prime protagonist age at 16 and 17- a true challenge. Hopefully my experiences are something you can learn from!



Your ELGAN ECHO Team wants you to know that you do not have to be alone with stress, depression, eating disorders, and/or other health problems. There are great people and therapy resources out there. If you think you might have an eating disorder, reach out to your primary care provider for help. For more information on eating disorders, refer to: <https://www.nimh.nih.gov/health/topics/eating-disorders>.

Announcements

ELGAN ECHO Phase 3: You may recall that ELGAN ECHO was initially designed to be two in-person study visits, at ages 15 and 17 years. The pandemic altered the timing of the 17-year visits and those continue today. For participants who have completed their 17-year visit, you are eligible for a newly added third study encounter—also known as the 18-year visit. This “visit” consists of remote (online) surveys only and should take no more than an hour to complete. Expect a call, email, or a letter from your study coordinator once you have turned 18 years of age with more info.

Updated ELGAN Website:

www.elganstudy.org

We hope you find our new and improved study website easier to navigate and more user-friendly! Check out ELGAN news, videos, publications, helpful resources, newsletters, contact info, and more. If you would like help navigating the site, feel free to contact your study coordinator who can walk you through it.

Vision Care: If you had treatment for ROP (retinopathy of prematurity) while you were in the NICU, yearly examinations by an eye doctor are a good idea. A sudden onset of floaters or flashes of light are a more urgent indicator to see an ophthalmologist or Optometrist. If you do not have an eye doctor, ask your primary care provider for a referral or recommendation.

ELGAN Advisory Board: Plans are underway for creating an ELGAN advisory board. The primary goal of this board is to brainstorm what issues are important to you so that we can study them and figure out creative ways for staying engaged and sharing resources. We have a handful of parents who have expressed interest and would love to have ELGAN young adults join this group. Contact your Coordinator for more info.

Staying in Touch: Please let your study coordinator know if your contact information changes. Each and every one of our ELGAN ECHO participants is important to the success of the study. We do not want to lose touch with you! Please keep us informed of your changing contact info so that we can keep you up to date on future research and helpful resources.

A Parent’s Advice on Eyeglasses: My son used to be so good about leaving his glasses alone - I’d have to replace them maybe once a year. Over the past couple of years, he’s developed anger issues and the first thing he takes his anger out on his glasses. He used to pull the temples and break those. So last year, I splurged for the expensive Flexon kind—the temples could be pulled and they would bounce back. Last year during a seizure, the metal from his glasses cut right under his eye when he fell. His current pair is plastic which I hope will be gentler.

My advice would be:

- 1) Do not to bother with the expensive frames.
- 2) If opting for metal frames, don’t choose the thin metal kind.
- 3) If possible, buy 2 pairs— a back up pair is good to have.



Supported Decision-Making Designation:

Some of our study participants may need ongoing support with decision-making into adulthood. To learn more about supported decision-making laws in your state, you may find this resource helpful

National Resource Center for Supported Decision Making:

<http://supporteddecisionmaking.org/States>



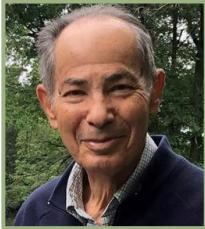
Your Study Coordinator:

Phone:

Email:

Messages from ELGAN Principal Investigators—Past & Present

ELGAN 1



Alan Leviton

You as a parent or as a former ELGAN are a hero. Reasonable people argue about how best to measure the [impact](#) of a research report or even a decades-long follow-up study. However, no matter how you measure, the ELGAN Study has had an enormous impact contributing to our understanding of what influences the wellbeing and development of ELGANs. My colleagues and I expected that families participating in the ELGAN Study would benefit from their participation. Whether it was the assurance that your child was receiving the highest quality care possible, confidence that you were being provided with the latest information about the development of ELGANs, or the personal, mental, and physical health benefits of contributing to the greater good. Yes, indeed, people who participate in medical research studies [do better than those who decline such opportunities](#). Doing well by doing good! Your participation in the ELGAN Study has contributed enormously to our understanding of all the influences on the well-being and development of ELGANs. Thank you so much.

ELGAN 2



Karl Kuban

My transformation more than 2 decades ago from primarily a clinician to a researcher and an ELGAN Study principal investigator (PI) was encouraged and enabled by my mentors, Paul Rosman, who gave me the space and the opportunity to pursue my research calling, and Alan Leviton, who helped me win my first grant, and who was the first principal investigator (PI) and inspirational force for The ELGAN Study. None of the inspiration or work that has ensued, however, could have led to the discoveries and successes reflected in nearly 200 peer-reviewed publications without my other research inspirations, the children and families of those enrolled in the ELGAN study, as well as those whose efforts rarely have a light shined on them, the Study Coordinators, the examiners, team leaders, statisticians, and support staff. It is clearly the engagement of “our” ELGAN children and their families, and the willingness for them to return to us time and again, sometimes at great inconvenience, for updated evaluations that have made funding from NIH, production of data, and publications possible. It is the children and families that largely can lay claim and take pride in what we believe are many new and important findings as well as reorienting the direction of research in this field.

ELGAN 3



Rebecca Fry

I joined the ELGAN study in its most recent phase (ELGAN 3 or ELGAN ECHO) and am so honored to work with the ELGAN team. I come to the ELGAN study as a Ph.D.-trained biologist and environmental scientist. My hope is that our research provides pregnant women and their children with the healthiest environments possible.

I also come to ELGAN with the personal history of being a mother of three children. My oldest child is the same age as the children from the ELGAN study, so I feel that I share a bit of an understanding of the ELGAN youth. Based on my own experiences as a mother, I can surmise that your participation in the ELGAN study has not always been easy. You and your child have devoted many hours to the ELGAN study, providing information on your own experiences and personal histories.

For your efforts over these many years, we say THANK YOU! You are the reason that this study is a success. Your dedication and commitment what has made the research possible for the improvement of the lives of ELGAN children. All the best wishes to you and your child as you embark on the next chapter of your lives!

ELGAN 3



Mike O'Shea

As a physician who cares for critically ill newborns from the time of birth through two years of age, I am profoundly impressed by the strength and goodness of parents who care for children born extremely preterm. For all that you have done to love, support, and strengthen your child, I am profoundly thankful. You have inspired me to be the best physician that I can be in supporting parents of infants and children who face challenges like the ones you and your child have faced.

I am grateful also for the many hours of service that you have contributed to make the ELGAN Study successful and thereby provide guidance to health care professionals and health researchers who strive to improve the well-being of children. You have inspired me to remain focused, for the rest of my career in medicine, on research about the challenges and achievements of the extraordinary people who are born extremely preterm.

Thank you, congratulations, and best wishes as you and your child journey forward in life to what will hopefully be an immensely gratifying future.