



Research Inclusion  
Supports Equity

March 2024  
ISSUE 6

# RISE REGISTRY QUARTERLY NEWSLETTER

*Our vision is to  
establish  
inclusive  
research that  
promotes equity.*

In this issue, you will find the latest news from the RISE team and partners as we continue to serve the LGBTQIA+ community.

## THE RISE REGISTRY

RISE is a research study being conducted by Emory University, the University of Nevada, Las Vegas (UNLV), and the University of Tennessee, Knoxville (UTK). RISE stands for Research Inclusion Supports Equity.

The RISE study includes a research registry created to help ensure the LGBTQIA+ community is represented in Alzheimer's research. RISE strives to create a network in research of Alzheimer's disease and related dementias for the LGBTQIA+ community through community-focused, inclusive approaches to research engagement, recruitment, and support of caregivers and people living with memory loss.

By registering with RISE, you'll receive:

- Notice of research opportunities related to aging or caregiving in your area and nationally
- Opportunities to participate in educational and advocacy events online or in-person
- Invites to participate in questionnaires, interviews or focus groups related to aging and the LGBTQIA+ population
- LGBTQIA+ friendly resources for adults with memory concerns and caregivers



*As of February  
2024, over  
**1,000 people**  
have signed up  
to be part of the  
RISE Registry!*

You can learn more and sign up for RISE today at  
[theriseregistry.org](https://theriseregistry.org).

## RISE IN THE NEWS AND THE COMMUNITY

*Miss Coco Peru recorded a video [sharing her own caregiving experiences and her support of RISE](#).*

Dr. Andrea Gilmore-Bykovskiy, RISE Co-Investigator, was highlighted in a recent NIA Research and Training Spotlight article. The article focuses on her work in the field of dementia research, the human experience of living with dementia, and the experience of caregivers. [Read the article here](#).

Dr. Jason Flatt and the UNLV team attended the US Association of Prides in Las Vegas. Dr. Flatt presented information about the RISE Registry, as well as best practices for more age-friendly and inclusive Pride celebrations to more than 40 attendees.



*CMS has released new state options for collection of SOGI data in research – find their blog post and download the tip sheet [here](#)*

## LGBTQIA+ NEWS, RESEARCH, AND CONTINUING EDUCATION

[LGBTQ+ Elders Conference](#) – Virtual – June 20<sup>th</sup>

[Alzheimers Association International Conference](#) – Virtual, Philadelphia, PA – July 28th-Aug 1<sup>st</sup>

[LGBTQIA+ Health Care Conference](#) - Atlanta, GA - August 15-17<sup>th</sup>

LGBTQIA+ Research: [Climate Change Related Disasters and the Health of LGBTQ+ Populations](#)

The RISE Registry Focus Group – share your experience as an LGBTQIA+ caregiver and ways we can make research participation more inclusive. Contact [Rainbows of Aging](#) for more information or call (833) 966-6974

CareVirtue Planner – a web-based financial and legal planning tool for LGBTQIA+ caregivers of people living with Alzheimer's disease and related dementias. Please contact [Dr. Nicole Werner](#), study team leader, to learn more

CareNet – a program investigating how multiple caregivers manage and coordinate caregiving activities for older adults with memory problems. Please contact [Dr. Mi-Kyung Song](#) or call (404) 727-3134 for eligibility or to learn more.

Family Caregiver Study – a project exploring the needs of family members caring for and living with people with dementia who may also have difficulty swallowing. For more information, contact [eatinglab@uoregon.edu](mailto:eatinglab@uoregon.edu) or call (541) 3496-7494

Social Support Networks – explores the social network support of LGBTQIA+ caregivers of people living with dementia. To learn more, please contact [Dr. Drew Pickett](#)

## RISE COMMUNITY PARTNERS – HIGHLIGHTS AND UPDATES

We are so grateful to the members of our National Advisory Board and Community Advisory Boards for helping us make RISE a success! Learn more about some of our advisory board members below.

Elise Hernandez (they/them) is interdisciplinary applied researcher, poet, and aspiring death doula who's been working in the non-profit space for the past seven years. As the Director of Research and Impact at SAGE, Elise: co-leads research partnerships and projects, manages a microgrant program, co-leads sexual orientation and gender identity data collection advocacy, and supports SAGE's Center of Excellence in other data and evaluation work. They have worked with Meals on Wheels America, Howard Brown Health, and most recently, UnidosUS, leading data strategy, evaluation, and community-based participatory research efforts. Elise is a proud Afro-Boricua-Cuban, born and raised in Miami, Florida, who went to undergrad at the University of Central Florida, and earned their MSW and PhD in Social Work and Psychology at the University of Michigan. Their research focus has always been understanding (and working to negotiate and improve) care networks and social support across the lifespan among multiply-marginalized people, which is why they're proud to serve on the RISE advisory board. In their free time, they play basketball with a queer BIPOC basketball club, create soundscapes, and dream of building an intergenerational community in nature with their friends and family.



Chloe Jordan is a native of Atlanta and a member of our Emory Community Advisory Board who discovered her passion for research after a journey in performing arts and business management. Although she didn't intend to become involved in research, the research field found her after joining the Emory University Hope Clinic's Community Advisory Board. She later became the United States Community Working Group (CWG) Protocol Team Representative.

UTK Community Advisory Board Member Angela Bartlett has worked with the older adult population since 2013 in assisted living and nonmedical home care. She has recently taken a role as Senior Director of Development and Marketing at Positively Living & Choice Health Network in Knoxville, TN. Congratulations, Angela!



### SHARE AND FOLLOW

If you enjoyed this newsletter, please share it with your friends and family!

Don't forget to follow RISE on [Facebook](#), [Twitter](#), and [Instagram](#)!

