



IMPACT REPORT 2025

A Year of Courage, Connection, and Progress!

2025 has been a year of courage, connection, and progress for the TSW community. At ITSAN, our mission to **Protect, Prove, and Prevent** guides everything we do. Every milestone this year reflects the power of patient voices, the dedication of our advocates, and the commitment of clinicians and researchers who believe in **a future without TSW.**

From state legislatures to international conferences, from patient registries to groundbreaking research, the work of 2025 demonstrates that **change is possible** when a community unites. This report celebrates our wins, honors the people behind them, and shows exactly how your support is **transforming lives.**

With hope and determination,

Kelly & the Team

Kelly Barta

TSW Warrior and President of ITSAN



OUR WORK IS CRUCIAL

TSW has been known within the medical community for over 5 decades, yet **almost nothing** has been done to prevent it.

It is estimated that over **70 million people** worldwide are either in TSW, or are headed for it right now, due to a lack of stewardship in prescribing practices and inaction from regulatory bodies with the power to end this.

We won't stop until this preventable man-made condition is eradicated and the needless suffering of countless individuals is over.

“
ITSAN helped me through the most challenging, darkest hours of my life. I don't know how I would have made it through the healing process without the support of the founders and community, as well as the resources this network provides.

Lorry

WHY WE'RE HERE

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.

For those who feel the calling to fight back...

We offer a way to be heard: amplifying our collective voice, raising awareness, turning pain into purpose, and fueling our vital mission.



A Platform for Action



An Agent of Change

For all who have been harmed...

We confront the system: exposing the truth to bring about the research, recognition, and reform needed to end this preventable crisis.

MEET THE TEAM



Our Values

COURAGE

CONVICTION

COMPASSION

GOODWILL

HUMILITY

Our Passion

ITSAN is headed-up by Kelly Barta – a TSW survivor who now leads a small yet mighty team – nearly all of whom are volunteers – who are working tirelessly to raise awareness of TSW and advance our mission.

Each member of our team has either been through TSW, cared for a loved one who has, or are dealing with the condition now.

Board Members, clockwise from bottom left:

Kathy Tullos, Natalie Lawton, Sarat Pothuri, Kelly Barta, Nick Gellar, Michelle Li, Tom Drysdale.



“Patients with TSW have been dreadfully let down by the medical professions and left to manage their catastrophic skin failure on their own...”

– Dr. George Moncrieff

Making TSW Credible

Our Medical Advisory Board is composed of volunteer medical, scientific, and healthcare professionals with expertise in TSW and related dermatological, pediatric, and patient care issues.

Together, they provide us with evidence-based, up-to-date medical guidance to support our mission and ensure the accuracy and credibility of our educational, advocacy, and outreach work.



Dr. Sandipan Dhar
MD, DNB



Dr. Koushik Lahiri
MBBS, DVD, FRCP



Dr. Peter Lio
MD, FAAD



Dr. Marcello Monti



Dr. George Moncrieff
FRCP, FRCGP, DPD, DRCOG, DCH



Dr. Martin Smith

OUR MISSION



PROTECT

People with TSW feel isolated, misunderstood, and without a clear path forward to healing.

Our number one aim is to create a safe space for those going through TSW, as well as for those who care for them, providing community and validation and hope.



PROVE

TSW remains unrecognized and dismissed by much of the medical community.

We are working tirelessly to gather the evidence needed to prove the severity and prevalence of TSW, so doctors and regulatory bodies take notice and address the issue.



PREVENT

TSW continues because systemic barriers allow inaction and a lack of accountability to persist.

We are a voice for everyone affected by TSW. We raise awareness, educate, and push regulators and medical bodies to take urgent, lasting action.

Honoring Dr. Rapaport



This year we honored ITSAN's co-founder, Dr. Marvin Rapaport, with a much deserved award, recognizing his immense contributions in RSS/TSW awareness, treatment and prevention.

For decades, Dr. Rapaport has been a voice in dermatology speaking up about the dangers of long-term topical steroid use, and whose pioneering research on Red Skin Syndrome has changed the way doctors and patients around the world think about these medications.

Even though his discoveries have been met with resistance over the years, due to his deep commitment to patients and to the truth, his work has given thousands of people hope and a path to healing when no one else would listen.

