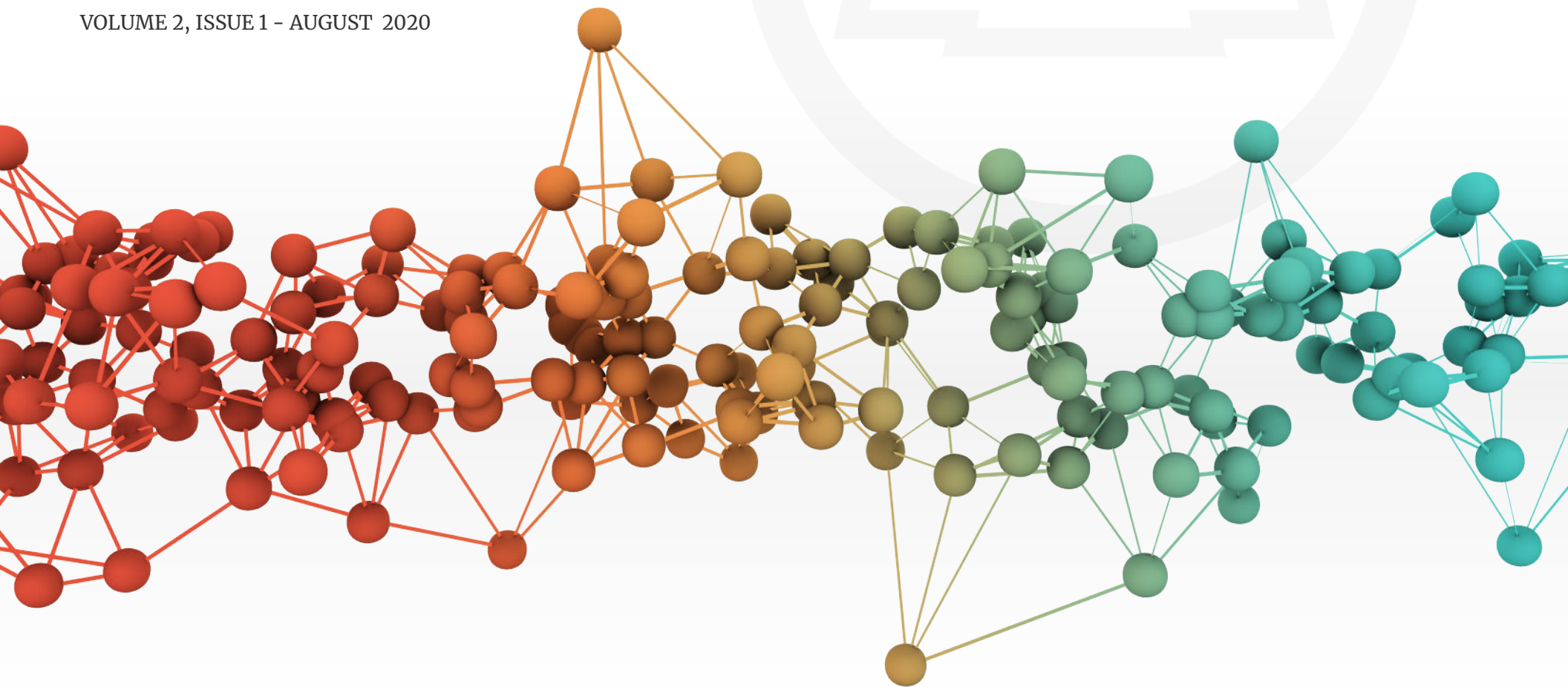


# Pericarditis

## Community Voice Report

VOLUME 2, ISSUE 1 - AUGUST 2020



DISEASE CATEGORY



CIRCULATION/CARDIOVASCULAR



**TREND Community**  
Turning Anecdotes Into Evidence™

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# 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 can be further complicated for certain rare or emerging diseases.

## 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, chronic, and emerging diseases, 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 the 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 de-identified 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.

