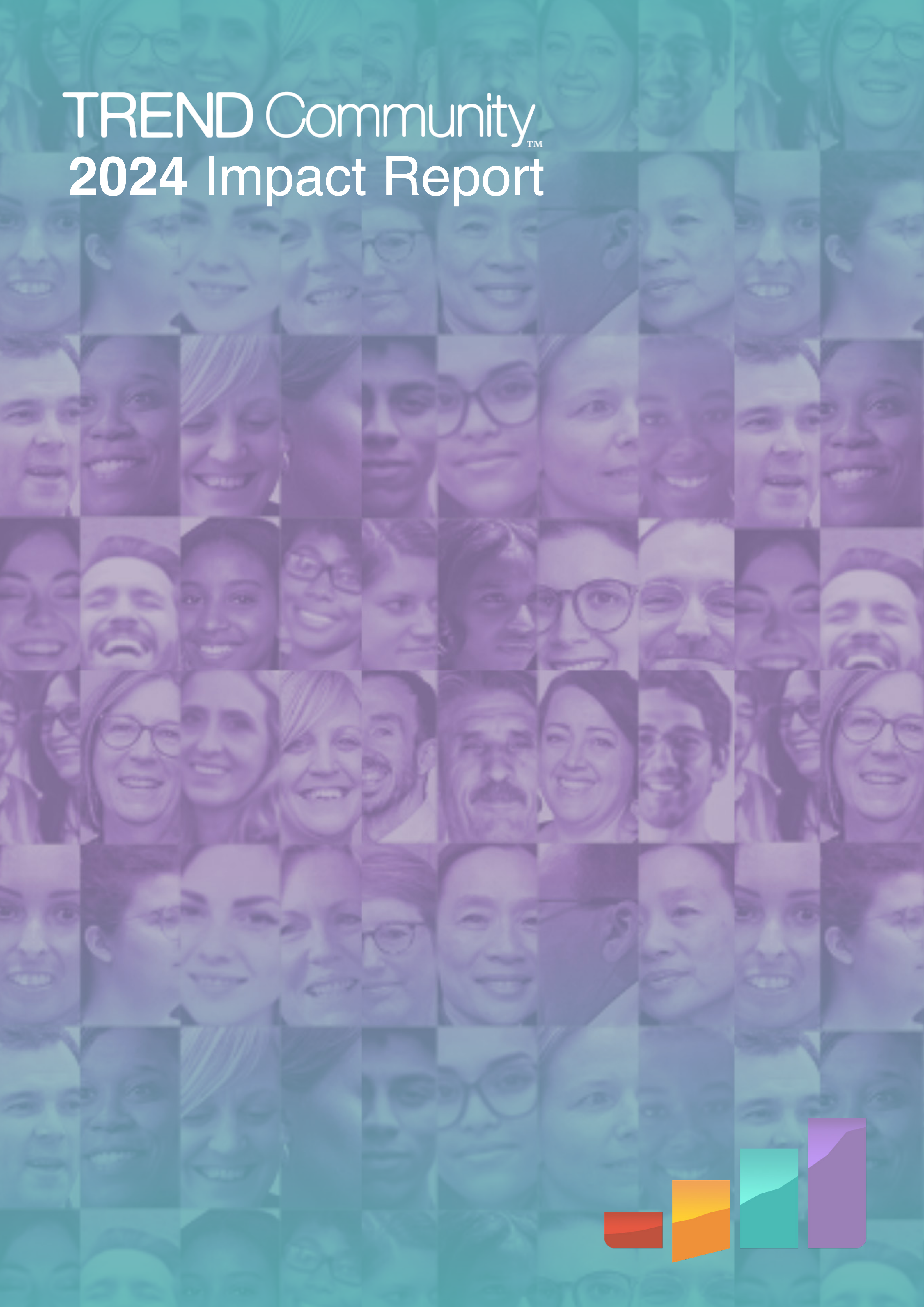
TREND Community™
2024 Impact Report



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1. Who Is TREND Community?

Who Is TREND Community?

TREND Community is a leader in AI-driven community-centered research, transforming real-world conversations into meaningful insights. We work at the intersection of advanced natural language processing and patient engagement, and use AI-driven analysis to uncover patterns, unmet needs, and opportunities for better outcomes.

Krystie™ AI

Krystie, our proprietary analytics engine, uses social listening, machine learning, and natural language processing to analyze community conversations and narratives to uncover the insights embedded within them.

Krystie was named in honor of a young girl whose story embodies the power of patient narratives. Following an experimental and extremely risky treatment, Krystie defied the odds of her Tay-Sachs diagnosis, living nearly twice as long as expected. Her fathers, Rick and Bruce, meticulously documented her journey—demonstrating how storytelling can catalyze research and instill hope. Krystie's story became a guiding force, reinforcing TREND's belief that every patient's journey holds the potential to drive meaningful change.

Our mission is simple: to elevate community voices and turn lived experiences into real-world evidence that informs research, policy, and healthcare decisions. By bridging the gap between patient communities, the non-profits that support them, researchers, and industry partners, we ensure that those most affected by rare and chronic diseases play an integral role in shaping the future of medicine.

