

Please note: Most images in this newsletter were taken prior to Covid-19



## MND-SMART Newsletter - November 2021

Hello

We're delighted to welcome you to our second newsletter of the MND-SMART clinical trial.

Since April 2021 we have made significant progress opening new recruitment sites across the UK. There are now 14 trial centres with Exeter, St George's, Norfolk, Ipswich, W Suffolk, Birmingham and Newcastle opening since our last newsletter. This has allowed us to recruit over 200 participants, including patients as far North as the Orkney Isles and as far South as the Isle of Wight.

We're delighted to announce that the Edinburgh site have just recruited their 100th participant to the trial, an incredible achievement.

Despite the many unprecedented challenges COVID-19 has brought, amendments to the trial have allowed our teams to continue to safely recruit and follow-up people in the trial. We would like to thank all the people with MND who have made suggestions and given feedback on the trial. These have guided some of the changes we've made and hopefully reduced trial burden for many MND-SMART participants. Specifically, more visits are now happening over the phone, via videoconferencing and even at home.

It has come to our attention that some trial participants have stopped taking their trial medication without prior discussion with their research team. If you, or someone you know, is thinking about stopping trial medication please contact your research team first. This is for your own safety, as there is a risk of side effects if you suddenly stop taking the drug. This can be safely managed by working with the research team and stopping the trial drug gradually.

We are delighted that we are now formally collecting information on people's expectations and experiences of MND-SMART as part of our new sub-study (more information below). Thanks to those who have agreed to take part in this important research.

In this newsletter we'd also like to thank the amazing team of researchers working at our sites across the UK; without them the trial wouldn't be possible. This includes our consultant neurologists, research nurses, research practitioners, data managers, laboratory staff and many many more.

Very best wishes

*Siddharthan Chandran*

Prof Siddharthan Chandran  
Co-Lead and Chief Investigator of  
MND-SMART



*Suvankar Pal*

Dr Suvankar Pal  
Co-Lead Investigator of MND-SMART



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## Update on recruitment

Thanks to our dedicated teams and people with MND across the UK we have now passed 200 participants in MND-SMART. This is a brilliant achievement and we look forward to seeing this grow further during 2022.

We'd like to welcome our sites and participants who have joined the trial since the last newsletter. This includes our first site in London at St Georges, you can read more about their launch on **page 7** of this newsletter.

Also a special mention to the Edinburgh team who recruited their 100th participant this week.

For readers who are part of the trial please do remember to get in touch with your research team if you are thinking about stopping your study drug. This needs to be done slowly for maximum safety and also to make sure the trial data is of the highest quality.



We now have sites recruiting participants in the following locations:

- Aberdeen
- Birmingham
- Dundee
- Edinburgh
- Exeter
- Glasgow
- Inverness
- Ipswich
- Newcastle
- Norfolk
- Salford
- St George's (London)
- Southampton
- West Suffolk

## The island experience



There are many beautiful islands in the UK, both near and far from the mainland. Our aim is for people living with MND anywhere in the UK to be able to enter the trial where it is safe to do so.

We are delighted to have been able to recruit people to MND-SMART from such locations and thank them for travelling by ferry or plane to their appointments.

We got in touch with a couple of our research teams and their participants from Orkney and the Isle of Wight to hear about their involvement in the trial.

You can read about their experiences on **pages 8&9**

## MND-SMART sub-study



MND-SMART was designed in partnership with people with MND to efficiently test drugs that have the potential to slow progression of the condition. Early input from patients and their families helped shape the current trial and make it as accessible as possible, e.g. by using liquid drugs and conducting some appointments remotely.

We are now striving to go further and understand how people with MND and their relatives/caregivers feel about joining the trial and what their experiences as participants are.

New participants, and caregivers are able to take part in a sub-study called 'Attitudes and expectations of participants of MND-SMART'.

You can read more on **page 10**



## A day in the life of.....



Tanya Van Der Westhuizen

Tanya is a Research Practitioner in Edinburgh and has been working on MND-SMART since the trial launched in January 2020. She is part of the team recruiting people from NHS Lothian and surrounding areas. She says that despite Covid-19 being “a taxing time to recruit to research”, she is proud to share how “exceedingly hard” the team has worked to make sure that people with MND could be seen and enrolled in the trial.