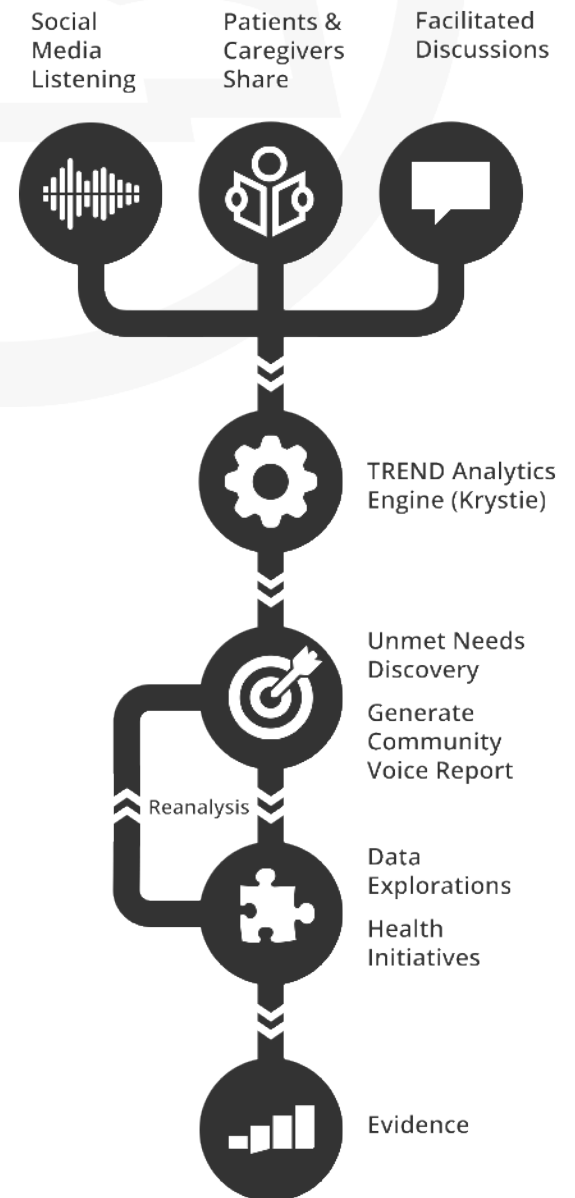
These Community Voice Reports are shared with the community free of charge, and our industry stakeholders have the opportunity to license the data for projects that address unmet needs and improve quality of life. These insights may be used to design Data Explorations or Health Initiatives.

## 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

Pericarditis is inflammation of tissue that surrounds the heart and is usually noticed as chest pain. A small portion of emergency room patients with chest pain has pericarditis. About one in four pericarditis patients have another event, or recurrence, within 18 months. Although viral infections are a leading cause, most recurring patients are diagnosed with idiopathic recurrent pericarditis, meaning the cause is not known. Other cases are linked to autoimmune and inflammatory disorders, or underlying cancer. Conventional initial treatments include non-steroidal anti-inflammatory drugs, colchicine, and glucocorticoids. Newer treatments focus on reducing immune activity in specific ways. Pericardiectomy, or surgical removal or stripping of the pericardium, is the most invasive treatment.<sup>1</sup>

*"I am no longer in control of my life: I don't know if I'll be able to work again, to travel or to leave alone as I used to do. On a good day, I cannot walk more than about 10 to 15 feet and very slowly. I feel vulnerable and incapacitated by this illness."*

