



APRIL 2021



Does early treatment with highly effective DMT improve prognosis for people with MS?

WELCOME TO THE DELIVER-MS NEWSLETTER

Spring seems to bring optimism with the roll out of the vaccine and some lifting of restrictions to our movement. We remain optimistic that with your help **we could complete recruitment this year.** We are keen to focus on the randomised arm and ask sites to try to recruit 1-2 participants per month. Check out below which sites have fulfilled this target since March. We are delighted to welcome Sheffield (UK) as the latest site to open - we look forward to working with David Paling (PI) to the DELIVER family. New sites Coventry and Edinburgh both recruited this month - look out USA!! We're delighted to showcase our Patient Advisory Committee this month, who share their experience of working in the trial.



DELIVER-MS ENROLLMENT LAST CALENDAR MONTH

(overall recruitment shown at the end of the newsletter)

2+ participants

- Coventry (2)
- Cleveland (2)
- Nottingham (3)
- Ohio Health (2)
- Swansea (3)

1 participant

- Baylor
- Cardiff
- Edinburgh
- Las Vegas
- Minnesota
- Wisconsin

0 participants

- Buffalo
- Colorado
- Cincinnati
- Leeds
- Leicester
- Imperial
- Manchester
- Newport
- Oxford
- Plymouth
- Rochester
- Sheffield
- UCL
- UT-Houston
- Virginia

DELIVER-MS FOCUS: PATIENT ADVISORY COMMITTEE

Public and patient involvement (PPI) has crucially informed DELIVER-MS from the original study concept, to trial design and conduct, and will play an important role in results dissemination. In 2018 a Patient Advisory Committee (PAC) was formed of people with MS (with and without scientific expertise), caregivers for people with MS, representatives from insurance companies (US) and the NHS (UK), DELIVER project managers, a health outcomes expert (Dr. Deborah Miller), and the co-PIs (Drs. Ontaneda and Evangelou). The PAC ensures that trial design is appropriate and answers meaningful questions, advises on recruitment and retention, and provides the perspective of public stakeholders in interpreting study results. Here we asked members of the PAC to share their experiences of MS, public involvement in research and DELIVER-MS in particular.

Clare Bale told us: *“DELIVER-MS is an important study for people with MS, as we often feel scared at the time of diagnosis, uncertain of disease progression, and of taking medications. As someone with MS and a PPI lead, I wanted to contribute to DELIVER-MS to help clinicians decide the most effective approach to treatment and to assist people in making informed decisions, whatever their circumstances.*



Even before DELIVER-MS began, its research team involved people with MS to shape the study aims and design. Through the work of the PAC, that involvement continues. Given the size of the study and that it is being conducted in the UK and USA, the research team are exceptionally well-organised, and really listen and respond to the comments of its patients' voice, which aim to represent people diagnosed and living with MS.

We would like to thank current participants. In my role, I often hear people say they want to be involved in research to help others like them in the future. DELIVER-MS has the potential to do this, so I encourage people to consider taking part if it fits with their needs and outlook.”

Anne Schwartz told us: *“I am grateful for the opportunity to be on the PAC. Each personal story and journey with MS is unique. Providing data to help make informed treatment choices can offer peace of mind to those that are newly diagnosed. Thank you to everyone that has contributed to this fantastic research!*



Paul Davis told us: *"I was diagnosed with MS 20 years ago. I needed to start using a wheelchair about five years ago. I think it's important to be involved in studies to help find a solution for MS. It makes me feel like I am doing something positive to end this disease and help others."* Paul also shared some thoughts that help keep him going:

