



Annual Report 2021

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International Topical Steroid
Awareness Network (ITSAN)

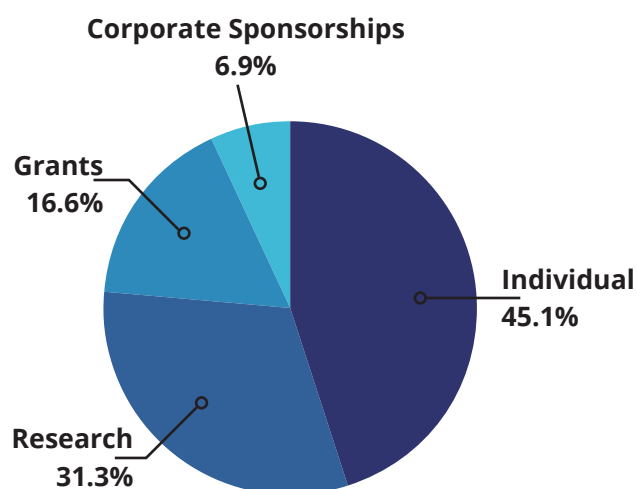


FINANCIAL OVERVIEW

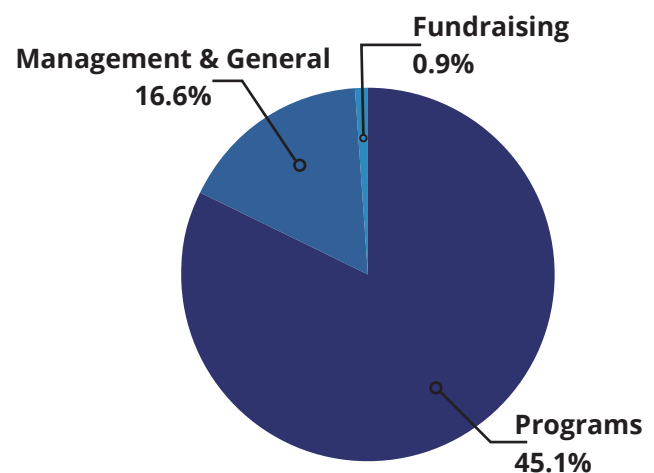
Statement of Activities Year Ended 2021

INCOME	
Individual Contributions	\$32,765
Research income	\$22,750
Grants	\$12,078
Corporate Sponsorships	\$5,000
Total Income	\$72,593

EXPENSES	
Programs	\$65,707
• Advocacy	\$33,190
• Community Support	\$32,197
• Research	\$320
Management & General	\$13,234
Fundraising	\$755
Total Expenses	\$79,696



INCOME



EXPENSES

LETTER FROM THE PRESIDENT

Sometimes life presents us with an opportunity to personally drive a change so significant, we can't believe how easy it is to make a real difference. Given how small our organization is, every donation is key for us. This year because of the generosity of our community, ITSAN was able to begin the journey toward a long sought-after goal: a patient registry. The registry will make it possible to collect credible clinical data points that will enable research into TSW Syndrome. We need your continued support to realize this goal, so please stick with it and bring others along!

I'm also inspired by the commitment of current and former ITSAN Directors toward this vision. Their philanthropic leadership was demonstrated by a matching campaign which provided the funds necessary to commit to the patient registry, while also maintaining ITSAN's presence at key industry dermatological conferences and FDA meetings. We've seen progress in recognition of TSW Syndrome by the very people that can enact change.

Thank you for your inspiring support. Onward!

Sincerely,



Kathryn Tullos, R.N.

President, ITSAN



Our Mission & Vision

Mission:

The mission of the International Topical Steroid Awareness Network is to raise awareness of Topical Steroid Withdrawal Syndrome and support affected individuals.

Goal:

Prevention, early detection, accurate diagnosis, and proper treatment of TSW Syndrome

ITSAN Priorities:

- 01 Patient Engagement Plan
- 02 Find prevalence and proof
- 03 Education and awareness
- 04 Research for biomarkers

2021 Highlights

ITSAN Members & Followers

5,404
followers



Instagram

8,613
followers



Facebook

13.1K
members



Members

Accomplishments for 2021:

Early January 2021

ITSAN ran a survey developed by ITSAN President Kathy Tullos and Allergy & Asthma Network's State Advocacy Project Manager, & ITSAN Board Member Kelly Barta to improve research & treatment for skin issues, including safer steroid prescribing guidelines, and to inform about cumulative steroid load.

March 2021

ITSAN collaborated with the National Eczema Association in expanding educational resources on TSWs at www.nationaleczema.org. This important collaboration will enable NEA to reach and educate millions of people about TSWs.

April 2021

ITSAN leadership meeting with FDA to discuss necessary label changes on steroid medications. With safer topical corticosteroid labeling, potential side effects of overexposure to steroids will become well defined and ultimately prevented by medical professionals.

ITSAN President Kathryn Tullos and ITSAN Treasurer Jodie Ohr presented on "Raising Awareness of Topical Steroid Withdrawal Syndrome: Patient Impact and Caregiver Responsibility" at the Dermatology Nurses' Association Virtual Convention.

