TREND Community

2023 Impact Report

TREND Community™
Turning Anecdotes Into Evidence™

Contents

Who Is TREND Community?

We're a community-powered data analytics company unlocking people's conversations about living with rare and chronic diseases, delivering actionable, real-world insights, and driving progress in healthcare.

We do this by creating communities or being trusted to listen to and analyze community conversations on social media. Using our proprietary AI technology we uncover emerging trends, which become the foundation for our evidence-based insights and create benchmarks where currently none exist.

We learn through listening, and we spark progress through insight. Our vision is to revolutionize the world's understanding of diseases.

The Need for Our Work

Without data and deep understanding, there can be no lasting impact on the 95 percent of more than 10,000 rare diseases and countless other chronic conditions that have no approved treatments.

Health authorities, healthcare providers, patients, and their organization representatives all agree that this lack of understanding denies people the right to the highest standard of health.[1,2]

People living with rare and chronic diseases are all confronted with **similar obstacles** including:

1. Long diagnostic journeys
2. Lack of information and support at the time of diagnosis
3. Inequities in access to treatment and care
4. Being dismissed by health professionals
5. Loss of confidence in medical and social services

We believe that too many voices are left out of the conversation, and limited disease understanding hinders progress. Our work helps to unveil a deeper understanding of disease presentation, symptoms, comorbidities, patient burden, unmet needs, and larger patterns.

While this understanding helps improve the quality of life for people today, ultimately it helps to accelerate the development and approval of new therapeutics for which the communities we serve are desperately waiting.

TREND Community's vision to **revolutionize the world's understanding of diseases** includes:

1. Abandoning the notion that "the patient voice" is singular. We believe that every individual facing a rare and chronic disease is unique and experiences the patient journey differently
2. Empowering entire communities to self-advocate using our evidence-based data and insights
3. Helping identify under-recognized symptoms, secondary diagnoses, unmet needs, and quality of life impacts such as mental health challenges
4. Promoting a holistic understanding of living with a rare and chronic disease beyond the people and family members directly affected
5. Creating a clear channel between people living with rare and chronic diseases and the experts who research and treat them

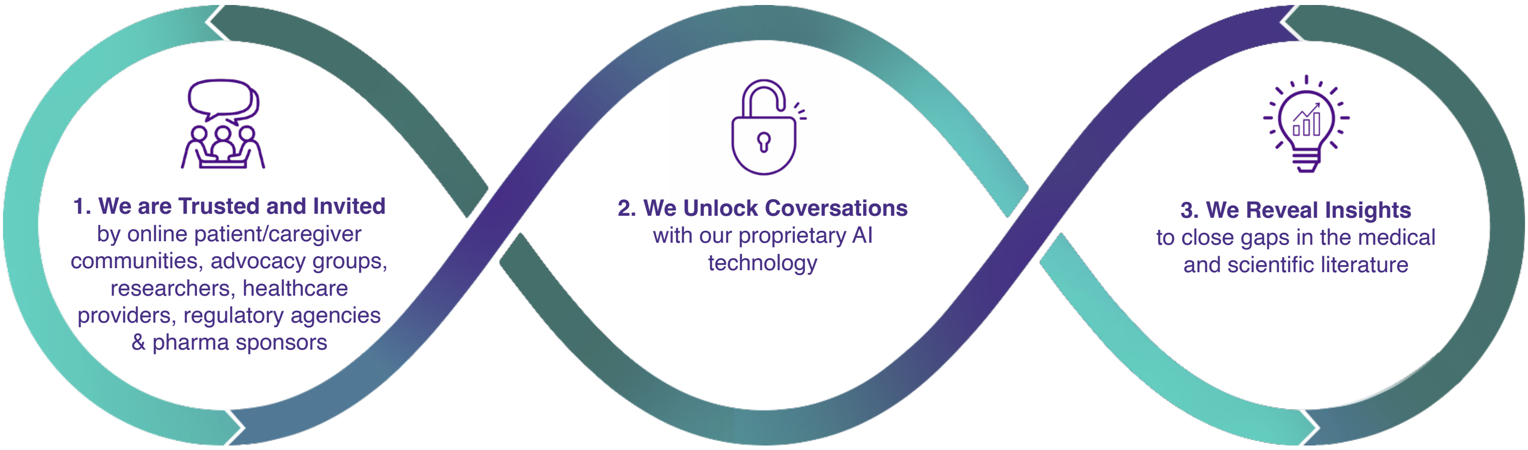
References: 1 - EURODIS, Study by the European Organisation for RareDiseases 2 - Rare Disease.org, The National Organization for Rare Disorders

Why We Started

TREND Community started with a **personal experience**:

Founders Maria Picone and Christopher DeFelice found themselves immersed in the frightening and disorienting experience of navigating life with a rare disease when their child was diagnosed with the genetic disorder Prader-Willi syndrome (PWS). Maria and Christopher felt isolated and ill-equipped to deal with what lay ahead. Everything changed when they connected with an online community of parents of children living with PWS. This community held the knowledge that could offer their child hope for an independent and happy future. Inspired by the power of these organic communities, Maria and Christopher created TREND Community.

