



CANADIAN  
SPONDYLOARTHRITIS  
ASSOCIATION

IMPACT REPORT 2023-24



# STRATEGIC PILLARS



## DISEASE AWARENESS

Reduce time to diagnosis



## PATIENT EDUCATION & SUPPORT

Amplify patient experiences and positive disease management



## ADVOCACY

Improve access to treatments



## CAPACITY BUILDING

Generate abundance and affiliation

Spondyloarthritis is a complex and challenging condition that demands a comprehensive and strategic approach. Our strategy is rooted in collaboration, innovation, and a deep understanding of the evolving needs of the spondyloarthritis community.

**Mission:** To be the leading voice for the Spondyloarthritis community in Canada, educating, supporting and advocating for people living with Spondyloarthritis

**Vision:** All people living with Spondyloarthritis can achieve their full health potential and live a better life

80,400

Number of Canadians Accessing Information, Programs & Support

1.2 M

Number of Canadians Engaged with the CSA

9,000+

Number of Members Supported

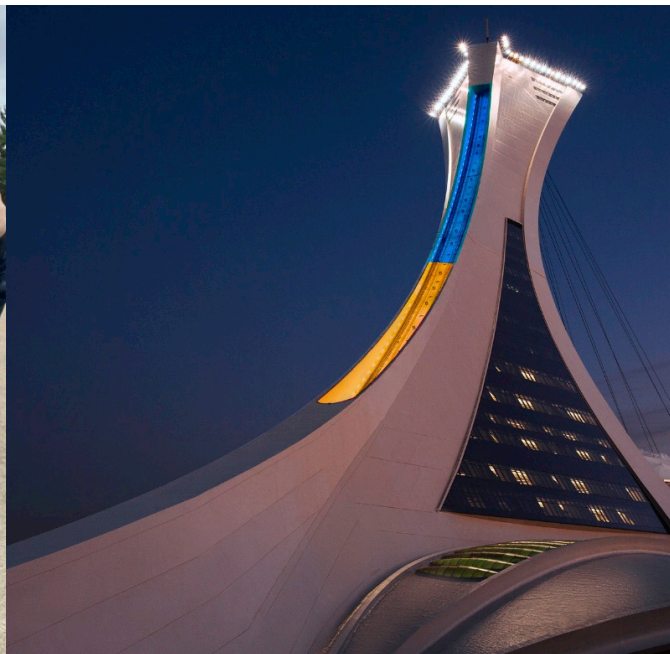
68,000+

Number of Times Digital Resources Were Accessed



# COMMUNITY CHAMPIONS

The CSA is fortunate to count on so many amazing and inspiring members who graciously inspire change and donate their time to raising both awareness and critical funds.



Diagnosed with Axial Spondyloarthritis (AxSpA) at a young age, **Michael Santillo** embarked on a journey that tested his strength and resilience in ways he never imagined.

The lack of awareness among the public and healthcare professionals comes at a high cost. Rather than allowing the diagnosis to define him, Michael chose to transform his experience into an opportunity for advocacy and support. With unwavering determination, he set out to raise awareness about AxSpA, educate others about the condition, and provide support for those navigating similar challenges.

A significant milestone in Michael's advocacy journey is annual the "Let's Get Loud for AS" Fundraiser Gala.

Michael and his team work passionately to organize an unforgettable evening that serves as a platform to raise funds for research, support programs, awareness campaigns, and community initiatives. More than just a fundraiser, the gala is a celebration of resilience and hope. In addition to raising awareness, Michael has successfully raised an impressive \$120,000 for the Canadian Spondyloarthritis Association.

This year's fundraiser gala will be held on May 3rd 2025. To learn more, visit **[lglas.ca](https://lglas.ca)**.



"I'm so proud and humbled that I've created this "Let's Get Loud for AS" Fundraiser Gala. I've been diagnosed with ankylosing spondylitis since 2018, and I'm very happy and proud to say that the wonderful treatments and the assistance of the CSA and my rheumatologist... have really helped me to live a better life with ease."

- Michael Santillo





# COMMUNITY SPOTLIGHT

## COLETTE LEROUX

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Early on in Collette's career at a fast-paced Toronto law firm, she spent countless hours at her desk, pushing through the daily grind and a load of overtime.

"I worked there for five years straight, and the pain symptoms continued to worsen, I remember thinking this must be how others feel everyday," she recalls. "At that point in my life, I remember thinking maybe my body isn't cut out for office work."

Looking back, Collette now recognizes the early signs of Ankylosing Spondylitis (AxSpA) in her teens and early twenties. She would often experience flares related to her diet, along with cervicogenic migraines and inflammation and overall, a very weak immune system.