ITSAN President Kathryn Tullos & Board Member Kelly Barta are collaborating with the Allergy & Asthma Network (Allergy & Asthma Network) on the steroid stewardship project, which includes a joint survey. Next we'll publish the findings in dermatological journals, driving awareness and recognition.

May 2021

ITSAN hosted its first-ever international virtual conference on May 15 with hundreds of registrants representing 20 countries. TSW sufferers and caregivers learned from experts about integrative treatments, mental health, mindfulness, advocacy, and shared TSW success stories. Breakout sessions were offered for TSW caregivers, adults, men, women, and a cartooning session for TSW kids and siblings.

June 2021

ITSAN Board Members, Jodie Ohr and Kelly Barta hosted an Advocacy deep-dive webinar as a follow-up from the ITSAN global conference in May.

August 2021

ITSAN President Kathryn Tullos joined Dr. Peter Lio to present "The Skinny on TSW and Steroids" at the National Eczema Association's Virtual Eczema Expo on August 28. Discussion included the severe potential side effects of topical steroid use and the need for TSW research, physician and patient education, and safer topical steroid prescribing and monitoring guidelines.

ITSAN President Kathryn Tullos and Executive Assistant Jolene MacDonald joined NEA's Eczema Expo panel, "TSW: What Now?" with Dr. Eric Simpson, Briana Banos the creator of Preventable and Linette ROUNGCHUN, TSW and eczema activist. Discussion included the current struggle many face to access an accurate diagnosis and the importance of recognition of TSW among medical providers, along with shared decision making

between doctor and patient.

ITSAN fundraising event raised \$1,723 thanks to a young TSW warrior named Chase who hosted a fun field day event. Thank you to Chase, his family and community for your support!

September 2021

Kathryn Tullos, ITSAN President/CEO and Kelly Barta, ITSAN Executive Board Member/Past President met with the FDA's Deputy Director of Safety and other FDA officials about Topical Steroid Withdrawal. ITSAN provided an overview of TSW Syndrome and discussed gaps in labeling and instructions.

On World Eczema Day September 14, 2021, ITSAN hosted A LIVE with Dr. Patrice Little and Briana Banos, the creator of Preventable. Discussion included meaningful steps a patient and doctor can take towards a positive partnership.

Jolene MacDonald, ITSAN Board Member, spoke to the FDA as a panel participant at the Little Airways, Big Voices Patient-Focused Drug Development Meeting. She discussed her son's asthma experience during TSW Syndrome, including challenges with treatment and strategies that helped.

As a member of the Coalition of Skin Diseases, ITSAN advocated for TSW patients at the 2021 American Academy of Dermatology Virtual Legislative Conference. ITSAN Board members Natalie Lawton, Kelly Barta and ITSAN Executive Assistant, Jolene MacDonald represented in the House and Senate, specifically for Pennsylvania, Georgia, Maine and Vermont – and ultimately for the voices of ALL of the TSW community.

Fundraising event - an anonymous TSW veteran matched donations in September, up to \$5k which

will go towards a patient registry, enabling us to turn anecdotal stories into data points and much needed research for Topical Steroid Withdrawal Syndrome. We are so grateful for the generosity of our members!

October 2021

The article "What Every NP Should Know About TSW," by ITSAN President Kathryn Tullos, RN, was published in NP Student Magazine.

ITSAN launched a blog page on the website with TSW healing stories about adults and children along with resources for individuals and caregivers affected by TSW.

Kelly Barta, ITSAN Executive Board member/Past President was interviewed by Abby Tai, the creator of The Eczema Podcast. Topics covered included TSW advocacy and raising TSW awareness.

December 2021

ITSAN's second meeting with the FDA to request safer steroid prescribing guidelines, labeling and patient monitoring.

ITSAN was accepted as a member of the National Organization for Rare Disorders (NORD), providing the opportunity to work in partnership to develop a patient registry to bring the scope and need of TSW sufferers worldwide into focus.

ITSAN ran a survey to help improve support and care for TSW sufferers and caregivers.

We heard from 282 survey respondents.

The ITSAN board hosted a virtual meet up with the ITSAN community to connect and discuss topics of importance to the TSW community that ITSAN can focus on in the coming year.

ITSAN Board of Directors:

All of ITSAN's Executive Board have either suffered from Topical Steroid Withdrawal Syndrome themselves or cared for a loved one who has.

Kathy Tullos, RN, President

Jolene MacDonald, Secretary

Jodie Ohr, Treasurer

Kelly Barta, Member, Board of Directors

Michelle Li, Member, Board of Directors

Natalie Lawton, Member, Board of Directors

Janelle Harris, Member, Board of Directors

Thank you to our Partners



ITSAN Medical Advisory Board:

Dr. Koushik Lahiri, MBBS, DVD, FRCP

Dr. Patrice Faye Little, DNP, FNP-BC

Dr. Sandipan Dhar, MD, DNB

Prof. Marcello Monti

"A heartfelt Thank You to all of our sponsors and those who donated. Without you, ITSAN can not be successful."

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www.itsan.org



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