Dr. Rapaport has not only saved lives, but his discoveries and work have been the catalyst to reshape an entire field of medicine.

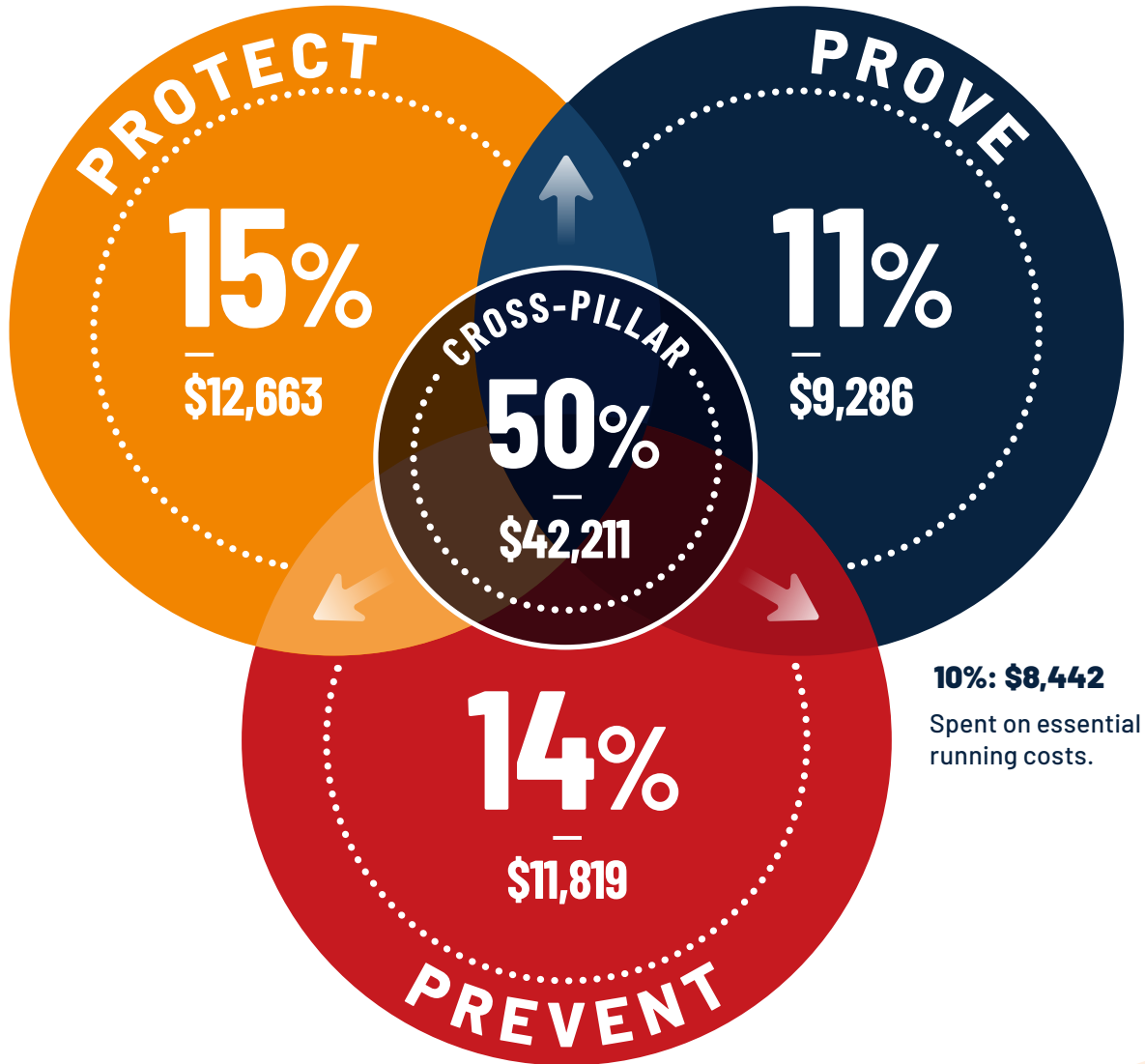
ITSAN honors him not just as a doctor, but as a true pioneer and advocate for patients. The "Marvin J. Rapaport Award of Distinction" will live in perpetuity, honoring Dr. Rapaport's legacy, and will be given annually by ITSAN to a researcher who has helped push forward TSW awareness and provided a better understanding of TSW and its treatment.