Our vision is to **revolutionize** the world's **understanding of diseases**.

2. Why We Started and Our Vision

Why We Started

TREND Community started with a personal experience. Founders Maria Picone and Christopher DeFelice found themselves immersed in the frightening and disorienting reality of navigating life with a rare disease when their child was diagnosed with Prader-Willi syndrome (PWS). Feeling isolated and ill-equipped, they searched for answers and support.

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. The conversations contained a wealth of knowledge—insights that could shape care, offer hope, and improve outcomes. However, this invaluable information remained largely untapped by traditional healthcare and research institutions.

Inspired by the power of these organic communities, Maria and Christopher created TREND Community—a platform designed to elevate communities by transforming real-world experiences into actionable insights.

Our Vision: Revolutionize the World’s Understanding of Disease

As a certified B-corporation, TREND Community is committed to reshaping the way rare and chronic diseases are understood and addressed.

Our work is guided by five key pillars:

1. **Uncovering Hidden Insights:** Identifying patterns and themes in patient experiences that might otherwise go unnoticed.
2. **Bridging the Gaps in Research:** Connecting patient communities with researchers, healthcare providers, and industry leaders.
3. **Empowering Communities:** Ensuring that lived experiences are recognized as essential to medical advancements.
4. **Accelerating Treatment Development:** Using real-world data to inform drug development and clinical trial design.
5. **Driving Meaningful Change:** Providing healthcare partners with the evidence they need to create solutions that truly reflect what matters most to patients.

By placing patient communities at the center of research, TREND is ensuring that their voices don’t just contribute to the conversation—they drive it.

3. The Values That Guide Us

At TREND, our commitment to community-centered innovation extends beyond data—it shapes how we operate, the values we uphold, and the impact we strive to create across the healthcare ecosystem.

Certified B Corporation

As a Certified B Corporation, TREND meets the highest standards for social and environmental performance. This certification reflects our mission to operate with ethics, transparency, and purpose.

The Power of Ethical Partnership

Our mission is powered by more than algorithms. It's driven by trust, humility, and deep respect for the communities we serve. Listening is a privilege—and TREND's ethical framework reflects that. We carefully preserve the privacy, dignity, and agency of every person whose story informs our work.

Tech in Motion Award Winner

In 2024, TREND was honored with the Best Tech for Good Award — a recognition of our innovative use of technology to elevate patient voices and transform real-world experiences into actionable insights.

> "We intentionally built our company to be mission-driven—not just in words, but in action. Choosing B Corp certification meant choosing transparency, integrity, and a commitment to measurable outcomes."
>
> **Maria Picone**
> CEO & Co-Founder

> "As we continue to grow, our commitment remains unchanged: to deliver insights that not only shape research and treatment but also honor the people behind every post, comment, and conversation."
>
> **Lauren Dougherty**
> COO

> "Innovation at TREND doesn't come from the top down—it comes from listening deeply to the pioneering communities and clients we serve. With their insight and partnership, we've remained committed to rapidly evolving our technology and approaches—driving meaningful disruption in how patient experience informs research, development, and care."
>
> **Christopher DeFelice**
> CTO & Co-Founder

4. Our Process:
TREND Real World Evidence Accelerators

Turning Community Conversations Into Results

TREND Community is redefining what it means to engage with people living with rare and chronic conditions. At the core of our approach is the TREND Real-World Evidence Accelerator — a three-part methodology that transforms unstructured community narratives into actionable, real world evidence. Built on trust, powered by advanced AI, and focused on results, this process enables us to turn real-world conversations into real-world change.

In short, we turn community **conversations** into **results**.

1. TRUST:
We Earn and Uphold Community Trust

TREND works hand-in-hand with communities, always guided by the principle that listening is a privilege that must be continually earned. Our ethical framework prioritizes privacy, transparency, and respect. We ensure every community member remains anonymous, and we never include personally identifiable information in our data analysis.

This commitment allows us to build meaningful, long-term relationships with rare and chronic disease communities. Without their trust, our work wouldn't exist—and we never take that trust for granted.

2. AI-DRIVEN INSIGHTS:
We Analyze Community Conversations Using Krystie™

Our proprietary analytics engine, Krystie, uses advanced natural language processing to identify patterns, extract themes, and surface meaningful insights from patient conversations.

Krystie doesn't just capture individual stories—it synthesizes thousands of shared experiences, helping to uncover unmet needs, emotional drivers, treatment barriers, and more. These insights reflect what truly matters to patients, in their own words.

3. RESULTS:
We Deliver Evidence That Drives Action

Through trusted partnerships and data-driven insights, we transform our findings into evidence, which informs stakeholders across the healthcare ecosystem: patients, advocacy groups, researchers, pharmaceutical partners, and clinicians.

