

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



# DIAN EXR Newsletter

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## Contact the Editor

If you have an idea for a story or have questions about the information in this newsletter, please contact the editor:

Jamie Bartzel  
[bartzel@wustl.edu](mailto:bartzel@wustl.edu)

 **Washington**  
**University in St. Louis**  

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**SCHOOL OF MEDICINE**

## March 2023 Investigator Meeting in Mexico City

On March 6-9, DIAN-TU research and pharmaceutical partners from 14 trial sites and 8 supporting organizations across 8 countries gathered for the DIAN-TU Investigator Meeting in Mexico City, Mexico. This gathering provided an important orientation for the launch of DIAN-TU trials and also offered attendees the chance to meet with fellow investigators and coordinators from around the world.

No research effort is without its challenges. Each DIAN-TU research site has at times faced its own unique difficulties, and the opportunity to learn from the wisdom of teams across locations is invaluable. In an open forum, research team members can discuss their perspectives and successes. Team members strategize with one another, as questions generate fruitful dialogue.

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## March 2023 Investigator Meeting in Mexico (Continued)

In addition, professionals from different areas can offer insights into their specialization, such as cognition testing, imaging, biomarker processing, or home health visitation, to name just a few. Such a complex trial does not often provide opportunities for individuals to meet with those outside their own areas of investigation, so it is important to soak up these valuable perspectives during the short time when we are gathered.

A large-scale meeting also helps us focus not just on present trial efforts, but also to take a long view of the future of Alzheimer's research in DIAN. In an early presentation, Director Randall Bateman, MD offered the perspective that the first Alzheimer's disease patient who was identified more than one hundred years ago is still contributing to knowledge of this disease. The data we collect and insights we learn from our trials will benefit not only our participants, but the field of neuroscience at large, as we advance our knowledge of cognitive decline, measures of disease progression, and effective testing and measurement of brain changes. We are not able to know the ways in which our research will touch other areas of neuroscience and lead to discoveries that will profoundly advance brain health in the future.

Finally, one of the most valuable offerings of the Investigator Meeting is a renewed sense of purpose and the invigoration of gathering with passionate champions of Alzheimer's research. A consistent theme was the incredible gratitude we hold for our participants and supporting families. Our discussions about procedure, consistency, and documentation ultimately focus on our desire to conduct the best trial possible, as we strive to gather valuable data for this and future generations affected by DIAD. In sharing our stories with one another, we turned time and again to the respect and appreciation we hold for our research participants. When the jet lag subsides and we return to our office routines, this is what fuels us: the chance to make a profound difference for the individuals and families we care so deeply about.

*Jamie Bartzel*



*Pictured: Dr. Randall Bateman compliments the acting skills of Drs. Jorge Llibre-Guerra and Eric McDade after a role-play demonstration of a trial participant intake session*

# You're Invited: Youngtimers Community Kickoff

You don't need to go it alone. Early-onset familial Alzheimer's disease is brutal, confusing, scary, and so much more. That's exactly why Youngtimers was founded by families just like yours to improve one another's lives. The co-founders and other volunteers have been working hard to create a safe, supportive, educational, and truly helpful place just for you!

Join the Community Kickoff to hear what Youngtimers is cooking up for you, contribute your ideas, and learn how you can participate for your own benefit and the benefit of others. Marty Reiswig will host, and Lindsay Hohsfield will share recent news in drug trials and answer burning questions.

This event will be conducted in English and closed-captioned. Participants may enable Zoom closed-caption translation in real time in the language of their choice.

## **Youngtimers Community Kickoff**

Wednesday, April 26th, 4:00 pm PDT (UTC-07:00)

<https://www.youngtimers.org/community-kickoff>

[Eventbrite Link](#) for full info and video

The leaders of Youngtimers are thrilled to meet with you and grow community support. (Please share this with your family members too. If you are concerned about privacy, you're welcome to register under a pseudonym.) If you have questions about the event or the Youngtimers organization, please contact [info@youngtimers.org](mailto:info@youngtimers.org).



# 2023 DIAD Regional Family Conferences

As COVID-19 pandemic precautions have lessened over the past few years and in-person gatherings have resumed, many DIAD families have become eager to meet up again at family conferences. The DIAD Family Conferences offer attendees information and support as well as an opportunity to share their experiences with each other and Alzheimer's researchers.

