

ARE YOU A BLACK CAREGIVER OF A CHILD WITH ANGELMAN SYNDROME?

Help us learn about family responses to COVID-19!



What is the goal of this project?

We are looking for parents and caregivers to tell us how the COVID-19 pandemic has impacted their day-to-day life. Your participation can help us learn how to support healthy, happy families during times of stress. There's also a need to address the black community in regards to healthcare, in midst of the COVID-19 pandemic as well as the recent focus on racial inequality.

Who can join the study?

We are looking for black parents and caregivers of children under the age of 10 with Angelman syndrome to join this study. Families must be living in the United States, and participants must live at least part-time with their child. Families should also speak primarily English at home and have a smartphone with internet access. Participants also must be willing to download ExpiWell, a free application available on the Apple Store or Google Play, as they will be asked to complete surveys using this app.



Why should I join the study?

We hope that data collected from this survey will help us understand how to support families during crises, such as a global pandemic. Participants will be compensated for their time with Amazon gift cards valued between \$25-\$40 per session (sessions occur biweekly).

What does participation involve?

Participation in this study will last 7 weeks, with potential opportunities to continue in the future. Participation occurs biweekly and involves an initial survey (45 minutes), a brief weekly update survey (30 minutes), completing brief surveys on your phone, and sharing videos with us of your family.

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