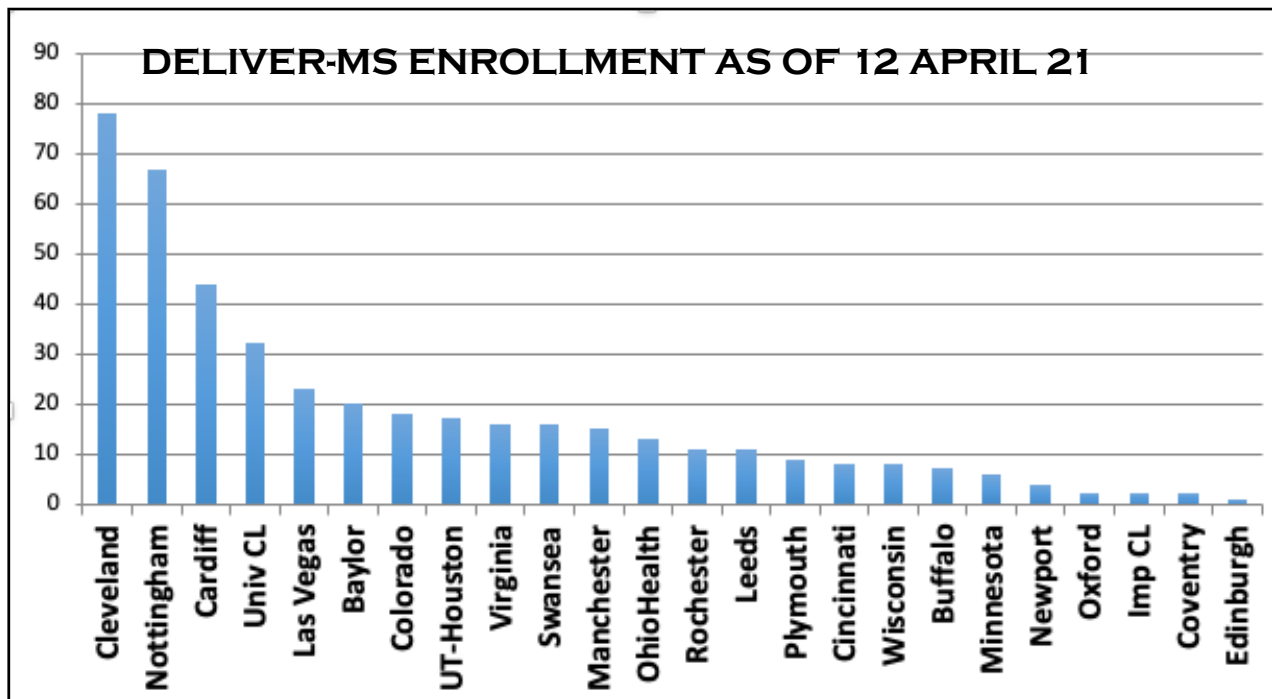


- *Never, Never give up; find a workaround (apologies Sir Winston Churchill).*
- *Participate in MS studies; it is a way to give something back.*
- *Talk about your MS with others. Listen to what others with MS have to say. You will learn a lot and they will appreciate your listening.*
- *Don't be afraid to yell in frustration- just notify those nearby before you do.*
- *Get a pet. A 4-legged one preferred.*
- *Do not be ashamed or embarrassed. Love yourself. It's not your fault.*

Burhan Chaudhry told us: *"My experience of the PAC has been wonderful and an eye opener even though I have had MS for a decade. Hearing other patients' experiences with the disease and having to navigate the challenges made me realize how others had more difficulties than me. Even though I've had my own challenges it can always be worse. The PAC gives me an opportunity to be a part of something that will make it easier for MS patients in the future. It reaffirmed how the public at large is not fully comfortable being engaged with research and we as patients can better advocate for it. I encourage study participants to complete the trial as it will hopefully bring about a positive change for MS patients down the road. And that is the goal!!"*



Dan Ontaneda also reflected on the role of the PAC: *"The PAC has been a tremendous asset and guide for our study. Every single PAC meeting we leave with some amazing actionable suggestions for improvements to our trial. This is a key part of DELIVER, and has convinced me on how bringing stakeholders to the table makes studies and research better. I am so thankful for members of the PAC. It has been an immense pleasure to get to better know everyone, who we now consider a big group of friends and partners in research!"*



Relevant Links

Our website is:

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