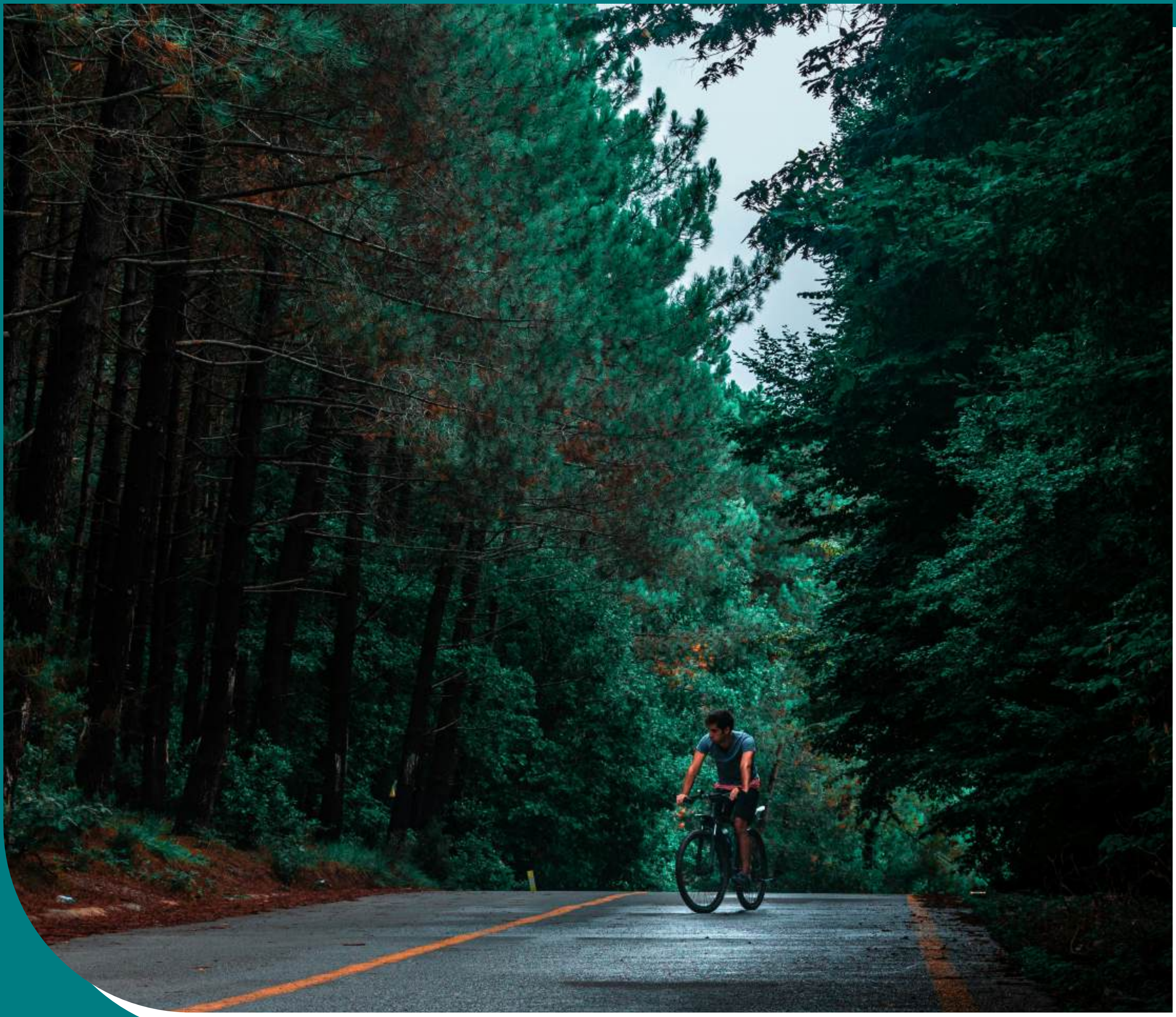
CANADIAN
SPONDYLOARTHRITIS
ASSOCIATION

ANNUAL REPORT
2024 - 2025



A MESSAGE FROM OUR EXECUTIVE DIRECTOR AND CHAIR OF THE BOARD

Dear Members, Partners, and Friends,

This past year has been one of real progress and impact for the Canadian Spondyloarthritis Association (CSA). Together, we advanced our shared goal to reduce Canada's average spondylarthritis (SpA) diagnosis by half within the next three years; which is currently 7 to 10 years and among the longest worldwide.

Our focus has remained clear: raising awareness, supporting patients, connecting with healthcare providers, and shaping policy for lasting system change. This isn't just strategy, it's a national effort to ensure no person with SpA waits years for the answers and care they deserve.

In 2024, our reach grew significantly: more than 102,000 people accessed our resources and services, and 1.4 million Canadians engaged with our educational materials, webinars, and advocacy content. Behind each number is a person impacted, whether a newly diagnosed patient, a healthcare professional using updated resources, or a policymaker responding to our advocacy.

