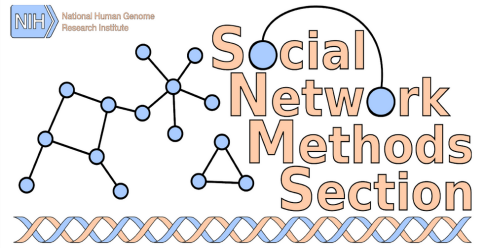


# THE CAREGIVING STUDY NEWSLETTER



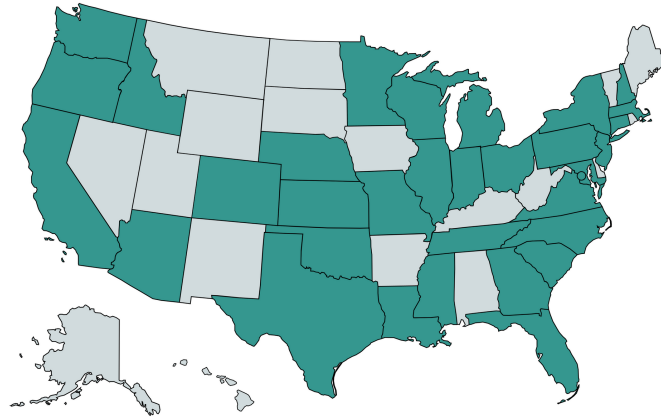
APRIL 2019

## Caregiving Study Updates

As of April 2019, over 155 families have participated in the Caregiving Study. These families have come from four different countries and 33 states across the US (shown in the map to the right). This includes families with children with an inherited metabolic condition or an undiagnosed disease, as well as families with children without a chronic medical condition. Within these families, parents and other caregivers have participated, including extended family, friends, and formal care providers.

Through study interviews, our team has gained so much insight into the lives of caregivers. Families have discussed the stressful elements of caregiving, including receiving and adapting to their child's diagnosis, coordinating care between different family members and medical providers, and dealing with insurance companies and medical costs. Participants have also shared their thoughts on the positive aspects of caregiving. Many felt that their experiences brought their families closer together, improved communication, and made them more empathetic to others in their community.

In addition to these interviews, many parents who have come to the NIH also participated in another portion of the study in which they provided blood and saliva samples, along with heart rate data. These samples will allow us to examine biomarkers related to stress. The study has been going on for nearly three years, and we are continuing to recruit and enroll families in all portions of the study.



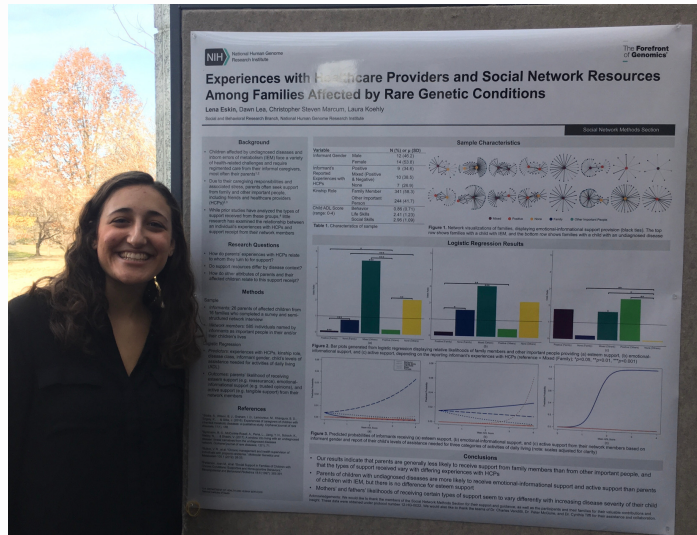
## Paper Publication

At the 2017 Propionic Acidemia Foundation meeting, parents contributed to a survey of dietary behavior. The survey data were analyzed and a paper was recently published in the *Journal of Parenteral and Enteral Nutrition*, titled "Dietary Management of Propionic Acidemia: Parent Caregiver Perspectives and Practices".

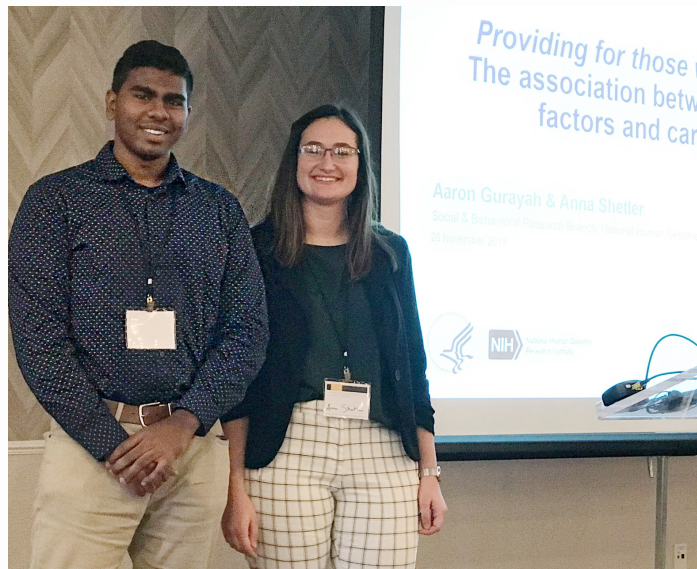
Parents responded that they "always" or "most of the time" followed the prescribed diet for children 4–20 years of age. Over seventy percent of parents made a "situational adjustment" to their child's diet for a variety of reasons, including illness, social events, or effect of prescribed treatments (such as an isoleucine rash). We are most thankful to the parents who shared their experiences, and we believe this is but a small step in promoting open lines of communication between parents and healthcare providers.