The network of DIAN research sites has expanded across the globe over the past several years as we have opened DIAN trials in new countries. Currently, our research spans the Americas, Europe, Asia, and Australia, and we hope to expand into Africa in the future. In light of this burgeoning global community of DIAD families, 2023 sees us implementing a regional model for family conferences. In conjunction with the Alzheimer's Association Satellite Symposium, a regional Family Conference for families living in Latin America will be held on Saturday, May 20 in Mexico City, Mexico. A DIAD Family Conference for families living in Europe will be held on Saturday, July 15 in Amsterdam, Netherlands, preceding the Alzheimer's Association International Conference (AAIC) that takes place the week of July 16. Families living in Europe and Latin America will receive information about conference registration in the coming weeks.

Our global participants, families, and study teams are always on our minds. In the near future, we are hoping the regional conference model will be able to include participants and families in Australia and Asia, and we will have meetings in North America again soon. As always, we have immense gratitude for the time and energy our North American, Australian, and Asian participants give to our studies, and the incredible work of the principal investigators and site coordinators who enable this research.

*Eric McDade, DO; Ellen Ziegemeier; Jamie Bartzel*

## April 29 Webinar for OLE

An hourlong webinar about the Open Label Extension (OLE) of the DIAN-TU-001 secondary prevention trial evaluating gantenerumab will be held on Saturday, April 29 at 4:00 p.m. CDT (22:00 BST). Details will be sent soon to a targeted audience.



# Reflections on Dutch Family Meeting in February 2023

After an almost three-year hiatus, we finally held the third in-person family meeting in The Netherlands on February 4, 2023. Despite the painful link that binds us, it was a joy to reunite with old and new friends. We had the highest attendance so far, with family members from the far north and deep south, and even some from Belgium. One cup of coffee was hardly enough time for catching up, but a full program awaited us—and a very special guest, as Dr. Eric McDade honored us with his presence to provide an extensive and very informative update on DIAN and research opportunities. Next, we were brought up to speed on advances in disease-modifying treatments for Alzheimer’s Disease by Dr. Niels Prins.

The scientific presentations alternated with moving and powerful testimonies from family members on what it’s like to participate in a clinical trial, how to become pregnant with IVF and embryo selection (without having to know your genetic status), and a summer camp for children and partners of affected parents. The afternoon offered support sessions, similar to the international DIAD conferences, followed by a panel on how to take in the new information and impressions and make the most of life. Sometimes that requires an evening of cookies and wine. On occasion, it’s okay to smash something, but there will always be those moments teaching us: if we can live through this, we can take on anything.

Many thanks to Lisa Vermunt, Sven van der Lee, and Ghiselinde Meijs as well as Alzheimer Center Amsterdam, Brain Research Center, Stichting Dioraphte, Alzheimer Nederland, and DIAN for facilitating this day.

*Jetske van der Schaar*



*Pictured: Edith Block speaks to individuals and families affected by DIAD at the Dutch Family Meeting in February 2023*

# Dr. Randall Bateman Given CTAD Lifetime Achievement Award

The Clinical Trials on Alzheimer's Disease (CTAD) has named Randall Bateman, MD as the recipient of the organization's 2023 Lifetime Achievement Award. Dr. Bateman serves as the Director of the Dominantly Inherited Alzheimer Network (DIAN) and of the Knight Family DIAN Trials Unit (DIAN-TU). The award announcement notes that Dr. Bateman's "lab reported a highly accurate amyloid-beta blood test for Alzheimer's disease amyloid plaques and also identified specific tau species in blood for accurate quantitation of amyloid pathology, has described the biology and pathophysiology of tau species in brain, CSF and blood, discovered unique soluble tau species that correlate with tau pathology, and also discovered that tau production is increased in Alzheimer's disease."



Congratulations to Dr. Bateman on this achievement! Access the full award announcement at <https://www.ctad-alzheimer.com/lifetime-achievement-award>, and learn more about the work of CTAD at <https://www.ctad-alzheimer.com/about>.

*Pictured: Dr. Randall Bateman presents clinical trial updates at the March 2023 Investigator Meeting in Mexico City*



*Pictured: Research Specialist Jennifer Stauber demonstrates proper biomarker collection and handling procedures at the March 2023 Investigator Meeting in Mexico City*

## Recent DIAN Publications

Dominantly Inherited Alzheimer Network research is enabled by our study participants, supporting family members and friends, and professional partners. In each newsletter, we like to highlight the research that *you* make possible.