5. How TREND Accelerates and Strengthens

> “TREND sits at the intersection of individual patient stories and large-scale clinical research—bridging the gap to inform every point along the medical spectrum, from everyday encounters to trial design.”
>
> **Dr. Brian LaMoreaux**
> Rheumatologist & Executive Medical Director, **AMGEN**

RESEARCH & DEVELOPMENT

CLINICAL TRIALS

DRUG DEVELOPMENT

Identify Promising Compounds

- Identify unmet needs & daily challenges
- Prioritize research based on real-world impact
- Inform product profiles with actual patients’ needs
- Define meaningful outcomes from the patient perspective

Prove Safety & Efficacy

- Define endpoints that matter to patients
- Improve recruitment and retention by understanding motivations and barriers
- Ensure criteria reflect real-world diversity
- Use participant feedback to make mid-study adjustments

TREND’S ROLE

Start Early:
TREND helps map the patient journey from the outset, capturing authentic patient language during early research stages. These real-world insights reveal unmet needs, disease burden, and emotional drivers that inform early pipeline planning.

Define Research Priorities:
With TREND as a partner, you can shape target product profiles and define meaningful outcomes that guide early-stage research and investment decisions by surfacing what truly matters to patients.

Design More Patient-Friendly Trials:
Apply TREND’s insights to optimize protocol design, inclusion/exclusion criteria, recruitment strategies, and study materials.

Continuously Educate and Build Awareness:
TREND helps uncover and address gaps in disease understanding and clinical trial awareness—both among healthcare providers and within the broader community—to continuously refine study materials, ultimately boosting participation.

Drug Development at Every Stage

REGULATORY REVIEW

Secure Approval

- Support submissions with testimonials and real world data
- Highlight quality-of-life improvements that regulators increasingly consider
- Shape risk/benefit discussions with patient perspectives
- Demonstrate patient need and demand

Give Patients a Voice:
Using TREND's insights, demonstrate which symptoms matter most, what risks are acceptable, and what outcomes are truly meaningful—ensuring regulatory decisions reflect real patient priorities, not just clinical benchmarks.

Support Regulatory Decision-Making:
TREND combines patient-centered narratives and real-world data to add relevance and depth to regulatory evaluations, ultimately strengthening the case for approval.

LAUNCH

Roll Out Treatment

- Tailor education and support to meet patients' needs
- Craft messaging that resonates authentically
- Build trust through early, transparent engagement
- Strengthen market access with patient-reported value

Build Launch Strategies Rooted in Trust and Authenticity:
TREND's insights ensure communication reflects the tone, properties and language of the community and supports the development of campaigns and messaging that genuinely resonate.

Leverage Real Time Feedback for Commercial Success:
Using TREND's insights, track initial reactions and sentiment around factors like cost, side effects, and access to shape ongoing support strategies, enhance patient experiences, and guide adjustments to commercialization efforts.

POST-MARKET

Track Real-World Impact

- Collect real-world data on long-term outcomes
- Monitor satisfaction, emerging trends, and community shifts in behavior
- Identify opportunities for label expansion
- Drive continuous improvement in support and adherence programs

Strengthen Market Position and Product Success:
Leverage TREND's insights by continuously monitoring community conversations to gain competitive intelligence and valuable insights into the effectiveness of product campaigns on community behavior and engagement.

Monitor Real World Experiences:
Use TREND's analysis to reveal real-world treatment outcomes, identify unmet needs, and monitor sentiment and language to uncover opportunities for enhancing patient support, access, and education.

6. Our Case Studies

TREND's work comes to life through the stories of the people and communities it serves. The case studies that follow demonstrate TREND's unique ability to bridge gaps — between patients and providers, advocacy and industry, lived experience and regulatory action.

Each case study highlights a distinct challenge — and showcases how TREND bridges gaps to unlock new possibilities in care and research.

1. Building the Case for the FDA: TREND's Ability to Turn Barriers into Breakthroughs

> "When others saw a dead end, TREND saw an opening. Their data, innovative thinking, and deep connection to the communities they partner with, didn't just support our trial — it helped shape it. They were the bridge that made this possible."

Cate McCanless
Chief Corporate Affairs Officer,
Harmony Biosciences

2. From Unspoken to Validated: TREND's Role in Mobilizing a Community to Drive FDA Approval

> "Working with TREND gave us a level of insight we couldn't have accessed through traditional research alone. Patients were hesitant to speak publicly — but TREND's approach made it safe for them to share what really mattered. That understanding helped shape not just our strategy, but the FDA's final decision."

Jennifer Gudeman
Vice President, Medical and Clinical Affairs, Avadel Pharmaceuticals

3. From Hesitance to Partnership: TREND's Model for Building Trust and Driving Change

> "The work TREND develops and delivers is as crucial as it is innovative. It highlights the relevance of real-world patient needs and the transformative role of social listening in reshaping clinical research and standards of care. TREND is the voice of real-world patients."

Ana Vieira
Vice President, Sjögren Europe

4. From Reactive to Proactive Care: TREND's Approach to Shifting Behavior Through Listening

> "TREND's insights didn't just inform our approach—it gave us the tools to truly connect with the gout community and drive lasting change. The impact on patient engagement has been transformative."