APRIL 2019

# Research Presentations



Several members of the Koehly team presented preliminary findings from the Caregiving Study at the North American Social Networks Conference and at the National Human Genome Research Institute’s annual symposium this past November. One of these projects, spearheaded by Lena Eskin, examined the relationship between caregivers’ experiences with their children’s healthcare providers and the support they received from important people in their lives. During interviews with our study team members, caregivers reported a broad range of support sources, including family, friends, neighbors and coworkers who provide much needed resources to their lives. Our results indicate that caregivers utilize these support resources when they have negative experiences with their providers.



In the fall of this past year, Aaron Gurayah and Anna Shetler presented preliminary findings at the 2nd Annual North American Social Networks conference in Washington, D.C. They explored how social networks—including family members, friends, and healthcare providers—affect health outcomes for parents who have a child with inherited errors of metabolism. Using survey information and network assessments, the researchers found intriguing results. The parents of children with an inherited metabolic disorder reported having more network members who live in close proximity to themselves, compared to controls. Additionally, this larger network size was significantly associated with better mental health outcomes. These findings may influence future interventions to reduce the stress levels of individuals who provide care to those with rare diseases. Aaron and Anna hope to extend their research by investigating how social networks and access to healthcare facilities can further relate to physiological stress levels.

## Looking Ahead

With the information collected through the Caregiving Study, we have been able to uncover some of the complex nature of the caregiving experience, including challenges and positive aspects. We are interested in how the experience of long-term caregivers changes over time, as they and their affected relatives develop. To this end, we are expanding the Caregiving Study to follow participants over several years. The proposed longitudinal, or natural history, study would include periodic assessments every 1-3 years during clinical center visits, as well as the option to participate in daily diary assessments at home. The periodic assessments would include survey and interview questions similar to what participants have been asked previously and provide families with an opportunity to share the ways in which their caregiving experience has stayed the same or changed. With the daily diary survey, we hope to capture the day-to-day experiences of caregivers by asking about their caregiving roles, mood, health, and stress every day for about a week each year. This expansion of our study would allow us to more closely investigate caregivers’ experiences and address research questions concerning the long-term implications of caregiving and variation in daily experiences.



## Meet the Study 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.

**Christopher Steven Marcum, PhD.** Dr. Marcum is an investigator/staff scientist in the lab. His research focuses on statistical methodology and how health and aging shape interpersonal processes over the life course. He enjoys spending time outdoors with his family and pooches on the weekends.

**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.

**Mindy Perilla, MPH CCRC.** Mindy is a certified clinical research coordinator and the lab’s Project Coordinator. She works on study documentation, regulatory processes, and data management. Mindy was a participant in clinical trials (phase 2,3) before getting involved in research professionally, and feels those experiences informed the perspective she brings to her work today. She is a self-described “public health geek,” interested in all sorts of global health issues.

**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. Megan enjoys spending time with family, especially her five-year-old son.

**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 well-being across the lifespan. She loves group fitness, going on nature walks, and traveling to new places.



**From left to right:**  
Back row - Calandra, Tracy, Aaron, Dawn, Anna, Mindy, Chris  
Front row - Jasmine, Laura, Kelly  
Not pictured - Lena, Megan

**Lena Eskin, BA.** Lena is a post-baccalaureate fellow in the lab. She works on a variety of aspects of the study, including recruiting, enrolling, and interviewing participants. As an undergraduate, Lena studied chemistry and chemical biology, and she will be starting medical school in the fall. She also loves to dance, bake, read, and do crossword puzzles.

**Aaron Gurayah, BA.** As a post-baccalaureate fellow in the lab, Aaron conducts interviews with participants, processes biological samples, and performs quantitative analyses. As an undergraduate, he studied molecular biology and received a certificate in global health. His research interests include investigating the interplay between genetic and environmental factors that contribute to negative health outcomes in adolescents and adults. He enjoys playing sports and dancing.

**Kelly Nguyen, BS.** Kelly is a post-baccalaureate fellow in Dr. Koehly’s lab. She is involved in developing a timeline project that captures important milestones of affected individuals via their caregivers. She also helps with coding, creating unique identification numbers for participants, and data cleaning. At San Diego State, Kelly studied health communication, but is now pursuing a career as an R&B and jazz singer. She loves to sing, dance, and cook.

**Anna Shetler, BA.** Anna is a post-baccalaureate fellow in the lab, involved with enrolling and interviewing participants. In college, she studied biology, chemistry, and psychology. While (unsurprisingly) still indecisive about her future, Anna hopes to pursue a degree intertwining health outcomes and disparities. She loves to cook and enjoys exploring new places.

**Tracy Swan, BA.** Tracy is a post-baccalaureate fellow in the lab. She works on enrolling participants in the caregiving study, as well as analyzing their oxytocin values from the blood data. She will potentially correlate those values with other hormone values collected (cortisol and arginine-8) to look at stress. She enjoys doing yoga.