

Purpose of Prader-Willi Syndrome (PWS) Research Studies

We study the “whole person” with PWS—their strengths as well as problems—and how these features relate to:

- Genetics (the various subtypes of PWS)
- Families (both strengths and concerns of families)
- Neurochemicals (that regulate mood and appetite)
- Aging (changes from childhood through old age)
- Successful living (with food, work, daily living, leisure)

With this information, we will develop behavioral and dietary interventions that lead to positive outcomes for persons with PWS and their families.

What Is Involved

- We invite individuals with PWS, ages 4 years and up to come for a day of study activities to the Vanderbilt Kennedy Center in Nashville, Tennessee. Parents or staff care providers should also come.
- We may ask participants to come back 3 times over 5-years, to track changes in that person’s life.
- We provide a comprehensive behavioral and developmental evaluation with a report for each participant.
- We will cover costs of transportation, lodging, and meals for the participant and a caregiver. We offer compensation for your time and effort.



**Contact: Elizabeth
Project
Coordinator**
elizabeth.roof@vanderbilt.edu
(615) 343-3330

Principle Investigator: Elisabeth Dykens, Ph.D.
Professor of Psychology, Psychiatry & Behavioral
Sciences, and Pediatrics; Co-Director, Vanderbilt
Kennedy Center for Excellence in Developmental
Disabilities



Prader-Willi Syndrome

Prader-Willi syndrome (PWS) is a genetic disorder of the 15th chromosome. It is associated with severe overeating, obesity, and behavior problems, including compulsive behaviors such as hoarding, skin picking, and intolerance to change in routines. Many people with PWS also have unusual strengths in their abilities to solve jigsaw and word search puzzles, and in their personalities.



VANDERBILT KENNEDY CENTER
FOR RESEARCH ON HUMAN DEVELOPMENT