Pediatric Narcolepsy Patient Reported Outcomes Scale

Help us improve pediatric narcolepsy care and receive $50!

Currently there is no clinical tool to assess the broad symptoms of pediatric narcolepsy and their impact on daily functioning. We are a group of researchers from different academic hospitals (Boston Children’s Hospital, Stanford University, Geisinger Medical Center, The Hospital for Sick Children, and National Jewish Health) testing a pediatric narcolepsy patient reported outcomes tool to assess pediatric narcolepsy symptoms and their effect on daily functioning and quality of life. Our goal is to develop a clinical survey that can improve the care of pediatric narcolepsy.

WHO IS ELIGIBLE?

- Children and adolescents with narcolepsy between the ages of 9-17 years
- Narcolepsy diagnosis must be verified by a signed letter from physician in order to participate
- Participants must be able to understand the purpose of the study

PARTICIPATION DETAILS

- If you sign up you will receive an email containing a link to complete HIPAA compliant online surveys about narcolepsy symptoms, quality of life, and daily function. Participation should take no more than 30 minutes.
- One week later, some participants will receive another email with a link to complete a 10-minute follow up survey
- As a thank you for completing all surveys, we will send you a $50 gift card

INTERESTED?

If you would like more about the study or are interested in participating please call the Neurology Sleep Research team at 617-919-212 or email us at NeuroSleepResearch-dl@childrens.harvard.edu