If you'd like to learn more about Dr. Rapaport's legacy and how he helped shape the TSW movement, check out the recently released book, "False Cure," by ITSAN's co-founder, Kelly Palace. You can find the book for free here:

[Download it here](#)

OUR PILLARS OF IMPACT

In 2025, we Raised \$84,422!



Where Your Money Went

Half of our income was invested into fueling our mission across integrated projects that spanned all 3 of our strategic pillars. The remainder was allocated to specific projects, as we worked to **Protect** people affected by TSW, **Prove** the existence and severity of this condition, and **Prevent** it from happening to others in the future.

NOTICE ANYTHING NEW?

We Rebranded This Year!

As the TSW crisis continues to grow at an ever-alarming rate, we took steps to better connect with our community and communicate our message to the many stakeholders we must engage to turn the tide on TSW.

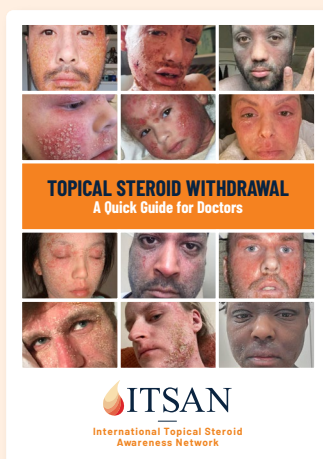
We are rolling out our new brand identity incrementally, so watch for updates throughout 2026. Have a peek at some of our new brand publications here:



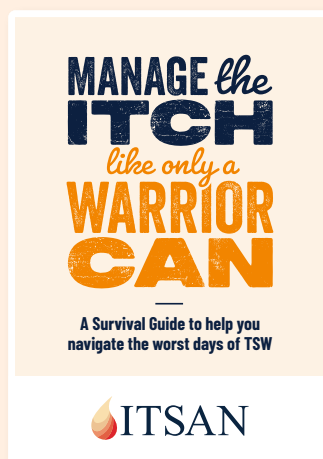
[↗ Awareness Book](#)



[↗ Fundraising Guide](#)



[↗ Doctors Guide](#)



[↗ Survival Guide](#)



[↗ Partners Guide](#)

2025 SNAPSHOT

1/3

We United a Global Movement!



P 11

Launching
the TSW
Action Hub

We Connected Internationally



P 12

Melbourne
Community
Gathering

We Supported Mental Health



P 13

Live Q&A
session with
Phoilex

We Helped our Community



P 14

We provided
a supportive
sanctuary

2025 SNAPSHOT

2/3

We Built the Evidence Base



P 15

We launched
a TSW Patient
Registry

We Promoted Research



P 16

We helped
usher in NIH
research

We Fostered State Recognition



P 17

New TSW
Resolutions
in 6 States

We Engaged Gatekeepers



P 18

We took our
message to
Capitol Hill

2025 SNAPSHOT

3/3

We Spoke Up in Prague



P 19
GlobalSkin
conference,
2025

We Spoke Up in Melbourne



P 20
ISAD
Symposium,
2025

We Exposed the Truth



P 21
Kelly Palace
released her
TSW book

We Raised Awareness!



P 22
Launched
Missing Person
Campaign

Cross-Pillar:

We United a Global Movement

TSW Action Hub Launch

November, 2025



A long-held vision of ITSAN Board member, Tom Drysdale, became a reality this year. Tom, who personally navigated the complexities of TSW alongside his daughter, saw an urgent, unmet need to mobilize our community. The TSW Action Hub is designed to “turn up the volume,” uniting our shared experiences into a single, powerful voice capable of applying pressure to a system that has long ignored this man-made crisis.

The Hub serves as a central engine for action; ready for that time in a person’s healing journey when physical suffering eases and gives way to a want to fight back against the terrible injustice of TSW.

We have been blown away at the response so far, with hundreds of sign ups and actions taken, and we can’t wait to see what 2026 brings!

- **Share our mission**
- **Sign our TSW petition**
- **Advocate for state-level change**
- **Alert the press to TSW**
- **Educate doctors**
- **Share your story**
- **Report TSW to regulatory bodies**
- **Take part in vital research**
- **Fundraise and donate!**

 [See the Action Hub](#)



Protect:

We Connected Internationally

The Melbourne Meet-up

October, 2025



In the heart of Melbourne, ITSAN hosted a powerful in-person gathering that proved community support is the ultimate medicine. Nearly 50 individuals, each personally touched by the grueling reality of TSW, came together to share their stories and offer the kind of support that can only come from those who truly understand. The event was also an opportunity to introduce ITSAN's advocacy efforts and encourage involvement.