— Community Member



**3,540**

**PEOPLE  
PARTICIPATING**

**10,412**

**POSTS  
SHARED**

**146,058**

**COMMENTS  
ELICITED**

**NOV 2012 - JUL 2020**  
**DATE RANGE**

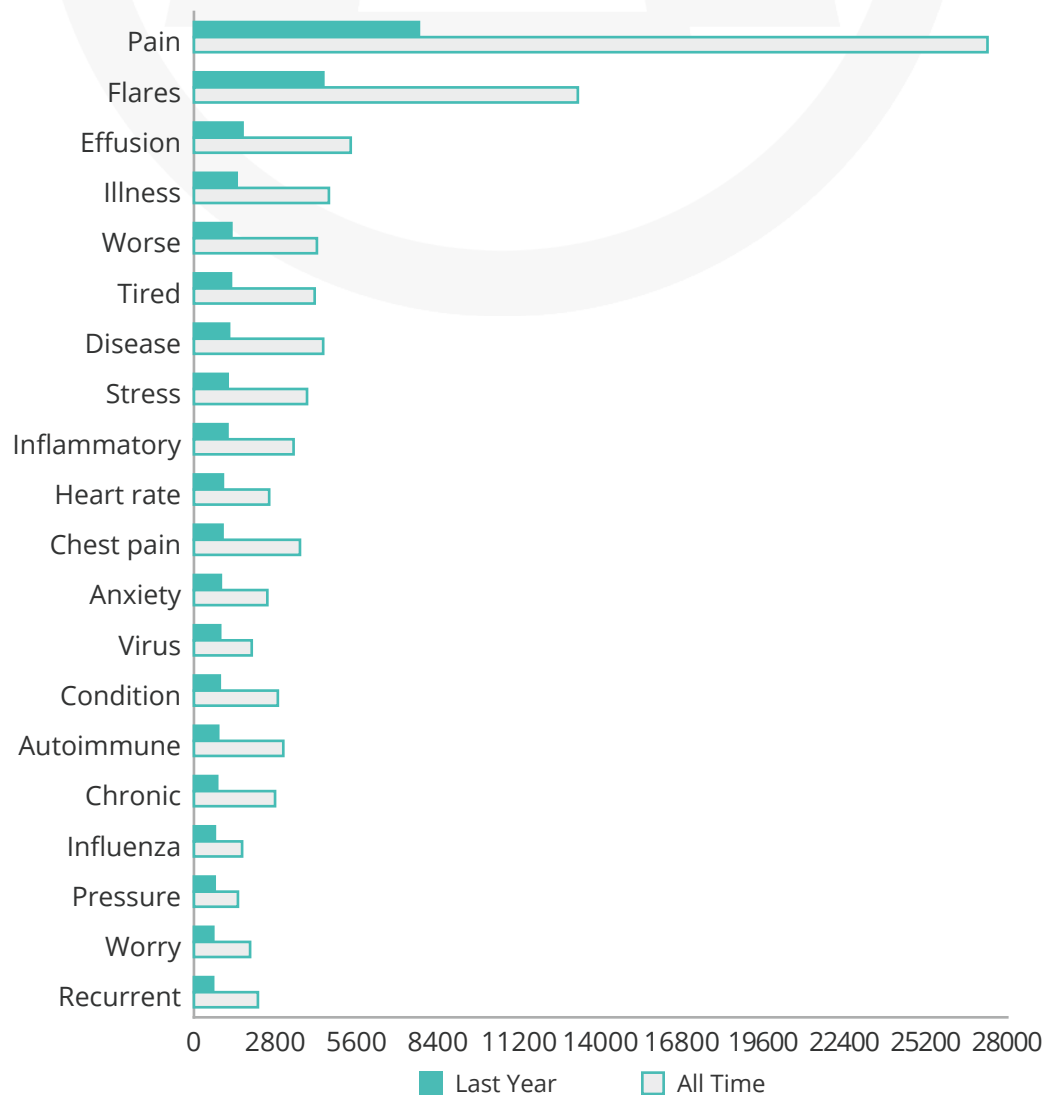
# Disease Burden

The main symptom, and most discussed by the community, is pain. *Pain* (27319 all-time mentions/7745 mentions in the last year) was discussed more frequently and mentioned more often than any other concept in our analysis. *Flares* (13216/4454) were also frequently discussed. People also discuss *worse* (4233/1288), *inflammatory* (1154/3430), *virus* (1989/903), *autoimmune* (3076/835), and *influenza* (1658/720) as both measures of how difficult recurrence is or as possible reasons for having the disease or flare. People also mentioned recurrent (2202/661), consistent with recurrence in some patients.

Other issues were less frequently mentioned and include the terms *effusion* (5397/1673), *tired* (4156/1275), *heart rate* (2590/997), and *chest pain* (3650/984). The concept tired includes fatigue and exhaustion. Many different concepts were used to describe the situation people experience including *illness* (4646/1471), *disease* (4449/1210), *condition* (2888/889), and *chronic* (2792/800). Emotional symptoms were also mentioned including *stress* (3893/1161), *anxiety* (2527/926), and *worry* (1933/666).

