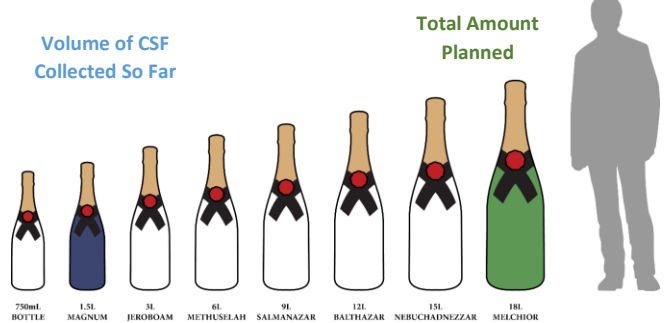


HDClarity

Newsletter

March 2018 Issue 10



Dear HDClarity Teams!

Thank you to everyone for all of your hard work, we have now completed 133 sampling visits and 49 repeat sampling visits!

! IMPORTANT EDC CHANGES

In preparation for a protocol amendment in HDClarity the EDC has undergone some changes. The most significant change means that the EDC now classes manifest as well as premanifest participants with a CAG <40 as ineligible. As you are still using protocol VerNo002 then you can still consent manifest participants with a CAG <40 but you will need to inform Central Coordination in advance of the visit so that we can inform IT and ask them to add a manual waiver to allow participation and also to manually add their disease stage.

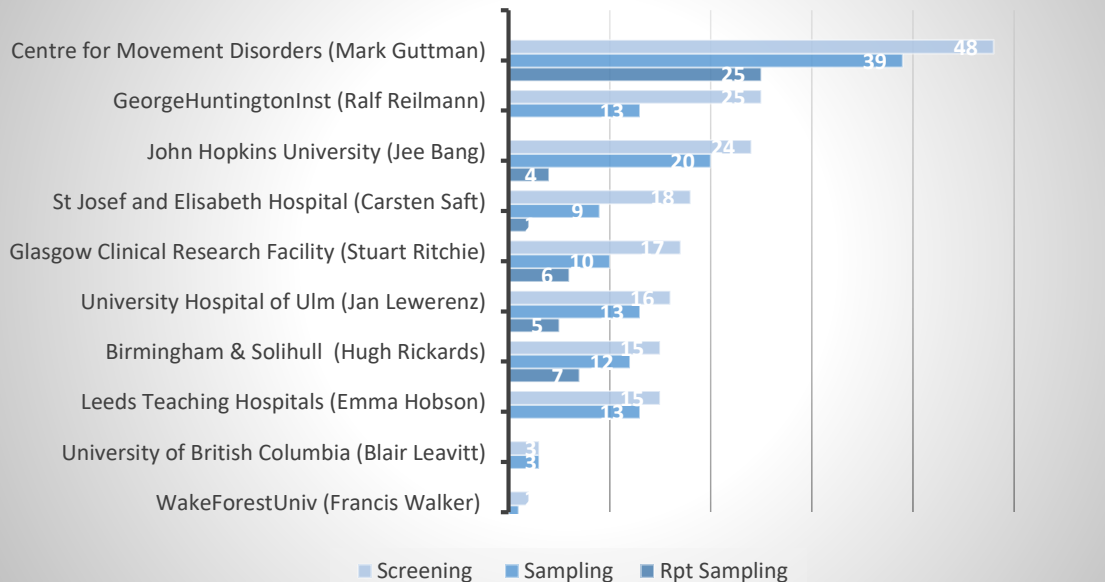
So, when you are checking the CAG repeat length as part of your pre-screening assessments and you notice that the long allele repeat length is < 40 please contact Central Coordination with the HDID, planned screening visit date and disease stage based on the most recent Enroll-HD TFC.

This only applies to manifest participants. The eligibility criteria for premanifest remains the same CAG \geq 40.



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HDClarity Site Recruitment



*The chart reflects recruitment data of initiated sites extracted from the HDClarity EDC to date. Any data not yet entered on the EDC will not be shown here.

Please contact UCL Central Coordination if you have any questions hdclarity-cc@enroll-hd.org

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