The event was made possible through the generous sponsorship of regional skincare companies, ensuring the gathering remained free and accessible for all. This allowed the focus to stay entirely on the participants, providing a safe environment where caregivers and patients alike could find a rare moment of respite. For many, it was the first time they had ever stood in a room with others who shared their physical and emotional scars.

By facilitating this space, we did more than just host a meeting; we fostered a sanctuary for healing. This gathering highlighted the profound power of openness and the necessity of peer-to-peer validation in the recovery process. We are committed to protecting our community by ensuring that no one has to navigate the darkest days of withdrawal alone, turning collective suffering into a foundation of shared strength.

CODEX
LABS™

AMPERNA

Salvida

Protect:

We Supported Mental Health

IG Live & Webinar Events

September, 2025



TSW is a journey that taxes the mind as much as the body, and this year we took a bold stand to address this hidden struggle. Through a live, powerful conversation in collaboration with Phoilex, featuring advocates Shanti and Chi, we explored the raw and often devastating intersection of TSW and mental health. The collaboration offered more than just insight; it offered a lifeline of support to those currently in the trenches of their healing journey.

We also hosted a webinar with Dr. Keira Barr, a double board certified dermatologist and somatic trauma specialist, on our YouTube channel. By speaking openly about the trauma, depression, and anxiety that often accompany physical symptoms, we validated the experiences of those who felt ignored by the traditional medical system. It was a vital reminder that healing the skin requires a holistic approach that first supports the soul.

This initiative served to protect the most vulnerable in our community by breaking the stigma surrounding mental health in the TSW space. We provided a roadmap for caregivers and patients to recognize these psychological tolls and seek the community support necessary to endure them. Our aim was simple: to ensure every warrior feels seen, supported, and mentally equipped to keep on fighting for their health.

 [Listen to Dr Barr](#)



Shanti Persaud



Chiquanna Villines

Protect:

We Helped our Community

A Supportive Sanctuary

Throughout 2025

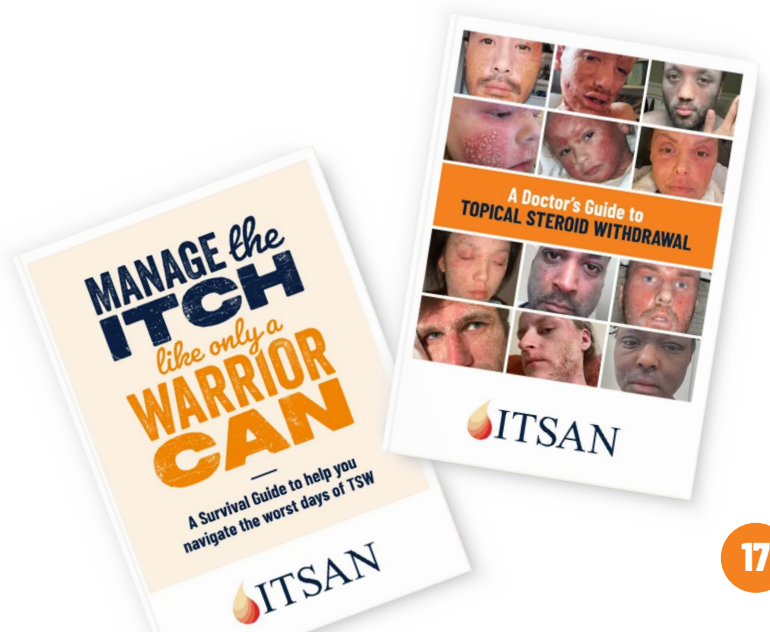


Behind the headlines lies the heartbeat of ITSAN: our 24/7 online support network and library of practical resources. In 2025, we continued to moderate a safe sanctuary on Facebook for almost 30,000 members, ensuring no one faces the isolation of withdrawal alone. Because TSW does not sleep, our commitment to providing a constant, reliable space for peer-to-peer validation remains our most foundational act of protection for patients and caregivers worldwide.

