

# DIAN EXR Newsletter

Volume 6, Issue 3, 2024

A newsletter distributed by the Dominantly Inherited Alzheimer Network Expanded Registry (DIAN EXR), Washington University School of Medicine Department of Neurology



Washington  
University in St. Louis  

---

SCHOOL OF MEDICINE

## **Moving Forward with Hope**

In July, a regional DIAD Family Conference was held in Philadelphia, Pennsylvania, USA for DIAD families and caregivers living in the United States and Canada. This year's theme, "Moving Forward with Hope," was selected by the planning committee to reflect the sense of optimism felt by family members and researchers alike, as disease-modifying drugs emerge and knowledge of Alzheimer's continues to accelerate.

As event emcee Dr. Eric McDade stated in his closing remarks, “We really are at a period of time where the drugs that we’re using are working ... the technologies are available for us to understand the disease in ways that we never have been able to ... but it’s your continued commitment to this that allows us to continue moving forward with these studies, so I cannot thank the [DIAN Observational Study and DIAN trials] participants more for being here and driving this forward.”

Morning presentations ([available online](#)) focused on understanding amyloid accumulation and timing, tau and tau therapies, and genetic testing, as well as DIAN trial updates. After lunch, afternoon sessions were more support-oriented, offering facilitated conversation groups on a variety of topics, including caregiving, coping with symptoms, and processing grief and other difficult feelings. Study participants were also able to meet and socialize with fellow trial and observational study members, and question-and-answer sessions were offered to help attendees parse the scientific concepts presented earlier in the day. Social opportunities were also offered throughout the weekend: a mixer at the nearby Mütter Museum the

evening of the conference and a family breakfast the following morning.

Information is power, especially when facing a rare disease. Even more powerful than knowledge, perhaps, is community. As one attendee stated when evaluating the conference experience, “The love, compassion, connection and understanding in the rooms was energizing.” Another remarked that the best part of the conference was “just feeling normal and being connected to families like ours.”

*When is the next DIAD Family Conference?* An international DIAD Family Conference will be held on Saturday, July 26, 2025 in Toronto, Canada, celebrating the tenth anniversary of DIAD Family Conferences. Details will be announced in this newsletter as they are finalized. DIAD family members also receive conference announcements from the [DIAN Expanded Registry](#). If you would like to contribute to future conferences, you may make a [monetary donation online](#).



*Pictured: a moment of levity during a question-and-answer session with DIAN-TU and DIAN Obs leaders; Dr. Randall Bateman addresses fellow panelists Dr. Eric McDade, Susan Mills, and Dr. Alisha Daniels: “Can I ask a question of the panelists? Cool, this is fun!”*

## Know Your Apps: ARC and MyDIAN

MyDIAN, DIAN ARC—the apps from our studies and the Expanded Registry can cause confusion at times. Let’s explore our apps: who uses each one, and how they help our research!



The ARC app with the green logo is for enrolled participants in a DIAN Observational Study. The ARC app with the orange logo is for participants who are enrolled in a DIAN clinical trial (E2814 or ART).



**ARC** (Ambulatory Research in Cognition) is an app for people who are *currently enrolled* in a DIAN observational study or DIAN clinical trial. ARC should be introduced during a participant’s first site visit. If you are a DIAN clinical trial or DIAN observational study participant and haven’t discussed the ARC app during a

site visit, reach out to your study coordinator at your site. In addition, if you'd like to schedule your testing reminders for a particular time, your study coordinator can facilitate this. If you have trouble reaching your study coordinator, please email [dianexr@wustl.edu](mailto:dianexr@wustl.edu).

ARC asks participants to take brief tests four times each day, for one week. Each test takes about one minute, with three tests per session. Participants are asked to complete as many tests as possible during the week. These tests are designed to be difficult for someone with average cognitive abilities, so test-takers shouldn't be concerned if they seem tough. *(Editor's note: I downloaded ARC and spent a day being prompted to take these tests and found myself frequently aggravated as well! ARC users will understand the experience of muttering, "Key, phone, pen" while scowling at my phone screen.)* Participants earn money for each three-minute test session they complete.

While cognitive tests are part of participants' annual study visits, this remote, slice-of-life testing offers more accurate data than an institutional setting. These tests catch people in their normal environments, at several times of day. The ARC team has already gathered

helpful data from the app and hopes to use ARC in future trials as evidence of drug efficacy. ARC data is also helping investigators determine whether preclinical changes (indicated by app data) can lead to advice about behavior modification before symptoms appear.

Those concerned about privacy should note that ARC does not have the capability to record video or sound. The app gathers general location information only so data analysts know the user's time zone. ARC can glitch after operating system updates. Contact your study coordinator if ARC is crashing or otherwise not working. ARC is available for both [Android](#) and [Apple](#) devices.



