

**Dubowitz Neuromuscular Centre**

Institute of Child Health

University College London

30 Guilford Street

London

WC1N 1EH

Date

Dear Parent/Gaurdian,

We are writing to inform you about a research study currently being undertaken at Great Ormond Street Hospital called SMA REACH UK (Spinal Muscular Atrophy REsearch and Clinical Hub UK). We understand you will soon be attending <insert details> with your child for a routine clinical appointment. In anticipation of this appointment we have enclosed some information about the SMA REACH UK study. This study has been ethically approved by a National Research Ethics Service (NRES) ethics committee.

Please refer to the enclosed patient information leaflet for an explanation of what will be involved and why we are asking your permission to record additional clinical information. If in advance of your clinic visit you would like to participate in the study please notify us and we will endeavour to co-ordinate your appointments appropriately.

During your visit to the hospital, a doctor, physiotherapist or study co-ordinator will discuss this study with you and you will have the opportunity to ask any questions you may have.

If you are interested in this study or you would like more information, please do not hesitate to get in contact. Additional information can be found on the study website www.SMAREACHUK.org

Yours sincerely,

|  |  |  |
| --- | --- | --- |
| <insert details> | <insert details> | <insert details> |
| Prinicipal investigator | Research Physiotherapist | Study coordinator |