



Alliance
FOR AGING RESEARCH

Catalyzing Innovation for Healthy Aging

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Extraordinary Opportunity to Become a Research Advocate

The Alliance for Aging Research's [Talk NERDY to Me](#) (NERDY stands for Nurturing Engagement in Research and Development with You) program is seeking advocates to participate in a **research-advocacy training program** designed to empower senior patients and their family caregivers to engage in patient-centered outcomes research (PCOR).

The 2020 Talk NERDY to Me training will occur over the course of four months, from August to November 2020. Participation will include:

- August: Completing a short survey (10 minutes)
- September: Attending 2 webinars and completing “homework” (3-4 hours)
- October 20-22: Attending the in-person training in Dallas, TX (2 days)
- November: Review of your Action Plan and post-training follow up (1 hour)



The Alliance is looking for advocates who are available during this timeline and who:

- Have experience as a senior patient or family caregiver with age-related macular degeneration, Alzheimer’s disease, atrial fibrillation, chronic pain, and/or heart valve disease;
- Want to become a research advocate; and
- Are excited about learning more about medical research.

No prior knowledge or expertise in science or medical research is required.

Anyone who meets these criteria and is excited about learning more about medical research is encouraged to apply by emailing Sarah DiGiovine at sdigiovine@agingresearch.org.

Please read the following pages to learn more about the Talk NERDY to Me program.

What is patient-centered outcomes research?

Patient-centered outcomes research focuses on questions that are truly important to patients and their caregivers.

How do patient and caretakers engage in research?

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 health conditions will be part of research-advocacy training program?

This year we are focusing on five health conditions: age-related macular degeneration, Alzheimer's disease, atrial fibrillation, chronic pain, and heart valve disease.



2017 – Washington, DC | Pilot training

How can I use this training?

There are many ways advocates can engage in research. This training will help prepare advocates to serve as merit reviewers for organizations like the Patient-Centered Outcomes Research Institute or the National Institutes of Health; sit on research-related committees such as Institutional Review Boards; and partner with researchers in designing, implementing, or disseminating research. We also hope that participants bring the training back to their own communities, which will increase the number of research-savvy advocates focused on the important issues of Alzheimer's disease, sarcopenia, atrial fibrillation, chronic pain, age-related macular degeneration, and/or heart valve disease.

What will I learn?

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 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 do?

How have prior participants made use of this training?

Participants have gone on to serve as research advocates in many ways, including serving on:

- The Alzheimer's Association's Early Stage Support Group National Team;
- An American Heart Association shared-decision making project;
- The Peer Review Medical Research Program of the Congressionally Directed Medical Research Programs for the Department of Defense;
- The Patient Centered Outcomes Research Institute (PCORI) Merit Review Process;
- The Food and Drug Administration.

Am I a good fit for this program?

We are looking for participants who have experience as a patient or caregiver of a patient with age-related macular degeneration, Alzheimer's disease, atrial fibrillation, chronic pain, and heart valve disease; want to become a research advocate; and are excited about learning more about medical research. No prior knowledge or expertise in science or medical research is required.



2018 – Chicago, IL | Second training

What is expected of participants?

We need participants to:

- Complete a short online survey to get to know you better. Access to a computer with internet will be required for this and many of the other parts of the program.
- Participate in two one-hour webinars prior to the workshop.
- Review some materials (online articles, a video, and a quick online activity) prior to the workshop. This should take no more than three to four hours.
- Participate in the two-day in-person workshop on October 20-22, 2020 in Dallas, TX. We will provide a two-night stay at an area hotel and will reimburse additional travel expenses (please request to see our Travel Reimbursement Policy for more details).
- Participate in a one-hour post-workshop phone interview to help refine the curriculum.

Participants will receive:

- Travel, lodging, and a stipend of \$400 for full participation.
- A Certificate of Completion for participating in the training.
- An opportunity to work directly with the Talk NERDY to Me Advisory Council.
- An opportunity to work and learn with other extraordinary advocates and join the Talk NERDY to Me Online Community of advocates who have formerly completed the training.

How do I apply?

Anyone who is actively engaged in advocacy in age-related macular degeneration, Alzheimer's disease, atrial fibrillation, chronic pain, and heart valve disease, and who is excited about learning more about medical research, is encouraged to apply.

For questions, to learn more about Talk NERDY to Me, or to apply please email Sarah DiGiovine at sdigiovine@agingresearch.org.



2019 – Dallas, TX | Third training

What is the Alliance for Aging Research?

The Alliance for Aging Research is the leading nonprofit organization dedicated to accelerating the pace of scientific discoveries and their application to vastly improve the universal human experience of aging and health. The Alliance was founded in 1986 in Washington, D.C., and has since become a valued advocacy organization and a respected influential voice with policymakers.

The Alliance believes that advances in research help people live longer, happier, more productive lives and reduce health care costs over the long term and that access to the latest scientific information empowers people to take control of their health. The Alliance strives to advance science and enhance lives through a variety of activities and initiatives—from policy issues to provider and consumer health programs—that generate knowledge and action on age-related issues.

Simply speaking, we strive to advance science and enhance lives through a variety of activities and initiatives. The Alliance has made aging research a fast-growing priority for medical research today. Since 1986 federal support for aging research has more than tripled, private research and development in aging-related health has reached an all-time high, and new discoveries are making a lasting difference to the lives of millions of Americans.