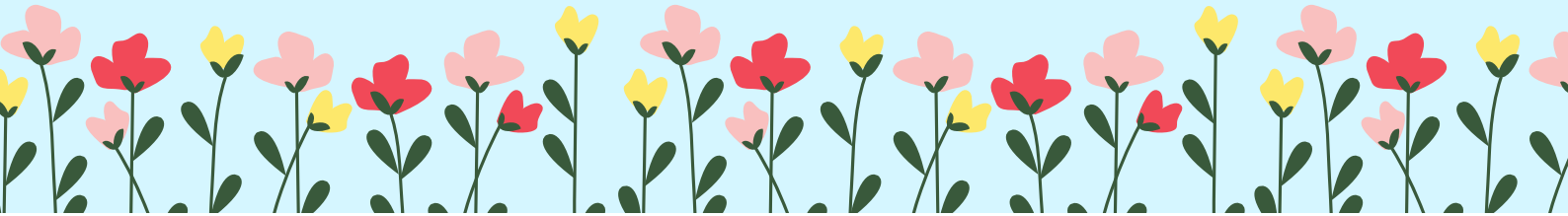


# THE CAREGIVING STUDY NEWSLETTER



*National Institutes of Health*



## Welcome

*Dr. Laura Koehly*

The Caregiving Study Team would like to thank you for your involvement in the study. As always, understanding the caregiving experience is a priority for the NIH, and we are so grateful for your participation. Our study continues to focus on understanding how family members cope with caregiving responsibilities, with the ultimate goal of developing approaches to help families manage these challenges.

Every year, we learn so much from you, but this past year it was especially true, as we all navigated an unprecedented time. As with everyone around the world, the coronavirus pandemic made 2020 a very different kind of year. Instead of seeing some of you at the NIH as we normally would, we spoke to you by phone, oftentimes from our homes to yours. We heard about your experiences as caregivers in normal times, as well as how COVID-19 has changed your lives, both in positive and negative ways. We cannot express enough how much we appreciate your time, flexibility, and willingness to tell us your stories.

Despite the challenges of the last year, our team produced multiple scientific publications, presented our findings at several conferences, and continued to collaborate with the teams of Dr. Dang Do, Dr. McGuire, and Dr. Venditti. This year we will start enrolling participants in a longitudinal study and begin implementing an interactive toolkit to provide peer support and resources to serve caregivers. Your time and contributions have made this possible.

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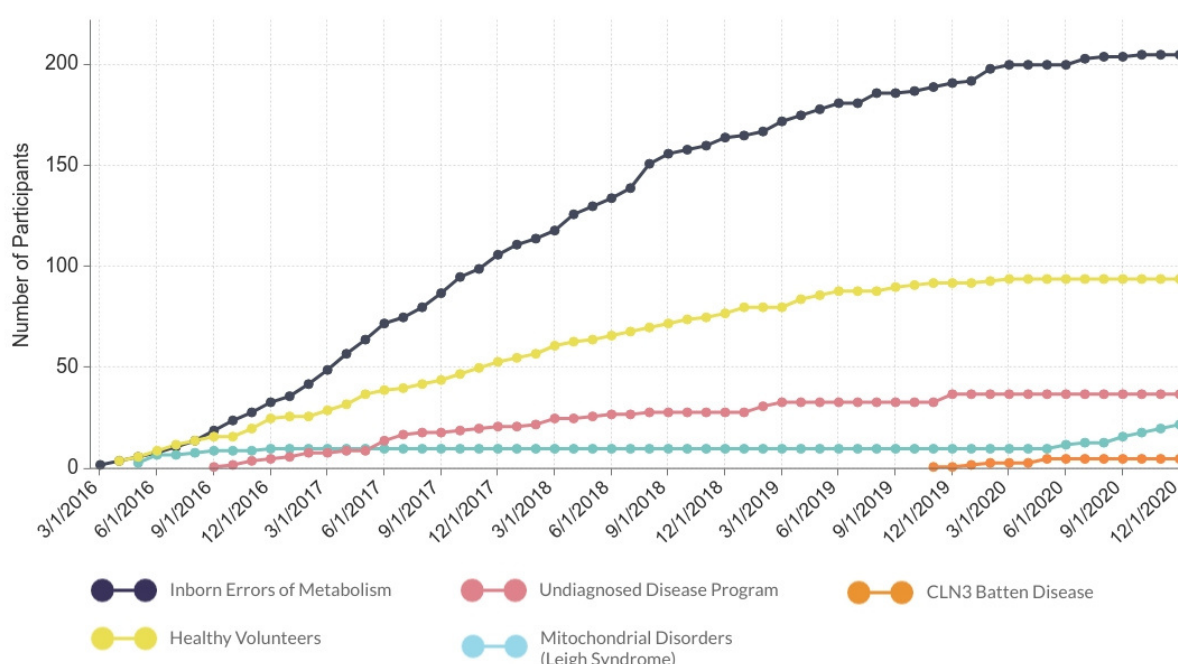
**MEET OUR TEAM**

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# Growth of the Caregiving Study

In the past five years, families have come from across the US (and other countries) to participate in our study. These families include those with children with rare genetic conditions or undiagnosed conditions, as well as families with children without a chronic medical condition.

