

Dear Parents/ Guardian,

Great Ormond Street Hospital has updated the process for identifying and recruiting patients to neuromuscular trials. As from 1st August 2019 we have adopted a recruitment strategy based on randomisation system to identify and select patient that would potentially be eligible for a clinical trial. We will also request that families confirm their interest in being selected for a clinical trial on a regular basis.

We believe this will be a fairer and transparent way to select patients compared to other systems previously used.

The randomisation will occur using the information on the database and the inclusion criteria of the trial. It is therefore important that we have sufficient and up to date information for us to assess the eligibility of children for specific studies, based on the study protocols.

The information that is required is

Childs full name:

Date of birth:

Condition:

Contact details (both phone numbers and emails):

Tertiary centre where the child is regularly assessed:

Additional questions relevant for some but not all conditions:

Ventilation status:

(e.g. type of ventilation, usual number of hours ventilated, plus any other relevant information)

Concomitant drugs:

(drugs regularly taken)

If you have not already sent this information through to Great Ormond Street please send this through to clinicaltrials.neuromuscular@gosh.nhs.uk.

IMPORTANT: We would also like to notify you that we do not have the resources within our team to call every family on the database that could potentially be eligible for a given trial; therefore we will only be getting in touch if your child has been selected from the database.

Finally, thank you very much for sending through your updated details.

