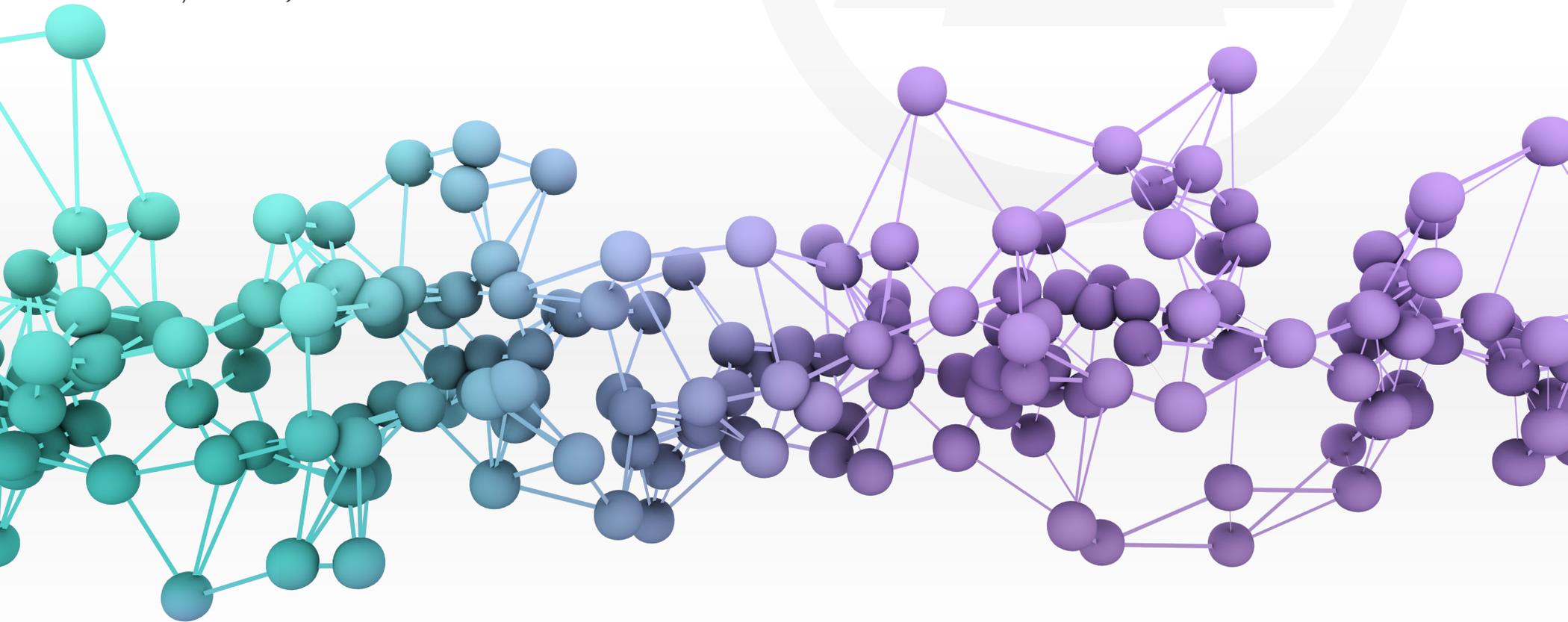


PANS, PANDAS, AE

Community Voice Report

VOLUME 1, ISSUE 1 - JANUARY 2020



DISEASE CATEGORY



NEUROLOGICAL



TREND Community[™]
Turning Anecdotes Into Evidence[™]

Capturing Patient Experience Data

The Problem

Capturing patient experience data and applying it to the drug development and regulatory process is often lengthy, laborious, and expensive. This is further complicated for rare diseases where affected patient populations are typically small, heterogeneous, and widely dispersed.

The Solution

TREND analyzes years of real-world experience data shared within social networks to gain valuable insights into the community's perspective on living with rare disease. These data are de-identified and summarized into a Community Voice Report, which can then lead to Data Explorations and Health Initiatives.

Community Voice Report

The Community Voice Report follows the FDA's patient input Guidelines for Patient-Focused Drug Development meetings and aims to quantify disease burden, disease management strategies, and possible unmet needs.

Data Explorations

TREND Data Explorations further analyze existing social data to uncover deeper insights. Unlike the breadth of a Community Voice Report, Data Explorations examine a single topic and reanalyze the surrounding posts, comments, and feedback to better understand the community's interest.

