

September 2025

Prader-Willi syndrome (PWS) is a rare genetic disorder caused by the loss of function of specific genes on chromosome 15.¹ It is characterized by a constant feeling of hunger, which can lead to chronic overeating and obesity. Other symptoms can include poor muscle tone, poor growth and physical development, delayed motor development, and sleep disorders. Best managed by a team approach, various specialists can help manage symptoms of this complex disorder, reduce the risk of developing complications and improve the quality of life for those living with the condition.²

Formed in 1975, the Prader-Willi Syndrome Association | USA (PWSA | USA) unites parents, professionals, and concerned citizens to improve the lives of those with Prader-Willi syndrome. PWSA | USA supports the PWS community through shared experiences, research, education, advocacy, and assistance. As the only national PWS support organization, it has chapters in most states to help individuals with the syndrome and their families at every step.³

TREND Community is a community-powered digital analytics company that turns the conversations of rare and chronic disease communities into actionable insights. This report explores the stories about birth — before, during, and after — that parents of children with PWS shared on PWS Connect, a discord channel started by TREND Community.

10

Authors
(parents)

481

Average story
length in words

56% (5/9)

Parents whose child
with PWS is their first

25% (2/8)

Children born
prematurely

80% (4/5)

Children diagnosed
within the first month

THE BIRTH EXPERIENCE, INCLUDING IRREGULARITIES

- When studying the pregnancy and labor/delivery experiences, some words related more specifically to the experience of PWS parents and the birth experience (e.g., “test”, “nicu”, “low”, “pws”, and “diagnosis”).
- We then looked at the irregularities experienced during pregnancy, labor, and after birth and captured them in the word cloud below. (The size corresponds to how many authors/parents experienced each.)
- For irregularities during pregnancy, both the baby being in breech position and a lack of movement were mentioned by 40% (4/10) of authors.
- Similarly, after the birth, 40% of parents mentioned that the baby had a weak cry, was overly sleepy, and had low muscle tone.



“I was living with my heart outside of my chest for the next 50 something days of him being in the NICU.”

¹U.S. Department of Health and Human Services. (n.d.-a). *Prader-willi syndrome (PWS)*. Eunice Kennedy Shriver National Institute of Child Health and Human Development.

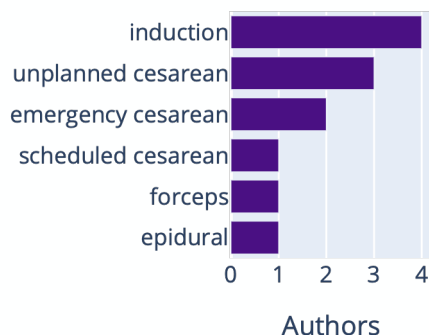
² Mayo Clinic: <https://www.mayoclinic.org/diseases-conditions/prader-willi-syndrome/symptoms-causes/svc-20355997>

³Prader-willi syndrome association USA - supporting families. USA. (2024, June 5). <https://www.pwsausa.org/>

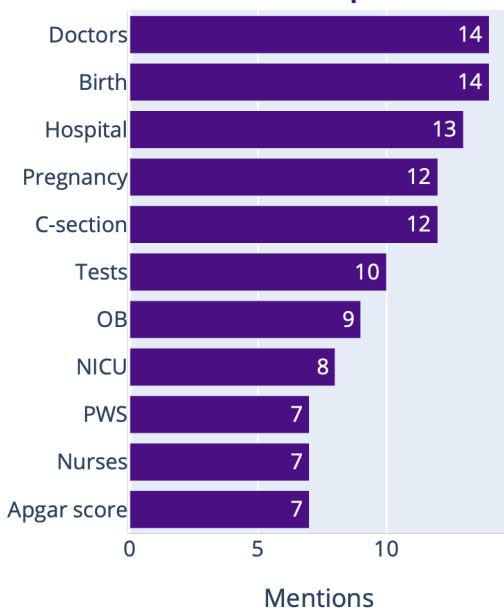
EXPERIENCES AND INTERVENTIONS

- For five of the journeys, the child was the parent's first-born. Two journeys were about a second-born, one about a fourth, and one about a fifth.
- Interventions mentioned included induction (40% mentioned) and Cesarean sections. Six birth journeys (60%) mentioned that the delivery method was a C-section, with only 1 of those being scheduled (due to placenta previa). The other five were either unplanned or emergency C-sections.
- A majority (80%) of babies spent time in the neonatal intensive care unit (NICU) and/or special care nursery (SCN), with an average duration of 17.7 days.

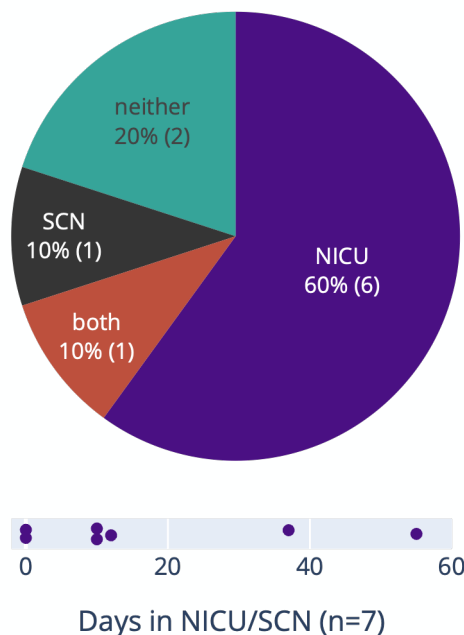
Interventions



Frequently Mentioned Clinical Concepts



Whether Baby Spent Time in NICU/SCN And How Long



COMMON BIRTH STORY CONCEPTS

- TREND's analytics engine, Krystie™, recognizes mentions of clinical concepts and links them to a medical knowledge base. The graph on the left displays the most frequently mentioned clinical concepts in birth journey stories.
- The three most common concepts — *Doctors*, *Birth*, and *Hospital* — relate to birth stories generally.
- The fact that *C-section* was mentioned so frequently, on par with *Pregnancy*, reveals how the experience of a cesarean, especially when unplanned or in an emergency, can have a lasting impact on the parent.

CONCLUSION

In many ways, the birth journeys for parents of children with PWS resembles those for all parents, with discussion of pregnancy, hospitals, doctors, nurses, and Apgar scores. However, some particular themes and common experiences did emerge. In the stories shared by 10 parents, at least half of whom were first-time parents, there were common irregularities in the pregnancy (like breech position and lack of movement) and interventions during labor (like induction and C-sections). Additionally, 80% of children spent time in the NICU or SCN and there were some common irregularities after birth (like a weak cry, sleepiness, and low muscle tone).

Childbirth and then becoming a parent of a new infant is already one of the most intense and stressful human experiences, especially for first-time parents. The added stress of an unknown health issue with the baby, possibly keeping them in the NICU, on top of an unplanned or emergency C-section, could easily become overwhelming. The frequency of these experiences in parents of children with PWS highlights the need for specific support for these parents in the early days after birth.