People mention that pain and feeling tired interact to be debilitating and make it difficult to manage life tasks.

## 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.



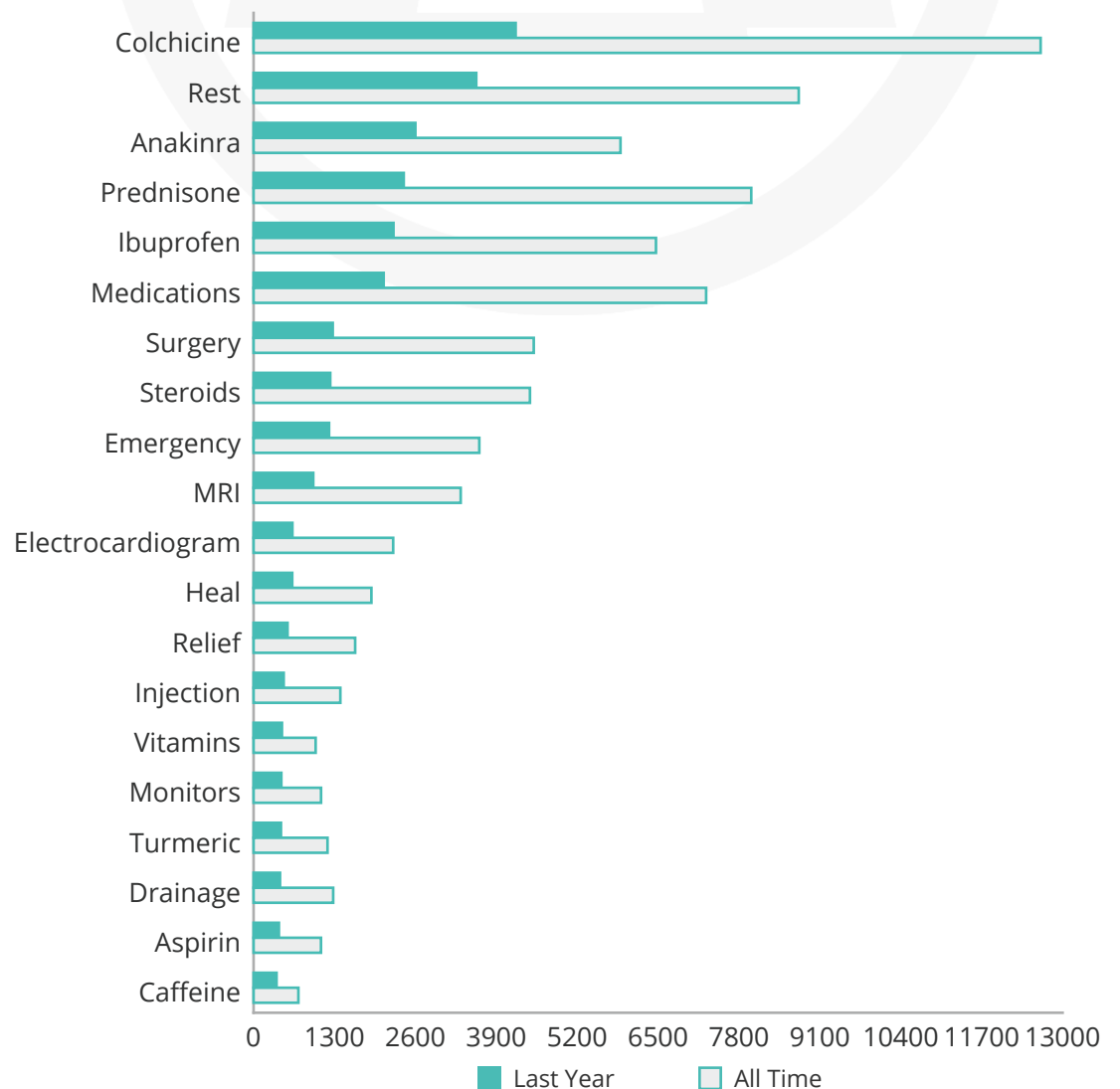
# Disease Management

Treatments for the disease are mostly medicinal. Colchicine (12647 all-time mentions/4211 mentions in the last year), anakinra (5896/2600), prednisone (7997/2413), ibuprofen (6466/2248), medications (7272/2090), steroids (4441/1232), and aspirin (1083/407) were the most discussed. Interestingly, two medicines *indomethacin* (993/271) and *naproxen* (1071/235) were discussed frequently in the group over all time, but not enough in the last year to make this list. *Vitamins* (997/456), *turmeric* (1188/440), and *caffeine* (720/369) are also mentioned frequently and may offer other ways to manage the disease.

*Rest* (8760/3578) and *surgery* (4502/1272) are mentioned as other techniques to manage the illness. People also mention various tests and diagnostic tools that often take place during a first *emergency* (3627/1213) visit to receive care. *MRI* (3328/959) and *electrocardiogram* (2243/624) are the most frequently mentioned tests.

**Disclaimer:** This report is not intended to be a substitute for professional medical advice. Mentions of specific treatments could be positive or negative and this is not reflected in the data.

