



DIAN EXR Newsletter

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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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Open Label Extension

Happy New Year! 2020 has arrived and will be a particularly important year for all of us involved with the DIAN-TU, DIAN, and DIAN-EXR. Things have been incredibly busy here preparing for the results of the recently concluded DIAN-TU study of solanezumab and gantenerumab. As we have previously mentioned, we anticipate the results of the trial will be available in the first quarter of this year and a press release will be posted on the DIAN [website](#). We will also send it out to all of those registered in the EXR and encourage anyone who is interested in receiving it to register if you have not done so.

This issue of the newsletter features information on an exciting new tool we are introducing for DIAN/DIANTU/EXR participants: the MyDIAN phone app. I want to thank Sarah Adams for all of the work she has been doing to get this moving forward and our partner DataCubed who developed the app. Please look out for invites to download the app and PLEASE sign up. This will be an important tool for all of us and helps to move the DIAN-related studies forward in mobile technology along with the Ambulatory Research in Cognition (ARC) cognitive testing app that some of you have been using. In addition, we are extremely pleased to hear that our colleagues and families in Germany have hosted another successful Family Meeting recently and we look forward to seeing them all join the DIAD Family Conference in Amsterdam this July. We would also like to express sincere thanks to Sophie Leggett for providing a piece on her experience participating in the trial and the strength that she and so many others have demonstrated to get to the end of THIS stage (certainly not the end of Alzheimer's research).

Lastly, we would like to point out that although the DIAN-TU trial of sola and gant dosing was completed in November 2019, there are plans for including an Open-Label Extension (OLE) in the event that one or both of the drugs demonstrate the potential for benefit. OLE means that those of you that participated in the randomized trial may have the opportunity to take the active drug (not placebo) for an extended period of time. There is a lot that goes into making the decision of whether or not an OLE will be offered, as we discussed recently in one of our webinars (linked here in [English](#) and [Spanish](#)). Please be on the lookout for a Frequently Asked Questions (FAQ) that will be coming out soon to provide more information.

As always, please reach out to us with any questions.

Eric McDade, DO



View from a Participant

I remember sitting in a support group meeting in London and hearing Prof. Nick Fox talking about the likelihood of a drug trial for people like me - at risk of having one of the dominantly inherited Alzheimer's disease mutations. As I digested that information, I knew that there was hope for a future that was different and I was absolutely certain that I was going to do everything that I could to be part of that future drug trial. I had no idea what was involved in being in a drug trial, but whatever it was - I was ready to do it.

I remember the day when the detailed information about the trial arrived in the post. I sat in my garden in the sunshine reading through the pack and sobbed. I was so happy to have the opportunity to be part of something amazing and at the same time I was absolutely petrified. My emotions were all over the place for a good while.

My biggest blessing was my wonderful trial nurse who, during my screening visit and on every visit after that, looked after me so well and always told me things before I needed to know them. After my first dose, she told me as I left that there would be a day when I just wished that I didn't have reason to be on a drug trial - I was on a high but several months later I sat on the floor in my kitchen with tears streaming down my face repeatedly saying to myself 'it's normal to feel like this' and I picked myself up off the floor and got my train to London for my drug dose. I have had highs and lows throughout the five years that I've been in the drug trial and I have been supported through all of them - I couldn't have asked for a better team to look after me for half a decade of my life.

The end of the drug trial has bought about a whole new bunch of feelings - heading to London every four weeks has become such a normal part of my life - I've threatened to keep going down there to make people cups of tea and bring biscuits and cake too! It only occurred to me recently that I might be on an active drug and that might be why I seem to be 'well' - in which case, what if I start showing symptoms once I get past the four weeks that I normally have between doses?! I'm dreading the press coverage of the results whatever the outcome. It's all so dramatised, so I'm only going to listen to information provided by DIAN or the Dementia Research Centre in London.

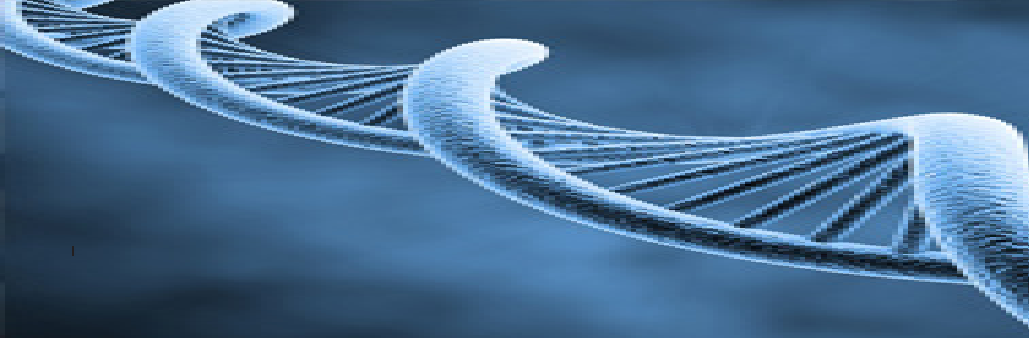
The one thing that I'm certain of is that this drug trial will result in so much new information and understanding about this disease. It will guide future research and drug trials. I firmly believe that there are no failures in drug trials because something is always learned.

One of the unexpected bonuses of being in the trial is that it has made Alzheimer's a casual part of my family's conversations. I've said 'I'm off to see my drug dealer!' so many times, my family have seen me come home like I've just been for a nice day out in London, and they've also seen me walk in the door crying with a lumbar puncture headache. Not only have I learned so much, but my family has too. If my daughter considers taking part in future trials, she's going to have a pretty good and realistic understanding of what it involves.