Health Initiatives

TREND Community Health Initiatives bring community members together on the TREND Community™ platform to collectively track specific data and explore potential solutions to address an identified unmet need.

“The TREND report was invaluable in helping us define the questions and multiple-choice answers that should be included in our Externally Led Patient Focused Drug Development Meeting last June.”

—Kyle Bryant, FARA, rideATAXIA Founder/

Program Director



How It Works

All of our projects start with community engagement. Due to the unique difficulties of rare and chronic disease, many groups have created social networks online to support and validate each other. In these groups, community members are able to tell stories, promote advocacy, and share advice for managing symptoms, navigating the health care system, and living with a rare or chronic disease. We connect with individuals and leaders in these communities to learn about their illnesses, understand the current state of medical knowledge, and determine how our partnership can best address their unmet needs.

Once we have established a relationship with the community and gained consent, we download the deidentified data from these social media streams. These data are run through our analytics engine, named Krystie after the dear daughter of one of our community members. Krystie quickly analyzes vast amounts of data from years' worth of community discussion. Analysts manually code a sample of the data to validate the algorithms and train the engine to identify deeper insights (for example, to detect whether the speaker is a patient or a caregiver). This analysis culminates in a custom Community Voice Report.

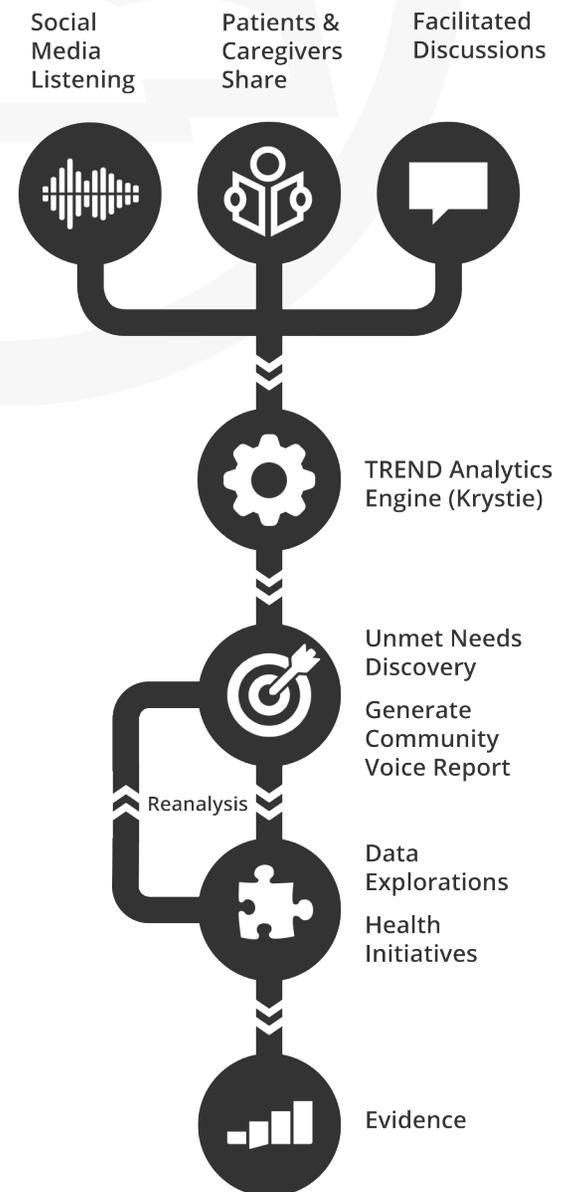
These Community Voice Reports are shared with the community free of charge, and our industry stakeholders have the opportunity to license the data for projects that address unmet needs and improve quality of life. These insights may be used to design Data Explorations or Health Initiatives.

Industry Stakeholders use TREND data to:

- Establish disease natural history
- Identify unmet therapeutic needs
- Understand quality of life issues
- Design better clinical trials
- Build a case for patient-centered regulatory approvals

Community Stakeholders use TREND data to:

- Inform medical and support teams
- Educate family members
- Catalyze research
- Spread awareness and advocacy



Analysis Background

Pediatric acute-onset neuropsychiatric syndrome (PANS), pediatric autoimmune neuropsychiatric disorders associated with streptococcus infections (PANDAS), and autoimmune encephalitis (AE) are three diseases that often manifest with neuropsychiatric symptoms. Each of the three diseases has distinguishing characteristics.¹²³

TREND analyzed PANS/PANDAS UK Support Group, which interacts on Facebook.

