



## Focus Group Study for Caregivers of a Child with GM1 Gangliosidosis (Type 2a and 2b)

We are looking for caregivers of individuals living with GM1 gangliosidosis (type 2a [late-infantile] or type 2b [juvenile]) to take part in an online research study. This global study is being conducted by Sprout Health Solutions, a health research company, on behalf of C-Path. The study is funded by the FDA.



### How will my participation help?

By taking part in this study, you will help researchers better understand the lived experiences of individuals with GM1 gangliosidosis and their families by providing feedback on two visuals describing the disease journey of GM1 types 2a or 2b.



### What will I be asked to do?

If you choose to participate, you may be invited to take part in the following:

- A virtual focus group discussion (approximately 90 minutes) with up to 5 other caregivers of individuals with GM1 type 2a or 2b
- All study activities will be conducted remotely using Zoom. With your permission, sessions will be audio-recorded.



### Who can take part?

You may be eligible if you:

- Are 18 years of age or older
- Are the current primary caregiver of an individual with a physician-confirmed diagnosis of GM1 gangliosidosis (type 2a or 2b), or a bereaved primary caregiver of a child with GM1 gangliosidosis (type 2a or 2b) whose death occurred within the past 12 months
- Are able to speak, read, and understand English fluently
- Have access to a computer or tablet with internet



### Will I be compensated?

**Yes. Participants will receive compensation as a thank you for their time:**

- \$150 USD (or the equivalent value in local currency) for completing a 90-minute virtual focus group discussion
- \$25 USD (or the equivalent value in local currency) for submitting confirmation of diagnosis (provided even if you are not ultimately selected to participate)



### Is participation confidential?

All information shared during the study will be kept as confidential as possible and securely stored. Your name will not appear in any reports or publications resulting from this research.



### Who should I contact if I am interested or have questions?

If you would like to learn more, please contact the study team through **GM1-study@sprout-hs.com**. The research staff can answer questions and explain the next steps in the screening and consent process.