It has also taught me that I'm stronger than I thought I was, that I can do things that my younger self thought that she could never do, and that when darkness is ahead, I can search for the light and I can dance in it - like nobody is watching!



Sophie Leggett



2019 German Family Conference

The 2019 German Family Conference took place on November 22nd and 23rd in Munich with over 80 participants in attendance. In lieu of a separate family meeting in 2020, current plans are underway for German families to attend the DIAD Family Conference in Amsterdam in July. We look forward to the opportunity to have so many families from Germany join us in 2020.

Picture to right: The DZNE Munich thanks Vilma Serron-Schwaiger, a psychometrician for the DIAN Observational study, for her outstanding service since 2013. Shown here with Prof. Johannes Levin

2020 DIAD Family Conference

The 2020 DIAD Family Conference will be held in Amsterdam, Netherlands on July 25th, 2020. We are working hard to put together yet another successful conference for participants and their families, so please watch your email for updates and announcements. If you have any questions or concerns in the meantime, please feel free to contact the [DIAN Expanded Registry](#).



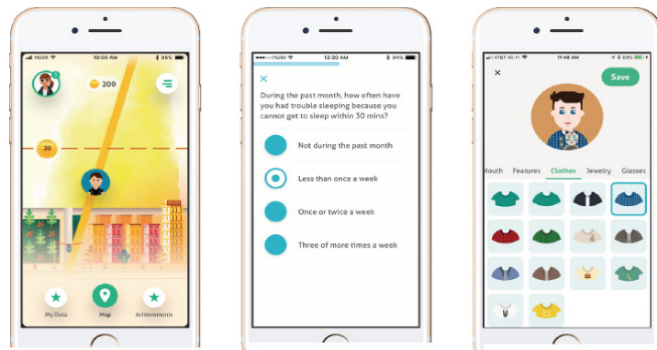
MyDIAN app Launched

We are excited to announce the release of MyDIAN, a smartphone app platform that is your direct connection to the Dominantly Inherited Alzheimer Network!

The app aims to make study participation and receiving DIAN-related information and easier and more engaging. Design your own avatar in the app and receive study activity invitations, reminders, articles, and newsletters (you may even be reading this on it now!). Complete activities and check out articles to move your avatar across colorful world maps and earn gems to spend on avatar customization. Future projects may even include opportunities to earn gift cards and connect with your fitness trackers or other devices!

Participants are slowly being introduced to MyDIAN via email invite. You may have seen an email invitation to download an app called LINKT. This is a secure communication from us and safe to interact with. These emails contain a username and password you can use to log in on the LINKT app and access the world of MyDIAN! If you haven't received an invite, don't worry. We aim to get more participants on board soon.

The DIAN research team is always working hard on the science of defeating Alzheimer's disease, but it can't be done without research participants like you. This is an important way for us to advance our understanding of DIAD, so we want everyone to get involved. MyDIAN represents our next step toward making research participation possible any time, from any place!



Contact us at dianexr@wustl.edu or 1-844-DIAN-EXR (1-844-342-6397) if you have any questions. Don't have a smartphone but still interested in MyDIAN? Please contact us to discuss a desktop-based site we have set up.

Biogen seeks Approval for AD Treatment

In October 2019, the pharmaceutical company Biogen reported that aducanumab, a new investigational treatment for Alzheimer's disease, reduced clinical decline in some patients with early Alzheimer's disease.

The results presented by Biogen were based on a new analysis of a larger dataset from the aducanumab Phase 3 clinical trials (EMERGE and ENGAGE). Both trials were discontinued in March 2019 after the company announced that the investigational product would miss their primary endpoints (expected outcomes to show effectiveness). However, a new analysis conducted after trial closure showed that the participants who received aducanumab at higher doses for the longest period of time experienced significant benefits on clinical outcome.

Aducanumab is an investigational human monoclonal antibody against amyloid beta studied for the treatment of early Alzheimer's disease. The positive results may represent an important proof of concept: a therapeutic intervention may delay progression of clinical symptoms in Alzheimer's by targeting amyloid pathology. Although future confirmation may be needed, this result brings hope to the Alzheimer's research field and, more importantly, to the families and people with Alzheimer's disease.

After consulting with the U.S. Food and Drug Administration (FDA), Biogen will pursue regulatory approval for aducanumab this year. See [AlzForum](#) for additional information.

Recent DIAN publications

Practical algorithms for amyloid β probability in subjective or mild cognitive impairment.

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6827360/>

Suicidal ideation is common in autosomal dominant Alzheimer's disease at-risk persons

<https://onlinelibrary.wiley.com/doi/full/10.1002/gps.5215>

An atlas of cortical circular RNA expression in Alzheimer disease brains demonstrates clinical and pathological associations.

<https://www.nature.com/articles/s41593-019-0501-5>

A harmonized longitudinal biomarkers and cognition database for assessing the natural history of preclinical Alzheimer's disease from young adulthood and for designing prevention trials.

<https://www.sciencedirect.com/science/article/pii/S1552526019351222?via%3Dihub>

Alzheimer's disease in the news

Major Alzheimer's study to open 5 new Latin American sites

<https://medicine.wustl.edu/news/major-alzheimers-study-to-open-5-new-latin-american-sites/>

Targeting immune cells may be potential therapy for Alzheimer's

<https://medicine.wustl.edu/news/targeting-immune-cells-may-be-potential-therapy-for-alzheimers/>

Dementia patients' adult kids diagnosed earlier than their parents

<https://medicine.wustl.edu/news/dementia-patients-adult-kids-diagnosed-earlier-than-their-parents/>

Why Didn't She Get Alzheimer's?

<https://www.nytimes.com/2019/11/04/health/alzheimers-treatment-genetics.html>

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.