



# CULTURE STATEMENT

One Cause | One Mission | One Voice

# Our Purpose

## **A Beacon of Hope**

For those in desperate need of help, we offer a sanctuary: a safe and understanding community providing the information and support people with TSW need to heal.

## **A Platform for Action**

For those who feel the calling to fight back against TSW, we offer a way to be heard: amplifying our collective voice, turning pain into purpose, and fueling our vital mission.

## **An Agent of Change**

For all who have been harmed by topical steroids, we confront the system: exposing the truth to bring about the research, recognition, and reform needed to end this preventable crisis.



# Our Values

## **Conviction**

We won't back down, because TSW is real and preventable.

## **Compassion**

We truly understand the devastation of TSW and we're here to help.

## **Courage**

We fight for change, speaking truth, even when it might be uncomfortable.

## **Goodwill**

We build bridges, with an attitude of forgiveness and the belief that people and systems can change.

## **Humility**

We listen and learn from all sides, open and receptive, willing to work together.



# Our Mission

We provide support and advocate for a global community living with topical steroid withdrawal; promoting research, educating medical professionals, and raising awareness of TSW.

**We enact our mission through our 3-step plan:**

**1. Protect   2. Prove   3. Prevent**

# ITSAN Culture Statement

## Background & Context



While ITSAN's main aim has remained the same since its inception, to raise awareness of TSW and support affected individuals, our work has evolved over time. ITSAN has grown from a small band of passionate individuals, supporting each other and raising the alarm, to significantly expanding its work; developing and managing initiatives, which have required a growing network and collaborating with those outside the field of patient advocacy to effect change.

The organization has moved beyond a repository of TSW information on a website and monitoring a forum/closed Facebook support group, to promoting evidence-based research, producing sophisticated scientifically credible work, publishing in peer reviewed journals, presenting at international and national conferences, and collaborating with physicians to provide needed educational resources for their peers.

Additionally, in recognizing the need for the TSW community to come together as one voice, turning their frustration into a catalyst for change, ITSAN has built an Action Hub; a platform to expand its remit into grassroots activism in order to unify and mobilize the growing global TSW community, applying needed pressure to change the overall system and push initiatives across the finish line. The Action Hub provides an opportunity for all voices from all nations to be heard and represented. Importantly though, this does not mean we've lost our measured advocacy voice or approach.

In light of this growth and evolution, it is critical that ITSAN's mission, values and overall message are carefully articulated, not only within the TSW community and those who partner with the organization, but also for those external stakeholders who are necessary to bring about change. ITSAN must be intentional and strategic in our relationships with the medical and science communities, policy makers and industry; nurturing these relationships, building trust, continuing to tell the TSW story, and keeping the pressure on until the system course corrects.

Due to the highly charged environment TSW creates and the critical nature of ITSAN's work, those serving in a leadership or staff position, or as representatives, must abide by the values and guidelines of this culture statement while actively affiliated with the organization; maintaining alignment with those priorities defined by its board of directors to ensure the organization's mission is not jeopardized and its initiatives successful.

# ITSAN Culture Statement

## What we are not



### Anti-medicine

We believe in the benefit of medicine and the importance of patient care – which includes safety and accountability.

### Anti-steroid

We believe steroids have a place in medicine and can be lifesaving, but that this class of drugs needs re-evaluation to provide more appropriate usage and prescription guidelines, and transparency around potential risks.

### Anti-doctor

We believe the majority of doctors practice according to their mantra “to do no harm,” but along with patients, have not been provided adequate information regarding risks of TSA/TSW and how to recognize, diagnose, treat and prevent the condition. Doctors are key to supporting patients through TSW.

### Anti-alternative treatment

Without a clear understanding of the underpinnings of TSW and targeted treatment, we do not censor discussion around treatment protocols that are working for patients but instead provide information to support patients in their decision-making process.

### Vindictive and antagonistic

While we are as furious and heart-broken at the injustice of TSW as anyone in our community, we believe the way forward as an organization is in standing behind the truth, without attacking but also without backing down, until there is accountability and systemic change.

# ITSAN Culture Statement

## Our positions



### Medical advice

ITSAN does not provide medical advice. While literature on the organization's website is reviewed by medical professionals for accuracy, ITSAN staff and volunteers are not doctors and cannot offer medical guidance.

### TSW treatments

ITSAN maintains a neutral position in terms of TSW treatments. We neither condemn nor condone treatments, but instead provide information on current known options, including those that community is talking about, but do not provide recommendations. That is for patients and their doctors to decide on.

### Building bridges, not walls

TSW has already caused enough destruction. We want to rebuild, not tear down further – whether that be regulators, doctors, industry, patient advocacy groups, TSW patients or other ITSAN team members/volunteers. We model respect, humility, patience and grace. We understand the gravity and appreciate the complexity of the TSW problem but will not retaliate and jeopardize key relationships. Instead, we will work to change the system.

### Conflicts of interest

Any corporate sponsors or partners must align with ITSAN's mission and philosophy to keep patients' holistic and long-term health and safety first, maintaining transparency around any potential risks or limitations in products. Additionally, individuals who partner with ITSAN must keep the organization's mission at the forefront, not as a means of personal gain.