

Study Advert

Share Your Experience: SMA Type 1 Parent Study

Are you a parent or carer of a child with Spinal Muscular Atrophy (SMA) Type 1 who has received a disease-modifying therapy (such as Spinraza / Nursinersen, Evrysdi)/Risdiplam or Zolgensma)?

We would love to hear from you.

Researchers at Guy's and St Thomas' NHS Foundation Trust are inviting parents and carers to take part in an **online interview for up to one-hour** exploring real-life experiences of **feeding and communication** in children with SMA Type 1.

Your insights will help clinicians and researchers better understand the challenges families face, and improve care and support for others in the SMA community.

Who can take part?

- Parents, guardians, or relatives with parental responsibility for a child with SMA Type 1
- Your child has received one or more disease-modifying therapies
- You can take part in an interview in English

What's involved?

- A **single online interview** (around 1 hour, via Microsoft Teams)
- You'll be asked about your experiences of **feeding, communication, and family life**
- Your participation is **completely voluntary**, and all information will be kept confidential

Interested?

To learn more or express interest, please contact:

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