

THE CAREGIVING STUDY NEWSLETTER

The National Institutes of Health

WELCOME

The Caregiving Team of the Social Behavioral Research Branch in the National Human Genome Research Institute would like to express our sincere thanks to all of you and your families for your participation. As always, a top priority of our Section is to better understand the experiences of our participants as caregivers and parents. We are incredibly grateful that you all are sharing your lives and experiences with us.

Our hope is to continue to learn the best ways to support caregivers. A core goal of our work is to inform healthcare professionals, other researchers, and the general public of the unique challenges and feelings you have expressed. We aim to develop resources that will provide support and facilitate communication.

In the past year, our study continued to navigate the challenging times brought on by the coronavirus pandemic. As changes were made, we really appreciate your participation and flexibility given the circumstances. Now more than ever, the unique experiences that you shared with our team will allow us to gain insight into what support and resources may be best suited for caregivers across populations and contexts.

Despite the ongoing pandemic, our team has been able to finalize publications and begin new projects. Part 1 of the Caregiving Study, our Cross-Sectional Study, has closed out and we are so grateful to all of you for contributing! Next launch is Part 2: Longitudinal! We are excited to announce that our Longitudinal Study has officially taken off, meaning more opportunities for you to participate. 🚀

Our first few participants have begun surveys, interviews and other measures to start an exciting new aspect to our Caregiving Study. Our Section prides itself in its multi-method approach to studying the caregiving experience as we gather survey data, biological data, and qualitative interview data. Your time and openness have made this research possible, and **we thank you to the moon and back for that.**

