



CASE WESTERN RESERVE
UNIVERSITY

SCHOOL OF MEDICINE

Department of Genetics & Genome Sciences
10900 Euclid Avenue
Cleveland, OH 44106-4955

Invitation to Participate

Dear sibling to a brother or sister with Prader-Willi Syndrome,

I am writing to ask for your participation in a study that will explore what it is like for siblings living in the home with a brother or sister with Prader-Willi Syndrome. There is limited research that has interviewed siblings to get an in-depth perspective of what it is/was like for them to live with a brother or sister with Prader-Willi Syndrome. Further research will allow for siblings to be better understood and provided with adequate resources and support that they may not be currently receiving. This study will be conducted for a graduate student's Master's thesis project through the Department of Genetics at Case Western Reserve University. The Institutional Review Board of the Hospitals Case Medical Center has reviewed and approved this study.

The interviews will be conducted over the phone with the primary researcher and should take approximately 30- 45 minutes. Participating in the interview is completely voluntary. Your responses to interview questions will be kept anonymous and confidential. Your responses to all of the questions will not be linked to your identity in anyway. **If you are 18 years old or older, have a brother or sister with Prader-Willi Syndrome that is at least 5 years old, and have lived in the same home as your sibling with PWS for at least one year, your participation in this study would be greatly appreciated.**

Participants of this study will receive a \$20 Amazon gift card to kindly thank you for your time and efforts. Some questions in the interview may bring up some situations that may be difficult for you. You do not need to answer any questions that make you feel uneasy. **If you do wish to participate in this study or have further questions, please contact Elana Wishnefsky at eww36@case.edu or (872) 251-1015.** Once you have expressed interest in participation, a letter of informed consent will be mailed to you as well as a letter asking when is best to reach you for the interview.

If you would like to talk to somebody other than the primary researcher about concerns regarding the study, rights of research participants, research-related injury, or any other human subjects' issues, please contact University Hospitals Case Medical Center's Chief Medical Officer at (216) 844-3695 or write to: The Chief Medical Officer, The Center for Clinical Research, University Hospitals Case Medical Center, 11100 Euclid Avenue, Lakeside 1400, Cleveland, Ohio, 44106-7061.

Thank you for your time and consideration,

Elana Wishnefsky, BSc.
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