Participants are primarily caregivers for children suffering from PANS or PANDAS in the UK. At the time of analysis, there were 2400 members in the group.⁴

"There are not words to explain how I felt when my children were at their worst with their condition. I cried every day for over a year. Every single day. I felt panic that I could see my children deteriorating in such a way, but doctors were sending us home...I felt desperation. I could not enjoy life. I could see my children's health deteriorating and I could do nothing to stop it."

— Community Member



2400
PEOPLE
PARTICIPATING

12,860
POSTS
SHARED

134,695
COMMENTS
ELICITED

FEB 2018 - NOV 2019
DATE RANGE



Disease Burden

The most frequently discussed physical symptoms were *tics* (4762 all-time mentions/3724 mentions in the last year), *pain* (2087/1585), and *fever* (1464/936).

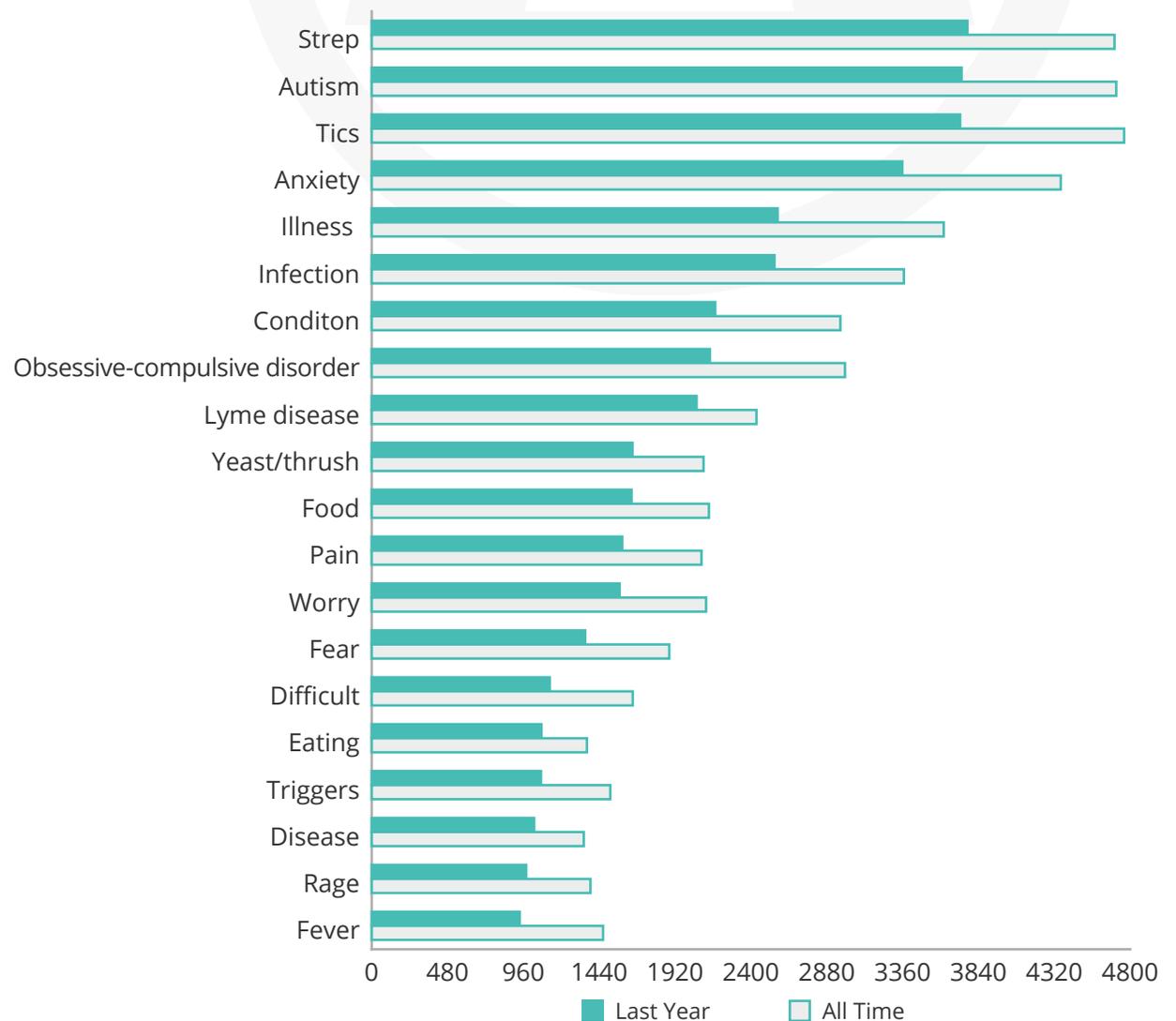
The neuropsychiatric symptoms most mentioned were *autism* (4712/3733), *anxiety* (4361/3358), *obsessive-compulsive disorder* (2995/2140), *worry* (2116/1569), *fear* (1883/1351), and *rage* (1384/977). *Food* (2134/1644) and *eating* (1362/1074) also came up in conversation, as eating issues can be associated with the neuropsychiatric problems of these diseases.