IN THIS ISSUE

Longitudinal Study
Page 2

New Papers
Page 3

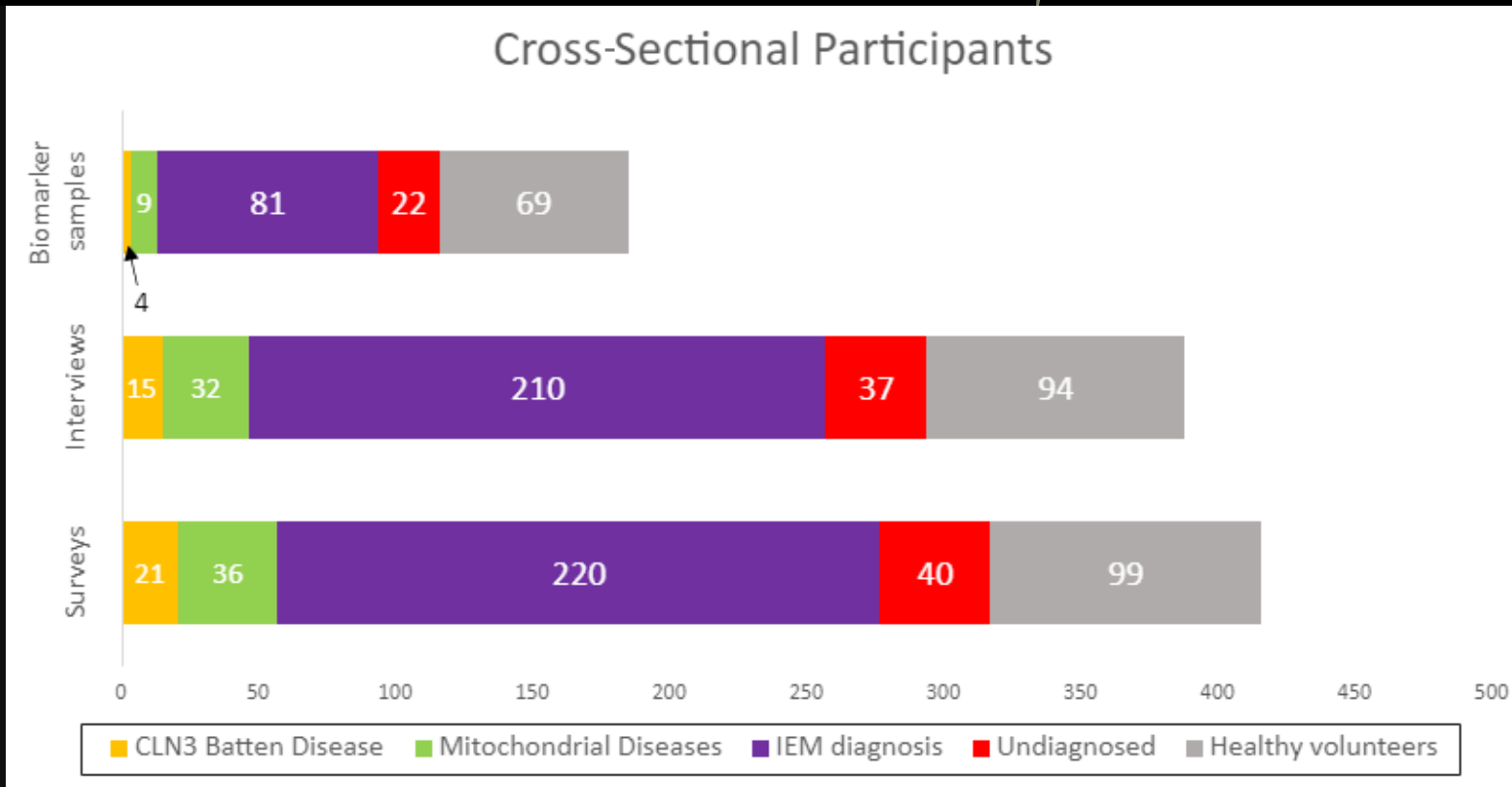
Ongoing Projects
Page 4

Meet the Team
Pages 5-6



CROSS-SECTIONAL STUDY: MISSION COMPLETE

As we move into a new phase of the Caregiving Study, we are reflecting on the success of the Cross-Sectional Study. Thanks to you, we had 500 participants total! The graph on the right displays how many biological samples, interviews, and surveys were collected and conducted, broken down by diagnosis.



LONGITUDINAL STUDY: JUST LAUNCHED

The goal of our Caregiving Study has always been to understand how caregivers manage the demands of caring for loved ones and how social relationships affect their ability to cope. To expand on this research, we are thrilled to announce a new phase of the study: the Longitudinal Caregiving Study.

Longitudinal means research that happens over time. With the introduction of this new phase of the study, we will now be conducting surveys and interviews with participants over the course of several years, instead of just once.

So, what does this mean for you? If you were a past participant of the Caregiving Study, you will have the opportunity to continue your participation in this new longitudinal phase of the study. If you choose to participate, you will be asked to complete assessments every year for five years. You will also be asked to complete three short surveys throughout the year, which will help us understand the day-to-day activities, stresses, and supports related to your caregiving role.

Additionally, we are recruiting new caregivers who are interested in sharing their experiences. In the past, our study participants have come from a few studies at NIH. In this new phase of the study, any caregiver of someone with a long-term health condition can participate.

We are excited to welcome you to this new phase of our study. We are honored that you have shared your stories over the years and continue to be grateful for the opportunity to hear more about your caregiving experiences.



NEW PAPERS

It is important for us to share what we have learned from you with the scientific community. Several papers stemming from the caregiving study are currently under review or recently published:

Caregiving roles and expectations among siblings of children with inborn errors of metabolism versus siblings of typically developing children: Analysis of parent perspectives

Madeleine Granovetter, Dawn Lea, Sydney Sumrall, & Laura Koehly

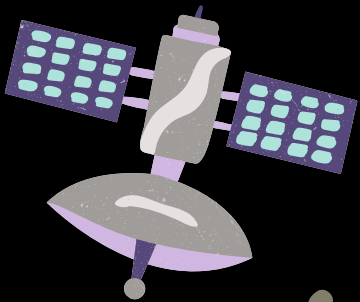
This paper explores how siblings contribute to caregiving of children with inherited metabolic disorders, and parent perceptions of these siblings' attributes and attitudes toward caregiving. The paper was started by a previous post-bac fellow in the lab, and has since been submitted for publication.



Links of pronoun use to caregiver social network systems, health, and well-being

Melissa Zajdel, Hannah Davidson, Dawn Lea, & Laura Koehly

Using the caregiving interviews we capture pronoun use to examine how communal coping with friends or family is linked to caregiver well-being and network involvement. We use this process to show how communal responsibility for caregiving is linked to more network member involvement as well as expectation fulfillment.



