



CONTACT US

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

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We hope you enjoy this edition of the newsletter. It arrives at an incredibly important time for all of us. With the annual DIAD Family Conference having recently concluded, we wanted to highlight this year's meeting and some related topics including information on the Youngtimers support group and a personal view from one of our participants. We also would like to introduce you to our DIAN-TU Fellow, Dr. Jorge J Llibre-Guerra, and some of the important work he will be leading to further expand our ability to reach more families for opportunities to get involved in research and trials.

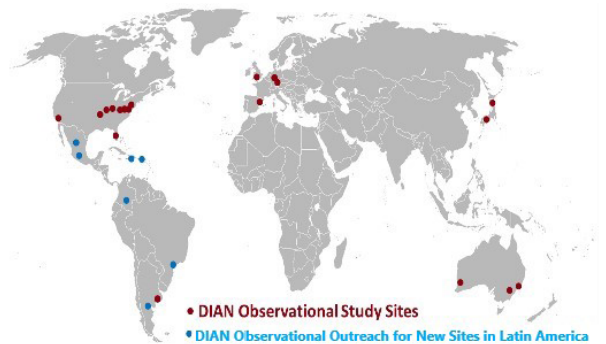
Meet Our Fellow

I continue to be grateful for the opportunity to serve as post-doctoral fellow for the DIAN-TU and for being involved in research for novel mechanisms, tests and treatments of Alzheimer's disease.

These are also exciting times to join efforts with the Expanded Registry in support of and outreach to new family members worldwide. As a growing number of family mutations have become known in Central and South American countries in recent years, over the next year and in collaboration with local researchers and family members, we will increase our outreach to the region and hopefully bring new DIAN observational sites to several countries. New sites will help accelerate research into Alzheimer's disease, enrollment in upcoming drug trials and expand the EXR global family.

In addition, in our commitment to address participant questions raised at the last DIAD family conference, we will launch new research opportunities to determine the influence of life-course risk/protective factors on symptom onset and disease progression (e.g., diet, physical activity, sleep and cognitively-stimulating activities, among

Lastly, with the end of the current trial approaching quickly, we know this is a time of great anticipation for all us, especially for those of you participating in the trial. We will be hosting a webinar October 26th (27th for those in Australia, Japan and Korea), where we will be discussing details surrounding next steps. Likewise, we will be dedicating the December edition of the EXR newsletter to this topic, so please look out for it. We are all in this together. *Eric McDade, DO*



others). Participants will be invited to complete surveys in each of these areas via a new electronic interface (web or app-based, under development), which will facilitate contribution to the research and avoid extra burden.

Finally, it's been a great pleasure to join family members and researchers in the worldwide effort to find better ways to treat Alzheimer's disease. I hope this brief introduction may serve as another way to show my appreciation for the time and thoughtfulness that many family members and researchers have demonstrated, and I'll continue to commit myself to our shared goal of working together towards a cure. As always, our doors are open if you have ideas to share and/or opportunities for continued success in our future endeavors.

Jorge J Llibre-Guerra, MD





View From a Participant

I love rollercoasters. I'm crazy about them. Waiting in anticipation, watching others return with windblown hair and wide eyes. Climbing in, pulling the bar down snug, riding up the steep ascent, and whoosh! Diving, twisting, falling, rising, flipping—strobing camera flashes—another few twists and turns before screeching to a gut-tightening halt. Laughing, panting, waiting for your stomach to settle. Following the crowd in a daze, and waiting for those silly pictures of you and your companions to appear on the screen. You might get a chuckle out of your friend's goofy expression, or the horror on someone else's face, but the picture doesn't do justice to the adrenaline rush you just experienced. What a ride!

Ten years ago I read about the DIAN study in the back of my cousin's book, "The Thousand Mile Stare." My father, brother, and I contacted the study and enrolled. As my brother, his wife, my wife, and I flew to St. Louis for our very first site visit, the anticipation was building. Finally, someone believed, as we had for generations, that we were valuable to the fight against Alzheimer's disease. Finally, we were climbing up the hill of the rollercoaster, about to embark on a journey toward making a difference—and possibly curing the disease that has plagued us. As we walked through the doors of the tiny first DIAN lab in a back alley of Washington University, my stomach dropped as if on the first hill of a rollercoaster. Surely this wasn't it. There were just a few team members and a cluster of machines that looked straight out of the 70's. There had to be more. We needed hope, and this wasn't the scale we had hoped for.