A major aim we have is to provide people with tools to face a skeptical world. Our new Doctor's Guide empowers patients to bridge the communication gap with medical professionals, providing the clinical language needed to explain the iatrogenic nature of TSW. We also launched a new community-sourced Survival Guide, offering a lifeline of practical tips to ease the physical suffering TSW brings.

We also created a new series of email automations that preempt the needs of those who sign up for support. This allows us to maintain a caring presence in their life for as long as they want. Together, these digital lifelines protect people from the despair that so often comes with TSW, providing the tools every warrior needs to advocate for their health, and the community to hold them up until they heal.

 [Download them here](#)



Prove:

We Built the Evidence Base

TSW Patient Registry

December, 2025



For decades, TSW has been systematically ignored, but we have finally launched the research platform that will change that forever. After three years of meticulous preparation by a committee of TSW expert physicians, researchers and patient representatives, the Global TSW Patient Registry is now a reality. This standardized collection of patient information is the high-level research our community has long required, specifically designed to show the medical world the true scale and severity of this condition through quantifiable data.

The registry is hosted on the National Organization for Rare Diseases platform, called I-AM-RARE. This tool allows us to build a comprehensive clinical profile of the syndrome, providing researchers with the clues needed to understand biological mechanisms and potential treatments. Every story added to the registry acts as a brick in the wall of evidence we are building to prove the reality of TSW.

We are immensely grateful to the investigators and participants whose dedication has made this registry a lasting gift to the global community. The faster we join together to provide this data, the faster we arrive at the truth that can no longer be denied by clinical skeptics. This registry is our collective voice made clinical, ensuring that our lived experiences are transformed into evidence-based research that will change medical practice forever.

 [Click to take part](#)



NORD[®]
National Organization
for Rare Disorders

Prove:

We Promoted Research

Groundbreaking NIH Study

March, 2025



A monumental shift in the clinical understanding of TSW occurred this year, sparked by the results of a groundbreaking study led by Dr. Ian Myles, with the help of his staff. ITSAN acted as the recruiter and co-author, also providing an international patient-reported survey to support the research. The study provided the evidence needed to identify TSW as a distinct condition, separate from atopic dermatitis. It was a long-awaited moment of validation that finally began to answer the scientific questions our community has been asking for many years.

This breakthrough was made possible by the extraordinary courage of 16 TSW warriors who volunteered to participate while still in the midst of their suffering. These individuals traveled to the NIH campus, to provide the biological samples and data required for this study. Their contribution is a testament to the strength of this community.

The impact of this research is profound, offering the first real clues into the mechanisms of the condition and potential future treatments. By proving that TSW is a physical reality at the cellular level, we have cracked the foundation of clinical skepticism. We are thrilled by this development, as it adds weight to the critical groundwork needed to advance medical coding, update product labeling, and prompt federal agencies to finally take action. The paper was published through the Journal of Investigative Dermatology, earning its place in peer-reviewed literature.

 [Click to learn more](#)



Prevent:

We Fostered Recognition

New TSW Awareness Days

Throughout 2025



The TSW community caught fire this year, transforming personal pain into legislative action across the United States. Through the tireless advocacy of families like the Vasquezes and Pothuris, and individuals like Tanya Gantiva Richards and Matt Lawas, we secured official Awareness Resolutions in six new states. From the steps of Boston’s Capitol to those in Austin, Texas, our advocates stood before lawmakers to demand that TSW be recognized as a devastating entity.

These resolutions provide a huge step forward in raising the profile of this condition. In states like Massachusetts and Georgia, young warriors and their parents shared their heartbreaking stories to ensure that future patients feel seen and supported. With eight states now on board, we are building a national momentum that signals to the medical establishment that the status quo is unacceptable.

By achieving these legislative victories, we are working to prevent the same tragedy from befalling others by forcing a re-examination of how steroids are prescribed. Each resolution carries the weight of official government record, calling for more research and declaring TSW Awareness Days. We will not stop until every state – and country – recognizes this preventable crisis and ensures that patients receive the informed consent they deserve.

