



Catalyzing Innovation for Healthy Aging

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Extraordinary Opportunity to Participate in a Research-Advocacy Training Program

The Alliance for Aging Research's Senior Patient and Family Caregiver Network (SP&FCN) 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).



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 six health conditions: Alzheimer's disease, sarcopenia, atrial fibrillation, chronic pain, age-related macular degeneration, and/or heart valve disease.

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 1) have experience as a patient or caregiver of a patient with Alzheimer's disease, sarcopenia, atrial fibrillation, chronic pain, age-related macular degeneration, and/or heart valve disease 2) want to become a research advocate, and 3) are excited about learning more about medical research. No prior knowledge or expertise in science or medical research is required.

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 in October 2019 prior to the workshop.
- Review some materials (online articles, a video, and a quick online activity) prior to the workshop in November 2019. This should take no more than three hours.
- Participate in the two-day in-person workshop on November 19-21, 2019 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 SP&FCN Advisory Council.
- An opportunity to work and learn with other extraordinary advocates and join the SP&FCN Online Community of advocates who have formerly completed the training.
- An opportunity to help design a national research advocacy training program.

How do I apply?

We are accepting participants based on nominations from Advisory Council members. However, if you have not been nominated by a Council member, there still may be room for you. Anyone who is actively engaged in advocacy in Alzheimer's disease, sarcopenia, atrial fibrillation, chronic pain, age-related macular degeneration, or heart valve disease, and who is excited about learning more about medical research, is encouraged to contact us. This is the beginning of a growing program and we look forward to including everyone.

For questions or to learn more information about the SP&FCN, please contact:



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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.