Our Process



1. We are Trusted and Invited by online patient/caregiver communities, advocacy groups, researchers, healthcare providers, regulatory agencies & pharma sponsors

2. We Unlock Coversations with our proprietary AI technology

3. We Reveal Insights to close gaps in the medical and scientific literature

At the simplest level, we are invited to use our specially-trained AI engine and social media listening to analyze what people living with rare and chronic diseases are saying across social media forums, groups, and communities.

Our approach turns on the flood lights, providing a high-volume snapshot of a community and illuminating elements of the patient experience that have previously gone unseen and unheard.

We deliver evidence-based insights from these trends, which help transform healthcare. But it's not just about gathering data. The process starts with trust.

This process in action is called **TREND Real World Evidence Accelerators**

TREND Real World Evidence Accelerators

TREND Real World Evidence Accelerators bring together all stakeholders, including online support groups, patient advocacy organizations, key opinion leaders, and industry stakeholders, to identify gaps in the medical and scientific understanding of rare and chronic diseases and other community unmet needs.

TREND Real World Evidence Accelerators

1. We are Trusted and Invited

We establish trusted, long-term partnerships with online communities formed organically by people affected by rare and chronic diseases. Our social media analyses impose minimal burden on community members.

2. We Unlock Conversations

We harness machine learning and natural language processing techniques with Krystie™, our proprietary analytics engine, that captures the perspectives and experiences of people within these trusted communities. Our approach is powerful yet respectful, allowing candid sharing without unnecessary intrusion.

Our analysis goes beyond individual stories, capturing the evolving, shared experiences of the community. Our insights provide a fuller picture of a disease narrative by identifying and extracting trends from the collective voice of the community.

Our process is low burden, high impact.

Why Krystie™?

Following an experimental and extremely risky treatment, a young girl named Krystie defied the odds of her Tay-Sachs diagnosis, living nearly twice as long as expected. Her dads, Rick and Bruce, documented Krystie's medical odyssey alongside their family's adventures. They demonstrated the potential for storytelling to catalyze research while instilling hope, so we chose the name Krystie™ to honor her as a pioneer.

3. We Reveal Insights

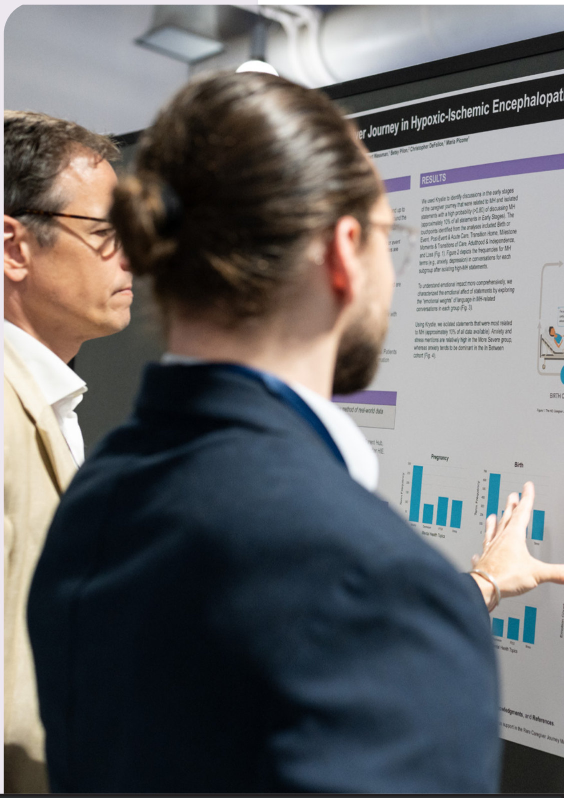
We then use the data and insights we derive from authentic patient voices to generate real-world evidence of disease presentation, symptoms, comorbidities, patient burden, unmet needs, and larger patterns.

We ensure these learnings are shared with the communities in question and empower their members to drive change.

We also present our findings at patient and scientific meetings, in peer-reviewed journals, and in various media outlets.

Our funding sponsors receive custom data science hours that can be used to generate insights to inform their internal programming.