### **Change in Cerebrospinal Fluid Tau Microtubule Binding Region Detects Symptom Onset, Cognitive Decline, Tangles, and Atrophy in Dominantly Inherited Alzheimer's Disease**

<https://doi.org/10.1002/ana.26620>

### **A call for clinical trial globalization in Alzheimer's disease and related dementia**

<https://doi.org/10.1002/alz.12995>

### **Comparison of amyloid burden in individuals with Down syndrome versus autosomal dominant Alzheimer's disease: a cross-sectional study**

[https://doi.org/10.1016/S1474-4422\(22\)00408-2](https://doi.org/10.1016/S1474-4422(22)00408-2)

### **Biomarker clustering in autosomal dominant Alzheimer's disease**

<https://doi.org/10.1002/alz.12661>

### **Pattern and implications of neurological examination findings in autosomal dominant Alzheimer disease**

<https://doi.org/10.1002/alz.12684>

### **Cross-sectional and longitudinal comparisons of biomarkers and cognition among asymptomatic middle-aged individuals with a parental history of either autosomal dominant or late-onset Alzheimer's disease**

<https://doi.org/10.1002/alz.12912>

The DIAN data are increasingly published in scientific reports to enable investigators worldwide to learn of our progress and to advance scientific understanding of Alzheimer's disease. Because of this, there is a small but possible risk that a DIAN participant reading or hearing of these scientific reports might guess, correctly or incorrectly, information about themselves. This includes guessing one's own or a family member's mutation status. We at DIAN take every step to minimize this risk, including ensuring that all DIAN data in journal articles, scientific meetings, press coverage, etc., lack identifying information for any participant, but it is possible that even such de-identified data may reveal a pattern of symptoms or a relationship with other medical disorders that could suggest that a particular person is mutation positive. You can avoid reading these scholarly articles or listening to presentations related to the DIAN study to decrease this risk.

# Alzheimer's in the News

## **Seeking Alzheimer's clues from few who escape genetic fate**

<https://apnews.com/article/alzheimers-memory-gene-resilience-5f7c6bfb3774d9d86c018cfcdfc3f425>

## **Researchers studying links between retinal appearance, Alzheimer's**

<https://source.wustl.edu/2022/12/van-stavern-raji-among-those-leading-research-into-links-between-retinal-appearance-and-alzheimers/>

## **FDA approves Alzheimer's drug that appears to modestly slow disease**

<https://www.npr.org/sections/health-shots/2023/01/06/1147513068/fda-alzheimers-drug-leqembi-lecanemab-accelerated-approval>

## **Gut bacteria affect brain health, mouse study shows**

[https://medicine.wustl.edu/news/gut-bacteria-affect-brain-health-mouse-study-shows/?\\_ga=2.159048504.328386246.1673964814-984021362.1668438204](https://medicine.wustl.edu/news/gut-bacteria-affect-brain-health-mouse-study-shows/?_ga=2.159048504.328386246.1673964814-984021362.1668438204)

## **Focused ultrasound technique leads to release of neurodegenerative disorders biomarkers**

<https://source.wustl.edu/2023/01/focused-ultrasound-technique-leads-to-release-of-neurodegenerative-disorders-biomarkers/>

## **Equity for African Americans in Alzheimer's disease**

<https://outlook.wustl.edu/equity-for-african-americans-in-alzheimers-disease/>

## **Discovery of T cells' role in Alzheimer's, related diseases, suggests new treatment strategy**

<https://medicine.wustl.edu/news/discovery-of-t-cells-role-in-alzheimers-and-related-diseases-suggests-new-treatment-strategy/>

## Stay in Touch!

We want to make sure our records in the DIAN Expanded Registry are up to date so we can reach our members. If you need to update the email or mailing address we have on file, email us at [dianexr@wustl.edu](mailto:dianexr@wustl.edu). You may also notify us if you know of someone connected to our work has passed away. Though this is not news anyone wants to deliver or receive, it does help us keep an accurate record of our members, and we appreciate the notification.

If you are supporting a family member or friend who is experiencing dementia symptoms, you are welcome to [join the DIAN Expanded Registry](#) as well. You may note that you are a support person in your registration and stay connected to our communications and events.



# Meet the Team: Clinical Research Coordinator Jamie Bartzel

## Jamie Bartzel



Jamie Bartzel joined the DIAN Expanded Registry team as Clinical Research Coordinator II in November 2022. Her professional background is in higher education administration and manuscript editing. Of note, she coordinated programming and outreach for the LGBTQ+ Culture Center at Indiana University. There she participated in public health outreach, led campus HIV education and prevention efforts, and facilitated student conversations about harm reduction and healthy living. Now with the Expanded Registry, she enjoys speaking with prospective research participants and designing communication materials. When she's not working, she partakes in the meditative art of cross-stitch and embroidery work.

The DIAN website is a great place to learn more about our research and find additional information. Please visit our [News page](#) for articles related to DIAN and Alzheimer's disease. Family members share their stories on the [Family Voices page](#). If you are interested in research opportunities, please contact the DIAN Expanded Registry at [dianexr@wustl.edu](mailto:dianexr@wustl.edu). If you are not part of the registry and would like to be, please visit [dian.wustl.edu](http://dian.wustl.edu) to register.



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