For those of you who are making arrangements to start using ARC, ask your study coordinator about **MyDIAN**. **MyDIAN** (accessed through the app Linkt in the app store) provides study updates and surveys for anyone who is enrolled in a DIAN observational study, DIAN clinical trial, or who carries or is at risk for a DIAD

mutation (as verified by the DIAN Expanded Registry [EXR]). MyDIAN users receive updates about research opportunities, invitations to events that are exclusively for DIAD family members (such as webinars and family conferences), and surveys. Unlike ARC, MyDIAN is not required as part of the DIAN Obs or DIAN-TU studies, but it is still a key tool that researchers use to collect important information.

The lifestyle surveys in MyDIAN allow EXR researchers to gather health information about DIAD family members, such as sleep habits, diet, and physical activities. The data from these surveys will help investigators design future studies that examine the extent to which controllable actions (such as sleep and dietary changes) may modify Alzheimer's symptoms.

While MyDIAN does not offer monetary compensation for completing activities, users are "paid" in-app gems that can be used to accessorize their avatar. MyDIAN does not record any sound or video, and any data collected is encrypted and securely stored. To activate MyDIAN, email [dianexr@wustl.edu](mailto:dianexr@wustl.edu). The Linkt app is available for [Apple](#) and [Android](#) devices.



## **Primary Prevention Informational Webinar**

The DIAN Expanded Registry will present a webinar, hosted by Dr. Eric McDade, on the Primary Prevention trial on Saturday, November 16, from 4:00–5:00 PM CST/22:00 GMT; 9:00 AEDT 17NOV. Dr. McDade will share new details about the study and remternetug, the drug selected for the trial.

Interpretation in Spanish, French, Italian, Portuguese, German, and Dutch will be available. The webinar will be recorded in all languages and made available the following week. This event requires preregistration and is open to anyone who carries or is at risk for a DIAD genetic mutation and their families and caregivers. If you have not already received the email invitation from the Expanded Registry, email [dianexr@wustl.edu](mailto:dianexr@wustl.edu) to verify your identity and register.

## **Coming Soon: New DIAN Website**

The Expanded Registry team, DIAN Obs, and DIAN-Trials Unit administrative staff have been hard at work redesigning the Dominantly Inherited Alzheimer



Network website! The new site will still be available via [dian.wustl.edu](http://dian.wustl.edu), but you may notice changes to its appearance beginning in November. While information will be available in the same areas (e.g., you will still find videos of Family Conference presentations in the For Families section), some links may change.

Watch for announcements of new features (including a searchable video library and publication archives) in future EXR newsletters!

## Recent DIAN Publications

[Detection of emerging neurodegeneration using Bayesian linear mixed-effect modeling](#)

[Association of Resilience-Related Life Experiences on Variability on Age of Onset in Dominantly Inherited Alzheimer Disease](#)

[Longitudinal associations between exercise and biomarkers in autosomal dominant Alzheimer's disease](#)

*DIAN observational study and trial data are increasingly published in scientific reports to advance scientific understanding of Alzheimer's*

*disease. Because of this, there is a marginal risk that a participant reading or hearing of these scientific reports might guess, correctly or incorrectly, information including their own or a family member's mutation or treatment status. We take every step to minimize this risk, including ensuring that all study data lack identifying information, but de-identified data may reveal a pattern that could suggest a person's mutation or treatment status. You can avoid these articles or presentations related to our studies to decrease this risk.*

## **Alzheimer's in the News**

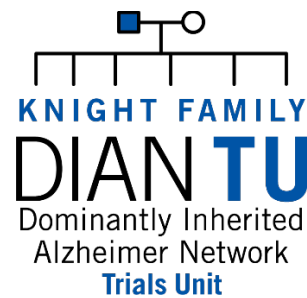
[Accuracy of diagnostic blood tests for Alzheimer's disease varies](#)

[Aging-related genomic culprit found in Alzheimer's disease](#)

[Multiple sclerosis appears to protect against Alzheimer's disease](#)

[The Burden of a Gene](#)

[Beyond Blood Biomarker Tests, Researchers Are Optimistic About These Advances in Alzheimer's Disease Detection and Treatment](#)



Learn more about our research at <https://dian.wustl.edu>. If you are interested in research opportunities, contact the DIAN Expanded Registry at [dianexr@wustl.edu](mailto:dianexr@wustl.edu).

## Contact the Editor

If you have an idea for a story or have questions about the information in this newsletter, please contact Jamie Bartzel: [bartzel@wustl.edu](mailto:bartzel@wustl.edu)

*The DIAN Expanded Registry is supported by the Alzheimer's Association, GHR Foundation, an anonymous organization, private donors, the DIAN-TU Pharma Consortium, DIAN-TU industry partners, and the National Institute on Aging of the National Institutes of Health under Award Numbers U01AG042791, R01AG046179, R01/R56 AG053267, U01AG059798, and R01AG068319. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.*