Ultimately, it is this holistic understanding that helps accelerate the development and approval of new therapies for which patients are desperately waiting.



Societal Impact

There's a global cultural shift to redefine "success," and as a Certified B Corporation, TREND is helping to pave the way. Certified B Corporations are companies that voluntarily meet the highest standards for social and environmental performance.

We requested to be judged and scored on how our operations and business model impacts our employees, our community, our environment, and the people we work with—and we chose to make the results transparent.

TREND Community™
Turning Anecdotes Into Evidence™

Certified B Corporation

In 2023, TREND Community was instrumental in helping communities, pharmaceutical companies, and regulatory agencies create solutions and impact that would not have been achieved otherwise.

Through our TREND Real-World Evidence Accelerators....

We pioneered advancements in patient care for the Sjögren's community by characterizing the lexicon used by the community to describe flares

We empowered community leaders to promote the proactive management of gout and documented a community-level shift in behavior

We paved the way for the FDA approval of a new therapy to treat narcolepsy by amplifying the voices of the community

We helped underserved communities by conducting research even without external funding, bringing our vision to revolutionize the understanding of disease to fruition

Our Work in Action: Case Studies

Case Study #1: Sjögren's disease

The Knowledge Gap

The Sjögren's disease (SjD) community frequently discusses episodic flares - a severe onset of symptoms - yet disease flares and flare lexicon are an incompletely understood aspect of SjD.

This disconnect has created friction between patients and their healthcare providers and can have significant consequences for the quality and effectiveness of patient care.

Key Takeaway

Our social media listening analysis confirmed that flares are a salient feature of the SjD patient experience which is frequently discussed in context with their symptoms - specifically pain, dryness of the eyes and mouth, and fatigue. The emotional impact of flares is also evident in mentions of fear and other negative emotions.

Additional research is required to more clearly understand the patient experience of Sjögren's flares, define the clinical parameters of flares, and clarify the clinical implications of such disease activity.

Our Process Drives Solutions

We are Trusted and Invited

During a workshop held at the EULAR 2023 Congress, a physician who was inspired by our trusted approach with communities shared that she and other colleagues had personally experienced issues of discrepancy in terminology employed by clinicians and patients when discussing Sjogren's flares.

We Unlock Conversations

We applied social media listening to characterize flare lexicon and conducted a retrospective, non-interventional study using documents (posts/comments) from the subreddit group "r/Sjogrens", which contained over 10 years of conversations from October 16, 2012 to August 7, 2023.

We Reveal Insights

The social media listening analysis confirmed that flares are a salient feature of the SjD patient experience. The SjD community discusses flares frequently and in context with their symptoms, specifically pain, dryness of the eyes and mouth, and fatigue. The emotional impact of flares is also evident, wherein flare conversations frequently mention fear and other negative emotions. Additional research is required to more clearly understand the patient experience of Sjögren's flares, define the clinical parameters of flares, and clarify the clinical implications of such disease activity.

TREND contacted and worked with Sjögren's community leaders, including Coralie Peter Bouillot, General Secretary, Sjögren Europe, Switzerland and Linda Jane Stone, Director, British Sjogren's Syndrome Association, United Kingdom and the physician from the EULAR Congress, Dr. Chiara Baldini, Department of Clinical and Experimental Medicine, University of Pisa, Italy, on the next steps to share our insights with the larger Sjögren's community - physicians, patient advocacy groups, patients etc.

See additional Sjögren's disease work conducted by TREND Community

The findings were presented at Sjögren's conference in Greece in October 2023.

An abstract was submitted to EULAR 2024, together with an article by RARE Revolution February 2024, and a manuscript is currently in progress.

Our Work in Action: Case Studies

Case Study #2: Gout

The Knowledge Gap

Gout is associated with negative impacts on physical, emotional, and mental health and, if left untreated, can lead to various complications and serious health problems.

Patients and healthcare providers alike lacked awareness of the significance of proactively managing the condition throughout the patient's lifetime, especially by actively monitoring and treating uric acid levels.

Key Takeaway

Our research showed patients tend to use more positive language when describing proactive experiences, and they may experience reduced mental and emotional distress when gout is monitored and managed using a proactive, long-term approach. The findings also suggest patients may benefit from education on adherence to such an approach.

In addition, these insights were shared back to the community and further language analysis showed they changed behavior and therefore topics discussed.

Our Process Drives Solutions

We are Trusted and Invited

Over the past two years, TREND has worked closely with the Patient Advocacy and Medical Affairs teams at Amgen Rare Disease and was invited and trusted by the Gout Support Group of America (GSGA) to deeply study the unmet needs of the community.