Kristina Davidson
Director, Patient Advocacy,
Amgen (formerly Horizon Therapeutics)

Case Study #1: Building the Case for the FDA: TREND's Ability to Turn Barriers into Breakthroughs

TREND Partners

The Problem: Under-recognized and Undiagnosed Symptoms, No Clear Path Forward

Prader-Willi syndrome (PWS) is a rare neurodevelopmental condition often associated with hyperphagia and obesity. However, for families living with PWS, the full spectrum of symptoms was more complex — signs like severe daytime sleepiness and unusual 'sleep attacks' were commonly observed but lacked clear medical terminology. Many parents misinterpreted these symptoms as behavioral issues, which made it even harder for doctors to understand the full extent of the condition. These undocumented symptoms were overlooked in medical literature, leaving patients and families without a clear diagnosis.

Without official diagnosis of these symptoms, pharmaceutical companies were unable to establish a foundation for developing new treatments, and families were left with few options. To complicate matters, there was a lack of accessible natural history data, making it difficult to design clinical trials. This created a regulatory dead end, where progress toward new treatments seemed impossible.

The Solution: Building a Path Where None Existed

Under-recognized and undiagnosed symptoms. Missing data. TREND and Harmony Biosciences were facing multiple roadblocks — so they got to work charting a new course.

First, by using Krystie™, TREND's proprietary analytics engine, TREND uncovered a consistent sleep signal in the PWS community, revealing key symptoms like excessive daytime sleepiness, narcolepsy, and cataplexy. These insights provided a new framework for understanding PWS and laid the foundation for a new treatment indication.

Next, TREND met Tiina Urv, Program Director at NIH, who connected TREND with the PI's of an unreleased natural history study.

With months of persistence and eventual intervention from NIH, TREND successfully gained access to supporting data, breaking through yet another roadblock.

Now, armed with more data and insights made available through their collaboration with the NIH, TREND turned to the FDA, presenting a rigorous case and seeking guidance from Dr. Janet Woodcock, former Principal Deputy Commissioner of the FDA. In their presentation, TREND highlighted critical insights into PWS-related sleep issues, compellingly establishing the urgent need for treatment. This led to the FDA suggesting an innovative solution, paving the way for a clinical trial that would have otherwise been impossible. TREND then brought this breakthrough to Harmony Biosciences, which opened an IND and launched a PK study involving children already accessing pitolisant through personal importation.

The Results: Bridging Voices, Data, and the FDA

TREND's insights and communication with regulatory agencies led to successful Phase I, II, and III clinical trials:

- PK Study: Complete
- Phase 2: Complete
- Phase 3: In Progress

TREND played a pivotal role in supporting Harmony's clinical trial recruitment, drawing on years of trusted relationships within the PWS advocacy community—earned through respect, collaboration, and meaningful contributions.

TREND elevated patient perspectives by presenting findings at major sleep conferences — bringing real-world insights to the scientific community at:

- SLEEP, 2019
- American Academy of Neurology, 2019
- PWSA | USA, 2023

TREND published peer-reviewed research in *Journal of Clinical Sleep*, turning patient-generated data into validated scientific evidence.

TREND co-developed the James P. Henson Jr. PWS Goal Inventory—an FDA-recognized tool transforming how clinical teams measure progress and quality of life through Goal Attainment Scaling (GAS)

What the FDA is Saying

> "To meet the needs of a community forced to operate under a different paradigm and spur the development of new drugs… we have to do things differently, try new approaches, and use new and modern technologies to advance innovation."
>
> **Dr. Janet Woodcock**
> Former Principal Deputy Commissioner, U.S. Food and Drug Administration

Case Study #2: From Unspoken to Validated: TREND's Role in Mobilizing a Community to Drive FDA

TREND Partners

Avadel pwn4pwn.org FDA

The Problem: Unspoken Burdens, Clinicians Left in the Dark

For years, the narcolepsy community lived with a contradiction. The medication that helped manage their condition also disrupted their lives — requiring them to wake in the middle of the night for a second dose of sodium oxybate. It worked, but not without trade-offs like lost rest and compromised safety. Avadel was hearing stories directly from patients about these challenges, but clinicians often weren't — creating a disconnect between lived experience and clinical perception. That's where TREND Community came in — not as an outsider, but as a trusted partner able to surface and validate what patients were already saying.

The Solution: Community Collaboration to FDA Approval

TREND Community, in collaboration with Avadel Pharmaceuticals, worked in close partnership with the patient advocacy group, PWN4PWN (People With Narcolepsy for People With Narcolepsy) — to analyze thousands of patient-shared experiences using TREND's proprietary analytics engine, Krystie™.

Through social listening and collaboration, TREND uncovered two core concerns: the burden of twice-nightly dosing and a widespread fear that speaking out might jeopardize access to existing treatment. By translating these community insights into real-world evidence, TREND was instrumental in the FDA approval of a once-nightly sodium oxybate therapy—expanding treatment choices for patients in a space where few exist.

