Alliance FOR AGING RESEARCH
Catalyzing Innovation for Healthy Aging

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Extraordinary Opportunity for Patients and/or Family Caregivers to Become Trained Research Advocates

The Alliance for Aging Research's *Talk NERDY to Me* Network empowers older adults and their family caregivers to accelerate and improve health care research in the aging population. We accomplish this by training them in health research, in particular Patient-Centered Outcomes Research (PCOR). This training is conducted through the lens of five diseases known to affect older adults: (1) Alzheimer's disease, (2) heart valve disease, (3) atrial fibrillation, (4) chronic pain and/or disability, and (5) macular degeneration. Participation includes a two-week online workshop, on-going access to a network of other advocates trained in PCOR, and a mentoring program.

Participants will meet virtually on Zoom three times a week for the last two weeks of October 2022, from 12:00 PM - 1:30 PM Eastern Time on Mondays, Wednesdays and Fridays, to learn from researchers in the field and each other. Participants will also complete assignments and have opportunities to collaborate online. The workshop will culminate in individualized action plans for each participant.

By completing the course, participants will learn the following:

- The purpose of—and best practices in—Patient-Centered Outcomes Research (PCOR);
- How to develop research questions meaningful to older adults with diverse backgrounds;
- Key scientific tools and concepts to better understand health research; and
- How to put this training to work.

At the Alliance, we strive to be a place where inclusion lives, and diverse voices are valued. We encourage patients and family caregivers impacted by one or more of the five disease areas to apply, including those of any race, color, religion, gender, gender identity or expression, sexual orientation, national origin, genetics, disability, age, or veteran status.

As alumni, our participants will receive our continued assistance in finding public and private advisory roles in research, policy, and health education-focused opportunities centered on improving outcomes in research and patient care.

We are looking for patients or family caregivers who:

- Have experience with one of the priority health conditions. *This program is NOT a deep dive into any one health condition, but we do organize working groups by health condition.*
- Are excited to learn about how patients and family caregivers can engage in the research process. *There is NO prior knowledge or expertise required.*
- Can participate in six 90-minute online sessions*. You do NOT need to be tech savvy in any way; we will walk you through every step of the "online" process.*
- Will complete homework prior to each session. *Expect 5 hours/week. NO grading we promise!*

Participants successfully completing the workshop will receive a stipend of $1,500 and a Certificate of Completion for participating in the training.

Course Sessions Schedule

Session One: Monday, October 17, 2022
Session Two: Wednesday, October 19, 2022
Session Three: Friday, October 21, 2022
Session Four: Monday, October 24, 2022
Session Five: Wednesday, October 26, 2022
Session Six: Friday, October 28, 2022

How to Apply

Anyone who is interested in health care advocacy for older adults, has experience in one of the priority health conditions, is excited to learn about medical research, and is willing to make a full commitment to the two-week program is encouraged to apply by emailing Beth Mathews-Bradshaw at bmbradshaw@agingresearch.org.

Questions & Answers

What is Patient-Centered Outcomes Research?

Patient-Centered Outcomes Research (PCOR) focuses on questions that are important to patients and their caregivers. To ensure that research is patient-centered, patients and caregivers engage in all aspects of the research process, from developing research questions to disseminating results.

What kind of topics will be covered in the training?

Participants will learn the nuts and bolts of research. How are research questions developed? How does funding impact the work? How do researchers decide how to design a particular trial? Participants will also learn about the unique properties of Patient-Centered Outcomes Research. What does meaningful patient/caregiver engagement look like? How do we determine the extent to which a research topic matters to patients? What do research advocates actually do?

How would I use this training?

Research advocacy training empowers patients and caregivers. This training will help prepare advocates to serve as merit reviewers for organizations like the Patient-Centered Outcomes Research Institute (PCORI) or the National Institutes of Health (NIH); sit on research-related committees such as Institutional Review Boards (IRBs); and partner with researchers in designing, implementing, or disseminating research. We also hope that participants bring the training back to their own communities.

Can I get medical advice?

This training is not designed for participants to address personal questions about their disease. Participants draw on their personal experiences to better understand – and help shape – medical research. Neither the Alliance for Aging Research nor their disease experts can provide health care advice.

Am I qualified?

If you are interested in engaging in advocacy and have experience with one of the priority health conditions, are age 65 or older or care for someone age 65 or older, are excited to learn about medical research, and willing to make a full commitment to the two-week program, then you are qualified!