

LAUNCH REPORT: PRADER-WILLI SYNDROME

July 8, 2024

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, leading to chronic overeating and obesity. Other symptoms include low muscle tone, short stature, cognitive disabilities, and behavioral problems. PWS can also result in developmental delays and a range of endocrine issues. Early diagnosis and management are crucial for improving quality of life and reducing complications.¹

TREND Community is a community-powered digital analytics company that turns the conversations of rare and chronic disease communities into actionable insights. With the help of our community stakeholders, our analytics engine, Krystie™, turns real-world discussions into insights that can spark broader understanding and therapeutic progress.

This report showcases the most recent themes discussed over the past two years on social media communities dedicated to PWS. The goal is to amplify the voices of those living with this condition to shed light on their experiences to drive action and improved outcomes. We are very grateful to our partners, Harmony Biosciences, Soleno Therapeutics, and Acadia Pharmaceuticals, for their support. We have been partnering with Prader-Willi Syndrome Association | USA (PWSA | USA) and appreciate their time and efforts as well.

DATA SOURCES

GROUPS: PWS Lovebugs, PWSA | USA Birth to Three, PWSA | USA Three to Five, PWSA | USA Kindergarten to Sixth Grade, PWSA | USA Parents of Teens and Older

POSTS ANALYZED:

4,544

COMMENTS ANALYZED:

45,229

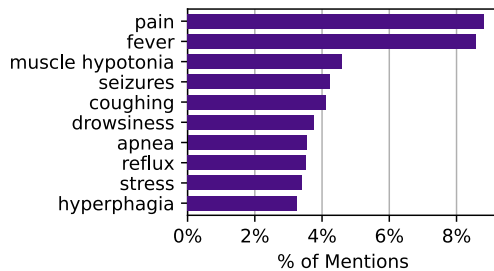
AVERAGE ENGAGEMENT:

9.9 comments per post

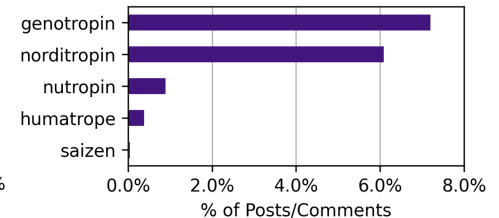
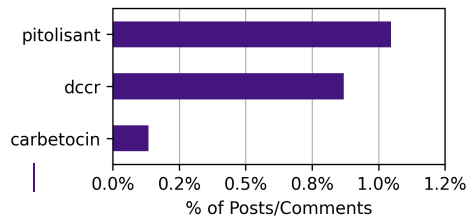
TIME RANGE:

April 2022 – March 2024

SYMPTOMS

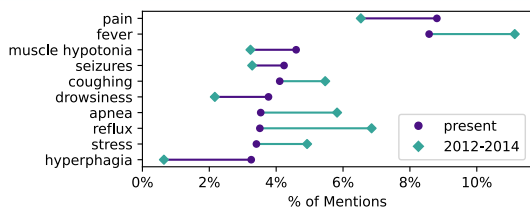


MEDICATIONS

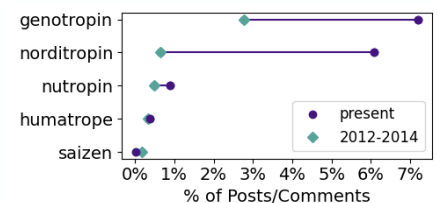
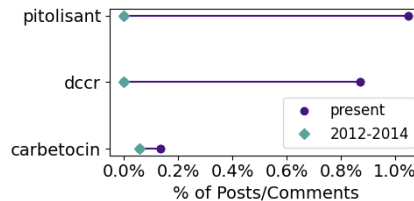


OVERALL: Krystie™ recognizes and extracts clinical terminology from a data source. Presented above are the top Symptoms and PWS-specific & growth hormone interventions mentioned over the last two years. For symptoms, the most frequent mentions were *pain* and *fever* (8.8% and 8.5% of all symptom mentions, respectively). Medications were evaluated in two groups: PWS-specific medications (left) and growth hormone (right). The most mentioned, across post/comments, in PWS-specific was *pitolisant* (1.0% of all posts/comments mentioning a medication), and *genotropin* (7.2%) amongst growth hormone medications.)

SYMPTOMS



MEDICATIONS



CHANGES OVER TIME: To evaluate shifts in terminology over time, these Symptoms and Medications were compared with their mentions from 2012 to 2014. For example, in Symptoms, *pain*, *muscle hypotonia*, *seizures*, *drowsiness*, and *hyperphagia* were mentioned more recently, whereas *fever*, *coughing*, *apnea*, *reflux*, and *stress* were mentioned less. For PWS-specific medications, all three medications experienced an increased relative frequency. Among growth hormone interventions, *genotropin* and *norditropin* experienced the greatest relative increase, while *saizen* saw a slight decline in relative mentions across posts/comments.

