



# Newsletter

December 2020 Issue 23

7 Nations Participating

25 Clinical Sites Worldwide

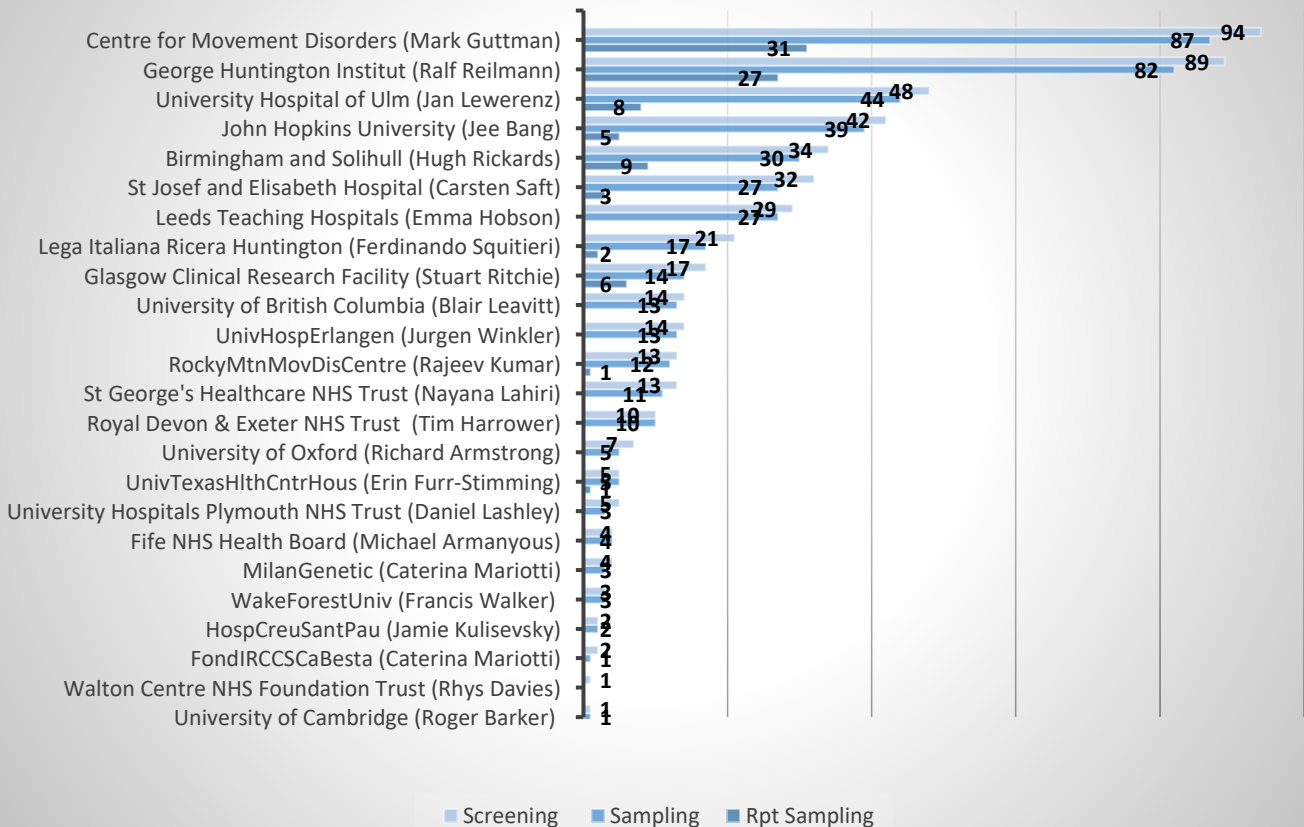
491 Participants

Dear HDClarity Teams

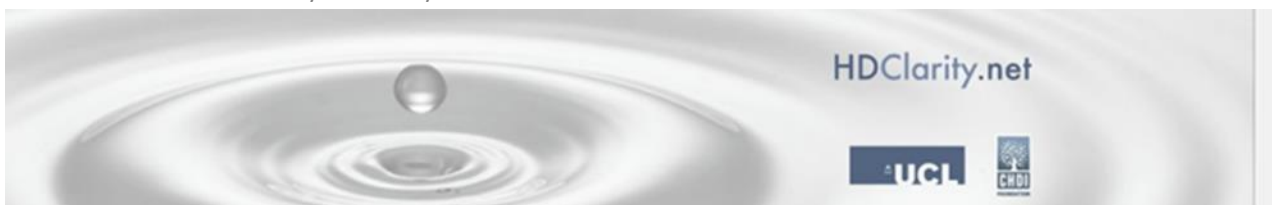
Thank you to everyone for all of your hard work, we have now completed 545 sampling visits, including longitudinal and optional repeat visits.

- 2020 has been one of the most challenging years and we are aware that many of you have been carrying out vital clinical duties. However, thanks to your continued efforts there have been 62 initial sampling visits, 2 optional repeat sampling visits and 11 longitudinal sampling visits. This is fantastic news and we are hopeful that these numbers will continue to grow in 2021. Congratulations to all!!
- Additionally, we would like to welcome our new sites in Barcelona, Warsaw and Washington DC who have recently joined HDClarity.

## HDClarity Site Recruitment



\*The chart reflects recruitment data of initiated sites extracted from the HDClarity EDC to date (14<sup>th</sup> Dec 2020). Any data not yet entered on the EDC will not be shown here.



## Recruitment by HDClarity Category

Completed Initial Sampling Visits						
# Early Premanifest HD	# Late Premanifest HD	# Early Manifest HD	# Moderate Manifest HD	# Advanced Manifest HD	# Controls	Total
61	92	165	15	13	95	441

Completed Longitudinal Sampling Visits						
# Early Premanifest HD	# Late Premanifest HD	# Early Manifest HD	# Moderate Manifest HD	# Advanced Manifest HD	# Controls	Total
1	1	2	0	0	7	11

### REMINDERS

- HDClarity lab manual V5.0 should be used for all future visits.
- The kits you have onsite may contain obsolete or expired components:
  - Spinal needles – kits containing 22G Whitacre spinal needles should be replaced with new kits that include the 24G needle, introducer and aspiration syringe.
  - Polypropylene pipette tips – these have expired in many CSF and blood processing kits.
  - Vacutainers – have expired in many blood collection kits.

Please notify HDClarity CC at least 14 days prior to a planned sampling visit and we will send replacements for the above. In the case of vacutainers, you may use a locally sourced replacement if you prefer, but please inform HDClarity CC of the replacement make and model and include a photo at least 7 days before the visit.

- Due to the above changes, please contact HDClarity Central Coordination before placing any new biokit orders on the EDC.
- BioRep is closed over Christmas and we ask that you do not ship samples or request new kit after Dec 18<sup>th</sup> in order to minimise risk of any shipment/delivery delays.

Please contact UCL Central Coordination if you have any questions [hdclarity-cc@enroll-hd.org](mailto:hdclarity-cc@enroll-hd.org)

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