



ITSAN's Position on Engaging with Science, Research, and Industry

A message to the TSW community from ITSAN leadership

We See You. We Hear You. We Are Here for You.

Living with TSW means navigating something most people around you cannot fully understand - the physical pain, the isolation, the exhausting search for answers, and the grief of having trusted a system that let you down. Many of you came to ITSAN not just looking for information but looking for someone who actually believed you. We do. And everything we do as an organization flows from that.

We know that for much of this community, trust has been hard-won and easily broken. Too many of you were dismissed, disbelieved, or handed another prescription when what you needed was acknowledgment. The idea of ITSAN forming any kind of relationship with pharmaceutical companies or research institutions may feel, at first, like another version of that betrayal. We understand that. And we want to speak to that concern directly - not to convince you to feel differently than you do, but because you deserve to know exactly how we think about these relationships and why.

We also know something else about this community: you are not passive. You are actively searching for ways forward. You are researching, experimenting, connecting, and doing everything within your power to find a path back to health - for yourself and for others. Many of you are trying newer medications and treatments in the hope that something will help ease the suffering while your body heals. You are not waiting for the system to catch up to you. ITSAN's role is to make sure that as you search, you have access to honest, balanced, medically sound information so that every decision you make is an informed one.

This document explains how we approach two important areas: our partnerships with the scientific and research community, and our relationships with pharmaceutical and biotech industry. These are different kinds of relationships, governed by different standards and serving different purposes. Both are grounded in the same foundation: our commitment to you.

Who We Are — And What We Stand For

ITSAN's mission is to raise awareness of TSW and to support every individual and family living with it. Our three-part plan - Protect, Prove, Prevent - guides everything we do. We **protect** by creating a space where you are believed, resourced, and supported. We **prove** by building the scientific and clinical evidence that makes TSW impossible to dismiss. We **prevent** by demanding the transparency, accountability, and systemic reform that will stop this from happening to the next generation of patients.

We are guided by five values: Conviction, Compassion, Courage, Humility, and Goodwill. We hold all five simultaneously, which means we fight hard and we listen carefully. We do not back down, and we do not lash out. We are also clear about **what we are not**: we are not anti-medicine, not anti-doctor, and not anti-steroid. We believe topical steroids have their place in medicine and can be life-saving in certain circumstances, but there must be better stewardship around their prescription, and far better guidance about their risks, their limits, and the questions that remain unanswered, so that every decision to use them is a fully informed one. That transparency is what we advocate for, and we hold that position whether we are talking to a patient, a physician, a researcher, or a pharmaceutical company.

PART ONE

Partnering with Science & the Research Community

Why Research Is at the Heart of Everything

One of the most painful realities of TSW is that healing is so slow, so unpredictable, and so unsupported. The average recovery takes two to five years. Some people take longer. And right now, there are no clinically validated treatments that can meaningfully shorten that timeline. You are largely left to navigate it on your own — in online communities, through trial and error, with little guidance from the medical professionals who should be your partners in recovery.

That has to change. And the only way it changes is through rigorous, credible, patient-centered research. Not just more of the same but deeper, more targeted investigation into what is actually driving TSW at a biological level: why some people are more vulnerable than others, what interventions genuinely support recovery, and how we can identify those at risk before lasting harm is done.

This is why ITSAN has partnered with NORD, the National Organization for Rare Diseases, to build and manage an international patient registry. It is why we support and help facilitate clinical research. And it is why we publish in peer-reviewed journals and present at national and international conferences, because the science must be visible, credible, and impossible to ignore.

Why What Currently Exists Is Not Enough

The existing body of research on TSW, while meaningful and growing, remains far too limited. It has not yet produced the clinical recognition, treatment protocols, or prescribing reform this community deserves. Many of you know this firsthand - you have searched for answers and found very little. Your doctors searched and found very little. What exists has opened the door. But it has not yet changed the room.

We need clinical studies with larger, more diverse patient populations. We need longitudinal data that tracks how people actually recover over time and what factors influence that recovery. We need mechanistic research that explains the biology of TSW in terms that move it from contested phenomenon to established medical fact. And urgently, we need treatment trials designed specifically around TSW and withdrawal, not simply borrowed from eczema management. None of that exists yet at the scale it needs to. ITSAN is committed to helping us get there, and to making sure the research that does exist reaches the clinicians, regulators, and policymakers who need to see it.

Every person who contributes to the registry, every clinical trial that moves forward, every paper published brings us closer to the day when someone newly diagnosed with TSW is handed a real roadmap, not sent home to suffer alone and search the internet for answers. That is what this work is for.

Our Commitments Around Research

Your privacy is non-negotiable.

We know that after experiencing a healthcare system that failed to protect you, being asked to contribute your personal health information - even to an organization you trust - takes courage. ITSAN is committed to the highest standards of data privacy in everything we do. Your information is yours. It is used only in the ways you explicitly consent to. It is never sold, never shared with third parties for commercial purposes, and never made available to anyone whose interests are not aligned with yours.

If you participate in a registry or research study connected to ITSAN, you will know exactly what you are agreeing to before you agree. You will not be surprised by how your information is used. That is a promise.

We do not do this for money. We do this to end TSW.

ITSAN does not recruit members of this community into research for financial gain. We do not facilitate access to your data or your stories as a commodity. We are a nonprofit, and every resource we have goes toward protecting, proving, and preventing TSW. Any funding we receive in connection with research goes directly toward that mission; supporting the science that will one day produce real treatments, real recognition, and real prevention. If a research partnership is not directly serving the goal of reducing your suffering and ending TSW for future patients, we will not be part of it.

