



The

CAREGIVING STUDY

Newsletter



National Human Genome Research Institute,
National Institutes of Health

WELCOME

"A great deal remains to be done before we can regard the shift in emphasis towards 'Caring for caregivers' as part of a typical health service."

Roy Bailey in "Coping with Stress in Caring," 1985

Decades after these words were published, our team continues in our pursuit to understand the unique experiences and challenges of those involved in informal caregiving. We express our sincere gratitude to all of you for sharing your and your family's experiences with us.

In 2022, we continued to work towards the goals of the lab: to learn how we may better support caregivers, to inform professionals, researchers, and the greater public of our findings, and to develop resources with this information to promote individual well-being and societal change.

We closed our cross-sectional study to enrollment in 2021 and transitioned to a longitudinal study. Thank you so much for helping us to move this important work forward. We hope that you, also, have benefited from being involved in the study.

Our team has been publishing our findings, which we hope will inform policy and practice as it relates to "caring for caregivers." We highlight our ongoing projects and recent publications in the pages below. This research would not be possible without you. We thank you for giving your time and sharing your experiences - both the difficult times and rewarding experiences. We have learned much from you.

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1) Meet the Team

DR. LAURA KOEHLI

Chief & Senior Investigator, Social Network Methods Section



PUBLICATIONS

Your time has contributed to our understanding of health and human behavior which will inform future programs to help caregivers along their journey.

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, Shani Gelles, Alicia Livinski, Bijal Kikani, Dawn Lea, & Laura Koehly

This paper reviews the current state of the literature examining caregiving for a child with a chronic condition and the impact of caregiving on caregivers' health. Studies in the review revealed inconsistent measurements and findings, and helped us identify gaps in research. We hope to use this information to guide future projects in our lab with your data, as we have already begun to do so with the paper described below!

Stress, Coping, and Physical Health in Caregiving

Melissa Zajdel, Tracy Swan, Taylor Robinson, Krystyna Keller, Lindsey Mountcastle, & Laura Koehly



In this paper, we explored how stress and coping can impact biological markers of the body's stress response and immune systems. We found a difference between caregivers of children with and without a rare or undiagnosed disease. While stress is linked to worse physical health in caregivers of children without a rare or undiagnosed disease, for caregivers of children with a rare or undiagnosed condition, stress was not linked to physical health. Coping strategies generally thought of as positive, such as reappraisal or acceptance, were used more by caregivers of children with a rare or undiagnosed disease. These findings suggest that many caregivers have developed resilient coping strategies to manage their stress!

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

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

This paper explores how communal language, such as "we," "us," and "ours," is linked to caregiver well-being and interactions with friends and family. We found that using more communal language is linked to more positive interactions with family and friends and listing more positive aspects of caregiving. These patterns held true for caregivers of children with and without rare diseases, suggesting more "we-talk" can be helpful for all types of caregivers!



PUBLICATIONS CONT.

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

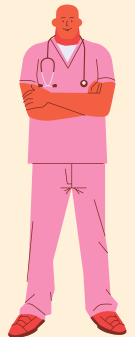
Madeleine Granovetter, Sydney Sumrall, Dawn Lea, Shani Gelles, & Laura Koehly

Since chronic illness caregiving management is a family process, we examined differences in the care roles taken on by siblings of children diagnosed with an inborn error of metabolism compared to siblings of an age-matched typically developing child, based on parent report. We found that siblings of children with inborn errors of metabolism were more likely to be involved in monitoring and providing emotional and social support than siblings of typically developing children. This work highlights the meaningful care role involvement of siblings in both caregiving contexts. This paper was spearheaded by one of our former Post-baccalaureate Trainees, who is now in medical school!

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

In this paper, we analyzed the interview transcripts using an ethical lens to uncover lessons learned from your experiences. We identified two domains for future policy and practice considerations related to medical management implications and psychosocial needs of families. Our hope is that this work will have an impact on guidelines for the integration of genomics in newborn screening programs. Two of our former trainees played significant roles in the analysis of the interview transcripts. Hannah Davidson is currently in a Genetic Counseling training program and Shani Gelles is off to medical school! Learning from you has played a pivotal role in their career path.