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

²Prader-Willi Syndrome Association USA - supporting families. USA. (2024, June 5). <https://www.pwsausa.org/>

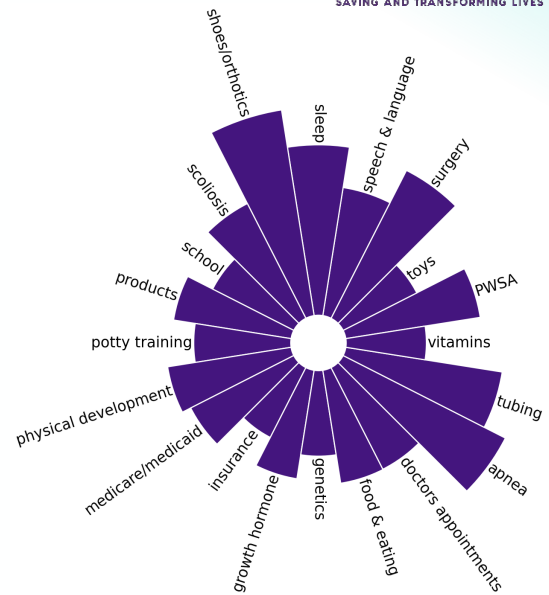
FREQUENT TOPIC ANALYSIS

LARGEST TOPICS: *shoes/orthotics* (602 posts/comments), *apnea* (514 posts/comments)

MIDSIZE TOPICS: *physical development* (324 posts/comments), *products* (304 posts/comments)

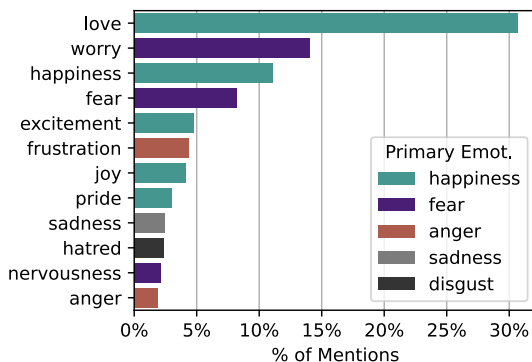
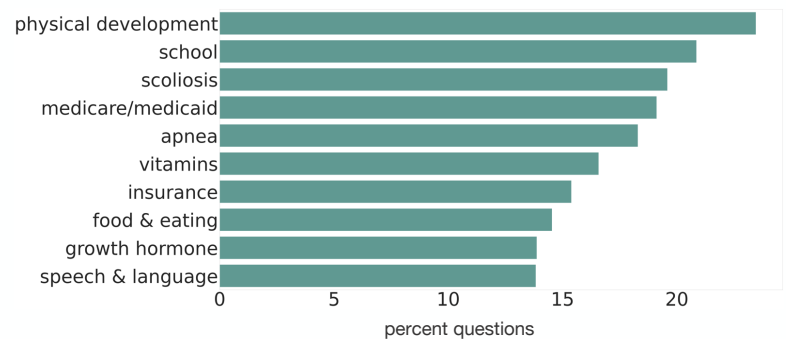
SMALLEST TOPICS: *vitamins* (175 posts/comments), *insurance* (169 posts/comments)

- Topic analysis involves clustering language that has similar meaning and occurs in similar contexts.
- The most frequent topics over the past two years are presented to the right. The larger the bar, the more posts/comments in the topic.



QUESTIONS ASKED

- For each topic, the proportion of posts/comments asking questions was calculated. The top 10 are presented to the right.
- The largest was *physical development*, with 23.5% of posts/comments including questions. *School* was second, with 20.1% of posts/comments including questions while *scoliosis* was third with 19.6%.



EMOTIONS EXPRESSED

- Six primary emotions (*fear, happiness, anger, sadness, disgust, and surprise*) were evaluated across posts and comments.
- When split into secondary emotions to better characterize the emotional experiences of community members, the most frequent emotions expressed were *love* and *worry*.
- Words and phrases most associated with *love* posts/comments included *group, support, thanks* and *grateful* while *worry* included *kids, future, and afraid*.

CONCLUSION

A variety of topics, symptoms, and medications were discussed in conversations over the last two years across PWS communities. A high priority of caregivers in the community appears to be understanding the role of PWS in their children's futures. A common theme of conversation was milestones and development (e.g., topics: speech & language, physical development). These conversations likely have some association with *worry*, where *future* and *kids* were associated terms and *physical growth* had more questions than any other topic. Another primary focus for the community seems to be management. Many themes in discussions included an array of management techniques (*growth hormone, vitamins, shoes/orthotics, etc.*). The positive emotions described in the community (e.g., *love, support*) demonstrate the supportive nature of the groups regarding their interactions with one another. The community may benefit from enhanced support services and educational programs, particularly those focusing on navigating critical stages of early life (e.g., *school, developmental milestones, etc.*). These initiatives would help ensure that community members can effectively manage the condition.

 **We are excited to announce the launch of PWS CONNECT...a community and research initiative focused on making a difference in the lives of those living with PWS and their families.**

Launched in May 2024, this online community is active with almost 50 members and growing! Future reports will summarize the group's conversations.