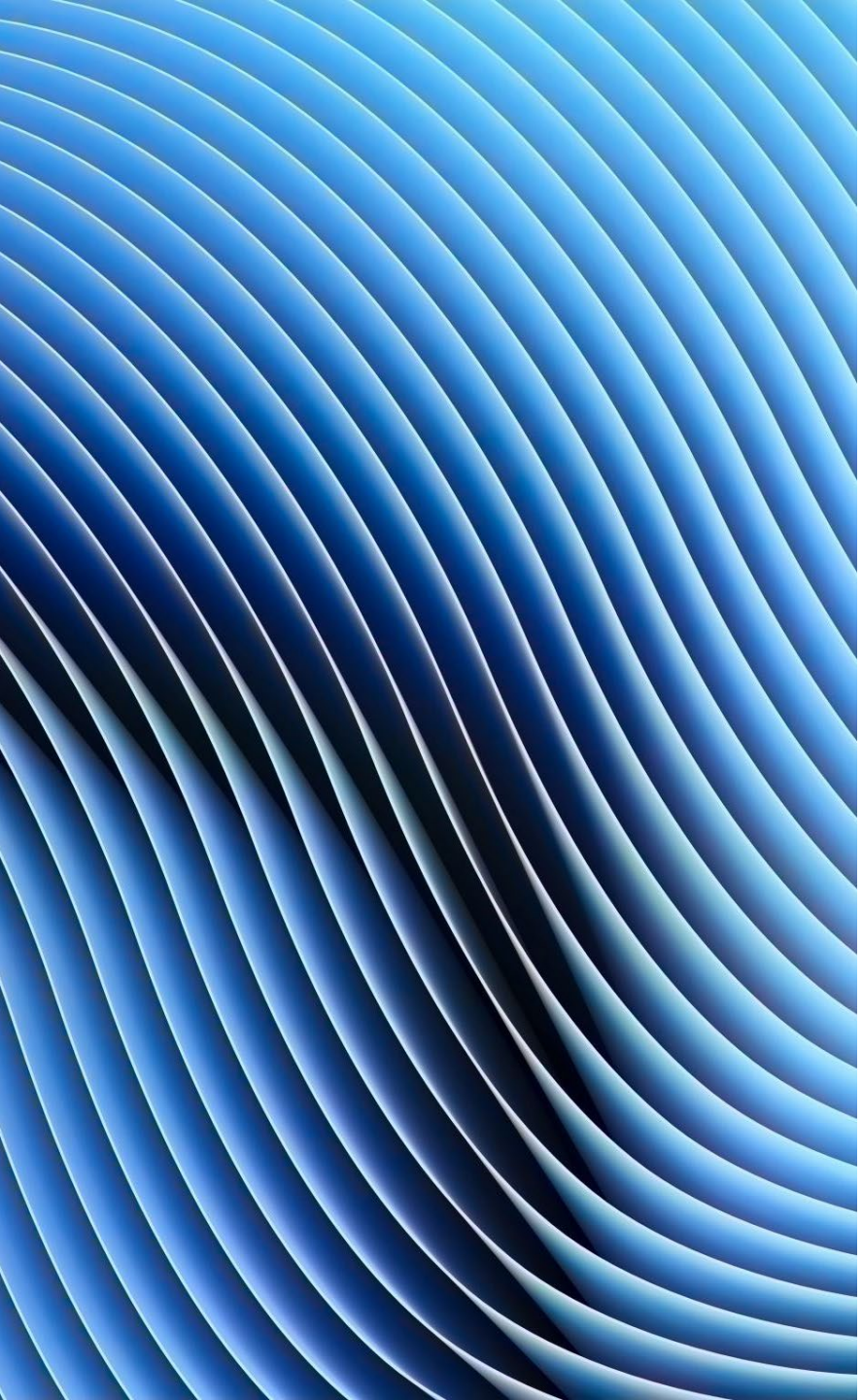
# MND SMART

The Role of the Research Nurse & the patient experience

# MND SMART

- Motor Neurone Disease Systematic Multi-arm Adaptive Randomised Trial
- Sponsor ACCORD (University of Edinburgh & NHS Lothian)
- Previous arms Memantine & Trazodone
- Currently looking at Amantadine Vs Placebo
- Plan to add in Tacrolimus arm (likely Jan 2025)
- 875 participants recruited nationally