The Results: TREND's Unique Role: Bridging Community with Pharma Partners and Regulatory Agencies

By reflecting voices and concerns of the narcolepsy community back to them and earning their trust, **TREND** was able to quickly mobilize the community — generating over 80 survey responses and 4 in-depth interviews in just two weeks.

> "There was so much fear in speaking out — we didn't want to risk losing access to the only treatment we had. But TREND made the community feel safe. They gave us language, community, and the chance to finally be heard. For me, once-nightly treatment has been life-changing — and I believe our voices helped make it possible."
>
> **Sarah Berkowitz**
> person living with narcolepsy

TREND translated the social media insights, surveys, and interviews into a compelling data packet and advocacy letter — delivering real-world evidence directly to the FDA to spotlight the unmet need for once-nightly therapy.

TREND elevated patient perspectives by presenting at three major sleep conferences — bringing real-world insights to the scientific community at:

- Advances in Sleep and Circadian Science, 2023
- SLEEP, 2023
- World Sleep Congress, 2023

TREND published peer-reviewed research i*n Brain Sciences*, turning patient-generated data into validated scientific evidence.

What Physicians are Saying

> "TREND's ability to listen to honest patient conversations and capture what's overlooked in clinical settings is extraordinary. Their data helped me ask sharper questions, uncover hidden concerns, and ultimately deliver more compassionate, personalized care. When people form communities on social media — speaking honestly and sharing their journeys — they aren't just supporting each other; they're contributing to the transformation of healthcare."
>
> **Dr. Anne Marie Morse**
> Pediatric Neurologist and Sleep Specialist at Geisinger Health, CEO of DAMM Good Sleep

Scan the QR code to listen to the full episode of **Sleeping Around** podcast

Case Study #3: From Hesitance to Partnership: TREND’s Advocacy Collaboration Model

TREND Partners

Sjögreneurope AMGEN

The Problem: Complex Needs, Cautious Communities

Sjögren’s Syndrome is a complex, often misunderstood condition marked by invisible symptoms, delayed diagnoses, and unmet needs. For patients, the journey can be isolating. Advocacy organizations like Sjögren Europe are essential to elevating patient voices — yet even as advocacy leaders living with the condition themselves, they recognized the need to ensure the community’s diverse experiences were represented.

When first approached by TREND with an offer to help, the advocacy community was understandably cautious and protective of their members and wary of new outside partnerships. But as pharmaceutical companies showed a growing interest and an urgent need to better understand the patient journey, it became clear that everyone — patients, advocates, the medical community, and industry alike — stood to gain by working together toward a shared goal.

The Solution: Co-Creation in Action

TREND, in collaboration with Amgen (formerly Horizon Therapeutics), partnered with Sjögren Europe and listened deeply — analyzing over a decade of online community conversations to identify emerging patterns and unmet needs. While initial caution from the advocacy community was understandable, TREND’s patient-centered approach built trust over time, transforming hesitance into trusted partnership.

What began as listening evolved into a thriving collaboration among patients, advocates, clinicians, and industry. Together, we co-facilitated workshops, conferences, and deeper engagements that uncovered rich insights — including the impact of flares, dental health challenges, sleep issues, and mental health. This continuous data feedback loop — where data sparked dialogue, dialogue surfaced insights, and insights drove action — fueled a more representative, community-powered understanding of life with Sjögren’s.

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The Results: TREND’s Model — Empowering Advocacy with Insight, Tools, and Trust

TREND elevated patient perspectives by presenting findings at five major conferences — bringing real-world insights to the scientific community at:

- EULAR 2023, 2024
- ISSjD Symposium, 2024
- World Sleep 2023
- ACR 2023
- SEGM Symposium 2023

TREND collaborated with Dr. Chiara Baldini — after connecting at a TREND led EULAR 2023 workshop — to co-develop a clinically relevant flare lexicon that bridges communication gaps between patients and providers.

TREND co-created the publicly available webinar “Breaking the Silence: Addressing Mental Health in the Sjögren’s Community” with rare disease psychologist Dr. Al Freedman, helping to reduce stigma and foster open, honest dialogue.

> “It’s truly been a pleasure to partner with TREND to help provide rare disease patients and families an opportunity to be heard. From facilitating listening sessions to leading support groups to collaborating on webinars, working with TREND to create space for rare stories to be shared - and acted upon - has been rewarding and inspiring.”
>
> **Dr. Al Freedman**
> Rare Disease Psychologist

TREND co-authored a manuscript with advocacy and industry partners — transforming community insights into scientific evidence now under review for publication

What Physicians are Saying

> “As a clinician, I’ve often sensed a disconnect between how patients talk about their experiences and how we, as physicians, define and document them. TREND’s approach helped bridge that gap. Our collaboration to co-develop a flare lexicon was an important step toward aligning patient narratives with clinical frameworks — and ultimately, delivering more empathetic, informed care.”
>
> **Dr. Chiara Baldini**
> Rheumatologist, University of Pisa

Case Study #4: From Reactive to Proactive Care: TREND's Role in Shifting Gout Community Behavior

TREND Partners

AMGEN
GOUT SUPPORT GROUP of America
If It's Over 6, You Need A Fix
GLOBAL HEALTHY LIVING FOUNDATION
ALLIANCE FOR Gout Awareness

The Problem: A Community Seeking Understanding and Answers

The gout community faces significant challenges in managing a painful, chronic condition. Misinformation around home remedies like cherry juice and apple cider vinegar often exacerbates the issue, preventing patients from accessing evidence-based treatments. Alongside physical pain, emotional burdens such as fear, guilt, and shame frequently emerge, particularly among younger individuals and those facing comorbidities like kidney disease.

