

Stevens-Johnson Syndrome Canada

Who Are We?

We are a registered non-profit organization dedicated to bringing awareness, education, and support to the SJS/TEN patient community.

SJS Canada aims to

- Promote health by providing people suffering from Stevens-Johnson Syndrome and Toxic Epidermal Necrolysis (SJS/TEN) as well as their families and caregivers with access to related counselling, support groups and information programs.
- To advance education by providing workshops, forums and seminars about the Stevens-Johnson Syndrome and Toxic Epidermal Necrolysis to the public and medical professionals.



Learn With Us!

We host two FREE virtual educational webinars annually. In February for Rare Disease Month and in August for Global SJS Awareness Month.

Registration is free on our website!

Get Involved

Volunteer with us!

Gain hands-on experience while supporting a vulnerable community. Your involvement will make a difference in the lives of our SJS/TEN patient community.



Donate today!

All donations make a difference and will help provide essential resources and programs and drive meaningful change for those in need. Donate today and be a part of the solution!

Donate by e-transfer at:
donations@sjscanada.org or click the
"Donate" button on our website.

**all donations over \$20 will receive a tax receipt*

Contact Us

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SJS/TEN: The rare diseases that burn the body from the inside out.



What are SJS & TEN?

Stevens-Johnson Syndrome (SJS) & Toxic Epidermal Necrolysis (TEN)



Stevens-Johnson Syndrome Canada
awareness . education . support



Questions & Answers

What is SJS/TEN?

A life threatening disease that results in blistering of the skin and eroding of mucous membranes (eyes, mouth, genitals). **SJS** is used when 10-30% of the body surface area has been affected. **TEN** is used when greater than 30% of the body surface area has been affected.

What causes SJS/TEN (if known)?

80% of cases are caused by an identifiable drug, 20% are unknown. Drugs are varied but anti-seizure medications, sulfonamides and allopurinol are top of the list.

What are the symptoms of SJS/TEN?

Early Symptoms: Fever, headache, cough, inflamed red eye, body aches (flu-like symptoms).

Later Symptoms: Flat, red rash that may start at the neck and spreads to the body. Blisters that form and peel easily. Blisters in the mouth, eyes and genitals. Difficulty breathing and swallowing. *If you experience any of these symptoms, seek medical help IMMEDIATELY.*

Where do survivors look for support?

If you already had SJS/TEN and need advice, contact SJS Canada for possible assistance. A network of support is necessary including your medical team, caregivers, supportive counselling and survivor support group.

Join our SUPPORT GROUP!

- Every 3rd Wednesday of every month.
- FREE over Zoom
- Sign up via email: info@sjscanada.org



SJS/TEN Facts

*SJS and TEN are two rare, acute, but LIFE THREATENING skin diseases.

Cases Globally

*Affects up to 7 people per million globally.

*Women are nearly 1.5 times more likely to experience SJS/TEN than men.

Recovery Rate

While most patients recover, the death rate can be as high as 25%.

Impact on Quality of Life

*Depending on the stage many patients will die. For those who survive there are life-long medical, physical and psychological traumas that persist.

SJS/TEN in Pediatrics

*More commonly seen than in adults

- 0.1% admissions in USA
- 23.9 cases / Mil in 5-9 yrs
- 19.6 cases / Mil in 10-14 yrs
- 16.8 cases / Mil in 15-19 yrs

SJS/TEN in Skin of Colour

*On darker skin, SJS/TEN may not look like the classic red rash. Instead, it may appear as purple, gray, or dark brown patches, making it harder for doctors to recognize quickly.

Care Recommendations

- Wear a medical bracelet
- Inform your health practitioners
- Frequent follow up with physician
- Stay away from medication that may have triggered SJS/TEN
- Avoid sun exposure
- Consider professional psychological support
- Consider assessment for genetic predisposition to drug allergies if possibly personal and familial.

Sonia's Story



Photo by: Patient Voice

In 2011, I survived Stevens-Johnson Syndrome/Toxic Epidermal Necrolysis. For many weeks I fought to survive in hospital. Burn-like blisters covered 90% of my body, the cause remains unknown. I fear its reoccurrence.

Within a week, I transitioned from perfect health, to an unrecognizable, burn victim, prognosis unknown. The burn was not caused by fire, but an acute life-threatening condition, causing my body to burn from inside-out. My family watched in awe as the medical team fought to keep me alive.

My muscles became so weak, I couldn't open my eyes, swallow, urinate, nor cough. My skin, including everything on its surface, burned and peeled off, leaving my body with black and white patches. I had to learn to exist in my new body.

Recovery remains challenging. I seem healthy, but I'm not. Numerous long-term challenges, severely compromise my quality of life and activities of daily living. I thank God, my husband, family and friends, for helping me reclaim a balanced life.

Very little resources were available for SJS/TEN survivors. I've dedicated my life to fill that gap, selflessly shared my vulnerable photographs and experience, to support others, bringing awareness to this deadly disease. SJS/TEN survivors won't journey alone.

Consequently; with the assistance of family, friends, medical personnel, and volunteers, Stevens-Johnson Syndrome Canada, a registered Canadian charity was founded.