Through in-depth interviews with all of you, our team has gained much insight into what it means to be a caregiver. This figure shows when each condition was added to the study and the increasing number of participants in each group. Thanks for being part of growth and allowing us to be a small part of yours!



## Where We've Been

Scientific conferences look a little bit different during a pandemic, but we were still thrilled to present our research virtually at the following conferences:

- North American Social Networks (NASN)
- Sunbelt International Network for Social Network Analysis (INSNA)
- American Psychological Association (APA)
- National Human Genome Research Institute (NHGRI) Symposium
- NIH Rare Disease Day

Read more about our work on the next page.

## Updates From the Longitudinal Study

Last year we shared that we're working on launching a longitudinal study. In a longitudinal study, researchers follow a group of participants over a period of time. This type of study will allow us to learn about your caregiving successes and struggles as your child grows. The protocol for this study is making its way through the approval process. The next review is in the Institutional Review Board, and we hope to be in the field soon.



## Ongoing Projects

Our research is constantly evolving based on the conversations we have with caregivers. These are a few of our ongoing projects:



### **Parent-Reported Caregiving Roles of Siblings of Children with Inborn Errors of Metabolism**

Team: Maddy Granovetter, Sydney Sumrall, Dr. Dawn Lea, and Dr. Laura M. Koehly

Parents in our study often describe receiving support from the siblings of their child with an inherited metabolic condition (IM). We wanted to identify the roles that these siblings play in caring for their affected sibling and supporting their parents. We found that siblings support their families in many ways and that siblings of children with IM were more likely to provide care by monitoring their relative and providing emotional support than siblings of TD children.

### **Familial Network Influences on Caregivers' Sentiment and Positive Aspects of Caregiving**

Team: Hannah Davidson, Dr. Melissa Zajdel, Dr. Raphael Heiberger, and Dr. Laura Koehly

For this project, we were initially interested in what it might look like to use sentiment analysis, a method that looks for positive and negative words in text, on our participant's interviews. We decided to link this work to the Positive Aspects of Caregiving measure to see if participants who have greater PAC also use more positive language. We also decided to incorporate our network data to see if different social network attributes have an impact on the relationship between positive aspects and linguistic sentiment.

### **Stress, Coping, and Positive Aspects of Caregiving in Rare Disease Caregivers: Application of the Stress Process Model**

Team: Dr. Jasmine Manalel, Sydney Sumrall, Hannah Davidson, Meghan Grewal, Madeline Granovetter, and Dr. Laura Koehly

We became interested in studying the positive aspects of caregiving (PAC) after reading interviews with participants and noticing that several people characterized their experiences as meaningful. Moreover, we wanted to see if there are any patterns in coping style and support among those who report experiencing PAC. We found that caregivers who provide a lot of support to their child are more likely to report experiencing PAC if they engage in emotional support coping and venting.



### **Resource accessibility for families affected by rare metabolic conditions: A mixed-methods approach exploring relocation and health**

Team: Anna Shetler, Aaron Gurayah, Dr. Christopher S. Marcum,  
Dr. Laura Koehly

During our interviews with caregivers, our team grew interested in learning more about the availability of nearby resources to participants. Specifically, we wanted to explore how moving from one home to another could affect families' resources, along with their health and well-being. We found that families often relocated to access better healthcare and social services for their child. In our commentary, we advise healthcare systems to review the distribution of these resources, and we recommend that social support programs be developed to benefit the entire family. We found that expanding resources can be advantageous for both the child and their caregiver.



### **Caregiver Convoys: Structure and Function of Caregivers' Social Relations**

Team: Dr. Jasmine Manalel, Anna Shetler, Aaron Gurayah, Dr. Laura M. Koehly

Given what we know about how important relationships can be, we were interested in describing what caregivers' support networks, or "convoys", looked like in terms of composition, support functions, and interpersonal strains. We were also interested in whether characteristics of the network members, like their gender or relationship to the caregiver, would make them **more** likely to provide support or cause strain. One of our interesting findings was that caregivers' family members were more likely to provide support AND more likely to cause strain. This is consistent with other scientific literature that suggests our closest social ties are the most supportive and the most stressful.