We Unlock Conversations

In January 2022, TREND launched the Gout Real-World Evidence Accelerator to bring together sponsors, thought leaders, and online support groups to turn the gout community's conversations on social media into actionable insights and discovered a link between management strategies and mental health.

See additional gout work conducted by TREND Community:

We Reveal Insights

TREND's specially-trained AI revealed gout community members tended to use more positive language when describing proactive strategies (e.g., treating underlying disease causes) than when describing reactive strategies (e.g., treating symptoms as they arise).

Analysis of community conversations showed that patients may experience reduced mental and emotional distress when gout is monitored and managed using a proactive, long-term approach, and findings also suggest patients may benefit from education on adherence to such an approach.

To give back to the community, TREND conducted workshops and created multiple abstracts and posters, which were then presented at conferences such as EULAR and ACR and published in manuscripts like Rheumatology and Therapy.

Our Work in Action: Case Studies

Case Study #3: Narcolepsy

The Knowledge Gap

Sodium oxybate (SO), a twice-nightly therapy for narcolepsy, has shown effectiveness; however, nighttime waking to take the required second dose can present its own challenges, including dosing errors.

The community was afraid to report their full experiences for fear of losing a therapy that had impacted their lives despite its shortcomings. As a result, healthcare providers believed that their patients were well managed.

Key Takeaway

This work demonstrated that actively listening to the unmet needs of the sleep community using social listening is an important step in understanding information that patients may not be comfortable sharing with their clinician, which can impact the efficacy and safety of a medication as well as their overall quality of life.

Evidence from TREND's research revealed that inherent risks associated with needing to wake for a second dose are common and have negative impacts on patients' physical health, mental health, and quality of life.

Following this evidence, TREND wrote a letter to the FDA on behalf of the community expressing the urgent need for a once-nightly solution. Shortly thereafter, LUMRYZ™ was approved. We learned the FDA had taken TREND's input from the community into consideration for the decision.

Our Process Drives Solutions

We are Trusted and Invited

TREND was invited into three private Facebook Groups, Discord Servers, and subReddits to survey members and analyze data from more than 25,000 posts and close to 300,000 comments.

We Unlock Conversations

Patient experiences with SO therapy (especially regarding the second dose) were assessed by collecting and analyzing survey results and conversations in patient-oriented narcolepsy social media communities. In-depth interviews were also conducted as a final method to capture the voices of these community members.

See additional narcolepsy work conducted by TREND Community:

We Reveal Insights

TREND's research revealed that inherent risks associated with needing to wake for a second dose, especially with missed doses and late doses, are common and negatively impact patients' physical health, mental health, and quality of life.

The required second dose is reported to disrupt the daily lives of these patients and their caregivers/care partners. People living with narcolepsy are also at increased risk for injury, with 30% to 50% of individuals living with narcolepsy experiencing accidents or injuries.

The anonymous nature of social listening and the survey allowed these community members to honestly share their experiences without the typical fear of losing access to the therapy despite the challenges associated with it.

As a final step, TREND wrote a letter to the FDA on behalf of the community expressing the urgent need for a once nightly solution. Shortly thereafter, LUMRYZ™ was approved and we learned that the FDA had taken the input from the community into consideration when making the decision.

Who Partners with TREND Community?

Communities:

We are founded on the belief that the conversations already happening within online communities are invaluable and have built a business model that not only elevates the patient voice, but legitimizes the patient experience through quantitative data for decision-makers. We work with communities to ensure that the meaningful action-driven insights are being heard by health care providers, regulatory agencies, and the people working on therapeutic progress.

And as part of our sustained commitment, we reinvest a portion of our profits back into the communities we serve, building long-term relationships and a lasting legacy to our collaboration. When it comes to spreading awareness and sparking new therapeutic possibilities, the community's voice is imperative.

Industry Stakeholder:

Partnering with TREND gives organizations the opportunity to engage with patient communities early, evaluate under-researched symptoms, identify gaps in care and therapeutic needs, find synergies across diseases, characterize the lexicon that patients are using to communicate with each other, and accelerate clinical trial recruitment, among other opportunities.

2023 Publications: Delivering on our promise to always share learnings back with the communities with whom we partner, in 2023 TREND authored 16 publications, which were presented at conferences in North America, South America, and Europe. Using our proprietary AI technology, we uncovered emerging trends in rare diseases that are often overlooked, which have now become the benchmarks in communities where none existed before.

For a full list of TREND's publications, including a brief summary and QR codes that link to the full publications, please turn to page 16.