Tanya has had a difficult, but rewarding year after being redeployed to the intensive care unit during the Covid-19 pandemic. She has been recognised for her contributions to MND research by winning the 2021 Hampton Award and being celebrated by NHS Lothian during the annual Health and Social Care Support Workers Week.

Read about Tanya’s experiences of working on the Trial on **pages 11&12**

## Publication from the MND-SMART Group

The MND-SMART group recently published a scientific paper reviewing clinical trials in MND. The aim of this review was to identify what the challenges were in finding effective treatments to slow, stop or reverse MND.

There were three main areas identified for improvement in clinical trials for MND:

1. Increasing the research on the biology of the disease: the more we know about what happens to the brain and body in MND the easier it will be to find drugs that might stop it.
2. Making trials accessible for more people with MND: by designing a trial in which people with MND can easily participate, there is a greater chance of recruiting participants, reaching the end point and generating meaningful results.
3. Using more efficient trial designs: a multi-arm, multi-stage trial design allows us to add new drugs to the same clinical trial, and benefit from having experienced sites already set-up and recruiting. We aim to face these challenges head on as part of MND-SMART. If you would like to see the full article it can be accessed on the Brain Communications website (<https://bit.ly/31Wes5l>)

## Our funders



Thank you also to all of the individual donors and fundraisers who have supported MND research and enabled MND-SMART to happen.

### Suggestions?

Is there something you'd like us to include in our next newsletter? [emc\\_admin@ed.ac.uk](mailto:emc_admin@ed.ac.uk) about content or suggestions.

If you would like to opt out of these newsletters, please email us at [emc\\_admin@ed.ac.uk](mailto:emc_admin@ed.ac.uk).

### Follow us

Catch up on MND-SMART news by following the MND-SMART on Twitter and the Euan MacDonald Centre Facebook page.



[www.mnd-smart.org](http://www.mnd-smart.org)

**The Euan MacDonald Centre for Motor Neuron Disease Research** is based at the University of Edinburgh and is a not-for-profit, charitable network of over 200 researchers across Scotland.

We use research to improve the lives of people living with motor neuron disease (MND) and related conditions.

The University of Edinburgh is a charitable body, registered in Scotland, with registration number SC005336. The University of Edinburgh Development Trust is a charitable body, registered in Scotland, with registration number SC004307.

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## Oct 2021: A new trial centre has opened to participants in London.



MND-SMART has started to welcome participants to the motor neuron disease research study from across the St George's University Hospitals NHS Foundation Trust region.

*"This is St George's first ever drug trial for patients with motor neuron disease. What excites me most about the trial is the innovative design and the fact that multiple drugs can be tested over time.*

*It is a much quicker way of helping us find a treatment for the condition, compared with traditional trial design which would test one drug at a time. My hope is that it brings us one step closer to finding a treatment for motor neuron disease."*

Dr Pablo Garcia-Reitboeck Consultant Neurologist, St George's Hospital

Eoin Egan, 39, from Wandsworth, was one of the first patients to be take part in the trial at St George's. Eoin was referred to St George's neurology team in 2019 after experiencing persistent twitching in his arms and legs.

Eoin had also developed foot drop, which is a muscular weakness or paralysis that makes it difficult to lift the front part of your foot and toes. Following various tests, Dr Pablo Garcia-Reitboeck diagnosed Eoin with MND.

*"I didn't know much about the condition, but I knew it was quite serious when Dr Garcia-Reitboeck asked me to bring my wife in too." said Eoin. "I didn't understand how progressive it was at the time, but he was very open about it and gave me all the facts I needed."*

Like many people diagnosed with MND, Eoin has researched what clinical trials are available for the condition.

*"The sheer quantity of trials and research that is happening right now is far more than has happened throughout history," said Eoin. "Even though there is no guarantee, I do pick up on a lot of hope in the medical research community.*

*I was immediately very keen to take part in the MND-SMART trial when I was invited. I understand that people need to do these trials in order to progress a solution for MND. And I've very happy and proud to be a part of trying to do that."*

We extend our thanks to both Eoin Egan and Dr Pablo Garcia-Reitboeck for their time in sharing their thoughts about the trial.

## The Island Experience



Nov 2021 A viewpoint from some of our island participants and research staff.