 [Get involved here!](#)



Prevent:

We Engaged Gatekeepers

Speaking on Capitol Hill

May, 2025



In partnership with the Coalition of Skin Diseases (CSD), Sarat Pothuri and her daughter Reva represented the community in critical briefings with federal legislators and their staffers. Their mission in Washington D.C. was clear: to move TSW from a misunderstood condition to a significant public health priority that demands federal research funding and urgent attention. Adding weight, Kelly Barta shared her TSW experience with more than 110 key decision-makers in attendance, including NIH leadership and other policy makers

These high-level engagements are designed to build the systemic pressure necessary to force change from the top down. Our presence on Capitol Hill served as a reminder to the government that the TSW community is organized and will not stop until our needs are integrated into federal health priorities.

Through these efforts, we are laying the groundwork to prevent TSW on a national scale. In the quiet offices of Congress, the Pothuri family's testimony proved that the TSW community deserves recognition, research, and reform. This advocacy milestone proves that our voice is successfully reaching the decision-makers who have the power to change the future of dermatology and ensure accountability.



Prevent:

We Spoke Up in Prague

GlobalSkin Conference

April, 2025



ITSAN solidified its place on the international stage by participating in the 10th anniversary GlobalSkin conference in Prague. Kelly Barta, who sits on the Atopic Eczema Advisory Council for the International Alliance of Dermatology Patient Organizations, and GlobalSkin, and TSW Warrior-Extraordinaire, Briana Banos represented our community, ensuring that TSW remained central to the conversation among global patient advocacy leaders. Briana took the stage as a “Patient Champion,” sharing her lived experience with an international audience to advocate for global support.

This engagement was critical for building international solidarity and ensuring that TSW is recognized as a global health crisis. As members of GlobalSkin, we are fostering a network of international allies who can help amplify our call for medical reform and informed consent across borders.

These conversations move TSW into the global spotlight, ensuring that patient voices are heard by those in influential positions, and that our community’s pain is no longer a peripheral story, but a primary driver in changing dermatological views and prescribing habits in the future.



GLOBALSKIN.ORG

International Alliance of
Dermatology Patient
Organizations

Prevent:

We Spoke Up in Melbourne

ISAD Conference

October, 2025



ITSAN took a courageous step into the clinical heart of dermatology by participating in the International Society of Atopic Dermatitis Symposium in Melbourne. Standing before more than 400 dermatologists from around the world, we shared the patient perspective on the TSW crisis. It was a moment of direct confrontation with the clinical establishment, requiring immense diplomacy to turn skepticism into a productive dialogue.

Despite the initial resistance in the room, our presence sparked a critical shift in the conversation regarding how topical steroids are discussed in medical literature and social media. The engagement led to invitations for future collaboration, with leading experts expressing interest in working with ITSAN on focus groups, research projects and the creation of social media content.

This breakthrough represents a major step toward changing the way topical steroid are understood and prescribed, ultimately affecting how patients are currently treated.

By engaging directly with the leaders of the International Society of Atopic Dermatitis, we are working to prevent the misdiagnosis of TSW at its source – the doctor’s office – and promoting much needed research into the condition. As a result, we are opening doors that were once firmly shut, helping to ensure that TSW is finally integrated into dermatological education. This clinical advocacy ensures that the doctors of tomorrow are equipped to prevent the crisis of today.



Prevent:

We Exposed the Truth

"False Cure" Book Release

December, 2025

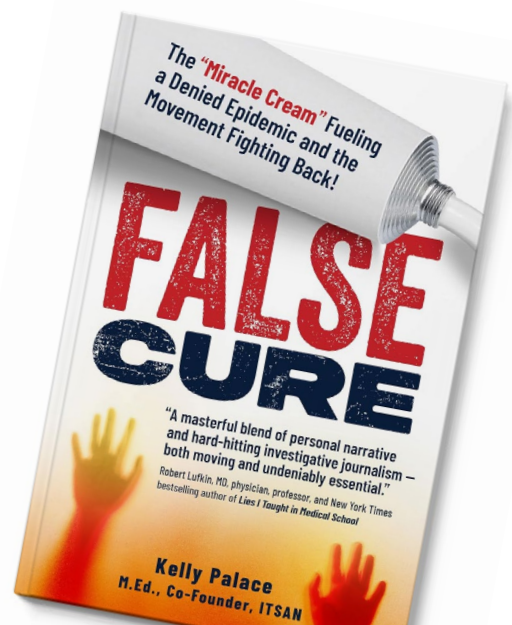


In a powerful move to sound the alarm, ITSAN co-founder Kelly Palace released her investigative book, *False Cure*, as a free resource for the entire community. Kelly utilized her background in journalism to document the history of medical resistance to TSW, tracing the movement back to its early pioneers. By offering free audio and e-book versions, she ensured that the evidence supporting this medical oversight is accessible to every patient and physician.

