

**Dubowitz Neuromuscular Centre**

Institute of Child Health

University College London

30 Guilford Street

London

WC1N 1EH

Date

Dear ………………….…………...,

Thank you for taking part in the SMA REACH UK study (Spinal Muscular Atrophy Research and Clinical Hub UK) at Great Ormond Street Hospital.

We are writing to invite you and your family to take part in a focus group on

[insert date]at the Institute of Child Health, WC1N 1EH.

A focus group is an informal discussion group, where questions are asked in an interactive group setting and each participant is free to talk with other group members.

The focus group will be an opportunity for you to tell us your perceptions, opinions, and attitudes on clinical trials and clinical assessment tools (outcome measures). This will help to inform the design of clinical and research asessment tools and help us to understand what meaningful changes in the condition are most important to you and your family. More information will be provided and explained to you on the day.

There will be a number of other families and children with SMA who will be invited to attend and the size of each focus group will be approximately 6-10 people. Each focus group will be led by one of the study team that you may have already met during routine clinic appointments.

The focus groups are sponsored by the SMA Trust as part of SMA REACH UK study. Lunch will be provided and reasonable travel expenses will be reimbursed.

Please RSVP by [insert date] by replying to this email or by contacting the one of the research team on the number below to let us know whether you would like to take part.

Yours sincerely,



Dr Mariacristina Scoto Dr Salma Samsuddin

Clinical Research Fellow Research Physiotherapist Trial Manager