ONGOING PROJECTS

These projects are being led by trainees, who are our next generation of clinicians and scientists.

Post-Traumatic Stress in Rare Disease Caregiving

This project focuses on how caregivers may experience stress in response to their caregiving roles and past experiences. Specifically, we are focusing on post-traumatic stress symptoms that some caregivers exhibit after undergoing the process of obtaining a diagnosis for their care recipient. We used both survey responses and interviews to understand how caregivers experience and discuss this type of stress. Our hope for this project is that it will be helpful in creating more effective resources and support for our participants by gaining a better understanding of the contexts and perspectives of each individual.



Exploring the Experiences of Rare Disease Caregivers Throughout the COVID-19 Pandemic

This paper aims to highlight the experiences of our caregiver population as they navigated the COVID-19 pandemic. Over the past few months, we have been reviewing interview transcripts and identifying common themes shared among this caregiver population as we all lived through the pandemic. We are sincerely grateful that our participants took the time to provide insight into their perspectives as caregivers during this unprecedented period. We acknowledge that the pandemic had a wide variety of effects on people around the world and we believe that this project will showcase the complexity of caregiving throughout the COVID-19 pandemic.

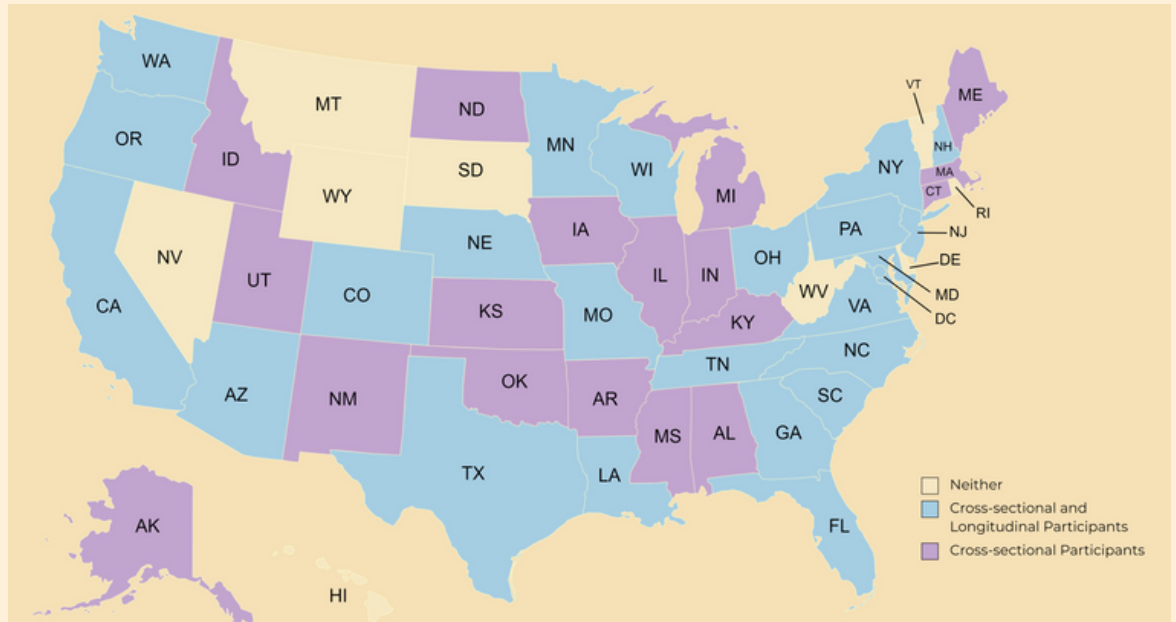


PARTICIPATION IN THE CAREGIVING STUDIES BY STATE

Thank you for your contribution!



The original (i.e., cross-sectional) study included caregivers from 42 U.S. states & territories and 5 countries total. The current (i.e., longitudinal) study began in October 2021 and, so far, includes caregivers from 24 states & territories and 3 countries total. We hope to continue to enroll many more caregivers from around the country and the world!



