

Quarterly Newsletter



**Stevens-Johnson
Syndrome Canada**

awareness . education . support

Welcome to our **first quarterly newsletter of 2024.**

We are thrilled to share with you details about what has happened in the past months and what will happen in the future at our organization.

Thank you for your support.

2023 Winter Concert & Trivia Night

On December 3rd 2023, SJS CANADA wrapped up the year with its traditional Winter Concert.

The event featured performances by various artists and exciting games to engage our SJSC community and raise awareness about SJS/TEN.

We thank everyone for their presence and donations!

Survivor Interviews

December and January were all about community connections! **We interviewed 4 inspiring SJS survivors**, sharing their impactful stories. These heartfelt interviews are hitting our social media channels soon.

If you're an SJS survivor or know one, please email us at marketing@sjscanada.org to join our mission.

Elpizo Counselling Support Group

We're thrilled to highlight another **successful partnership with elpizo Counseling during the first months of 2024**, during which we hosted thirteen engaging sessions.

Each session was expertly facilitated by two elpizo Counseling professionals, Nada and Shivani. Email us at info@sjscanada.org if you or a survivor you know would like to join our support group!

Monthly Support Group

Every third Wednesday of the month, we have the support group.

In **January**, we had the special guest **Dr. Marlene Dytoc MD, PhD, FRCPC**, a renowned dermatologist from the University of Alberta specializing in vulvovaginal dermatology. **Every third Wednesday of the month, we have our group support meeting. Each month, we welcome a special guest.**

In **February**, we had the illustrious presence of **Dr. Daniel Schneider, PsyD**, a Licensed Clinical Psychologist from MedStar Washington Hospital Center.

In **March**, the special guest was **Dr. James Chodosh, MD, MPH**, who is a Professor and Inaugural Chair of the Department of Ophthalmology and Visual Sciences at the University of New Mexico School of Medicine.

In **April**, we will have the presence of **Robert Micheletti, MD** is a graduate of Stanford University and Duke University School of Medicine. He completed a combined residency in internal medicine and dermatology at the University of Pennsylvania, where he is now Associate Professor of Dermatology and Medicine.

Join the support group and participate in the sessions. It's completely free! For more information, email us at info@sjscanada.org.

February Town Hall & Rare Disease Month & Day

At our recent SJS Canada Town Hall, we gathered to shed light on SJS/TEN and beyond, focusing on the theme of **"Empowering Through Awareness."**

The event drew an enthusiastic crowd, with survivors bravely opening up about their journeys with SJS, offering insights and inspiration to all attendees. Moreover, a dedicated segment was dedicated to promoting awareness of rare diseases worldwide, **emphasizing the importance of advocacy and support.**

February | Rare Disease Month

SJS/TEN are rare skin diseases.
Common symptoms include:

Fever

Body blisters

Headache

Cough

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February | Rare Disease Month

Over 300 million people around the world are living with a rare disease.

Have you or someone you know been diagnosed with a rare skin disease?

www.sjscanada.org

info@sjscanada.org

SJS TENS CA

@sjs.canada

Sonia W. Croasdaile

Stevens-Johnson Syndrome Canada

Contact us!

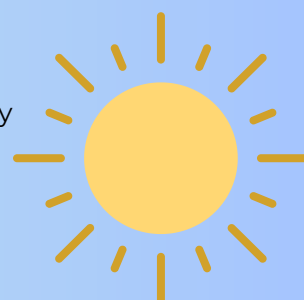
We can help!

To celebrate **Rare Disease Month**, in collaboration with GlobalSkin, SJS Canada launched postcards with information about Stevens-Johnson Syndrome. Visit our website to download your own!

Survivors' Corner WEATHER ALERT!

As the weather changes and the sun becomes more prevalent, don't forget that your daily care habits may change too! Don't forget:

- **Your sunscreen** and **hats** for skin protection,
- **Your lips!** Wear lip balm with SPF 15 or more
- **Your sunglasses!** Have them with you wherever you go, whether indoors or outdoors.



[sjscanada](https://www.sjs.canada)



[SjsTensCanada](https://www.sjstencanada)



[Stevens-Johnson Syndrome Canada](https://www.sjscanada)

Rare Disease Month/ Black History Month

During Rare Disease/Black History Month in February, Sonia had the privilege of attending and hosting a booth at the "Building From the Past, inspiring the Future Guided by Faith" Black History event in Tillsonburg, ON.