Research partners are held to independent scientific standards.

Our scientific and research collaborators - physicians, academics, clinical trial investigators, patient registry partners - operate differently from commercial industry partners. They are bound by ethical review processes, informed consent requirements, and scientific integrity standards that exist independently of commercial interests. ITSAN only engages with research partners who uphold those standards and who are genuinely committed to advancing the understanding and treatment of TSW for the benefit of patients, not for profit.

Our hope for research:

*That one day, no one will spend two, three, or five years not knowing if they will heal. That there will be a clinical pathway - evidence-based, physician-supported, and accessible - for every person who develops TSW. We are not there yet. But we are moving. And every contribution from this community - every data point, every story shared, every person who participates in a study - is what makes that movement possible. That is what this is for. **You** are what this is for.*

PART TWO

How We Engage Industry — And Why It Matters for You

We Understand Your Hesitancy

We want to be honest with you: we know this section may be the hardest to read. The pharmaceutical industry is not a neutral presence for most people in the TSW community. For many of you, it is directly tied to your suffering - to a product prescribed without adequate disclosure, and to a system that, when you raised concerns, too often responded with silence or dismissal. That history is real. It matters. And it shapes how we think about every industry relationship we consider.

We are not asking you to forgive that history or to set it aside. We are asking you to understand why ITSAN believes that engaging carefully and on clear terms with select industry partners can ultimately serve you better than refusing to engage at all, and to hold us accountable to the standards we set out below.

Why We Engage — And What We Are Trying to Accomplish for You

Many of you are already navigating the world of newer medications and treatments. You are trying biologics, immunosuppressants, and other therapies - not because you trust pharmaceutical companies, but because you are suffering and searching for anything that might help you heal while your body goes through withdrawal. You deserve to make those decisions with accurate, complete, and unbiased information. That is what ITSAN is here to provide.

When ITSAN engages with pharmaceutical and biotech companies at events like the TSW Summit, the goal is education - not promotion. We create space for you to ask the hard questions directly, to hear medically accurate information about what these products can and cannot do, and to leave better equipped to have informed conversations with your own healthcare providers. We do not bring industry into our spaces so that companies can market to you. We bring them in so that you have access to information you are already seeking - in a setting where ITSAN is present, the standards are set by us, and your interests come first.

We also believe that the path to systemic change runs directly through industry accountability. Getting pharmaceutical companies to the table - where they answer questions, provide transparent educational materials, and engage with patients as full human beings - is itself a form of advocacy. It is far harder for a company to maintain comfortable distance from the consequences of their products when they are sitting across from the people affected by those products.

What We Require from Every Industry Partner

Engaging with ITSAN is not a neutral act for industry. It comes with clear expectations, and any company unwilling to meet them is not one we will work with.

Patient wellbeing must come first — across the whole of a patient's life.

We will only work with companies that genuinely approach patient care holistically - not just at the point of prescription, but across the full arc of a patient's health journey. Companies must demonstrate a real commitment to long-term patient safety and wellbeing, not just short-term symptom management or commercial outcomes.

Full transparency about products, including their risks and limitations.

Lack of transparency and informed consent is one of the core failures that has harmed this community. Any company not willing to be open and honest about what their products do, what they do not do, and what the known risks are, has no place in our spaces. This is non-negotiable.

A qualified person who can answer real questions.

At ITSAN events, every industry exhibitor must have at least one credentialed individual present - a Medical Science Liaison, a licensed clinician, or equivalent - who is prepared to engage substantively with questions from patients and caregivers. Not a representative primed with talking points. A person with genuine medical knowledge who will sit with our community and respond honestly. You deserve real answers, and we ensure that is what is available.

Educational materials that serve patients, not marketing goals.

Industry partners must provide materials that attendees can take home and use, written in accessible language and including honest safety information alongside any information about their products. If the material reads more like an advertisement than a resource, it does not meet our standard.

No conflicts of interest.

ITSAN is not a marketing platform. We are not a channel for accessing a captive patient audience. Any partner who approaches us with that intent will not remain a partner. Our community's trust is not for sale, and we protect it accordingly.

Lines We Will Not Cross

- We will never allow an industry relationship to compromise the integrity of the information and support we provide to you.
 - We will never endorse, recommend, or promote a specific product or treatment. ITSAN's position on TSW treatments is neutral, and that will not change.
 - We will never provide medical advice, and no association will alter that.
 - We will never allow our community to be treated as a marketing audience or a data source for commercial gain.
 - We will never stay silent if an associate's conduct is not in your interest. If something is not right, we will say so - and we will act.
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Our Promise to You

Whether we are working alongside a research team or sitting across from a pharmaceutical company, the question we ask ourselves is always the same: does this serve our community? Does it protect the people who came to us because they had nowhere else to turn?

We will never stop being moved by the injustice of what this community has endured. And we will never stop working to make sure it does not happen to the next person. You came to ITSAN because you needed someone that believed you, fought for you, and refused to abandon you. That is what we are, and it is what we will remain - no matter who else is at the table.

We engage with science and with industry because it serves you. When it stops serving you, we stop. That is our commitment, and we will keep following it - one decision at a time.

With conviction and compassion,

ITSAN Leadership

International Topical Steroid Awareness Network | www.itsan.org