There are many beautiful islands in the UK, both near and far from the UK mainland. Our aim is for people living with MND anywhere in the UK to be able to enter the trial where it is safe to do so. We are delighted to have been able to recruit people to MND-SMART from these locations, with some participants travelling over 260 miles to their appointments.

All the MND-SMART research teams across the UK are working hard to recruit and follow-up people with MND. We asked participants from the Orkney Islands and the Isle of White to share with us what it was like to participate in the Trial. We also asked the teams in Aberdeen and Southampton what it was like working with participants on islands at both ends of the UK.

*"I am so grateful to have the opportunity to take part in MND-SMART clinical trials. While I live in hope that I may have a 'miracle drug', I also feel strongly that the only way forward to lessening the impact of this condition is through research."*

*We are overwhelmed by the care and kindness of the Aberdeen team at my initial assessment, who truly went above and beyond to make everything work as smoothly as possible for us, as we travelled from Orkney. It has given me great confidence in the trials, and being in easy contact has been very reassuring."*

Irene MND-SMART participant living in the Orkney Islands

*"It has been our privilege to work with all the participants in the study, who have each shown dedication and enthusiasm, with no complaints about the tests and assessments we put them through. A first for our Research Network is being able to recruit participants from the Orkneys and Shetland, as well as being able to recruit people who do not speak English. Usually trials do not allow the use of interpreters, or are not flexible enough to enable island residents to take part."*

Alison McBain Clinical Studies Officer  
(Neuroprogressive and Dementia  
Research Network), Aberdeen



*"I first heard about the SMART trial from Dr Pinto about 2 years ago and after reading about it, registered straight away. Unfortunately the pandemic delayed enrolment but as soon as I was contacted I was eager to proceed.*

*Just the knowledge that there may be some help available, not a cure, but something that could ease the symptoms was encouraging. Although I was nervous about the tests for the Trial, once I was accepted for SMART it was a relief. I was anxious about the side effects of the drug, I didn't want to feel ill and fall at the first hurdle, but I've been absolutely fine. I feel well in myself and haven't had any deterioration in the 4 <sup>1/2</sup> months I've been on it. I feel positive about being on the Trial.*

*I'm not under any illusion that there is a cure at this moment in time, but I feel proud of myself and my husband for undertaking the Trial and feel proud that I might be doing my bit in the fight against MND."*

Anita MND-SMART participant living on the Isle of Wight

*"The Trial office are always on hand and were there to advise when we had a query regarding travel compensation/overnight hotel stay for a patient from the Isle of Wight. Aside from that, it hasn't been any different recruiting a participant from the mainland thanks to the courier service for delivering Trial drug which helps our ability to conduct visits remotely.*

*Overall, delivering MND-SMART at University Hospital Southampton has been incredibly rewarding. It's an intensive study in terms of coordination and planning, but it is all worthwhile to be able to offer access to interventional research opportunities for people with MND."*

Ashley Villanueva Senior Clinical Trials Assistant, Southampton

Even without the need to cross water some of our participants travel considerable distances to participate in MND-SMART. The trial management team would like to extend their heartfelt thanks to all participants, and their families, for attending their appointments. Thanks also to all our research trial colleagues whose dedication and support help make the trial possible. We couldn't run MND-SMART without them.

## MND-SMART Sub-study-1



To understand how people feel about joining the trial and what their experiences are, we have added a sub-study to MND-SMART. A sub-study is an 'add-on' to the original design and participants have the option of consenting to be part of it.

We want to know not only what peoples' expectations of the trial are, but also how these expectations may change during participation. We will collect data by asking participants and care-givers to answer a questionnaire when they join the trial, after 2 months participation and again after 6 months.

Nov 2021: The sub-study will examine the attitudes and experiences of MND-SMART participants.

*"I am part of the team that designed MND-SMART Sub-Study 1.*

*It's important to hear feedback directly from participants, and their caregivers. This will help us to understand why people choose to participate in a trial, continue to be involved, or stop participating. The feedback from the study will be used to help us make decisions about the future of the Trial, and support other researchers who are designing trials for people with MND. I am grateful to everyone who has already taken the time to complete the questionnaires on their expectations and experiences of being involved in a clinical trial."*

Emily Beswick PhD Candidate, MND-SMART & Euan MacDonald Centre

If a participant chooses to withdraw from the trial, there is a specific questionnaire to gather information on this decision. We are also asking if people would be willing to have an interview about this with the central research team in Edinburgh.

