

ADELPHI VALUES

Dear Potential Participant,

We are writing to invite you to participate in an interview study that is being conducted by Adelphi Values. Adelphi Values is a health outcomes organization that works with pharmaceutical companies to assess the impact of health conditions and treatments on people's lives.

Adelphi Values are conducting a study on behalf of a pharmaceutical company who wish to further understand meaningful change on the Revised Hammersmith Scale (RHS). This assessment is used by clinical experts to assess physical abilities. We want to gain the perspective of individuals living with SMA and their caregivers, from the United Kingdom (UK) and the United States (US), to better understand how the abilities assessed by the RHS relate to daily life and the importance of changes in these abilities.

We are looking to speak with:

- Individuals aged 12-30 years old with a diagnosis of SMA, either able to walk or not able to walk
- Caregivers of individuals aged 2-30 years old who have a diagnosis of SMA, who are either able to walk or not able to walk

If you fit either of the criteria listed above, Adelphi Values would like to invite you to take part in two 60-minute telephone/video call interviews (with breaks as needed). The second interview will be scheduled approximately 3-4 months after this first interview. The interviews will be conducted by a trained Adelphi Values interviewer and will be scheduled for a date and time that is convenient for you. All information that you provide will be treated confidentially and will be anonymized by assigning you with an ID number. For your participation, you will receive £100/\$110 per interview completed. Your involvement in the study is voluntary and you will need to agree for the interview to be audio-recorded.

In order to take part in this study, the individual living with SMA must not be participating in a clinical trial with the RHS as the endpoint.

If you have any questions or would like to register your interest in participation, please contact **Sophie Wallace** via email (sophie.wallace@adelphivalues.com) or telephone (+44(0)1625578200).

When registering your interest, please be prepared to provide the following information:

For individuals living with SMA:

- Your age
- Whether you are able to walk unaided for 10 meters or more or not

For SMA Caregivers (must be 18+ years old):

- Age of the individual living with SMA you provide care for
- Whether the individual you care for is able to walk unaided for 10 meters or more or not
- Whether you would like to take part in a caregiver interview **or** if the individual you care for would like to take part in a patient interview.

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- Note: In the first instance, only you, the caregiver, or the individual you care for can take part in the study. Should this change, we would like to be able to re-contact you.

Next Steps:

Once you have registered your interest, Adelphi Values will contact you to provide further information about the study and to collect background information to see whether you are eligible to participate.

If you are eligible to participate, Adelphi Values will send you an information and consent form to read. If you wish to take part in this study, you will be asked to sign the consent form and return this to Adelphi Values before any research activities can take place. Adelphi Values will then inform you about the next steps of the study and schedule a convenient time for the interview.

Thank you for reading this letter. We hope to hear from you regarding your participation in the study.

Kind regards,

Adelphi Values