Our Company Culture

As our name suggests, everything we do starts with community. We are bridge-builders, always striving to create new connections across patients, families, healthcare providers, biotech and pharmaceutical companies, and regulatory agencies who share a collective mission to agitate and accelerate scientific progress while strengthening advocacy. As a company that prioritizes purpose over profit, we grow to the size of our convictions and no larger.

“TREND’s culture is collaborative, friendly, honest, and humble. When a task requires multiple people/teams, everyone is respectful of each other and works together to get the job done. At the same time, no one pretends to know more than they do. If there’s something that one person doesn’t understand, they’re honest about it, and if somebody else has that knowledge, they’re happy to explain.”

Zach Cline,
Data Research Analyst

“Teamwork makes the dream work. TREND is all about collaboration, growth, and high energy.”

Jonna Piira,
CFO

“One of the things I admire most about our team is how they fuse the intelligent output of our technology with the compassion of the human touch. Everyone shares a value of using technology to create meaningful impact for our communities, while prioritizing safety and ethics. And I think that drives us through technology’s ever-evolving landscape. It’s how we leave a lasting positive imprint on the communities we serve”

Christopher DeFelice,
CTO & Co-Founder

“The thing that makes TREND stand out to me is the way the company stays grounded in its mission, because the owners and founders are living every day with the tough realities that we as a company are trying to make better for the communities we serve.”

Tim McLerran,
Product Manager

“TREND is a place where everyone believes in the vision and mission and this drives the culture. Everyone here is smart, committed, creative, and collaborative and it’s an absolute pleasure to be part of this team!”

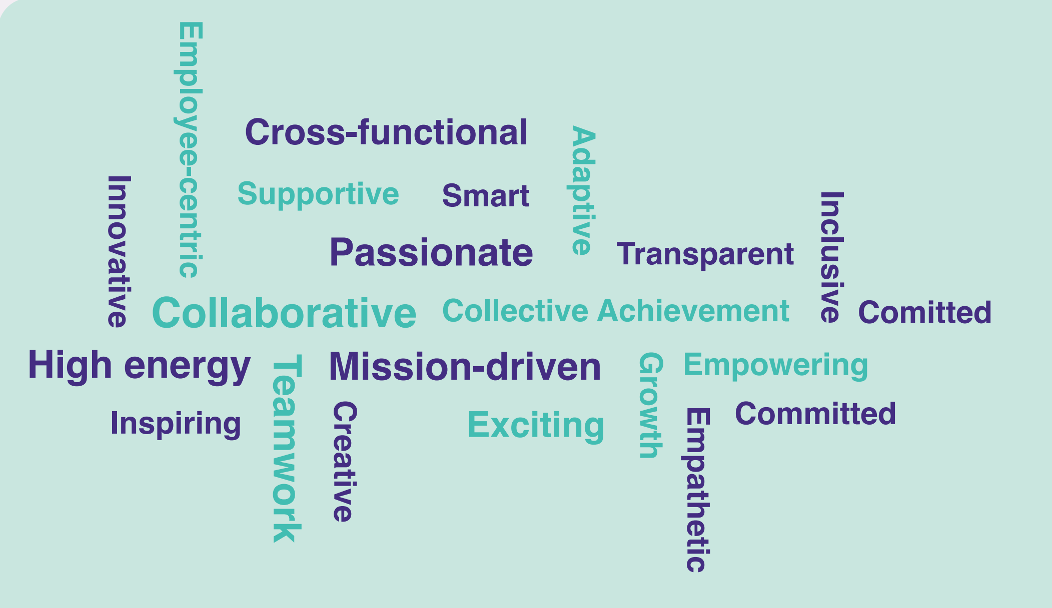
Lauren Dougherty,
COO

“ “I’m immensely proud of the purpose-driven culture we’ve cultivated here at TREND. From data science to operations to leadership, there’s a shared dedication and compassion evident in our efforts. Our profound impact on the communities we served in 2023 speaks volumes about our collective commitment to the company’s mission.”

Maria Picone,
CEO & Founder

“Innovative, employee-centric, ethical, transparent, empowering, inclusive, and passionate are some words that perfectly describe TREND’s DNA.”

Gary Ho,
Senior Community Director



Citizen Scientist Award

The TREND Community Citizen Scientist Award is awarded to community members who demonstrate a true commitment to advancing scientific knowledge and empowering their communities to become active participants in the scientific process.

In recognition of his tireless efforts to promote scientific literacy and empower the gout community to contribute meaningfully to the advancement of knowledge, Gary Ho was awarded the 2023 Citizen Scientist Award.