Traditional educational campaigns have struggled to shift community behavior, leaving patients stuck in a cycle of reactive care — only seeking help during flare-ups or after experiencing severe pain. This gap in effective education tools underscores the need for a more collaborative approach — one that begins by reflecting the community's expressed experiences, rather than simply reiterating existing clinical literature that often contains gaps and leaves patients feeling disconnected and unheard.

The Solution: Continued Support and Analysis, A Measurable Shift in Community Behavior

TREND, leveraging its proprietary social listening and analytics platform Krystie™, partnered with Amgen (formerly Horizon Therapeutics) and Gout Support Group of America (GSGA), to analyze online patient community conversations. Initial findings confirmed that discussions around home remedies like cherry juice and apple cider vinegar were widespread. Additionally, TREND's insights revealed the emotional toll gout takes on patients. When these findings were shared back with the community, patients felt truly seen, their experiences validated, which inspired them to continue collaborating with TREND for further insights.

Over the next three years (2022–2024), TREND continued to analyze community conversations, generating quarterly reports that were shared back with the community.

These reports continued to surface insights ranging from the importance of proactive care and uric acid monitoring to the emotional burden faced by younger patients dealing with the stigma around gout. TREND and GSGA used these insights to inform ongoing education and engagement efforts, and not only saw a reduction in home remedy discussions but also fostered an increase in conversations about proactive care such as uric acid monitoring. Together, TREND and GSGA achieved what traditional educational materials rarely accomplish—not just observing a shift in community behavior, but actually measuring it.

The Results: TREND's Model — Listening, Learning, and Leading Behavior Change

TREND published a series of reports that captured evolving insights from the gout community over time:

- 2022 Gout Real World Evidence Accelerator
- 2024 Q1 Report: Gout
- 2024 Q2 Report: Gout and Comorbidities
- 2024 Q3 Report: Gout and Activities of Daily Living
- 2024 Q4 Report: The Emotional Impact of Gout: Shame and Guilt

TREND gained external validation through presentations at major conferences, showcasing TREND's insights and findings. Notable conferences included:

- EULAR Conference (May 2023)
- ACR Convergence (Nov 2023)

TREND hosted The Art and (Data) Science of Rheumatology, at Sparks Gallery in San Diego aligned with ACR 2023. The event brought together patients and advocates, giving them a platform to share their experiences with rheumatic conditions.

TREND published findings in the peer-reviewed journal *Rheumatology and Therapy*, contributing to the literature on community-driven education.

What Patient Advocates Are Saying

> "Through TREND, we saw a real shift in community behavior—our members took action in ways we hadn't seen before."

Gary Ho
Patient Advocate and Co-Founder of
Gout Support Group of America

7. 2024 **Publications, Conferences, Advocacy Events**

Below is an overview of where and how TREND shared its work this year:

13 Conferences & Advocacy Events

- World Symposium
- The 5th International Symposium of IgG4-RD
- The 16th International Symposium Sjögren's Disease
- SLEEP 2024
- American College of Rheumatology
- World Orphan Drug Congress
- EULAR
- PWSA | USA D.C. Fly In
- Rare Disease Week on Capitol Hill
- Rare Disease Day At NIH
- Patients as Partners
- PWSA | USA Residential Providers Conference
- MGFA National Patient Conference

3 Peer-Reviewed Journals

- *Clocks & Sleep*
- *Sleep Epidemiology*
- *Brain Sciences*

11 TREND Reports & Webinars

- **Launch Reports:** Summarize the primary discussions taking place in the online communities.
- **Quarterly Reports:** Provide insights on a key topic of interest to the community based on their conversations.
- **Pulse Reports:** Provide rapid-response summaries reflecting communities' lived experiences, based on real-time language analysis.
- **Community Voice Reports:** Deep-dive reports co-created with patient communities to explore lived experience and highlight gaps in care.
- **Webinars:** Designed to spark dialogue and raise awareness, TREND webinars bring together community voices, healthcare experts, and advocates to explore key topics affecting people living with rare and chronic conditions.