The book serves as a vital tool for prevention by exposing the systemic failures that lead to steroid addiction and withdrawal. It provides advocates with the language and historical context needed to challenge dismissive healthcare providers and demand safer prescribing practices. For many in the community, reading *False Cure* has been a moment of profound realization, confirming that their suffering was both real and entirely preventable.

By arming the community with this knowledge, we are creating a more informed patient base that can advocate for their own safety. *False Cure* acts as a permanent record of the TSW struggle, ensuring that the lessons of the past are used to protect the patients of the future. We believe that education is the first step toward systemic change, and this resource is pivotal tool for making that happen.

 [Download it here](#)



Prevent:

We Raised Awareness

Missing Person Campaign

February, 2025

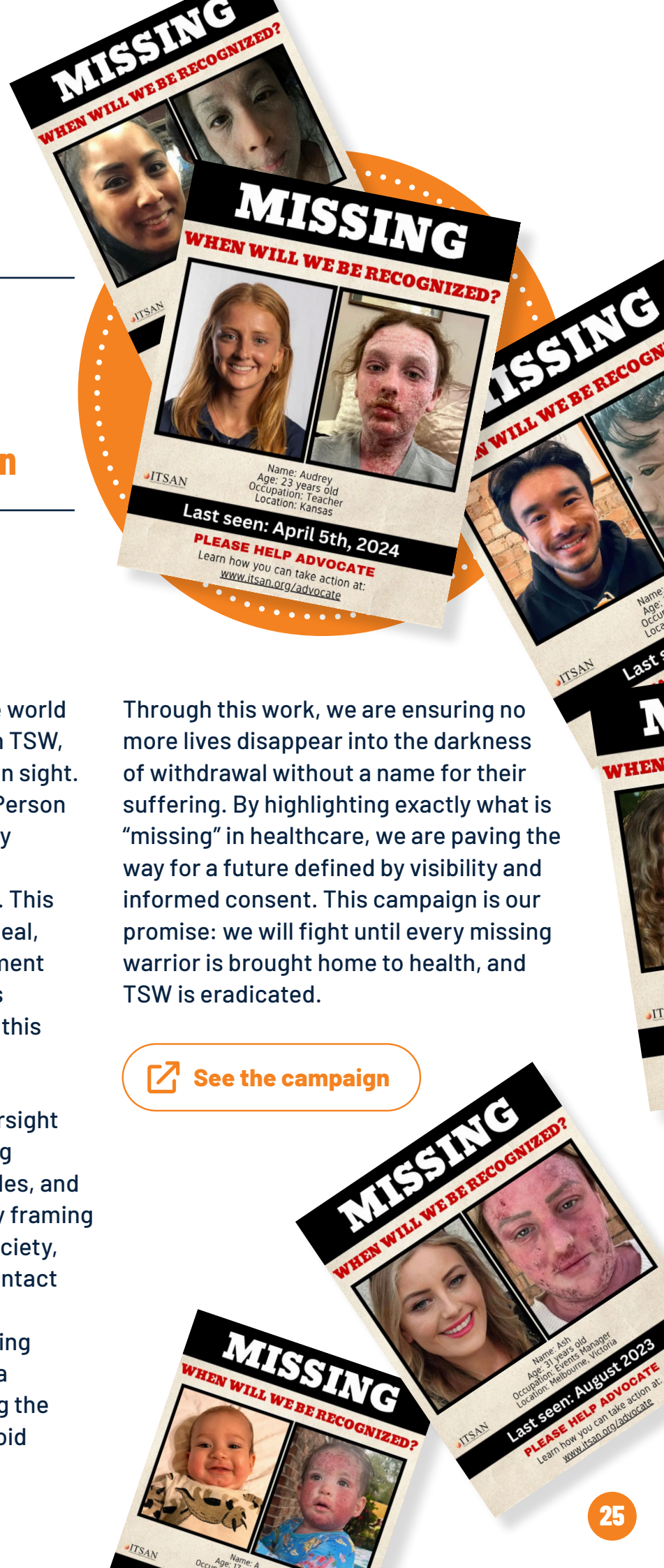
When someone goes missing, the world stops to look – yet for millions with TSW, the disappearance happens in plain sight. In 2025, we launched our Missing Person campaign to highlight a community vanished from medical textbooks, research, and their own daily lives. This initiative served as a powerful appeal, demanding the medical establishment finally account for untold numbers lost for months to years on end by this preventable, man-made crisis.

