

What's TRENDing: Community Themes and PWS

October 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, using our proprietary analytics engine, Krystie™. This report explores the themes discussed most over the course of the past year in social media spaces dedicated to PWS.

DATA SOURCES

PWS Connect (Discord), "pooled" reddit community

DOCUMENTS:	AUTHORS:	TIME RANGE:
1,514	538	Oct 2024–Oct 2025

This dataset is based on the following: 49% of documents (posts or comments) from Discord conversations and 51% from reddit. The "pooled" reddit community consisted of documents from across health-related subreddits that mentioned PWS, as well as closely related documents. The distribution of subreddits whose documents form this pooled community is shown in Figure 1, shedding light on where PWS is discussed.

A portion of the Discord conversations were guided by topic-specific prompts exploring specific aspects of the PWS journey, which could influence topic prevalence.

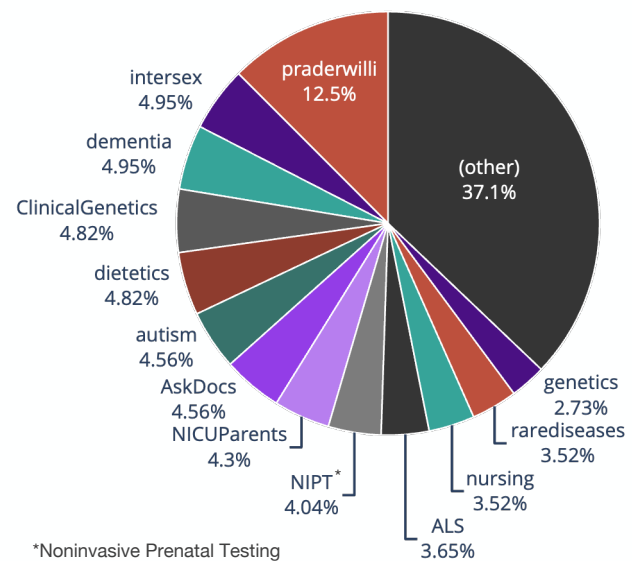


Figure 1: Distribution of source subreddit for documents in the reddit pooled community.

FREQUENTLY MENTIONED CONCEPTS

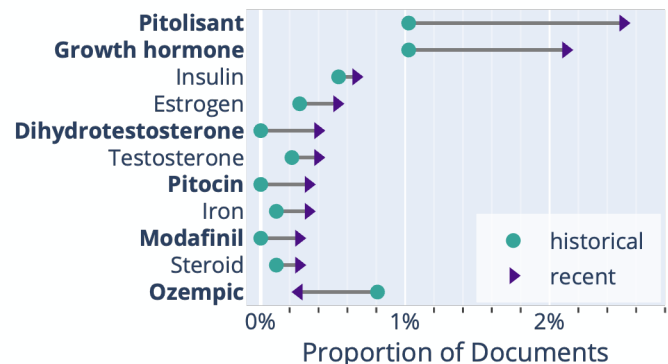
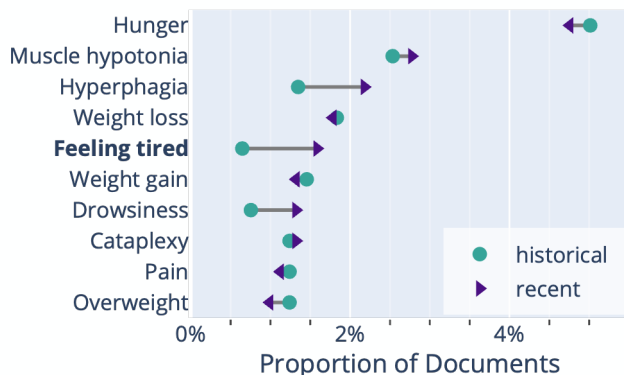


Figure 2: Frequently mentioned symptoms (left) and medications (right) in the past year, as identified by Krystie™. To evaluate shifts in themes of discussion over time, the frequency of each concept in the previous three years is also shown (historical). **Statistically significant differences are bolded.**

- Hunger is by far the most discussed symptom, nearly double any other.
- Hyperphagia, tiredness, and drowsiness have seen the largest increases in discussion.
- Pitolisant and growth hormone dominate medication-related discussions, and have seen the largest increases over time.
- Almost all discussions about medications have increased, except for Ozempic, which has seen a drop.

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/>

TOPIC ANALYSIS

Topic analysis involves clustering paragraphs that are semantically similar. The most frequent topics over the past year are shown in Figure 3. The largest topics were **Sleep & Sleep Disorders**, **Prader-Willi Syndrome**, and **Neonatal Feeding Difficulties**.

- Topics relating to specific disorders were the most common, as depicted by the red bars.
- Multiple topics relating to food, eating, and hunger emerged in the top topics.