In her 30s, Collette, a single mother of two boys, continued to work full-time while relocating closer to her home in Burlington, Ontario. She was in a service manager role which required a lot of desk work and phone usage which only escalated her pain. She experienced severe neck pain and in the journey of trying to understand what was wrong was bounced around

**“As a single mother, exhausted and in chronic pain, I struggled to navigate the medical system while caring for my two young kids.”**

from pain clinic to physiotherapists to surgeons. Despite numerous MRIs, no diagnosis was made.

“My mom asked if I talked to my cousin who had some rare spine disease and that is when I learned that he indeed had the HLA-B27 marker.”

Finally with this knowledge, Collette was referred to a rheumatologist, testing positive for the HLA-B27 marker. She finally received a diagnosis of Ankylosing Spondylitis, after decades of pain and frustration. Collette also helped her younger cousin receive an early diagnosis, sparing her years of frustration.

Collette was fully aware that the journey had just begun. She tried to spend time learning about the diagnosis with a focus on her primary goal of being an active involved mom to her boys while continuing to work fulltime. Collette spent years on anti-inflammatories, nerve and muscle medications, biologics and so on while never actually finding relief.

“I never knew what the next hour would be like. It was so difficult to schedule with family and friends, always

cancelling, rescheduling, and cancelling again. It is so hard on you mentally this disease letting all your loved ones down all the time.”

Collette continued to research holistic approaches to healing through nutrition, exercise, stress management, and mental well being.

In 2020, Collette, employed as a public servant, began working from home due to the pandemic. Through her research, she discovered that desk jobs, requiring prolonged sitting, worsened her AxSpA symptoms. Using the Ministry of Labour’s Second Career program, she successfully shifted careers, finding a role that not only supported her health but also proved deeply rewarding.

Managing a health and safety department, Collette felt exhausted and strained. Determined to improve, she began a daily 5 a.m. yoga routine. This commitment significantly improved her well-being, allowing her to stop biologics with her rheumatologist, Dr. Inman, support.

By combining Western and holistic medicine, massage, yoga, physiotherapy, diet, and meditation, Collette’s life transformed. At 48, she now works with a lifestyle coach, prioritizing happiness despite chronic pain.

This year, Collette participated in Walk Your AS Off, earning the top steps award. Her goal each day is to ignite a new passion. She is sharing her story to inspire others facing similar challenges that there is so much hope.

