

Help Us Understand Infantile Spasms Awareness in the Down syndrome Community

Your insights could help us learn about how to improve recognition of infantile spasms in babies with Down syndrome. We invite you to take part in a survey study about Down syndrome and infantile spasms (IS). Infantile spasms are a type of seizures that are more common in babies with Down syndrome.

This brief survey is part of a research project conducted by the Boston Children's pediatric neurology team (PI: Christina Briscoe, MD EdM, IRB #P00052144). Through this survey, we are hoping to learn more about:

- Whether caregivers have received information about infantile spasms from healthcare providers
- Regions or communities that may benefit from additional education and support

Who can participate?

We are looking for adult caregivers (parents, guardians, or close relatives) of people with Down syndrome of any age, across the United States.

What does participation involve?

To participate in this study, you would complete a short online survey. It takes about 5-10 minutes to complete

What are possible benefits and risks to me to participate in this study?

This study is not funded, and you will not receive compensation for completion of the survey.

While we ask for your state and zip code to better understand regional patterns, we do not collect names or other personal identifiers, and we will not use location data to identify you or the person you care for with Down syndrome. We do not anticipate any risks to completing the survey.

Thank you for considering this important effort.

To take the survey, click here:

https://redcap.tch.harvard.edu/redcap_edc/surveys/?s=RX9MYDJL4T7WKR3X

If you have any questions about the survey or the study, please don't hesitate to reach out to daniel.loizzo@childrens.harvard.edu.

With appreciation,
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