PANS, PANDAS, and AE are often triggered by a reaction to another disease or infection. As a result, the term *triggers* (1510/1071) was often mentioned. *Strep* (4701/3770), *illness* (3620/2569), *infection* (3368/2549), *Lyme disease* (2435/2056), and *yeast/thrush* (2100/1650) were all frequent topics of conversation.

The disease names most mentioned were:

- PANDAS 18066
- PANS 16487
- PANS/PANDAS 3814
- Autoimmune 914
- Encephalitis 1034
- Autoimmune encephalitis 387

DISEASE BURDEN: LAST YEAR VS. ALL TIME



This figure shows the number of mentions of concepts related to disease burden for a 12 months' worth of conversations and all of the conversations.



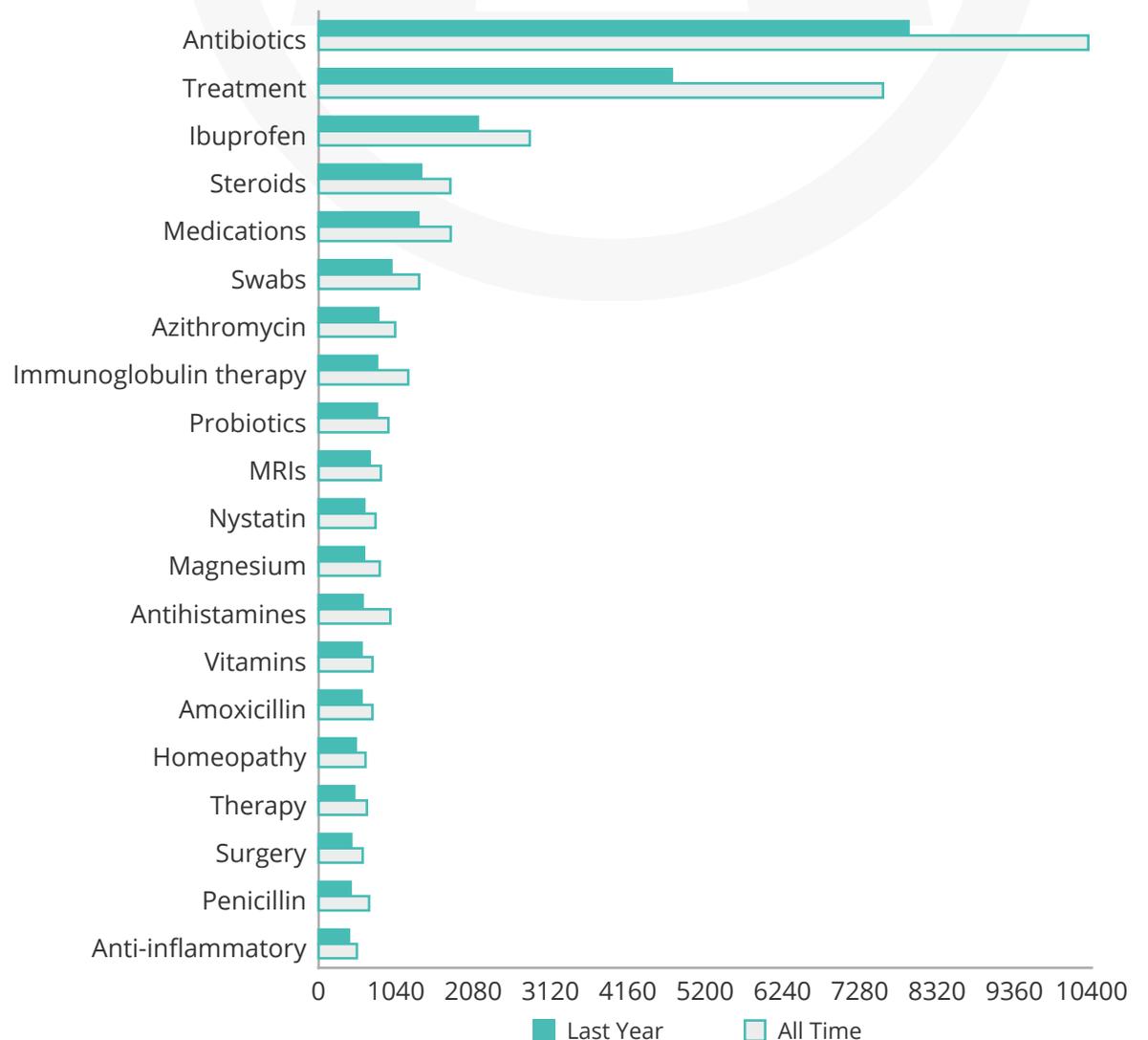
Disease Management

Treatments for these diseases are mostly medicinal. *Antibiotics* (10354 all-time mentions/7935 mentions in the last year) were discussed the most. *Medications* (1771/1341) were also talked about. Medications were discussed both generally by type and specifically by name.

Medications by type:	Medications by name:
Antibiotics 10354/7935	Ibuprofen 2840/2141
Steroids 1771/1379	Azithromycin 1029/801
Antihistamines 964/592	Nystatin 765/614
Probiotics 938/784	Amoxicillin 723/577
Anti-inflammatory 514/408	Penicillin 678/430
Antifungal 406/191	Melatonin 417/322
SSRIs 233/163	Sertraline 430/310

Other treatments include *immunoglobulin therapy* (1205/786). People also discussed *swabs* (1351/978) and *MRIs* (837/686), which tend to be diagnostic tools. *Vitamins* (724/578), particularly *magnesium* (822/611), along with *homeopathy* (630/500) were also discussed as ways to manage the disease.

DISEASE MANAGEMENT: LAST YEAR VS. ALL TIME



This figure shows the number of mentions of concepts related to disease management for 12 months' worth of conversations and all of the conversations.