2024 Conferences & Advocacy Events

20th ANNUAL WORLDSymposium February 4-9, 2024	**Poster:** Cognitive And Mental Health Challenges In Fabry Disease: A Real-World Evidence Study Using Social Media
THE FIFTH INTERNATIONAL SYMPOSIUM ON IgG4-RELATED DISEASE	**Poster:** Understanding the Needs of the IgG4-Related Disease Community by Taking a Patient-Centric Approach
rita The 16th International Symposium for Sjögren's Disease	**Satellite Symposium:** Sjögren's Satellite Symposium Summary: From Noise To Knowledge: Combining Social Media Conversation And AI To Reveal Lived Experiences In Sjögren's Disease
SLEEP 2024 HOUSTON, TX | JUNE 1-5	**Poster:** Beyond Brain Fog: A Social Listening Analysis Of Impaired Cognitive Functioning In Sleep Disorders
ACR Convergence Where Rheumatology Meets #ACR24	**Poster:** Using Social Listening To Understand The Patient Voice: The Daily Impacts Of Sjögren's Disease
WORLD OrphanDrug Congress USA 2024	**Poster:** Adaptation Of Goal Attainment Scaling For Prader-Willi Syndrome: Development Of A Goal Inventory For Standardized Implementation
	Poster: The Symptoms, Challenges, And Issues Of Prader-Willi Syndrome: The Development Of A Conceptual Model

eular | EUROPEAN ALLIANCE OF ASSOCIATIONS FOR RHEUMATOLOGY

Abstract: Using Social Media Listening to Characterize the Flare Lexicon in Patients with Sjögren’s Disease

Abstract: Barriers to Diagnosis, Treatment, and Care for IgG4-Related Disease: Data from a Large Cohort of Italian Patients

Abstract: How Does Pain Vary? Identifying Unique Pain Experiences Between Arthritis Communities on Social Media

Abstract: The Use of Natural Language Processing to Characterize Disease Burden: Sexual Distress in Sjögren’s Disease

D.C. FLY-IN
ADVOCACY IN ACTION
D.C. FLY-IN 2024

RARE DISEASE WEEK
ON CAPITOL HILL

RARE DISEASE DAY at NIH

PATIENTS as PARTNERS®
in Clinical Research

Prader-Willi
SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES
RESIDENTIAL PROVIDERS Conference

MGFA’s National Patient Conference

2024 Peer-Reviewed Journals

clocks & sleep	**Article:** Use Of Basket Trials To Solve Sleep Problems In Patients With Rare Diseases
sleep epidemiology	**Opinion:** Listening To Patients: Incidence And Distribution Of Sleep Disorders In Prader-Willi Syndrome
brain sciences	**Article:** Understanding The Patient Experience With Twice-Nightly Sodium Oxybate Therapy For Narcolepsy: A Social Listening Experiment

2024 TREND Reports

Myasthenia Gravis Facebook Support Group	**Launch Report:** Myasthenia Gravis
TREND Connect IgG4-RD Connect on Discord	**Launch Report:** Igg4-Related Disease
Prader-Willi SYNDROME ASSOCIATION | USA SAVING AND TRANSFORMING LIVES	**Launch Report:** Prader-Willi Syndrome
	Pulse Report: PWS And Pain

2024 TREND Reports (Continued)

GOUT SUPPORT GROUP of America If It's Over 6, You Need A Fix	**2024 Q1 Report**: Gout
	2024 Q2 Report: Gout And Comorbidities
	2024 Q3 Report: Gout And Activities Of Daily Living
	2024 Q4 Report: The Emotional Impact of Gout: Shame and Guilt
Schinzel-Giedion Syndrome Foundation	**Community Voice Report:** Schinzel-Giedion Syndrome
PROJECT 8P	**Community Voice Report:** Chromosome 8p
Sjögreneurope	**Webinar:** Breaking the Silence Addressing Mental Health in the Sjögren's Community

8. 2024 **Citizen Scientist Award**

Honoring the Legacy of James P. Henson Jr.

This year, the TREND Community Citizen Scientist Award is presented in honor of James P. Henson Jr., whose life has inspired a new path forward for how progress is defined—and measured—within the Prader-Willi syndrome (PWS) community.

In the face of unimaginable hardship, James's family chose to turn grief into purpose. With courage, clarity, and deep love for their son, they became advocates not only for James, but for every family navigating the complexities of PWS. Their advocacy, in partnership with TREND Community, Ardea Outcomes, and Miller's Kids Fund, led to the creation of the James P. Henson Jr. PWS Goal Inventory—a tool now guiding clinical teams and caregivers in setting and measuring personalized goals through Goal Attainment Scaling (GAS).

Recognized by the FDA and built on conversations with experts and families across age groups, this first-of-its-kind inventory is already helping to shift how therapeutic progress is understood for those living with PWS. It offers clinicians, researchers, and caregivers a more meaningful way to track what matters—individual growth, milestones, and quality of life.

James's story, and the legacy carried forward by his family, is a reminder that even in the hardest moments, one voice—and one child's journey—can spark lasting change for an entire community.

Previous Citizen Scientist Award Winners:

2019

Lara Pullen, PhD, co-founder of CHION Foundation, was honored for her unwavering dedication to the Prader-Willi syndrome (PWS) community. Her research and advocacy played a key role in securing FDA approval for a new treatment indication. Her commitment to elevating patient voices, advanced both scientific progress and hope in the rare disease space.