## 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.



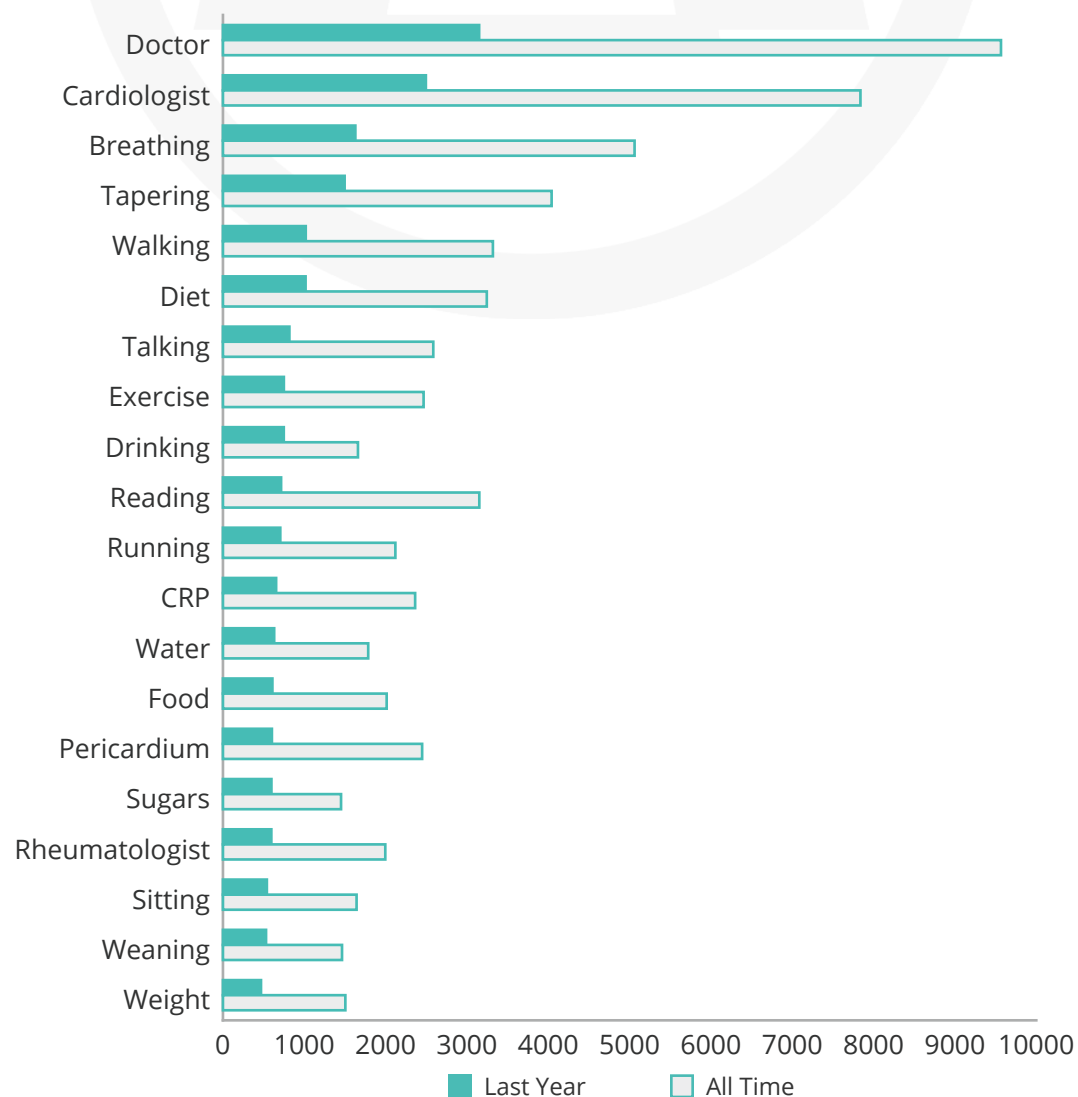


# Significant Terms

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. Some are common life terms such as “reading” or “talking” which often refer to reading about the disease or speaking to health professionals. Further analysis would be required to understand the nuances within the conversation.

For pericarditis, exercise can be detrimental to the healing process, so *walking* (3319 all-time mentions/1018 mentions in the last year), *exercise* (2467/749), and *running* (2120/705) may be about these issues. Similarly, many of the medications must be decreased slowly, and thus *tapering* (4041/1496) and *weaning* (1464/530) may be mentioned frequently as people discuss how to reduce their doses. *Doctors* (9566/3150) are frequently mentioned, with *cardiologists* (7838/2495) mentioned the most. *Rheumatologists* (1996/595) also get some mentions.