But the ride was just beginning. Hope grew. It grew because of Dr. Bateman, Wendy, Ellen, Dr. McDade, and so many more team members who were warm, welcoming, brilliant, and hopeful. Their hope was contagious, and their hard work was paying off. The community of participants began to form real relationships, both online and in person. We, the X-Men, grew more and more united in our fight and the belief that we could make a difference. There have been ups and downs, to be sure. We have lost some of the best among us along the way—my dad included. But we've ridden this coaster with passion, commitment, and community. And

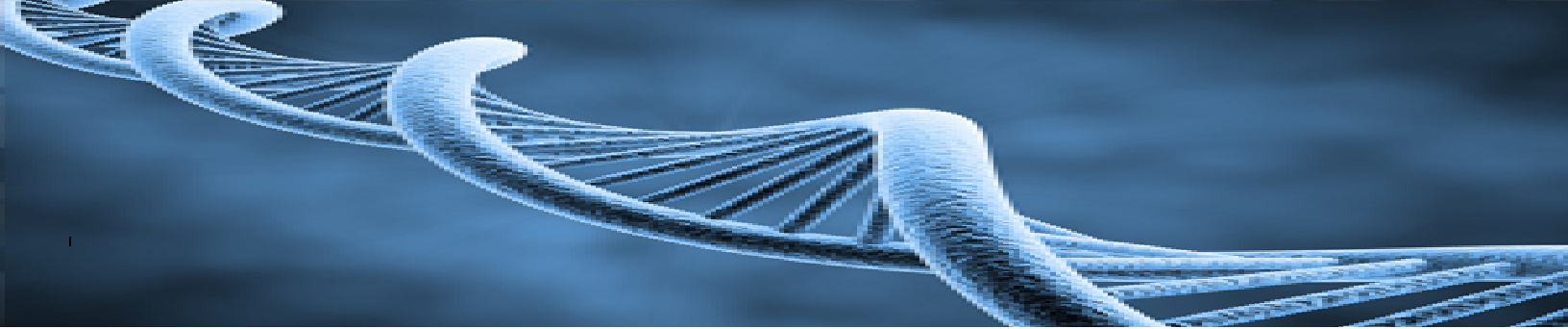
hope continues to grow. Yes, it's discouraging every time another drug study fails or pharmaceutical company drops out. But we



will remain hopeful. Not blindly and ignorantly hopeful, either. We are hopeful because we carry within us answers to the unsolved mysteries of Alzheimer's. We are hopeful because research funding continues to grow exponentially. The research team from that little basement lab at WASH-U is now world-renowned. Every bit of data gathered from us and others around the world continues to inform the scientific and pharmaceutical communities. Each time there is a "failed" drug trial, we learn. Even the design of our DIAN-TU drug trial gives us hope because we'll just keep trying the most promising drug treatments until we find the one that can eradicate Alzheimer's.

As we continue to ride the DIAN-TU rollercoaster to the end of this drug arm study and wait for the results, I'm reminded of all the good times and the bad. Friends gained and loved ones lost. It steels my resolve. I'm hoping and praying that the results demonstrate effectiveness and we can begin receiving treatment soon. If not, we will mourn with our loved ones and with each other, and then we'll press on. I'm deeply honored to be a part of this community. I believe that if we keep fighting, with hope and determination, we will contribute to the end of Alzheimer's. Hang on tight, friends. The ride isn't over yet.

Marty Reiswig



Youngtimers Support Group

My name is Lindsay and I'd like to take this opportunity to introduce Youngtimers to you. [Youngtimers](#) is a nonprofit that myself along with a group of DIAD family members and other stakeholders have started to help better address the needs of DIAD individuals and families. Over the course of the last few years, many from this community have faced many difficult decisions and situations, either when it comes to making a decision about getting tested, coming up with better caregiving strategies, getting insurance, making family planning decisions, or figuring out how best to tell kids/friends/family about the disease. To date, we have yet to find an organization that helps us adequately navigate these difficult and complex issues that affect our unique disease population. We hope Youngtimers can fill this need.

We believe that our greatest strength/asset is ourselves, especially those that have gone through and navigated many of the complex issues that arise during the course of this disease. With this in mind, we'd like to set up support groups for individuals affected by DIAD, whether that be individuals who know their status but are not symptomatic, symptomatic individuals, young adults with symptomatic parents, or caregivers. To determine how to best set up these support groups, we would like to ask you a few questions

regarding your interest in participation and commitment.

If you're interested in joining a support group or would like to help facilitate one, I'd like to ask you to please go to this link <https://www.surveymonkey.com/r/87WFB9K> to fill out a short survey (less than 10 short questions) about support groups.

We look forward to hearing from you.

Lindsay

Note: This survey is conducted on behalf of Youngtimers, a nonprofit that is independent of Washington University of St. Louis.



2019 DIAD Family Conference

"Mutation, Participation and Innovation" was the title to this year's 2019 DIAD Family Conference held in Los Angeles, California. These three words describe when the heart of research and the heart of DIAD families work together to find a cure for Alzheimer's.

This year's conference hosted 131 family members and 114 researchers from all over the world, including 14 different countries. The conference included scientific talks, trial updates and 4 family presentations for researchers and family members. The afternoon focused on informational and support sessions for DIAD family members, including separate sessions for those already experiencing symptoms, at-risk family members and those in support roles.