Malfeasant, nonfeasant and uplifting caregiving interactions and behaviors in pediatric care contexts:

Laura Koehly, Sato Ashida, Sydney Sumrall, & Sarah Hyman

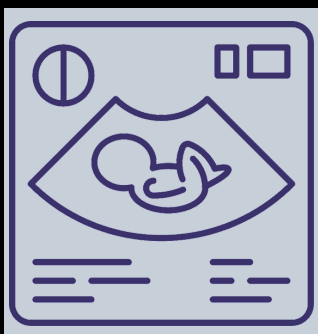
We characterize caregiving-related interactions and behaviors of network members that may represent interpersonal stressors as compared to interpersonal supports. We identified disengagement as more stressful than active disagreements about care roles for families with children diagnosed with rare disease. This work can inform interventions that aim to address the stress associated with unmet caregiving role expectations.



Experiences of families caring for children with newborn screening-related conditions: Implications for the expansion of genomics in population-based neonatal public health programs

Lynn Bush, Hannah Davidson, Shani Gelles, Dawn Lea, & Laura Koehly

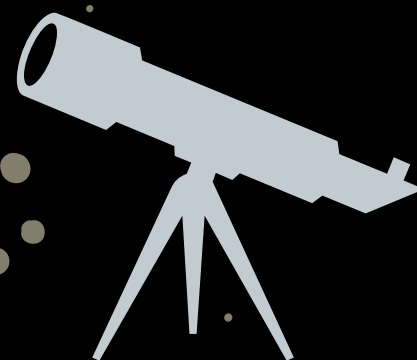
We describe the diagnostic odyssey continuum of caregivers caring for children diagnosed with conditions detectable through newborn screening. Based on caregivers' experiences, we provide policy recommendations around inclusion of genomics in population based newborn screening programs.



Stress, coping, and positive aspects of caregiving among caregivers of children with rare diseases: Application of the stress process model

Jasmine Manalel, Sydney Sumrall, Hannah Davidson, Meghan Grewal, Madeleine Granovetter, & Laura Koehly

Many research studies focus on the stress of caregiving, but it is also an incredibly rewarding experience. In this paper, we examined what aspects of caregiving were related to positive aspects of caregiving (PAC). One key finding was that coping through venting was associated with lower PAC, and emotional support was associated with greater PAC. This highlights the potential of support-based interventions for promoting PAC.



ONGOING PROJECTS

We are currently working on the following projects using data from the Caregiving Study:

The impact of caregiving for children with genetically-linked conditions on the hypothalamic-pituitary-adrenal axis: A scoping review

Lindsey Mountcastle, Melissa Zajdel, Taylor Robinson, Krystyna Keller, Dawn Lea, Shani Gelles, Bijal Kikani, & Laura Koehly

The scoping review project explores the current state of the literature in pediatric caregiving and physical health outcomes. This paper charts the literature to determine what is known about the impact of caring for a medically complex child on caregivers' physical health, such as dysregulation of the HPA axis.



Early life experiences in a rare disease context

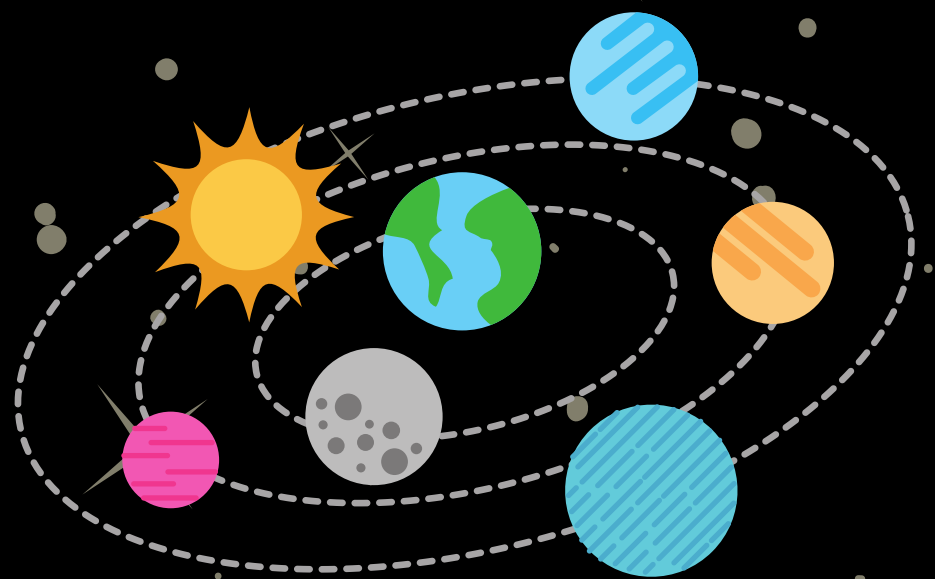
Hannah Davidson, Shani Gelles, Krystyna Keller, Melissa Zajdel, & Laura Koehly