## 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.



# Conversation Shifts Over Time

In our analysis of the data, we looked at the key burdens and treatments over the whole period of time people were in these groups and the past year.

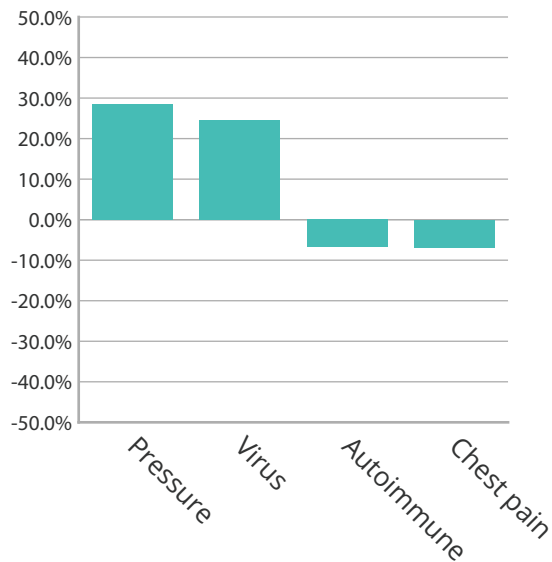
For disease burden, the concepts of *pressure* (+28.6%) and *disease* (+24.5%) were mentioned more frequently in the last year. *Autoimmune* (-6.7%) and *chest pain* (-6.9%), on the other hand, were mentioned less frequently. For

disease management, *caffeine* (+39.4%) and *vitamins* (+25.3%) were mentioned more frequently, and *electrocardiogram* (-5.8%) and *steroids* (-5.9%) were mentioned less. *Drink* (+23.7%) and *sugars* (+15.3%) were mentioned more frequently, and *CRP* (-6.0%) and *reading* (-12.1%) were mentioned less.