The information we gather from this sub-study will be used to further enhance the design of MND-SMART and other clinical research studies for people with MND.

If you are joining MND-SMART soon and interested in the sub-study please ask your research team for more information. (Participation in the sub-study is a completely optional aspect of the trial and does not affect the ability to take part in MND-SMART.)

## A day in the life of Tanya Van Der Westhuizen



Oct 2021: We caught up with Tanya Van Der Westhuizen, Research Practitioner in Edinburgh.

Tanya Van Der Westhuizen is a Research Practitioner at the University of Edinburgh and has been working on MND-SMART since the trial launched in January 2020. She is part of the team recruiting people from NHS Lothian and surrounding areas. She says that despite Covid-19 being 'a

taxing time to recruit to research', she is proud to share how 'exceedingly hard' the team has worked throughout the year to make sure that MND patients could be seen and enrolled in the trial.

Tanya has had a difficult, but rewarding year after being redeployed to the intensive care unit during the Covid-19 pandemic. She has been recognised for her contributions to MND research by winning the Euan MacDonald Centre's 2021 Hampton Award and being celebrated by NHS Lothian during the annual Health and Social Care Support Workers Week. We asked Tanya to take some time out of her day to tell us about her experiences of the trial.

Interview with Tanya

### **Why were you interested in getting involved in neurology research?**

I first moved to Edinburgh and started a job working in the neurology department. I found a passion and love in working with patients with neurological disorders and conditions. I really wanted to work in research so that I could help with the development of new therapies and treatments which will be beneficial to people living with neurological conditions.

### **Tell us about your role in MND-SMART?**

I currently work as a Research Practitioner in MND-SMART at the Anne Rowling Regenerative Neurology Clinic in Edinburgh. I am responsible for contacting and recruiting participants to the Edinburgh site. I organise patient appointments and perform patient outcome assessments such as respiratory function tests.

I also work with our couriers to organise delivery of trial drug when necessary.

When I'm not working with patients, I make sure all our trial documentation is up to date and help with monitoring visits and reports. We have to send documentation and logs to the trial Sponsor every 3 months. It is also important that we feed back all information to the trial team about what is working and what is not working so that we can implement amendments if needed.

### **What are the challenges and rewards of working on the MND-SMART trial (particularly in the advent of Covid-19)?**

I think we at the Edinburgh site were lucky as we could still recruit participants during a lot of the pandemic. The main difficulty faced was that the rooms had to be big enough to accommodate 3 people with social distancing.

The training for new medics was also difficult as they could not be in the room due to capacity issues, so a lot of training was done over video.

As part of our strategies to reduce the spread of Covid-19, we couldn't carry out respiratory function tests or process blood samples for several months. I was responsible for keeping the documentation to record this up to date.

Adapting to these changes was tricky but the reward was that we could still bring in participants and that was very important because there were people who registered on the website when the trial was first launched. It is so rewarding to come in and talk with the participants at every visit and for them to tell us about themselves. I mean, what's a greater reward than working on a trial that aims to find new medications to slow down the rate of progression in MND.

**What advice would you have for research nurses working on the trial?**

Talk to the participants and get to know them. They've been given a difficult diagnosis and may need someone to talk to. From an administrative side, always check everything has been filled in after the visit and signed appropriately, it's easy to miss this when we get busy.

**What are your hopes for the trial going forward?**

I really want there to be treatment options available for people with MND so that their quality of life improves and they get to spend longer with their loved ones. The dream would ultimately be a cure, but I know we must take this one step at a time.

**What do you like doing when you're not working?**

I am a very activity-based person and love going to different places with my partner, friends and family. In the past two months I have visited the Highland Wildlife Park to see the animals, the corn maze in Cupar to pick pumpkins, experienced a light show at Hopetoun House and enjoyed an orchestra performance in a planetarium.

I really enjoy doing these nice things in my spare time as the participants I speak to on the trial have stated that people need to live their lives by doing things that make them happy. This year, I have taken their advice on board and am really enjoying doing things I love with the people I love, as often as I can. It has given me a wholesome way of living.