This project examines the meaning that parent-caregivers apply to their experiences during the first year of their child's life, encompassing birth and postpartum. This project is in the final stages of a write-up, and identified a diverse range of themes spanning parental experiences with the healthcare system, identity and relational shifts, and adjustment and adaptation to their child's condition. We're excited to submit this project soon for publication!

Shared responsibility and network collaboration in caregiving

Melissa Zajdel, Krystyna Keller, Lindsey Mountcastle, & Laura Koehly

This paper examines pronoun use to assess communal coping. Our team found that communal caregiving is linked to more positive and less negative interactions with family and friends as well as better caregiver well-being. This paper is important because it shows the influence of family support in caregiving. We are hoping to submit this paper for publication in the coming months.



Below are team member bios, including fun space-related facts, jokes, and anecdotes:

Laura Koehly, Ph.D.

Role: Head of the Lab, Branch Chief
Background: Quantitative Psychology and Family Systems
Space: My dad worked on the Gemini X project, leading aspects of the Gemini-Agena Target Vehicle. He was working on this when I was born – and my zodiac is the Gemini.

Dawn Lea, Ph.D, MSN.

Role: Nurse Consultant
Background: Nursing Science
Space: My favorite space movie is Space Cowboys.

Jielu Lin, Ph.D.

Role: Staff Scientist
Background: Sociology & Gerontology
Space: I've been following the Voyagers since I was in first grade, looking at the first pictures of Jupiter and Saturn they took. Now both probes are in interstellar space.

Melissa Zajdel, Ph.D.

Role: Post-Doctorate Fellow
Background: Health Psychology
Space: I've literally never ever wanted to be an astronaut. I think it sounds like a horrible job, given claustrophobia and how people get motion sick.

Julia Nummelin, MPH.

Role: Scientific Program Analyst
Background: Public Health
Space: As an a cappella nerd I really like the song "Cells Planets" by Chanticleer.

Patricia Cooper, LGPC.

Role: Clinical Research Coordinator
Background: Counseling & Psychology
Space: Why did the star go to school? – To get brighter!

Megan Cooper, MSW.

Role: Clinical Social Worker
Background: Social Work
Space: What do stars say when they apologize to one another? – I'm starry!

Luis Lopez, BA.

Role: Post-Baccalaureate Fellow
Background: Computational Science
Space: Favorite space related book is "The Three Body Problem" by Cixin Liu.

Shani Gelles, BS.

Role: Post-Baccalaureate Fellow
Background: Anthropology
Space: The sun is so big that approximately 1.3 million Earths could fit inside (if squished) or 960,000 Earths (unsquished, regular spherical shape).

Lindsey Mountcastle, BA.

Role: Post-Baccalaureate Fellow
Background: Psychology
Space: I saw Tom Cruise on a spacecraft at the Air and Space Museum in DC.

Taylor Robinson, BS.

Role: Post-Baccalaureate Fellow
Background: Anthropology
Space: There are more trees on Earth than stars in the Milky Way. There are about three trillion trees on Earth and 'only' 100-400 billion stars in the galaxy! – Source: ASU.

Krystyna Keller, BA.

Role: Post-Baccalaureate Fellow
Background: Psychology & English
Space: My favorite song is "Drops of Jupiter" by Train.

Bijal Kikani, BS.

Role: Post-Baccalaureate Fellow
Background: Neurobiology & Physiology
Space: Why didn't the sun go to college? – Because it already had a million degrees!

Isaias Torres, BS.

Role: Post-Baccalaureate Fellow
Background: Kinesiology & Chemistry
Space: I enjoy exercising the idea with my wife that aliens exist in the universe. We like to imagine that we are not the only life civilization in this infinite universe.

Hannah Allen, BS.

Role: Post-Baccalaureate Fellow
Background: Neuroscience, Psychology, & Chemistry
Space: I recently went to a Dark Sky Park in West Virginia and saw the most amazing stars I have ever seen!

MEET THE TEAM



MISSION CONTROL