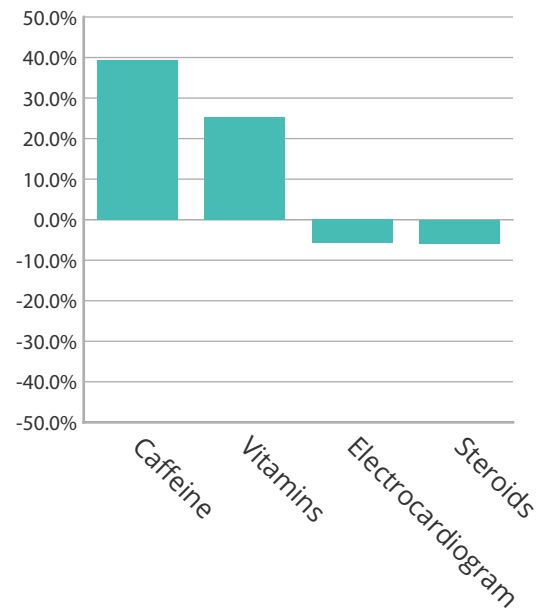
***"[The ability to connect with other people affected by this same condition online] has been of great support, especially in gathering information about my symptoms. I realised that most doctors do not know enough about this illness."***

— Community Member

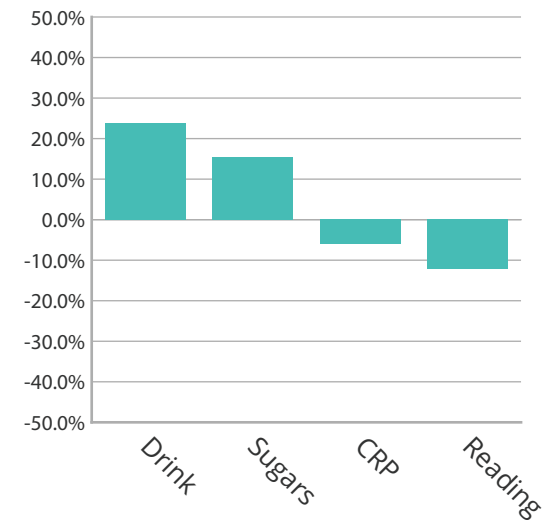
## DISEASE BURDEN



## DISEASE MANAGEMENT



## SIGNIFICANT TERMS



The above figures chart the percent change in mentions of concepts in the three areas of interest, burden, management, and significant terms.





# Discovering Unmet Needs

Pericarditis is a painful and debilitating disease. People who experience symptoms are often physically restricted by them. The combination of pain and fatigue make it difficult to perform daily tasks and impact quality of life. This puts pressure on their loved ones and generally makes life unpleasant.

Finding ways to treat this pain so patients can get back to their lives seems to be the greatest unmet need. People discussed the current method of combining drugs, particularly colchicine and ibuprofen often with prednisone help the pain. The pain sometimes returns during the tapering process making it difficult to stop the drugs.

Additionally, people expressed frustration with the care from doctors. Some mentioned being unable to visit with a cardiologist when

needed. Others mentioned not getting enough of a particular medicine from doctors who didn't understand the nature of the illness and the tapering of medicines. Many mentioned traveling to particular clinics that understand the symptoms and management better.

Some also mentioned concerns about the long-term effects of some of the medications, particularly ibuprofen.

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***“[My biggest source of worry/concern is] not accessing the right treatments and therefore being unable to regain my life.”***

— Community Member



# Data Exploration and Health Initiatives

The data analyzed for this report revealed areas in need of further research. SARS-CoV-2 infection or COVID-19 disease may be increasing the rates of pericarditis incidents, which is another reason to get a handle on this illness and its treatments. Within the group, people discussed many aspects of COVID-19 including the concern about risks from the disease for them, taking ibuprofen and other medications, and issues about getting to their doctor and getting their medications.

Caffeine and vitamins were mentioned more frequently in the last year. Some of the mentions of caffeine appear to be about people stopping use of caffeine to help with sleep issues or interactions with other medicines, such as prednisone. Given that feeling tired or fatigued is one of the burdens, understanding

caffeine use may give insights into how people manage these issues.

Pericarditis can be idiopathic, meaning that the cause is unknown, which is obviously frustrating to patients. In addition, it can be associated with autoimmune issues or viral issues. These differences may have implications for treatment. Working with these conversation data and the community, it might be worth exploring whether the varied causes of the disease and comorbidities influence how the disease is treated and managed.

