SLEEP IN PRADER-WILLI SYNDROME

September 27, 2022
Prader-Willi (PRAH-dur VIL-e) syndrome is a rare genetic disorder that results in a number of physical, mental and behavioral problems. A key feature of Prader-Willi syndrome is a constant sense of hunger that usually begins at about 2 years of age.

People with Prader-Willi syndrome want to eat constantly because they never feel full (hyperphagia), and they usually have trouble controlling their weight. Many complications of Prader-Willi syndrome are due to obesity.

“Phase 3 is characterized by hyperphagia, typically accompanied by food-seeking and lack of satiety (median age of onset: 8 years; quartiles 5-13 years).”  
- Miller et al., 2011  
https://doi.org/10.1002/ajmg.a.33951
“Science is a bit like the joke about the drunk who is looking under a lamppost for a key that he has lost on the other side of the street, because that’s where the light is. It has no other choice.” – Noam Chomsky
One night a policeman found a man searching for his keys under a streetlight. He joined to help, only to realize after hours of searching, that the man had lost his keys in the park.

“Then why are you searching here?” asked the policeman.”

“Because this is where the light is,” replied the man.
TURNING ON THE LIGHTS
A PARADIGM SHIFT

Ethical Framework
• Trusted relationships built
• Social data sources identified
• Consensus reached/Data Access Agreement signed

Conversation Analysis
• TREND engine analyzes anonymized co-social data
• Conversations categorized using TREND’s lexical knowledge-base

Evidence Accelerator
• Community stakeholders convene
• 6 to 12 months
• 2-4 workshops
• Define needs and priorities
• Data Exploration

Real-World Evidence
• Publish in peer-reviewed journals
• Present at conferences and scientific meetings
• Data used for medical product development
TREND Community harnesses machine learning and natural language processing techniques to capture the perspective and experiences of people living with rare and chronic conditions. In January 2022, we launched the Gout Real-World Evidence Accelerator to bring together sponsors, thought leaders, and online support groups to turn the community’s conversations on social media into actionable insights.

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"Living with rare diseases can feel dark and lonely. It’s an honor to join TREND Community’s efforts bringing light and acceptance."

— Dr. Christopher Parker
Coast Support Group of America

**REAL-WORLD EVIDENCE**

16,904 POSTS SHARED
210,544 COMMENTS ELICITED

**DATE RANGE**

June 2004 - November 2018

Facebook Group: The Gout Support Group of America (12.4k members)
Subreddit: /r/Gout (12.7k members)

**PATIENT MENTAL HEALTH OUTCOMES IN THE MANAGEMENT OF GOUT**

**MANAGEMENT STRATEGIES**

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**FOCUS SELECTED**

**REVIEWED DATA**

**REAL-WORLD EVIDENCE**

**Digital Strategy & Innovation for Medical Affairs Summit**

Expanded Patient Advocacy Through Peer-to-Peer Online Support Group Partnerships
Maria Picone, TREND & Jen Cooper, AFFPA
Leveraging Social Media to Capture Real-World Patient Insights
Maria Picone, TREND, Dr. Bob Wisoner, TREND.
Gary Ho, ISGA, Dr. Christopher Parker, ISGA

Abstract Submitted to ACR Convergence 2022
RWE From Social Media Provides Insights Into Patient MH Outcomes in the Management of Gout
TREND, GHEF, Horizon Therapeutics
DATA SOURCES & METHODS
METHODS: HARNESSING THE POWER OF AI

- Descriptive statistics
- Trends
- Topic Model

Information Extraction
- Identify Entities of interest
- Comparison Analysis

Network
- Co-occurrence network
- Sleep sub-networks
DATA REVIEW: TRENDS AND TOPICS
<table>
<thead>
<tr>
<th>TOP 10 ALL TOPICS DISCUSSED</th>
</tr>
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<tbody>
<tr>
<td>Milk substitute</td>
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</tbody>
</table>

- tube feeding
- sleep apnea
- breast feeding
- diet
- testicle surgery and HCG
- speech therapy
- genotropin
- acid reflux and treatment
- insurance issues
- mct oils
- eye surgery and vision therapy
- Coq10
SLEEP NETWORK
SYMPTOMS DISCUSSED
SLEEP CONDITIONS DISCUSSED

- Sleep apnea: 1589
- Sleepiness/hypersomnia: 374
- Narcolepsy: 259
- Cataplexy: 197
- Snoring: 90
- Sleep problem: 85
- Night terror: 70
- Nightmare: 22
- REM: 20
- Sleep disturbance: 12
- Insomnia: 9
- Sleep deprivation: 7
MENTAL HEALTH TOPICS DISCUSSED

- anxiety: 886
- stress: 733
- autism: 453
- behavior problem: 231
- tear: 155
- fear: 154
- frustration: 149
- tantrum: 137
- worry: 122
- joy: 115
- adhd: 113
- guilt: 87
- ocd: 82
- happiness: 81
- meltdown: 78
- excitement: 72
- depression: 69
- anger problem: 69
- ptsd: 64
- sadness: 60
- mental problem: 56
- exhaustion: 49
- panic: 46
- psychosis: 32
- ed: 31
PROVIDER TYPES DISCUSSED
LOCATIONS DISCUSSED

- Hospital: 2780
- Home: 2395
- NICU: 2254
- School: 1510
- Office: 1010
- ER: 540
- Work: 496
- Daycare: 415
- PWS Clinic: 378
- Kitchen: 350
- Clinic: 330
- Children's Hospital: 313
- Store: 268
- Hotel: 251
- Pharmacy: 238
- Pool: 190
- Bathroom: 162
- Preschool: 160
- Restaurant: 152
- Park: 145
- College: 133
- Kindergarten: 111
- Lab: 110
- Grocery Store: 107
- High School: 83
SUBSTANCES DISCUSSED

- Growth hormone: 8072
- CoQ10: 1087
- Carnitine: 820
- Vitamin B12: 754
- Acetaminophen: 484
- Oxytocin: 480
- Pitolisant: 363
- Modafinil: 328
- Hormone: 319
- Cannabis: 297
- Miralax: 282
- Vitamin D: 224
- Opioid: 218
- Cortisol: 208
- Steroid: 198
- Zantac: 146
- SSRI: 123
- Magnesium: 118
- Cholesterol: 116
- Prevacid: 115
- Testosterone: 114
- Alcohol: 100
- Creatine: 87
- Benadryl: 80
- Melatonin: 73

(count)
THANK YOU!

Matthew Horsnell, Community Director
mhorsnell@trend.community