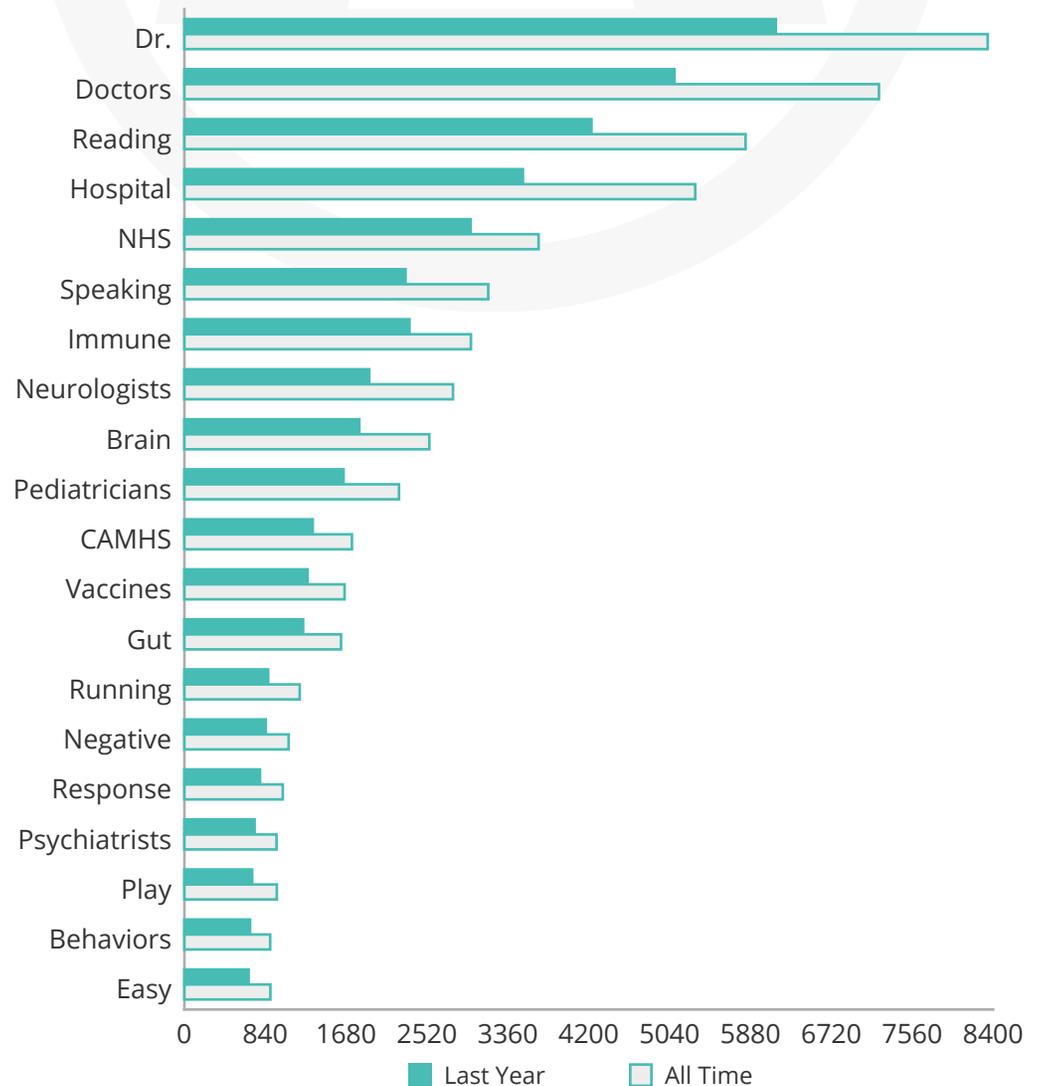


Significant Terms

Many terms discussed in the group are not easily identifiable as a term about the burden of the disease or the management of the disease. Further analysis would be required to understand the nuances within the conversation.

Doctors (7214 all-time mentions/5090 mentions in the last year) and types of doctors were frequently discussed. We separated the term doctors from *Dr.* (8344/6143) because we found the abbreviation to indicate references to particular doctors. People recommended doctors with expert knowledge of PANS/PANDAS to each other specifically. *Neurologists* (2790/1920), *pediatricians* (2229/1653), *psychiatrists* (957/729), and *immunologists* (777/602) were mentioned as experts for dealing with the disease. Because the group is based in the UK, the *National Health Service (NHS)* (3679/2973) was also a major point of discussion, as was *Child and Adolescent Mental Health Services (CAMHS)* (1740/1333). *Gut* (1627/1233) was mentioned frequently.

SIGNIFICANT TERMS: LAST YEAR VS. ALL TIME



This figure shows the number of mentions of concepts that are significant but not clearly related to burden or management for 12 months' worth of conversations and all of the conversations.



Discovering Unmet Needs

One of the biggest frustrations among participants is that symptoms of these diseases are often mistaken as psychiatric rather than bacterial or viral. When doctors see signs of OCD, they don't necessarily know to check for an underlying problem. Parents expressed difficulty getting the proper tests in a timely fashion or getting the right medications to fix the underlying problem.

Further, because the disease is triggered by a wide variety of potential harms, parents often feel they need to be hypervigilant. As we discussed in Disease Burden, the triggers for different people vary. Vaccines may be a trigger for some, and that is discussed. It would be helpful to have a better understanding of how certain diseases and bacteria can trigger PANS, PANDA, or AE.

Prevention research would be beneficial, especially because—for some people—each iteration of a reaction is worse than the one before.

“When my children were at their worst with PANS/PANDAS the Facebook group was the only time that I could talk about what we were going through.”

— Community Member



Data Exploration and Health Initiatives

This report is a starting point for research into how the community lives and deals with PANS, PANDAS, and AE. Areas in need of further research include a better understanding of the symptoms and burdens of the disease, a better understanding of AE, more information on the bacteria, viruses, allergens, fungi, and other triggers of the disease, along with differences between the three diseases.

People in the groups often mentioned mental health services being offered for the symptoms of the disease rather than treatments that focus on the underlying cause. This offers two interesting areas for research. The first is when doctors should try to look for underlying causes to psychiatric symptoms. Using the stories of diagnosis in these conversations, along with insight from expert doctors, might