Our advocacy was ambitious. On Parliament Hill, we worked with national arthritis organizations to push for shorter specialist wait times, stronger research funding, and equitable treatment access across Canada. At the provincial level, we mobilized 500+ petition signatures, spotlighting critical gaps in access for SpA patients.

We also invested in patient empowerment. This year, we launched four Pain Management Journals and expert-led webinars, giving patients the tools to actively shape their care and improve outcomes.

With every milestone is a committed community of patients, caregivers, healthcare professionals, and volunteers. We are grateful for your time, energy, passion and expertise that expands our collective impact.

As we enter the final year of our Strategic Plan, we remain committed to:

- Accelerating diagnosis through awareness and systems change
- Ensuring improved and equitable access to care
- Empowering patients with knowledge and tools
- Strengthening CSA as Canada's leading SpA voice

Together, we are not only changing timelines, we are changing lives. We look forward to building on this momentum and working with you to ensure every Canadian with SpA receives timely, effective, and compassionate care.

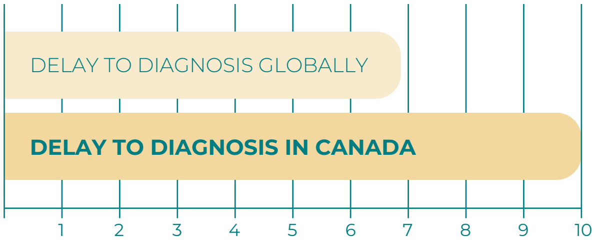
With gratitude and determination,

BRENDA DELODDER
Executive Director

ÉLIE KARAM
Chair of the Board of Directors

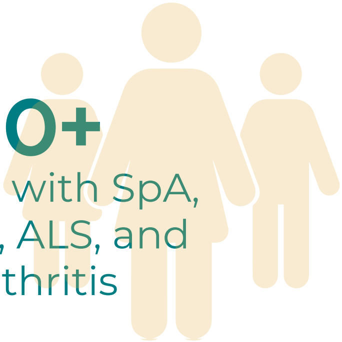
SPA IN CANADA: A HIDDEN EPIDEMIC

Canada has one **of the longest diagnostic delays in the world**



7-10 YEARS

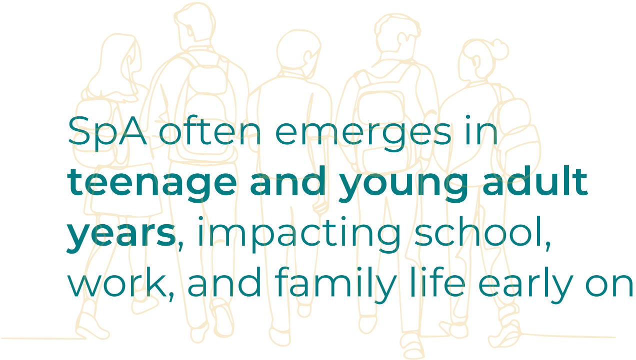
Average diagnostic delay



More than

500,000+

Canadians live with SpA, more than MS, ALS, and rheumatoid arthritis combined

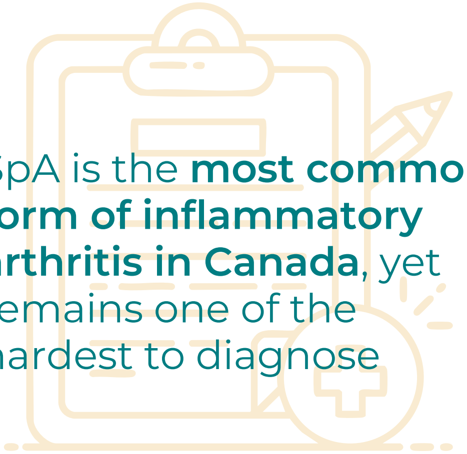


SpA often emerges in **teenage and young adult years**, impacting school, work, and family life early on

Arthritis is the

#1 cause of disability

in Canada; more than injury, heart disease, or cancer



SpA is the **most common form of inflammatory arthritis in Canada**, yet remains one of the hardest to diagnose

The earlier we detect SpA, the more we can prevent irreversible damage and protect quality of life.

