

# COMPREHENSIVE ASSESSMENT OF BODY COMPOSITION, PHYSICAL ACTIVITY, AND HEALTH MARKERS IN PEDIATRIC PRADER-WILLI SYNDROME

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# NEXUS

CHILDREN'S HOSPITAL

THE WOODLANDS

MENDING MINDS.

A Nexus Health Systems Facility

## PRIMARY AIM

To develop effective, healthcare management strategies for patients with Prader-Willi syndrome with data obtained from comprehensive fitness assessments

## BACKGROUND

Prader-Willi syndrome (PWS) is a rare genetic disorder that results from the loss of paternal genes on chromosome 15 (1). PWS is a multisystem disorder characterized by a lack of feeding ability during infancy, followed by excessive eating and the development of morbid obesity, if not controlled, in later life. Excessive eating tendencies result from hyperphagia or loss of the ability to feel full after eating (1). Other characteristics include sleep disturbance and type II diabetes mellitus (1). Behavioral abnormalities such as impulsive tendencies, skin picking, aggression, and agitation are also common. Management and treatments for individuals with PWS include strict supervision of daily food intake (2). This can also include tracking daily calorie intake, physical activity, and using physical therapy to improve muscle strength (2).

## RATIONALE

Despite the well-documented clinical manifestations of Prader-Willi Syndrome (PWS), there remains a lack of comprehensive research focusing on body composition, physical activity, and associated health markers specifically in pediatric individuals with PWS. This study aims to address the significant scientific gap by examining body composition, physical activity levels, and health markers in pediatric PWS, thereby providing valuable insights to optimize management strategies for this population.

## STUDY DESIGN

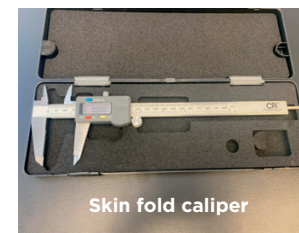
**LOCATION:** Nexus Children's Hospital is a pediatric specialty medical hospital with a dedicated in-patient program that specifically treats patients with PWS. This is a single-center, exploratory, and observational study with a target of 30 participants.

**INCLUSION/EXCLUSION CRITERIA:** Patients diagnosed with PWS and treated per Nexus' JumpStart Program, were included. Patients who exhibited aggressive behaviors were excluded due to the lack of ability to keep the Fitbit on for the duration of their stay.

**METHODOLOGY:** Upon admission, within 24 hours, baseline fitness measurements will be obtained using InBody® scanner, and digital skinfold calipers. Patients will then be given a Fitbit Inspire 3 watch which they will wear throughout their stay excluding charging times. Other assessments include grip strength and endurance testing. Weekly evaluations, assessments, and measurements are conducted by PT and staff.

**DATA ANALYSIS:** De-identified data is collected and managed using Research Electronic Data Capture. The following data are collected: date of birth, age at diagnosis, diagnosis, treatment and medications, etiology, and medical history. Data collected is analyzed using SPSS.

**ENDPOINT:** The completion of the entire JumpStart treatment program is considered the endpoint of this exploratory and observational study.



## RESULTS

The preliminary data we have on one participant, 18 days into their treatment program, shows the following metric changes from baseline (Day 1):

- 26.7% decrease in weight
- 28% decrease in body fat mass
- 34.3% decrease in BMI
- 26.1% increase in 6MWT measure
- 15.7% decrease in average heart rate

## FUTURE DIRECTIONS

Building upon the findings of this initial exploratory and observational study, we will continue to expand our data collection, analysis, and scope to encompass longitudinal assessments of pediatric PWS patients, focusing on both short-term and long-term outcomes. The knowledge gained from this study will serve as a foundation for multidisciplinary approaches to managing PWS in pediatric populations, potentially improving their overall health and quality of life. Furthermore, we will explore the development of tailored interventions for children with PWS involving the design of age-appropriate exercise regimens and dietary plans that consider the unique challenges and needs of pediatric PWS patients.

## REFERENCES

1 Cassidy, S. B., Schwartz, S., Miller, J. L., & Driscoll, D. J. (2012). Prader-willli syndrome. *Genetics in Medicine*, 14(1), 10-26. [https://www.gimjournal.org/article/S1098-3600\(21\)03284-6/fulltext](https://www.gimjournal.org/article/S1098-3600(21)03284-6/fulltext)

2 Butler, M. G., Miller, J. L., & Forster, J. L. (2019). Prader-willli syndrome - clinical genetics, diagnosis and treatment approaches: An update. *Current Pediatric Reviews*, 15(4), 207-244. <https://www.eurekaselect.com/article/99672>

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