THE SUPPORT GROUP



Thank you for your input! We hope this has meaningfully added to your experience of the study.

This year we launched a pilot of a virtual support group for caregivers. One aim of the caregiving study is to develop strategies to help caregivers cope better, and this group is just one way that we are trying to do that. The virtual support group was created to provide a space for caregivers to connect, support each other, learn coping strategies, and share resources. We hope to have the opportunity to continue with this group in the future.

2022 HCU/OA/PA CONFERENCE

We are so happy for the opportunity to attend a conference offering mutual support and care for all involved!

In June, a few members of our study team attended the 2022 Land of the Free, Home of the Brave Conference, hosted by the HCU Network America, Organic Acidemia Association, and Propionic Acidemia Foundation. Two members of our team also volunteered at the event, photographing the presenters and attendees and helping with the activities for kids. We all enjoyed the opportunity to connect with families, professionals, and members of the rare disease community, while also sharing information about the Caregiving Study. We were also able to sit in on several presentations throughout the weekend and learned so much from the speakers. We hope to be able to attend more conferences like this in the future!

MEET THE TEAM



Laura Koehly, Ph.D., Chief and Senior Investigator

What is something you enjoyed working on this year? Mentoring and sponsoring emerging scholars as they navigate the next steps in their professional journey.



Jielu Lin, Ph.D., Staff Scientist

What is something you enjoyed working on this year? Brainstorming how to visualize our data on relationship networks in Germany!



Lisa DeRoo, Ph.D., M.P.H., Staff Scientist

What is something you enjoyed working on this year? I enjoyed joining the research group and working on the ongoing Gender Roles in Caregiving project led by Patricia & Julia.



Julia Nummelin, M.P.H., Scientific Program Analyst

What is something you enjoyed working on this year? I have enjoyed collaborating with the study team and helping to ensure the new Longitudinal study runs smoothly!



Patricia Cooper, M.S., LGPC, Clinical Research Coordinator

What is something you enjoyed working on this year? As always, this year I enjoyed speaking with the families in our study. In every interview, I feel so grateful that our participants are willing to trust me with their stories and share their experiences.



Dawn Lea, Ph.D., RN, Nurse Consultant

What is something you enjoyed working on this year? I am happy that two papers we have worked on came out, so that we can share caregivers' experiences more broadly.



Melissa Zajdel, Ph.D., Postdoctoral Trainee

What is something you enjoyed working on this year? Learning about different parts of the caregiving experience and writing papers with as many different types of interviews as possible.

Thank you for making this research possible! We would not be able to research and help others without your time & support!



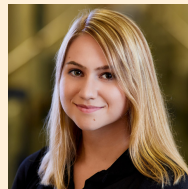
Krystyna Keller, B.A., Post-baccalaureate Trainee

What is something you enjoyed working on this year? I have particularly enjoyed developing my post-traumatic stress in caregiving project and I look forward to continuing the progress in the new year.



Taylor Robinson, B.S., Post-baccalaureate Trainee

What is something you enjoyed working on this year? This year, I have really enjoyed working with our DNA analysis project because I think it can offer an exciting biological clue into ways stress may impact caregivers on a molecular level.



Lindsey Mountcastle, B.A., Post-baccalaureate Trainee

What is something you enjoyed working on this year? I enjoyed learning more about the biological outcomes of stress for caregivers.



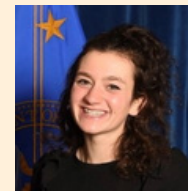
Helen Wang, B.A., Post-baccalaureate Trainee

What is something you enjoyed working on this year? I love the fact that I was able to get a more nuanced understanding of the positive and negative aspects of the caregiving experience as I read through the transcripts we collected.



Kamryn Wilson, B.S., Post-baccalaureate Trainee

What is something you enjoyed working on this year? Analyzing DNA in a lab setting! I have really enjoyed researching the biological aspects of social network relations.



Zoe Waldman, B.A., Post-baccalaureate Trainee

What is something you enjoyed working on this year? I really enjoyed becoming apart of a team that cares so strongly about its participants and the quality and impact of its research!