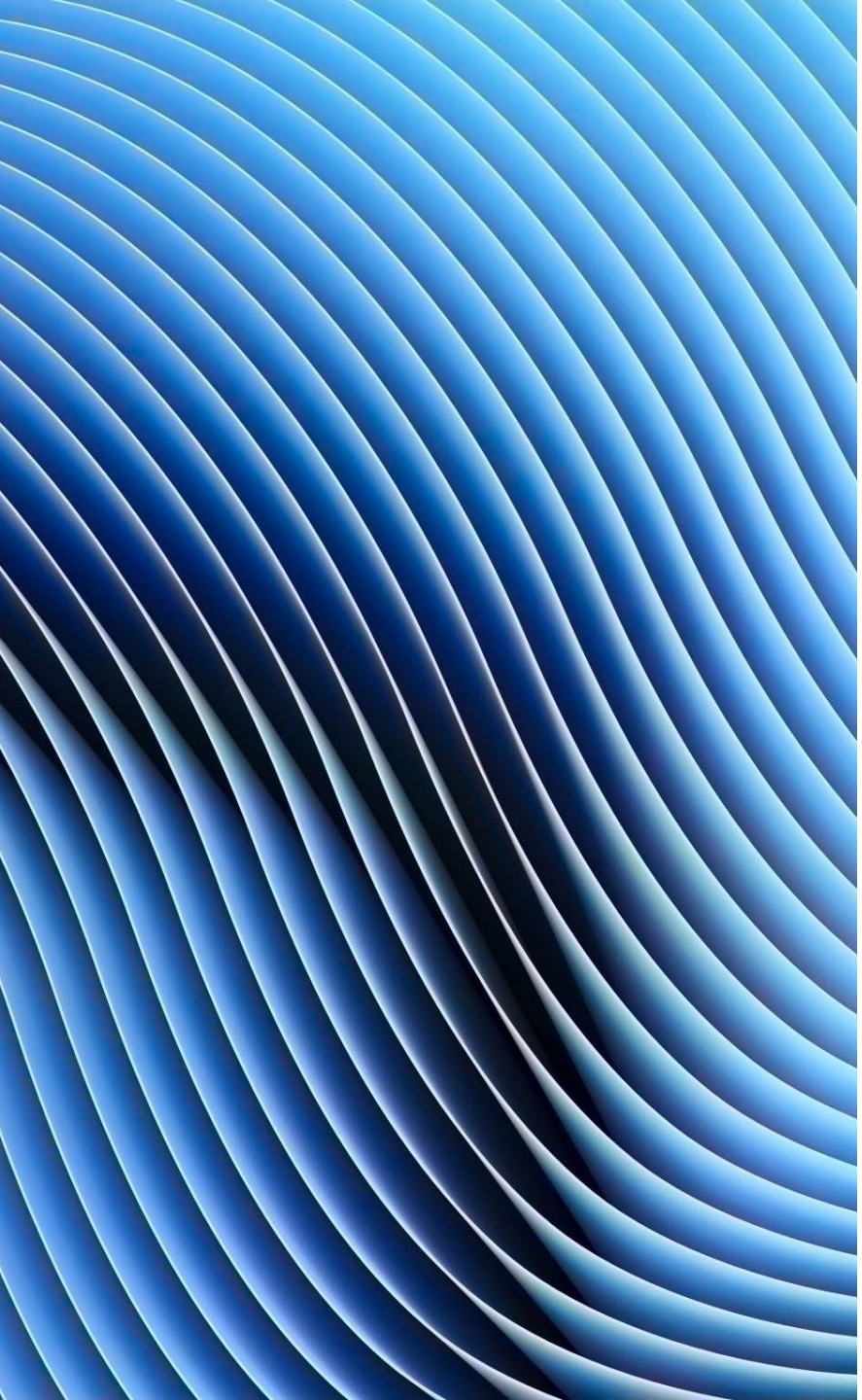


# The Role of the Research Nurse in MND- SMART

- Patient Identification & Pre-screening
- Close working relationship with Neurologists and MND coordinator
- Database of patients interested in clinical trials
- Review of patients notes
- Pre-screening telephone call
- Booking screening visit

# The Role of the Research Nurse in MND- SMART

- Coordination of the study & study visits
- Main point of contact for patients, investigators, study sponsor, pharmacy, research labs
- Visit Prep
- Performing assessments on the study e.g. ECAS, ALS FRS, bloods, ECG, vital signs etc.
- Follow up visits
- Monitoring medication titration, adverse events and reactions and any changes for the patient



# The Role of the Research Nurse in MND- SMART

Data collection and query resolution

Maintenance of site files

# The Patient Experience of MND SMART

- Possibly discuss research at their clinic visit
- Initial phone call to assess interest
- Sent PIS and given time to read/digest
- Follow up pre-screen phone call/chance to ask questions

# The Patient Experience of MND SMART

- Attend the CRF for a screening visit (bloods, ECG, Neuro Exam, C-SSRS)
- Re-attend the CRF within 4 weeks for Baseline visit (FVC, ECAS, ALS-FRS, King's Staging, randomisation)
- Week 1, 2, 3 follow up phone calls, titration of study medication
- Two Monthly phone calls checking AE's, Medication changes & ALS-FRS
- Clinic visits at Month 6, 12, 18 (FVC, ECAS, ALS-FRS, King's Staging)

# The Patient Experience of MND SMART

Study medication is all liquid

Couriered to patients' home

Visits can be done remotely if accessing site becomes impractical