

REPAIR-MDS Newsletter

January 2023, Issue 11

A message from the CI

"To all the Investigators, your clinical teams, patients and their families, on behalf of myself and the wider Trials Team, as we pass the one year anniversary of the trial being open to recruitment, we would like to thank you for all your efforts so far in respect to the REPAIR-MDS trial, especially as the wider healthcare environment remains challenging.

We already have some notable achievements within the trial, with 14 centres now open to recruitment including centres in Wales and Scotland, in addition to England. Participant registrations are now above 19 and randomisations into double figures. I and the whole trials team are looking forward to continuing working with you as the trial expands and we approach our first milestone within this valuable and landmark trial, for this often-overlooked patient group.

Dr Stephen Jenkins
Clinical CI REPAIR-MDS"



Achievements

We are pleased to kick off 2023 with the **BEST MONTH FOR RECRUITMENT** since opening the trial!

Well done to **Good Hope Hospital & University College London Hospitals NHS Foundation Trust** for randomising 1 participant each and **Royal Cornwall Hospital NHS Trust** for randomising 2 participants

A big thank you to **Colchester General Hospital, University College London Hospitals NHS Foundation Trust** and **Kent and Canterbury Hospital** for registering 1 participant each

A huge welcome to **James Cook University Hospital** who opened to recruitment in January!

Recruitment Update

19 Registrations
13 Randomisations
14 Sites Open to Recruitment

Patient Meeting with MDS Patient Support Group



Following the success of the trial Launch Meeting in October, UK MDS Patient Support Group in collaboration with the trial team hosted a virtual **Patient Meeting** on **27-Jan-23**

Nearly **70 people** attended the meeting - Thank you to all who have attended!

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Website: [REPAIR MDS \(warwick.ac.uk\)](http://REPAIR_MDS.warwick.ac.uk)

Patient Diaries - How to Complete

Patient Diaries are really important to help you, and the Central Trial Team, check if patients are taking the trial treatment correctly or if they have missed doses.

Complete with Trial Number (TNO) and Initials

Include the start date for the sheet so the patient is clear on when to start using the diary sheet

Include your team contact details so the patient can contact you for support

Review the diary at every clinic visit and please return original copies of completed Patient Diaries to the WCTU Team using the supplied pre-paid envelopes.

Don't forget to redact any identifiable information the patient may have added!

Patients should write the date they had the trial treatment

Patients should write the **number** of tablets taken at each time of the day (i.e. Morning, Lunch, Evening)

Re-screening patients

Patients who have been screened and failed the eligibility criteria to enter the trial may be re-screened if their circumstances have changed at a later date.

For example if patients who were responding to ESAs at the time of first screening are no longer responding to ESAs OR the patient is no longer receiving Vitamin K-Antagonist Anticoagulation etc.

Please record as a separate entry on the screening log.

Ordering Supplies

Sample boxes

Please order sample boxes for Samples for Science directly by emailing:

colmds-c-trialkits@adf.bham.ac.uk

Please remember to include "REPAIR-MDS" in the email subject line.

Patient ID Cards

All patients should be issued with a Patient ID Card at randomisation. To order more Patient ID cards by email REPAIR-MDS via:

RepairMDS@warwick.ac.uk