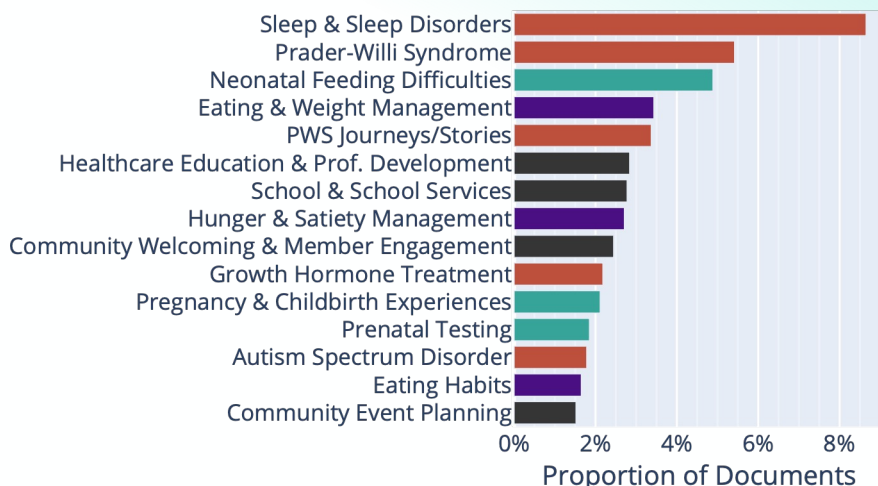


Figure 3: Most common topics in the past year. Topics are colored by overarching theme.

QUESTION FREQUENCY

For each topic, the proportion of paragraphs that ask a question was calculated. The top 10 are shown in Figure 4.

- Questions were asked at the highest rates in relation to **Hunger & Satiety Management** and **Eating & Weight Management**.
- There were also high question rates in relation to disorders, especially sleep disorders.

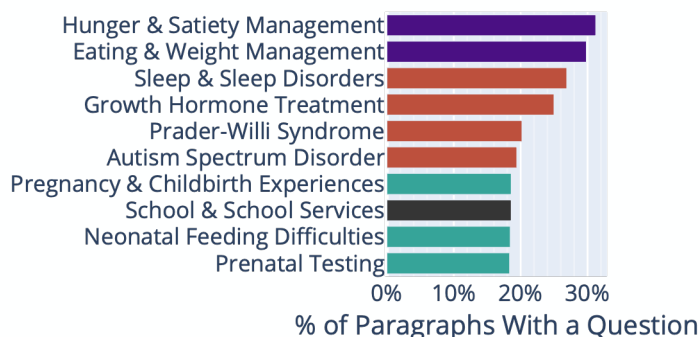


Figure 4: Common topics with the highest question rates.

EMOTION MENTIONS

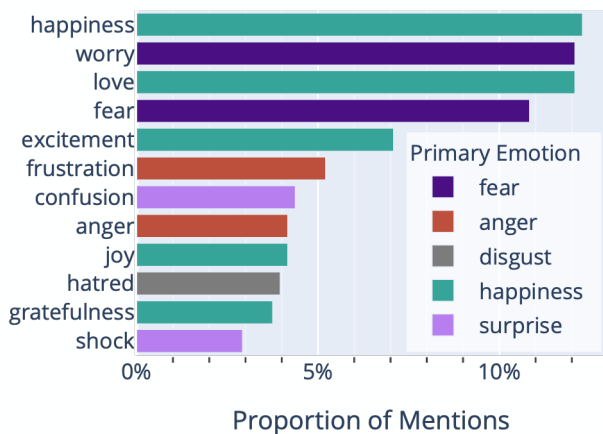


Figure 5: Most common emotions mentioned.

Mentions of emotions across posts and comments in the past year were extracted and categorized into six primary emotions (fear, happiness, anger, sadness, disgust, and surprise).

- The most frequent emotions were **happiness, worry, love, and fear**. Broadly, emotions in the primary categories of happiness and fear were the most common.
- Words and phrases associated with *happiness* mentions were 'proud', 'kids', 'help', 'thanks [for] sharing', 'support', and 'excited [to] hear'.
- Words and phrases associated with *fear* mentions were 'baby', 'normal', 'eat', 'doctor', and 'putting food'.

"Her doctor was not scared to let us feed her, even though most feeding therapists were. We followed the recommendation of the doctor." (paraphrased)

THOUGHT STARTERS

Across the past year, a variety of topics and themes emerged in the social media conversations relating to PWS. One common theme was sleep and sleep disorders, appearing as the top topic of conversation, and with pitolisant, a medication approved to treat narcolepsy and in clinical trials for PWS, as the top medication mentioned by far. Another primary focus of these conversations seemed to be hunger and eating, with hunger being the most frequently mentioned symptom, hyperphagia appearing in the top three symptoms, and multiple of the most common topics relating to eating/hunger. Based on the language associated with fear emotions, there seems to be some anxiety about eating and food. With topics relating to sleep and eating having such a high rate of questions, the community may benefit from more educational material and support services regarding sleep disorders and hyperphagia. The frequency of positive emotion mentions, as well as the topics of *Community Welcoming & Member Engagement* and *Community Event Planning*, reveal the supportive nature of the PWS community.