



Opportunities for Engagement

Whether you're living with dementia or caring for someone who is, the Alzheimer's Association and the National Institute on Aging (NIA) **IM**bedded **P**ragmatic **A**lzheimer's disease (AD) and AD Related Dementias (AD/ADRD) **C**linical **T**rials (IMPACT) Collaboratory offers a variety of opportunities to engage in the cause.

ALZHEIMER'S ASSOCIATION OPPORTUNITIES

Advocacy

Help persuade policymakers to make Alzheimer's a national priority. Dedicated advocates like you are needed to build on prior successes in Congress and in every state capital. The <u>Alzheimer's Impact Movement</u> (AIM), a separately incorporated advocacy affiliate of the Alzheimer's Association, will train you to advocate in a variety of ways, some of which take just an hour or two every few months. Whatever your experience and availability, they're eager to have your support.

Chapter Engagement

Get connected with the <u>Alzheimer's Association chapter in your area</u> or visit <u>alz.org/crf</u> to learn about what programs, volunteer opportunities, support services, and events are happening virtually where you live.

Clinical Trials

Don't just hope for a cure, help us find one! Recruiting and retaining trial participants is now the greatest obstacle, other than funding, to developing the next generation of Alzheimer's treatments. Individuals with dementia, caregivers and healthy volunteers are all needed to participate in clinical studies focused on Alzheimer's and other dementias. IrialMatch is a free clinical trials matching service that connects individuals living with Alzheimer's, caregivers and healthy volunteers to current research studies. Alzheimer's, caregivers and healthy volunteers to current studies.

National Early Stage Advisory Group

Individuals living with Alzheimer's disease have a unique opportunity to turn their experience into inspiration for others living with dementia. Their voice and actions taken, big or small, are powerful tools that can help to raise concern and awareness and empower others. The Alzheimer's Association National Early-Stage Advisory Group (ESAG) has helped bring the voice of dynamic individuals living with dementia to the national forefront. Members provide a unique perspective to the key efforts of the Association including increasing concern and awareness, enhancing care and support, advancing public policy, and accelerating research.

Online Community

<u>ALZConnected®</u> (alzconnected.org), powered by the Alzheimer's Association®, is a free online community for everyone affected by Alzheimer's or another dementia, including people living with the disease, caregivers, family members, and friends. Start or join in forum discussions on various dementia topics and make connections with other users to share information, expertise, and support.

Volunteerism

Our volunteers are passionate, inspired, and making a difference in the fight to end Alzheimer's disease. Whether you can spare a few hours a week or can make a more significant time commitment, please consider becoming an Alzheimer's Association volunteer. From community representatives to support group facilitators to Walk to End Alzheimer's committee members, the Association offers multiple ways to get involved and make a difference.

NIA IMPACT COLLABORATORY OPPORTUNITIES

News

By signing up for NIA IMPACT Research Collaboratory's mailing list, you will receive periodic announcements, news updates, communications, and events including workshops and podcasts on dementia related research. The NIA IMPACT Research Collaboratory is a group of health systems leaders and researchers dedicated to bringing together diverse health organization stakeholders to improve the care of people living with dementia and their care partners. If you have questions about the Collaboratory, contact: impactcollaboratory@brown.edu.

Collaborate with Local Investigators

We encourage you to share biannual calls for <u>pilot study applications</u> with your community researchers in order to build the nation's capacity to care for people living with AD/ADRD and their care partners through non-pharmacologic intervention research.

Engage Your Local Health Care System with the Learning Health Network

<u>The Learning Health Network</u> is a consortium of individuals representing care settings and organizations joined by the common goal of improving care quality, equity and accessibility for people living with dementia and their care partners. Ask your local Health Care System to <u>enroll</u> to participate in important opportunities to share experiences and generate new knowledge.

OTHER OPPORTUNITIES

Dementia Peer Coalition

"Local peer coalition run by and for people with dementia. The <u>DPC</u> creates opportunities for peers living with dementia to support and empower one another in four areas: peer support, advocacy, community education, and research."

UsAgainstAlzheimer's A-LIST

"A-LIST is a diverse online community of people living with Alzheimer's and other dementias and caregivers who are committed to delivering their voices to develop a growing understanding of how Alzheimer's affects people's lives. A-LIST's purpose is to generate new insights into what matters most to those at risk for, living with, or caring for someone with Alzheimer's."

FDA Patient Engagement

The broad range of <u>FDA Patient Engagement Opportunities</u> were formed to seek guidance from patients to inform researchers about medical conditions, "as they move from early stages of research to later stages of approving new products." Learn more about <u>FDA Patient Engagement</u>.

The Association for Frontotemporal Degeneration

AFTDs mission is to improve the quality of life of people affected by FTD and drive research to a cure. We collaborate every day with people living with FTD and their families to advance our mission. AFTD volunteers are involved in all aspects of our work: awareness, support, education, advocacy, and research. For more information on volunteer opportunities and special projects, visit www.theaftd.org or contact info@theaftd.org.

Contact researchers near where you live for local opportunities.

Please write to carolyn_malone@brown.edu if there are national opportunities we can add to this listing.

ENGAGE WITH IMPACT

Training Modules

The IMPACT Learning Library Training Modules are designed to engage and educate the research community and other key stakeholders interested in conducting ePCTs among PLWD and their care partners.

Knowledge Repository

Get access to IMPACT resources to help build the nation's capacity to conduct pragmatic clinical trials of interventions embedded within health care systems for PLWD and their care partners.

Grand Rounds

The IMPACT Grand Rounds are free webinars welcome to all and occur on the 3rd Thursday of each month at 12 noon ET addressing topics related to ePCTs for PLWD and their care partners.