# AWARENESS

1,000,000+

LEARNED ABOUT AXSPA

300,000

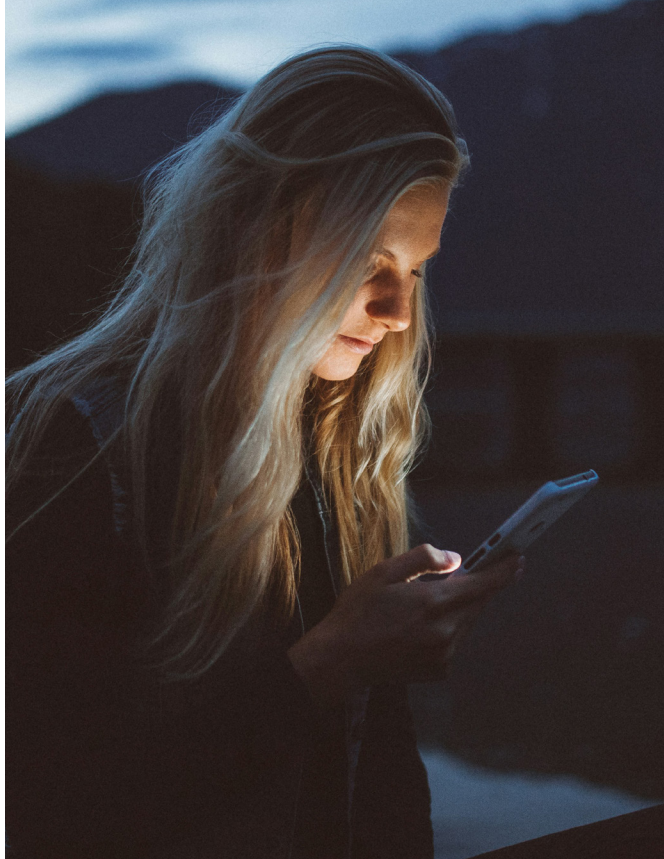
ENGAGED WITH THE CSA

10,000

REQUESTED INFORMATION

1,750+

DOWNLOADED TOOLS

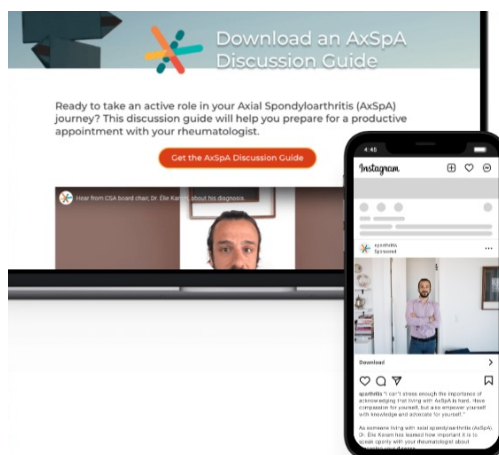


## SUPPORT GROUPS

The CSA fosters a vital community for individuals living with SpA, offering support groups that encourage experience sharing and emotional connection.

## NATIONAL AWARENESS INITIATIVES

World AS Day  
Psoriatic Arthritis Day  
Enteropathic Arthritis Day  
Arthritis Awareness Month  
Pain Awareness Month





# EDUCATION & SUPPORT

Expert-led sessions have provided essential insights and practical strategies for managing SpA. Participants report a stronger connection to others and enhanced understanding of their condition. We are proud to continue offering valuable, life-changing support through these impactful webinars.





**DR. ROBERT INMAN**  
MD, FRCPC



**DR. NIGIL HAROON**  
PHD, MD, FRCPC



**LAURA PASSALENT**  
PT, BSCPT, MHSC, ACPAC

**CSA & SPARCC**  
**2023**  
**SPONDYLOARTHRITIS PATIENT FORUM**

Monday November 6, 2023 | 5:00 - 8:30PM  
**BMO Education Conference Center**  
(60 Leonard Ave, Toronto, ON)

Complimentary Dinner for all registrants and their guests!



## Dealing with a New Diagnosis



**Dr. Dayna Lee-Baggley**

## ENTEROPATHIC ARTHRITIS Q&A

Recorded

TUESDAY  
APRIL 25, 2023

TIME  
7:30PM EST



WITH SPECIAL GUEST  
**DR. SHERRY ROHEKAR**  
MD F.R.C.P. (C)

# HEALTHCARE PROFESSIONAL PORTAL

Our updated HCP portal contains free tools and resources for clinics. Our aim is to support both healthcare providers and patients to optimize patient outcomes.



ORDER PRINTED  
& DOWNLOADABLE  
RESOURCES

Dear members,

We're excited to reflect on the incredible progress the Canadian Spondyloarthritis Association (CSA) has made this past year increasing awareness, supporting healthcare professionals, advocating for better patient care, and offering crucial support to those living with spondyloarthritis. Together, we've accomplished great things across the country.

We've successfully completed the first year of our three-year Strategic Plan, which is centered on cutting the time to diagnosis by 50%. Over the last two years, we've worked closely with the patient community and partners both in Canada and abroad to understand the reasons behind the lengthy diagnosis process for SpA and to identify the barriers causing these delays.

Our strategic objectives include:

**Disease Awareness** - *Reducing the time to diagnosis*

**Patient Education & Support** - *Amplify patient experiences and positive disease management*

**Advocacy** - *Improve access to treatments*

**Capacity Building** - *Generate abundance and affiliation*

Our accomplishments are a testament to the dedication and hard work of our team, volunteers, and supporters. Together, we are making a difference in the lives of those affected by spondyloarthritis.

Thank you for your continued support and commitment.



Brenda Delodder  
Executive Director



Dr. Élie Karam  
Chair of the Board



# OUR GENEROUS SUPPORTERS



The Dave and Anne Trick  
Family Foundation



# BOARD OF DIRECTORS



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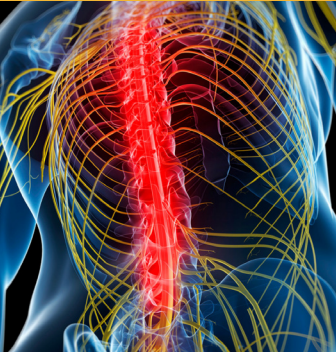


Don Bindon  
Director

# HISTORY

In 2006, SPARCC (Spondyloarthritis Research Consortium of Canada) in collaboration with SpA patients nationally, established the Canadian Spondyloarthritis Association (CSA).

The CSA is the only patient-led organization in Canada solely dedicated to supporting people living with spondyloarthritis (SpA).



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[sparthritis.ca](https://sparthritis.ca)