When Gary's journey with gout began at the age of 24, he was met with skepticism from medical professionals who doubted his diagnosis due to his age. Despite enduring 16 years of relentless pain and debilitating flare-ups, Gary refused to succumb to the limitations imposed by his condition. Through a steadfast resolve to reclaim his quality of life, Gary demonstrated that effective gout management is indeed attainable.

Recognizing the dearth of resources and understanding for those navigating gout, Gary co-founded the Gout Support Group of America (GSGA) in 2015, along with his rheumatologist, Dr. Chris Parker.

This invaluable platform provides a safe space for individuals affected by gout to share experiences, exchange knowledge, and receive unwavering support from a community that truly understands the complexities of the disease.

Over the last three years, TREND Community and GSGA have generated high impact, real-world evidence and presented our findings through posters, panels, workshops, and social events at scientific conferences around the globe.

In partnership with Amgen Rare Disease, Global Healthy Living Foundation, and the Gout Education Society, our work recently culminated in a publication in Rheumatology and Therapy that shed light on the emotional impact of proactive vs. reactive management strategies on a patient's mental health.

Gary is a beacon of hope for people living with gout and the GSGA has grown to become a source of scientifically sound information for its community members.

Looking to the Future

Understanding the full burden of disease and its natural progression is vital for advancing healthcare, science, and medicine. Unfortunately, current methods such as disease registries and natural history studies struggle to keep pace with the rapid identification of new diseases and diagnostic technologies, thus hindering progress.

At TREND Community, we are pioneering a paradigm shift in how we collect data about rare and chronic diseases. We are seizing the potential of emerging AI technologies like natural language processing and machine learning to characterize rare and chronic diseases in real-time as communities share their stories and experiences within their trusted online support groups. With advancements in AI, we look to further empower our communities with tools to accelerate research, reduce the diagnostic journey, and ultimately find treatments and cures for rare and chronic diseases.

2023 Publications

Month	Conference	Name of Abstract / Poster	Purpose of Abstract	Results/Impact
Jan. 2023	Frontiers in Neuroscience	A draft conceptual model of SLC6A1 neurodevelopmental disorder	To document the current understanding of the lived experience of SLC6A1-NDD.	The discrepancy between the domains of disease reported in the literature and those discussed in patient conversations suggests that a formal qualitative interview-based disease concept study of SLC6A1-NDD is warranted.
Feb. 2023	INBBC 2023 14th International Newborn Brain Conference	Mapping the Rare Caregiver Journey in Hypoxic-Ischemic Encephalopathy (HIE) Using Real-World Insights from Social Media	To characterize the unmet and/or disconnected mental health and emotional wellbeing (MH & EW) needs of those in the rare disease caregiver community, regardless of where they are in the continuum of their caregiving journey.	TREND Community identified key MH and emotional wellness touch points along the HIE caregiver journey. Give an Hour used the findings to develop Rare Care peer support training, a 6-week training series designed to equip rare disease caregivers with support tools.
Feb. 2023	Sleep Research Society Advances in Sleep and Circadian Science	Understanding the Patient Experience With Sodium Oxybate Therapy for Narcolepsy	Excessive daytime sleepiness (EDS) and disrupted nighttime sleep are two of the pentad of symptoms affecting quality of life (QoL) in persons living with narcolepsy. A twice-nightly sodium oxybate (SO) therapy, has shown effectiveness; however, presents its own challenges to patients as a result of nighttime waking to take the required second dose, including dosing administration errors.	The required second SO dose was reported to disrupt the daily lives of patients and their caregivers/care partners. This work ultimately contributed to the approval of LUMRYZ™, a once-nightly sodium oxybate therapy.

Month	Conference	Name of Abstract / Poster	Purpose of Abstract	Results/Impact
Feb. 2023	World Symposium 2023 on Lysosomal Diseases	Understanding Pain and Its Impact on Mental Health in Fabry Disease Using Real World Evidence From Social Media	Individuals living with Fabry disease (FD) are at an increased risk for poor mental health (MH) outcomes. However, the relationship between MH and other disease-specific challenges is not well-defined. The aim of the current study was to explore the MH impacts of FD and to explore symptoms in pain conversations.	Our findings illuminated the connection between the physical symptoms of FD and negative MH impacts. Specifically in the data, we see the strongest relationship between the symptom of pain and MH.
Feb. 2023	NIH Day	Identifying Mental Health Challenges Experienced by Caregivers in Rare Disease Communities: a Social Media Analysis	It has been documented that rare disease caregivers are at risk for negative mental health (MH) consequences. In this exploratory study,we aimed to identify MH challenges and the factors that might elicit them across multiple communities of caregivers for individuals living with rare diseases.	Between 10% to 16% of all community conversations analyzed were related to mental health. This work catalyzed further research into the mental health impact on caregivers in the rare disease community.