See presentations online at: <https://dian.wustl.edu/families/family-conferences/2019-diad-family-conference-mutation-participation-innovation/>. For more in-depth coverage, [Alzforum](#) showcased 4 stories from the DIAD Family Conference at: <https://www.alzforum.org/news/conference-coverage/2019-diad-family-conference-mutation-participation-innovation>.

Preparation for next year's conference on July 25, 2020, in Amsterdam (The Netherlands) will soon be under way. More information will be announced in future newsletters.

As we near the final funded year for our annual conferences, our team will be submitting requests for renewed funding. An important part of the grant packet are letters of support from past attendees, demonstrating the benefit obtained from past gatherings and the continued need for future conferences. If you are willing to contribute to this effort or have any questions about the family conferences, please email dianexr@wustl.edu.

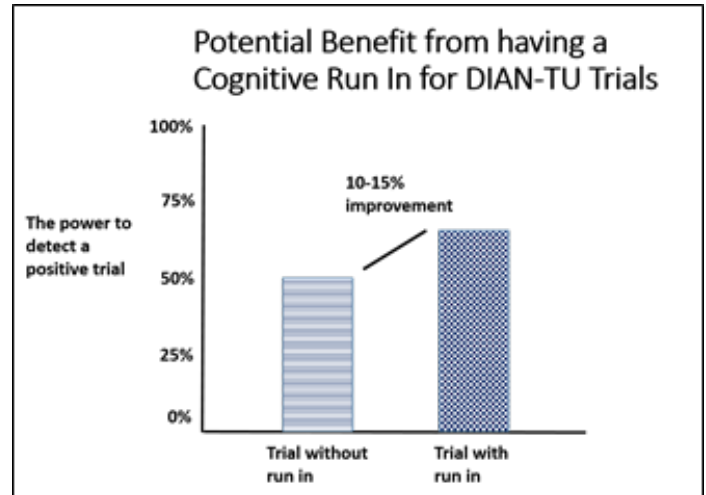


DIAN-TU Clinical Trial-001: Cognitive Run-In (CRI) update

As we mentioned in the last [newsletter](#), we have officially begun to enroll in the Cognitive Run-In (CRI) period of the DIAN-TU trial in preparation for future drug (treatment) arms coming into the trial. During the CRI, there is no drug treatment, so some of you may wonder why we would be asking you to start to enroll for a trial that does not yet have a drug included. First, having a group of participants already enrolled once a treatment is chosen cuts down on the time needed to complete the trial and get an answer whether or not the drug is working. This could mean finding an effective drug one year earlier than if recruitment time is longer without a CRI.

The figure shown here highlights another important reason for the inclusion of CRI, as it compares two trials (one without and one with CRI before the drug trial starts) that are testing the same drug and assumes that the drug works equally well in both trials. The boxes demonstrate that including a CRI before starting a drug (checked box) could increase the chance of showing a drug actually works by up to 10-15%. That might seem like a small number but could be the same as concluding one out of every 10 trials (10%) did not work, even if the drug was actually working.

Additionally, CRI helps our trial sites and participants work together and be better prepared to start trials when they are ready. If you have not contacted your trial site about CRI, please do so. If you are new to the DIAN-TU, you can reach out to the [DIAN EXR](#) for additional information.



Upcoming DIAD Family Webinar

Please register at <https://tinyurl.com/y4r25db7> for the next DIAD Family webinar on **Saturday, October 26th** from 4:00-6:00 PM CDT / 22:00 – 00:00 BST. Featured topics include discussion of the DIAN-TU Open Label Extension (OLE) for current DIAN-TU trial participants and new drug arms for the DIAN-TU secondary prevention trial. Of note, we will be using a different system for this webinar through Zoom, which allows audio streaming over computer, an option not possible for past webinars. You may also choose to dial-in via telephone, using local phone numbers provided upon registration. The webinar will be recorded and uploaded to the DIAN website in November. We will offer the same webinar content in Spanish on November 15 and will share registration details soon via email and on our [Spanish webpage](#).

Recent DIAN publications

From the Farm to the Clinic, This Potamkin Prize winner has made research inroads in aging and Alzheimer's disease

https://journals.lww.com/neurotodayonline/Fulltext/2019/08220/From_the_Farm_to_the_Clinic_This_Potamkin_Prize.9.aspx

Impact of Cognitive Impairment Across Specialties: Summary of a Report From the U13 Conference Series

<https://www.ncbi.nlm.nih.gov/pubmed/31436318>

Alzheimer's disease in the news

Alzheimer's missing link ID'd, answering what tips brain's decline

<https://medicine.wustl.edu/news/alzheimers-missing-link-id-answering-what-tips-brains-decline/>

Blood test is highly accurate at identifying Alzheimer's before symptoms arise

<https://medicine.wustl.edu/news/blood-test-is-94-accurate-at-identifying-early-alzheimers-disease/>

Genes linked to Alzheimer's risk, resilience ID'd

<https://medicine.wustl.edu/news/genes-linked-to-alzheimers-risk-resilience-idd/>

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