2020

Terry Jo Bichell, PhD, founder of COMBINEDBrain, was recognized for her leadership in accelerating clinical research for people with severe, rare genetic neurodevelopmental disorders. Her work helped unite cross-condition communities and drive the path toward treatment.

2021

Claire Crisp & Lindsay Jesteadt, co-founders of Sleep Consortium, were recognized for their leadership in accelerating next-generation therapy development for central disorders of hypersomnolence. Their advocacy helped shape national research conversations and champion sleep health in rare disease communities.

2022-23

Gary Ho, patient advocate and co-founder of Gout Support Group of America (GSGA) was honored for empowering the gout community through science-driven advocacy efforts. His work helped generate peer-reviewed research and positioned GSGA as a trusted source of scientifically sound information and hope.

9. What Our Partners Are Saying

TREND Community operates at the center of a unique ecosystem, bridging the worlds of patients, advocacy groups, and industry stakeholders. Our partners span rare and chronic disease communities, researchers, pharmaceutical leaders, and clinicians—each working alongside us to elevate patient voices and translate experience into action.

Client & Industry Collaborations

Across the healthcare ecosystem—from biotechs and pharma to payers, providers, and regulators—clients rely on TREND to surface real-world needs and inform critical decisions.

> TREND's insights played a key role in the successful launch of the first approved treatment for PWS. They enabled our team to quickly understand the community's perspectives and needs, shaping an approach that truly resonated with families.

Meredith Manning
Chief Commercial Officer,
Soleno Therapeutics

SOLENO
THERAPEUTICS

> For too long, clinical trials in Prader-Willi syndrome have relied on standardized measures that overlook the real struggles families face each day. With TREND's insights, we were able to develop a new tool grounded in real-world experiences—one that brings us closer to personalized outcome measures and, ultimately, more meaningful and effective treatments.

Dr. Jennifer Miller
Pediatric Endocrinology,
University of Florida, Miller's Kids Fund

UF UNIVERSITY of FLORIDA
Miller's Kids Fund

> TREND taps into the value of community, communication, and different ways of delivering valid information. Its work informs on the symptom spectrum, care gaps, and associated challenges and this is making a real difference in the lives of people living with rare and chronic conditions.

Dr. Anne Marie Morse
Pediatric Neurologist and Sleep Specialist
Geisinger Health, DAMM Good Sleep

DAMM
Good Sleep

> Social listening allowed us to uncover crucial insights that patients were too hesitant to share through traditional methods. By addressing missed doses, sleep disruptions, and safety concerns, we were able to advocate for a treatment that truly meets their needs—helping shape both scientific understanding and regulatory decisions.

Jennifer Gudeman
Vice President Medical and Clinical Affairs,
Avadel Pharmaceuticals

Avadel

> Through our partnership with TREND, we were able to better understand barriers to recruitment, mitigate those barriers, and successfully enroll our phase 2 study.

Ann Adee
Senior Director Clinical Operations,
Harmony Biosciences

HARMONY
BIOSCIENCES

What Our Partners Are Saying

Community Partnerships

We believe that meaningful insights start with trust. TREND has built long-term collaborations with communities who recognize our commitment to privacy, transparency, and shared purpose. These relationships are foundational to our work.

> TREND helped our community find its voice and together we played a pivotal role in the approval of a new treatment for narcolepsy.

Feri Ascension
Vice President, PWN4PWN

pwn4pwn.org

> It's truly been a pleasure to partner with TREND to help provide rare disease patients and families an opportunity to be heard. From facilitating listening sessions to leading support groups to collaborating on webinars, working with TREND to create space for rare stories to be shared - and acted upon - has been rewarding and inspiring.

Dr. Al Freedman
Founder, Rare Counseling

Rare Counseling

> The work TREND develops and delivers is as crucial as it is innovative. It highlights the relevance of real-world patient needs and the transformative role of social listening in reshaping clinical research and standards of care. TREND is the voice of real world patients.

Ana Vieira
Vice President, Sjögren Europe

Sjögreneurope

> TREND's insights drove the rapid development of a new outcome measure for our community.

Andrew Gilly
Founder and President,
Miller's Kids Fund

Miller's
Kids
Fund

> Partnering with TREND has been incredibly empowering. It's given me a sense of agency in the face of something that often feels beyond my control. Together, we've also made meaningful progress in amplifying the often-overlooked experiences of women in our community.

Alex Streczyn
Patient Advocate and Admin,
IgG4-RD Connect on Discord

TREND Connect
IgG4-RD Connect
on Discord

> Through TREND, we saw a real shift in community behavior—our members took action in ways we hadn't seen before.

Gary Ho
Patient Advocate and Co-Founder,
Gout Support Group of America

GOUT SUPPORT GROUP
of America
If It's Over 6, You Need A Fix

10. Future Vision

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.

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.

RARE™
REVOLUTION
MAGAZINE

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