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May 2023	European Alliance of Associations for Rheumatology	The Mental Health Impact of Sexual Dysfunction in Sjögren's Disease: A Social Media Approac to Real-World Evidenc	The objective of the current study was to shed light on the mental health impacts associated with vaginal dryness in SjD. We also aimed to explore common topics shared by community members discussing these symptoms to understand their impact on daily living.	Our findings suggest that vaginal dryness and sexual dysfunction in SjD are prevalent and associated with specific negative mental health symptoms. This social listening approach also revealed that individuals living with SjD openly share intimate details of their journey online, including experiencing physical pain during sex (i.e. dyspareunia), impacts on marriage/relationships and management techniques (e.g. lubrication) for sexual discomfort. This work demonstrates how interrogating social media conversations can be invaluable to elucidating patient perspectives on sensitive and intimate topics such as sexual health and, furthermore, to identify opportunities to improve quality of life.
May. 2023	European Alliance of Associations for Rheumatology	Using Social Media Conversations to Understand Patient Care: Factors Driving Proactive vs Reactive Management of Gout	Gout is a chronic disease of monosodium urate deposition marked by hyperuricemia, painful arthritis flare-ups, and tophi. Gout management can be categorized into distinct approaches: proactive (e.g., regular doctor visits, treating the underlying illness) and reactive(e.g., urgent care/walk-in clinic visits). Despite numerous guidelines, the optimal management strategy for gout is debated.	Two online gout communities were analyzed to contrast proactive and reactive gout care/ management. These findings suggest that 'flares', 'pain', 'swelling', and experiences related to 'uric acid' are primary motivators for individuals seeking gout care. One possibility is that pain and swelling from gout flares drive individuals to reactive care, whereas discussions on uric acid occur proactively in outpatient primary care offices.

Month	Conference	Name of Abstract / Poster	Purpose of Abstract	Results/Impact
June. 2023	Sleep 2023	Patient Experiences With Sodium Oxybate Therapy for Narcolepsy: A Social Listening Analysis	In this study, we used social listening and a survey to identify concerns in the narcolepsy community. Individuals with narcolepsy may experience increased socioeconomic burden and decreased quality of life (QoL). People with narcolepsy also are at increased risk for injury, with 30% to 50% of individuals living with narcolepsy experiencing accidents or injuries. Sodium oxybate (SO), a twice-nightly therapy, has shown effectiveness for sleep issues associated with narcolepsy; however, SO can present its own challenges for patients as a result of nighttime waking to take the required second dose.	This work demonstrated that actively listening to the unmet needs of the sleep community using social listening is an important step in understanding the efficacy of drugs, dosing regimens, and patient-reported QoL impacts, to then find solutions that reduce clinical and socioeconomic burdens. TREND was also invited to speak about these findings, emphasizing the important nature of this work.
July. 2023	National Scleroderma Foundation	Understanding the Mental Health Impact for People Living With Scleroderma Using Real-World Evidence: A Social Media Analysis	Scleroderma, or systemic sclerosis, is a chronic autoimmune condition manifesting in diverse ways. This study was designed to explore the relationship between scleroderma and mental health (MH) using personal experiences shared on social media.	Our analysis of social media data sheds light on the complex relationship between MH and scleroderma. This study characterized the impact of scleroderma on patients' mental well-being. The identification of common MH issues such as stress, anxiety, and depression further emphasizes the psychological burden experienced by individuals with scleroderma.

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July. 2023	International Journal of Molecular Sciences	The Arduous Path to Drug Approval for the Management of Prader–Willi Syndrome: A Historical Perspective and Call to Action	A call-to-action to the FDA to apply the broadest regulatory flexibility and remove obstacles to the approval of reasonable and effective treatments for people with Prader–Willi Syndrome (PWS).	Key opinion leaders determined that patients and their families are willing to accept greater risk and uncertainty for the opportunity to ameliorate the severely disabling, life-threatening symptoms of PWS.
Oct. 2023	World Sleep Congress	Understanding the Patient Experience With Sodium Oxybate Therapy for Narcolepsy	Excessive daytime sleepiness (EDS) and cataplexy are 2 of the most common symptoms affecting people with narcolepsy. Although medications for treating these symptoms have existed for decades, sodium oxybate (SO) was the first to demonstrate efficacy in relieving both symptoms in clinical trials. However, the need to wake to take the second dose presents risks for patients, including potentially dangerous dosing administration errors, such as early second doses.	Patient experiences with SO therapy (especially regarding the second dose) were assessed by collecting and analyzing survey results and conversations in patient-oriented narcolepsy social media communities. Evidence from both suggests that the inherent risks associated with the need to wake for a second dose in the middle of the night, especially with missed doses and late doses, are common and have negative impacts on patients' physical health, mental health, and quality of life. The fact that this was the 2nd accepted encore presentation of this work highlights the important contributions being made to medicine and science.