It was a fantastic opportunity to share and raise awareness about SJS/TEN. Committed to raising awareness about SJS/TEN **we reached over 20k people on major social networks.**

Your donation helps us sponsor posts and increase awareness among individuals who have never heard of SJS or TEN.

Thank you for helping us fulfill our mission.

CORD - Rare Disease Day Summit in Ottawa, ON

Sonia shared her experience attending the **two-day CORD event** virtually, where she emphasized the significance of celebrating "firsts" in the rare disease community. However, she highlighted that the true importance lies in collaborating to translate these milestones into actionable initiatives.

These actions should aim to enhance outcomes for patients and families, such as reducing hospitalizations, facilitating return to work and school, minimizing disability, enhancing mental health, and empowering individuals to pursue their aspirations.

Donate via CanadaHelps!

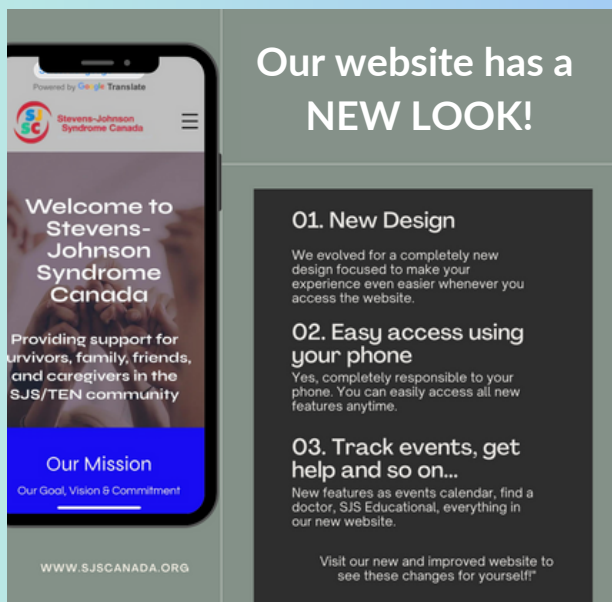
Donate to SJS Canada through our partnership with CanadaHelps. If you would like to make your donation, please scan the QR code.

Thanks to everyone who has donated and supported us!



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Our website has a NEW LOOK!

01. New Design

We evolved for a completely new design focused to make your experience even easier whenever you access the website.

02. Easy access using your phone

Yes, completely responsible to your phone. You can easily access all new features anytime.

03. Track events, get help and so on...

New features as events calendar, find a doctor, SJS Educational, everything in our new website.

Visit our new and improved website to see these changes for yourself!

Check out our new website design!

- 1.Brand new design!
2. Easy phone access!
- 3.Brand new SJSC events calendar
- 4.Physician referral list
- 5.MUCH more...

Check it out!

www.sjscanada.org

World Congress on Rare Skin Diseases

We're thrilled to announce that partnered with GlobalSkin, SJS Canada will be participating in the **2nd World Congress on Rare Skin Diseases** (WCRSD) in Paris, France!

We're pleased to share that **Coleen Lambert, will be attending the congress as an SJSC representative.**

World Skin Health Coalition

We were thrilled to introduce you to the Global Awareness Campaign, spearheaded by our esteemed partner, Global Skin, in collaboration with the World Skin Health Coalition. The 4-week initiative aimed to shine a spotlight on the profound impact of skin diseases and conditions worldwide.



Upcoming Events!

April is Volunteer Appreciation Month! All month long we'll highlight the work of our brilliant volunteers with a Volunteer Appreciation Night occurring on May 1st! Volunteers, check your email for updates and thank you to all of our wonderful volunteers!

Stay tuned for our next Fundraiser which will be a Virtual Trivia Night during the Spring! Watch our social media channels as we'll be posting details soon! Join us for a fun-filled evening featuring Jeopardy, Bingo, and Murder Mystery games. Winners will walk away with amazing prizes!

Our Annual General Meeting (AGM) is scheduled for Sunday, **May 5th, at 3:30 pm via Zoom.** Interested individuals were warmly welcomed to attend and gain insights into the affairs of the organization. It's free to attend! Register at www.sjscanada.org.

August is Awareness Month! Watch your email for announcements!

Thanks for reading!
We're Stronger Together!
-SJS Canada Team



[sjs.canada](https://www.sjs.canada)



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