

Health Outcomes, Resilience, Independence, and Executive functioning in Neurodevelopment (HORIZON) for Patients with Williams Syndrome

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WHAT ARE THE GOALS OF THIS STUDY?

To characterize physical, mental health, cognitive, social, adaptive, aging, and quality of life outcomes for adults with Williams Syndrome (a deletion at 7q11.23), stress and resilience for caregivers, and the interplay between caregiver stress and resilience with outcomes for adults with WS.

This study aims to understand and possibly find new ways to improve quality of life in adults with WS, and reduce stress in their caregivers

WHO CAN BE A PART OF THIS RESEARCH STUDY?

We are inviting pairs of individuals with Williams syndrome and their caregivers.

WHAT WILL YOU BE ASKED TO DO?

- Fill out online survey (~1-1.5 hours): both individuals with WS and their primary caregivers will be asked to do it.
- Individuals with WS will be asked to share medical records.

WHAT ARE THE BENEFITS OF TAKING PART IN THIS RESEARCH STUDY?

Results of the study may increase our understanding of good strategies for promoting better outcomes in adulthood, and improving quality of life for adults with WS and their loved ones.

WILL I BE PAID FOR TAKING PART IN THIS STUDY?

Caregivers will be paid for each visit.

I'M INTERESTED! HOW DO I PARTICIPATE?

If you have any questions or would like to join the research study, please contact: ACE-WS-research@pennmedicine.upenn.edu or call 1-888-722-34-97 ext#3 for more information!