Month	Conference	Name of Abstract / Poster	Purpose of Abstract	Results/Impact
Oct. 2023	World Sleep Congress	Amplifying Voices in Sjögren's and Lupus Communities Through Social Listening: Real-World Evidence From Their Sleep Experiences	Sjögren's and lupus are chronic autoimmune diseases with shared symptoms such as joint pain, skin rashes, fatigue, and decreased sleep quality. Sleep disorders have been identified in both communities and are linked to disease progression. However, clinical guidelines and screening approaches lack a standard assessment for sleep disorders in these populations. Unrecognized sleep disorders can lead to impaired quality of life (QoL) and a proinflammatory state, compromising optimal disease management.	Data analysis revealed that insomnia, sleepiness, sleep apnea, and narcolepsy emerged as sleep issues in both the Sjögren's and lupus communities. The findings helped increase our understanding of these sleep issues from the perspective of patients living with these chronic conditions. This is pivotal for the optimal management of these disorders, as this information may not arise in the clinical setting during patient-clinician conversations.
Oct. 2023	American Association of Neuromuscular and Electrodiagnostic Medicine	Using Real-World Evidence to Understand the Diagnostic Journey of People Living With Myasthenia Gravis and Its Impact on Mental Health	Myasthenia Gravis (MG) is a neuromuscular autoimmune disease characterized by fluctuating muscle weakness and fatigue resulting from auto antibodies binding to receptors at the neuromuscular junction of skeletal muscles. This complex disease has been known to negatively affect mental health in patients, which can reduce health-related quality of life (HRQoL) and exacerbate symptoms.	Our analysis uncovered unique mental health profiles associated with members of the MG community at different stages in their diagnostic journey. Pre-diagnostic conversations were defined by more mentions of "anxiety" than post-diagnostic. Inversely, post-diagnostic conversations included significantly more mentions of "depression".

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Nov. 2023	American College of Rheumatology	Understanding Community Perspectives on Disease Management: A Social Media Analysis of Gout Care Strategies	Gout is a chronic inflammatory arthritis characterized by painful joint flare ups secondary to uric acid (UA) accumulation. Gout has been associated with negative impacts on physical, emotional, and mental health. Virtually all subspecialty groups recommend a proactive "treat-to-target" strategy to reduce serum urate levels; however, a large proportion of US patients with gout are not on urate-lowering therapy or are on too low of a dose and are therefore following a "treat-to-no symptoms" strategy.	In a comparison of the top 5 most positive management topics, UASure/ua monitoring achieved the highest mean polarity, which was significantly higher than that for other management techniques (cbd/thc, allopurinol, prednisone). Although the functional impact of polarity differences is not easily appraised, these contrasts could suggest that gout community members tend to have more positive experiences with UA monitoring than with reactive management interventions such as prednisone.
Nov. 2023	TREND Website	Living with Fabry Disease: Voices From Young Adults	To better understand the overall impact of Fabry disease (FD) on the young adult patient population and to identify opportunities to create supports tailored to their specific needs.	Insights gathered provide qualitative data on the patient experience in 3 key focus areas: 1) challenges faced by young adults living with FD; 2) unmet medical, mental, and emotional needs; and 3) a path toward solutions for tailored educational and psychosocial interventions to improve overall care and QoL.

Month	Conference	Name of Abstract / Poster	Purpose of Abstract	Results/Impact
Dec. 2023	Rheumatology and Therapy	Social Listening in Gout: Impact of Proactive vs. Reactive Management on Self-Reported Emotional States	This study aimed to characterize patient-reported outcomes from social media conversations in the gout community. The impact of management strategy differences on the community's emotional states was explored.	Proactive treatment of the root cause of gout (hyperuricemia) appears to positively impact mood. It is likely that an alternative reactive approach which downplays the reality of gout as a chronic condition could contribute to the increased levels of stress, anxiety, and depression known to affect individuals with gout [14–16] and the negative emotional states observed in this study. This research has demonstrably raised awareness within the community of the importance of proactive management of gout.

Community conversations

hold the key to untapped knowledge

Unlocked Insights

empower and evolve communities

RARE™
REVOLUTION
MAGAZINE

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