The campaign highlighted the oversight that allows TSW to persist: missing diagnostic criteria, absent ICD codes, and a lack of steroid label warnings. By framing TSW as a “disappearance” from society, we mobilized our community to contact officials for legislative action.

109 warriors took part, transforming individual stories of isolation into a collective roar for justice, ensuring the system can no longer ignore the void where our health used to be.

Through this work, we are ensuring no more lives disappear into the darkness of withdrawal without a name for their suffering. By highlighting exactly what is “missing” in healthcare, we are paving the way for a future defined by visibility and informed consent. This campaign is our promise: we will fight until every missing warrior is brought home to health, and TSW is eradicated.

 [See the campaign](#)



LOOKING AHEAD

2026, Here We Come!

In July 2026, ITSAN will host our hotly anticipated TSW patient conference in Atlanta.

The event will blend clinical science with workshops on mental health and integrative care, as well as providing a safe place for people living with TSW to meet and find hope of healing. In addition, Dr. Myles will be conducting phase 3 of NIH's study, for interested attendees to participate in.



Look out for our "Let's Talk TSW" video series, bringing expert knowledge directly to the community.

Featuring interviews with leading doctors and researchers, the series will explore TSW and provide guidance on a multitude of important topics.

We'll be working closely with International Eczema Council (IEC) and International Society of Atopic Dermatitis (ISAD) on TSW studies and publications.

Plus, we'll be continuing outreach to the FDA and World Health Organization for an ICD-11 code, and building the Global TSW Patient Registry.



**PROTECTING
PROVING
PREVENTING!**

SUPPORT OUR MISSION

Please Help End TSW!



How many more must suffer the devastating effects of TSW before authorities take action?

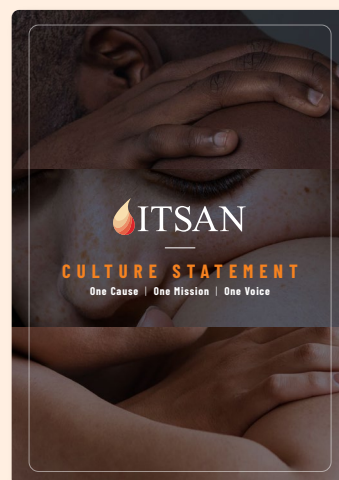
Without the generosity of supporters like you, ITSAN simply could not continue its vital work. Please consider donating today – your contribution brings us one step closer to a world free from TSW.

DONATE NOW

Learn more about or plan to take on TSW and where we stand.



[Our strategy](#)



[Culture statement](#)

C O D E X
L A B S™

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eczema
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SKIN · SOLACE
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Acknowledgments & Gratitude

We are deeply grateful to everyone who made this year's progress possible:

TSW Warriors & Caregivers

For sharing your stories, participating in research, and lending your voices to advocacy efforts. Your courage is the foundation of all we do.

Amazing Donors

Alexander Chen, Kelly Palace, Dr Rapaport, and everyone who donated to support our work, thank you! Without your generosity, ITSAN would simply not exist.

Our Skin-Tastic Partners

Codex, Eczema Clothing, Phoilex, Balmonds, Skin Solace, and all who support our mission financially or through collaboration. Your generosity fuels education, research, and community initiatives.

ITSAN Board Members & Volunteers

For tireless dedication to Protecting, Proving, and Preventing TSW every day.

ITSAN Medical Advisory Board

Dr. Sandipan Dhar, Dr. Koushik Lahiri, Dr. George Moncrieff, Dr. Peter Lio, Dr. Marcello Monti, and Dr. Martin Smith.

ITSAN Advisory Council

Dr. George Moncrieff, Deanna Baxam, Julia Labaton, Kelly Palace, Kristen Fletcher, Timothy Smith, and others who provide guidance, strategy, and expertise to advance our mission.



**International Topical Steroid
Awareness Network**