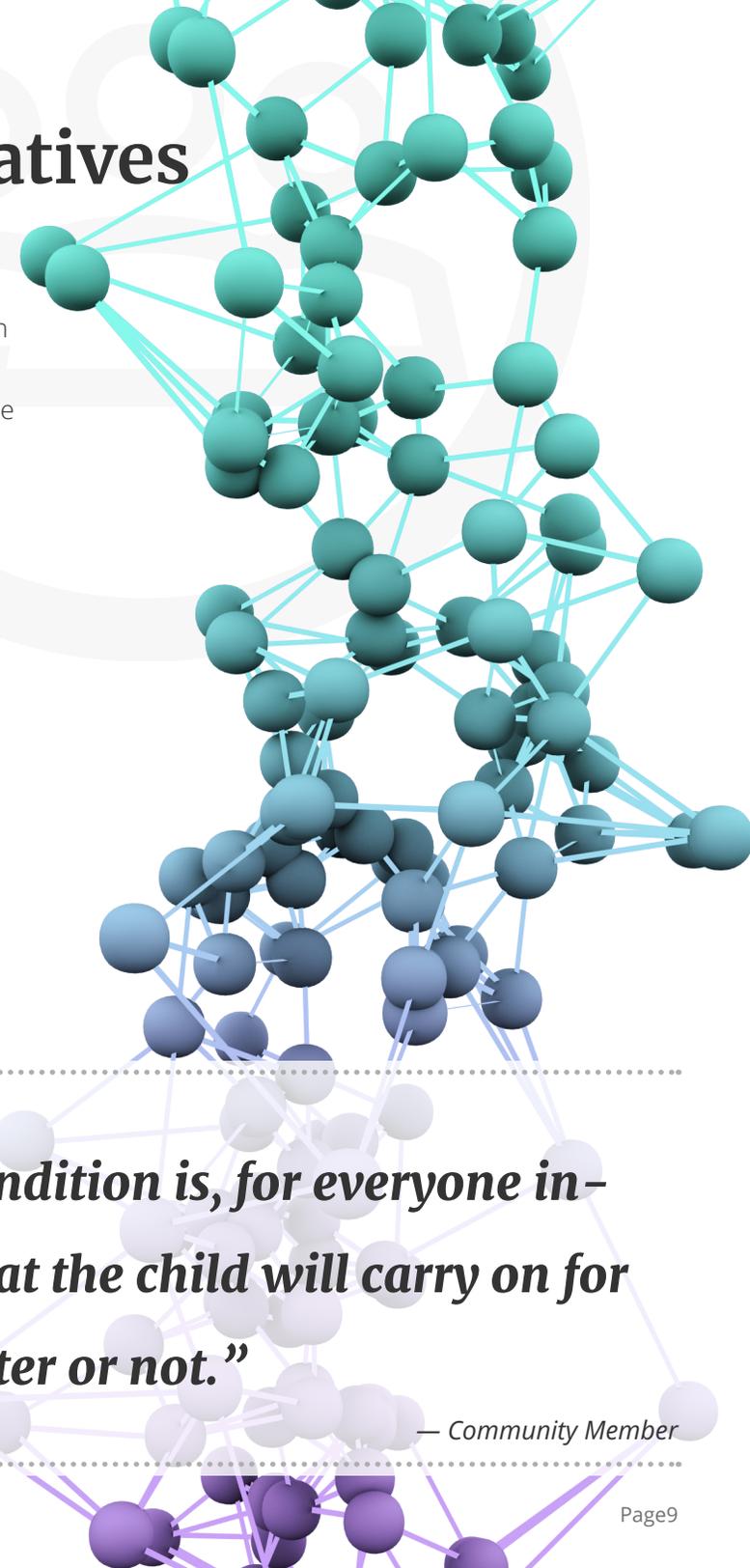
help determine easier ways for pediatricians to identify PANS, PANDAS, or AE as the reason for psychiatric symptoms. The second would be identifying which psychiatric therapies were helpful for PANS, PANDAS, or AE patients and which were irrelevant.

More could be known about what triggers the diseases. Looking further into this conversational data might give a better sense of the different triggers, the timeline of the triggering, and some potential methods for preventing or treating them.

Finally, the group's focus seems to have been more on PANS and PANDAS rather than AE, so it may be worth finding other groups and analyzing those conversations to get a better picture of the impact of each disease.

“I wish specialists understood how horrible this condition is, for everyone involved, but especially the child. This is a trauma that the child will carry on for the rest of their lives regardless of them getting better or not.”