### **Ongoing Work in the Laboratory**

Team: Tracy Swan, Meghan Grewal, Dr. Faith Pangilinan, Dr. Laura Koehly

The Koehly lab is interested in learning about how the chronic stress of caregiving is associated with altered biological mechanisms, particularly in the realms of epigenetics and telomere biology. Epigenetics is an evolving field and its basic premise is that environmental stressors can impact the expression levels of genes by methylating DNA nucleotides, which effectively silences those genes. Through our work we hope to uncover whether methylation patterns differ between parents of children with rare diseases and parents of healthy children, specifically on genes related to stress susceptibility and resilience. Telomeres are regions at the ends of DNA that shorten each time a cell divides, Short telomeres are associated with aging. Our work is examining telomere length in parents of our study to determine if chronic stress is associated with an accelerated phenotype. We hope to examine if the presence of certain coping strategies can modulate the methylation patterns and telomere length of the parents in our study.



## Our Virtual Team

### Laura Koehly, PhD.

Dr. Koehly heads the lab. Her background is in Psychology, with an expertise in family systems. Her research aims to identify pathways for intervention to help families communicate about and adapt to inherited disease risk. Dr. Koehly is a "military brat" who has landed in Maryland. She is married with two adult children and two grandchildren.

### Dawn Lea, PhD, MSN.

Dr. Lea is a nurse scientist in the lab. Her research aims to investigate predictors of outcomes in community dwelling individuals affected by chronic diseases; specifically, the role of caregivers and how the social and familial system influence health outcomes.

### Megan Cooper, MSW.

Megan is the clinical research coordinator for the Caregiving Study. She is a Licensed Clinical Social Worker with a background in working in crisis intervention, substance abuse, and inpatient mental health settings. Outside of work, Megan stays busy by keeping up with her seven year old son.

### Patricia Cooper, LGPC.

Patricia began as the clinical research coordinator for the Caregiving Study in June 2020. She is a Licensed Graduate Professional Counselor with a background in family counseling and trauma. Patricia enjoys reading, baking, and spending as much time at the beach as she can.

### Jasmine Manalel, PhD.

Jasmine is a postdoctoral fellow in the lab. Her background is in developmental psychology. Her research focuses on how close, social ties are linked to health and psychological wellbeing across the lifespan. She loves group fitness, going on nature walks, and traveling to new places.

### Melissa Zajdel, Ph.D.

Dr. Zajdel is a postdoctoral research fellow in the lab. With a background in social and health psychology, she focuses on how interpersonal processes such as communication and coping are linked to health and well-being. She loves playing sports, reading, and her rescue dog named Potato.



### Jielu Lin, Ph.D.

Jielu recently joined the lab as a staff scientist. Trained as a sociologist, Jielu studies the social determinants of health over the life course, particularly those related to race/ethnicity, interpersonal relationships and genomics. She has a rescued pet goldfish named Gordon.

### Julia Nummelin, MPH.

As a Scientific Program Analyst, Julia handles administrative and regulatory tasks to support the Caregiving Study. She has a background in public health research, communications, and business development. Julia enjoys winter sports, running with her American Bulldog, singing, and weightlifting.

### Luis Lopez, BA.

Luis is a post-baccalaureate fellow who helps with data and computational tasks in the lab. He is a proud graduate of Westminster College, a small, "hippy-dippy" liberal-arts college where Luis's love of interdisciplinary research began. Off the clock, Luis enjoys teaching yoga, going on hikes, and gossiping about *The Real Housewives of Salt Lake City*.

### Shani Gelles, BS.

Shani is a post-baccalaureate fellow who joined the lab this fall. Her background is in Anthropology and Pre-Health, and she is excited to be involved in several upcoming projects. Shani loves to play sports and spend time outside, as well as baking and reading good books.

### Lindsey Mountcastle, BA.

Lindsey is a post-baccalaureate volunteer, primarily working on the caregiver supportive intervention team. She earned her BA in psychology from the University of Maryland, Baltimore County, graduating summa cum laude December 2020. Outside of research, Lindsey enjoys photography, bird watching, and weightlifting.

### Hannah Davidson, BA.

Hannah is a post-baccalaureate fellow in Dr. Koehly's lab. She is involved in several aspects of the caregiving study. She is also interested in how people grow and make positive meaning through the caregiving experience. She loves venturing out to weekly farmer's markets, hiking the amazing trails around the DC area, and making art.

### Tracy Swan, BA.

Tracy is a post-baccalaureate fellow in the lab. She is working on a project investigating the methylation patterns in stress-related genes of caregivers. She enjoys cooking recipes from *New York Times* and exploring museums in DC.

### Meghan Grewal, BA.

Meghan is a post-baccalaureate fellow in the lab. In addition to working directly with participants, Meghan studies physiological biomarkers of stress. Meghan enjoys hanging out with her cat and will be going to medical school in the fall.

### Sydney Sumrall, BA.

Sydney is a post-baccalaureate fellow in Dr. Koehly's lab. She is working on projects such as the measurement of interpersonal stressors and the utilization of coping strategies among caregivers. She loves running outside, cooking healthy food, and listening to audiobooks.