Cincinnati Children's Research Foundation
Office for Clinical and Translational Research (OCTR)
Web Text – BIDS Phase 2 - for Cincinnati Children's Clinical Study Web Site Pages
Version 1
CCHMC IRB #2024-0186

Down Syndrome Study for Caregivers of Children and Teens 2 to 17 Years Old

Why are we doing this research?

Cincinnati Children's is conducting a research study to create a tool to better measure problematic behaviors in children with Down syndrome. We're on a mission to create the first ever tool of behavioral concerns that is specifically made for youth with Down syndrome and created with the Down syndrome community.

Who can participate?

Caregivers of children and teens 2 to 17 years old with Down syndrome may be eligible to participate.

What will happen in the study?

Caregivers will be asked to complete online surveys. The surveys will take about 20 to 50 minutes to complete, and you can return to the surveys if needed. Optional additional surveys may be offered, to complete validation behavioral surveys, or complete the initial survey again two weeks later.

What are the good things that can happen from this research?

Child will not have a direct benefit from participating in this study. However, we hope to develop a more effective screening tool for behavioral concerns for Down Syndrome to be used in clinic.

What are the bad things that can happen from this research?

Possible risks and discomforts will be discussed with those interested in learning more about the study.

Will you/your child be paid to be in this research study?

Caregivers will receive up to \$45 for time and effort.

Who should I contact for more information?

<u>DSresearch@cchmc.org</u> Cincinnati Children's Hospital Medical Center 3430 Burnet Ave. Cincinnati, OH 45229-3039

Study Doctor:

Anna Esbensen, PhD Developmental & Behavioral Pediatrics Cincinnati Children's Hospital Medical Center

Where can I find additional information? https://redcap.link/BIDS2