— Community Member

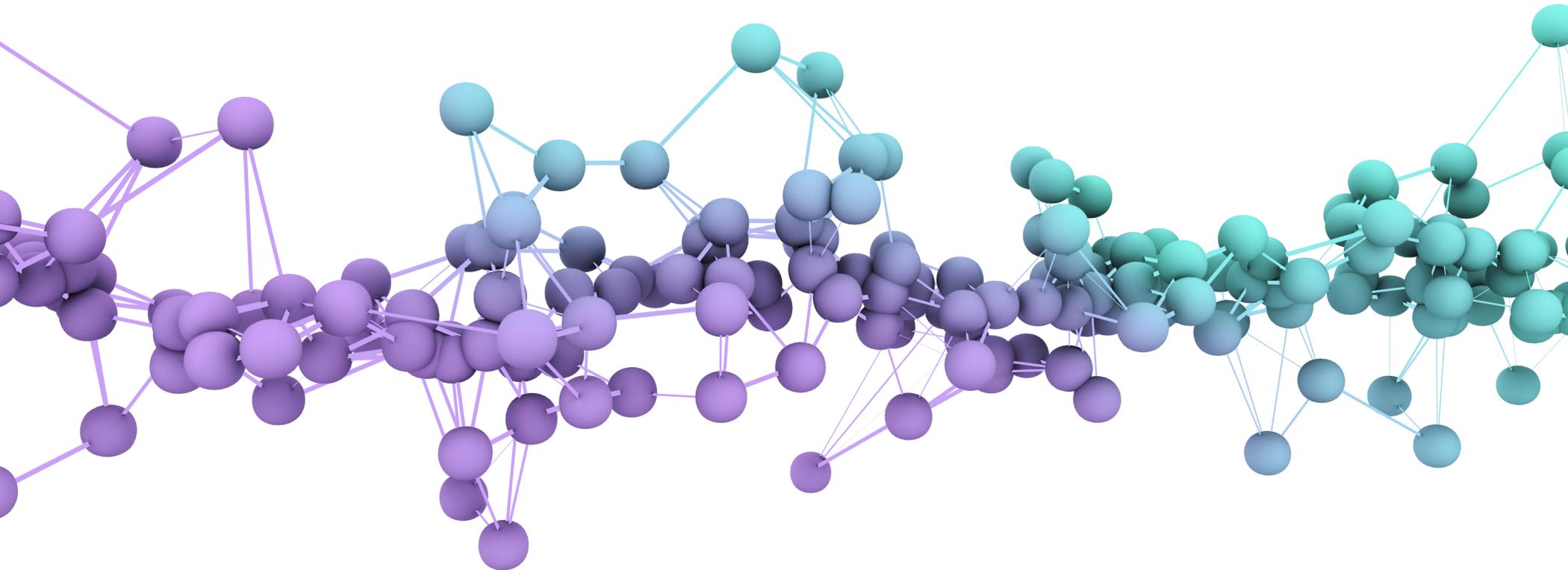


Appendix

Endnotes

- 1 <https://rarediseases.info.nih.gov/diseases/13087/pediatric-acute-onset-neuropsychiatric-syndrome>
- 2 <https://rarediseases.info.nih.gov/diseases/7312/pediatric-autoimmune-neuropsychiatric-disorders-associated-with-streptococcus-infections>
- 3 <https://rarediseases.info.nih.gov/diseases/11979/autoimmune-encephalitis>
- 4 See Social Channels Analyzed Table*

*Social Channels Analyzed	People	Posts	Comments	Gender	Age	Top 5 Countries
Facebook Group: <i>PANS/PANDAS UK Support Facebook group</i>	2400	12860	134695	Female: 89.4% Male: 10.4% Other: 0.2%	46.10% 35-44 Years	UK,Ireland,USA,Australia, United Arab Emirates



About TREND Community

Founders

TREND Community™ was founded by the parents of a child with Prader-Willi Syndrome who understand the needs of the rare and chronic disease community.

Our mission is to improve the quality of life for everyone living with rare and chronic disease.

Security

TREND secures all social data with state-of-the-art, private cloud servers. Our security practices comply with current HIPAA, FDA, and GDPR guidelines.

Disclaimer

The researchers who prepared this report are not doctors, are not providing medical advice, and are only reporting what was said in the online conversations.

IRB Exemption Status

Western Institutional Review Board determined that this study is exempt under 45 CFR § 46.104(d)(4), because the aim of the research is to collect de-identified information from social media posts to better understand disease

burden, disease management strategies, quality of life, and the unmet needs of patient communities living with rare and chronic diseases. The research is not FDA-regulated nor classified, does not involve prisoners, and is consistent with the ethical principles of the Belmont Report.

Quotes

All quotes were provided by consenting community participants through one-on-one interviews or online focus groups conducted on the TREND Community™ platform. Names are not included to protect participant privacy.

Data Ownership

Ownership of public posts or conversations from other social media platforms shared with TREND for analysis are subject to the social media platform's privacy policy, terms of service and other applicable policies. Participants who share data and experiences on the TREND Community™ platform give their consent for TREND to analyze it. TREND Community owns the results of our analysis and all other data and output that we produce including our Community Voice Reports.

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