Pain and fatigue are both significant burdens of this disease and are difficult to measure. In our conversations with patients previously, they shared descriptions of pain and fatigue that helped us understand these burdens in new ways. We expect analyzing the conversations in

more detail could reveal new ways to measure these symptoms.

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***“I don’t know how painful it will be to lie down each night, so that’s difficult. Sleepless nights complicate the next day.”***

— Community Member



# Appendix

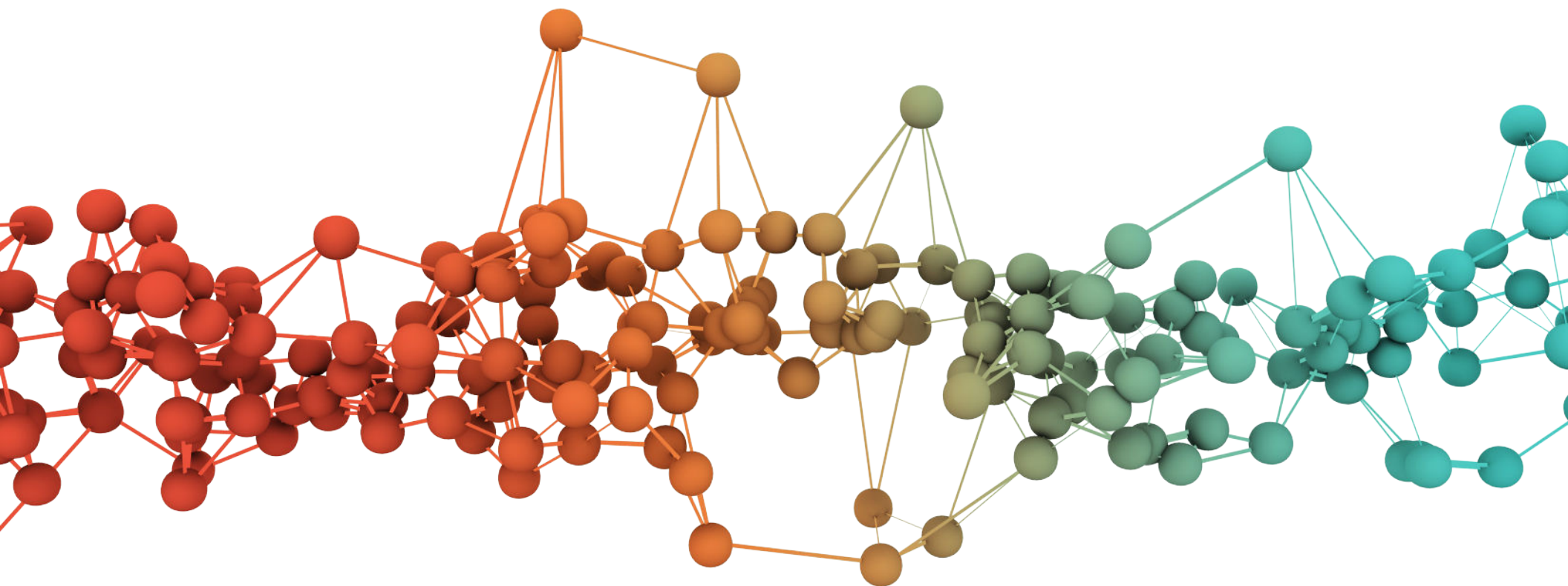
## Endnotes

1 Perricone C, Katz D, Ciccacci C, et al. The Heart Matters: Contribution of Genetic Factors in Recurrent Pericarditis. *Isr Med Assoc J* 2019;21:487-90.

Social Channels Analyzed	People	Posts	Comments	Gender	Age	Top 5 Countries
Facebook Group: Pericarditis	3540	10412	146058	Female: 67% Male: 33% Other: 0.0%	33.0% 35-44 Years	United States, United Kingdom, Australia, Canada, Saudi Arabia

## Acknowledgments

We thank the Global Pericarditis Support Group administrators and M. Chadi Alraies (Twitter: @chadialraies), MD FACC, Director, Interventional Cardiology Research, Detroit Medical Center for providing access to the data used to create this report.



# 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, chronic, and emerging diseases.

## 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.

## License

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