OUR STRATEGIC PILLARS

Disease Awareness

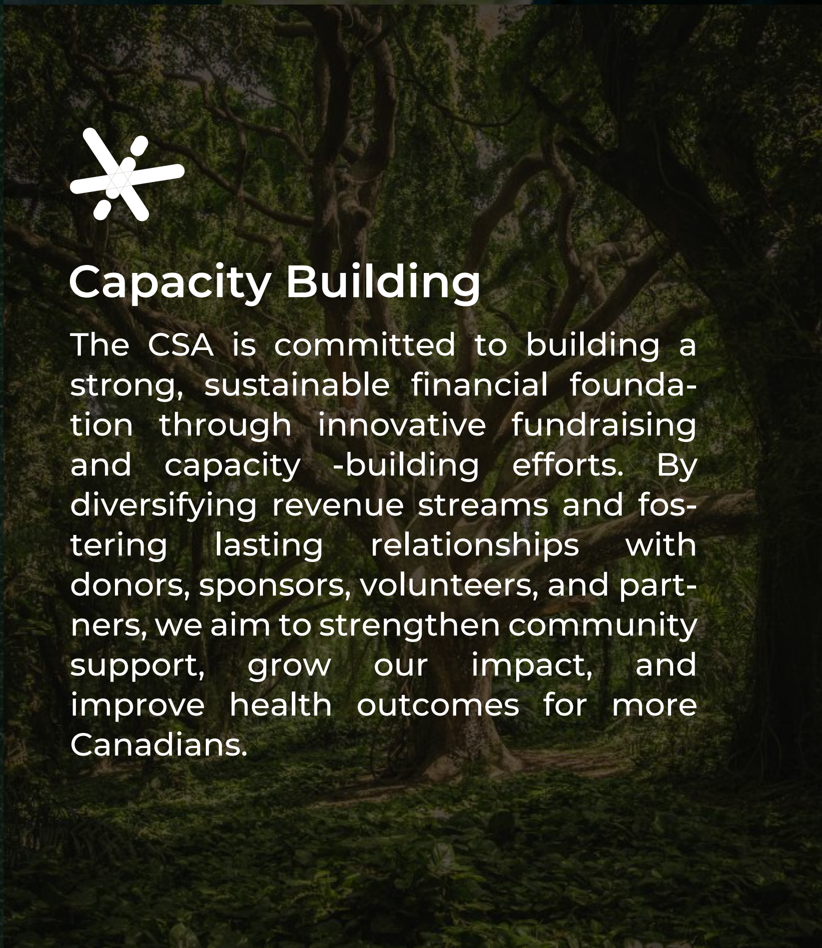
The CSA is committed to reducing the time it takes for individuals to receive a proper diagnosis. Through targeted initiatives, public awareness, system improvements, and collaboration with healthcare professionals, we aim to streamline the diagnostic process. By promoting early identification, advocating for efficient pathways, and providing educational resources, we are working relentlessly to shorten the diagnostic timeline.

Patient Education & Support

The CSA is committed to championing impactful improvements in the journey of diagnosed Canadians living with spondyloarthritis. Through resourcefulness, education, support, and collaboration, we serve as a catalyst for positive change, empowering patients and fostering strong partnerships to help individuals manage their condition effectively.

Advocacy

The CSA is dedicated to improving the accessibility of treatment options for individuals living with spondyloarthritis. Our objective is to advocate for and implement measures that ensure Canadians have timely and equitable access to new treatment options, innovative therapies, and high impact support services. By collaborating with policy makers, healthcare stakeholders, raising awareness, and leveraging innovative solutions, we aim to break down barriers and reduce treatment disparities.



Capacity Building

The CSA is committed to building a strong, sustainable financial foundation through innovative fundraising and capacity -building efforts. By diversifying revenue streams and fostering lasting relationships with donors, sponsors, volunteers, and partners, we aim to strengthen community support, grow our impact, and improve health outcomes for more Canadians.

9,300+ CSA MEMBERS

102,924 PEOPLE SUPPORTED THROUGH CSA RESOURCES

1.4 M NUMBER OF TIMES CANADIANS ENGAGED AND ACCESSED SUPPORT, MATERIALS AND RESOURCES.

LET’S GET LOUD FOR AS: AN EVENING OF GENEROSITY AND CHANGE: $250,000 RAISED

Led by longtime advocate Michael Santillo, Montreal’s annual gala unites patients, supporters, and advocates for a night of generosity and purpose, raising $250,000 in three years for awareness and community programs.

The event brought together people living with SpA, supporters, and advocates for an unforgettable evening of connection, generosity, and purpose.

We are deeply grateful to Michael, the committee, our event partners, and every guest who contributed to making this year’s gala a powerful show of support for the axSpA/AS community.

Mark your calendars: the next Let’s Get Loud for AS Gala will take place on May 2, 2026.

RIDE YOUR AS OFF: ONE MAN'S PASSION RAISED $110,000 FOR SpA AWARENESS

In honour of his wife Monica, Matthew took on an extraordinary challenge: riding 77 km to reflect the daily struggles Monica faces living with Spondyloarthritis (SpA). What began as a deeply personal mission quickly resonated with people across the country, raising more than $110,000 in two years.

His determination and heartfelt story inspired donors nationwide. These funds support patient programs, educational resources, and national advocacy campaigns, helping ensure that people living with SpA have access to the support and awareness they deserve.

Through his ride, Matthew not only honoured Monica, but powerfully highlighted the resilience of the 500,000 Canadians living with SpA.

MEMBER SPOTLIGHT

ELECTRIFY AS: CYCLING ACROSS CANADA FOR AWARENESS AND HOPE

Tyler's 16,000+ km solo ride across Canada and back is a message of solidarity: every kilometre is for the thousands living with SpA, reminding them they are seen and supported.

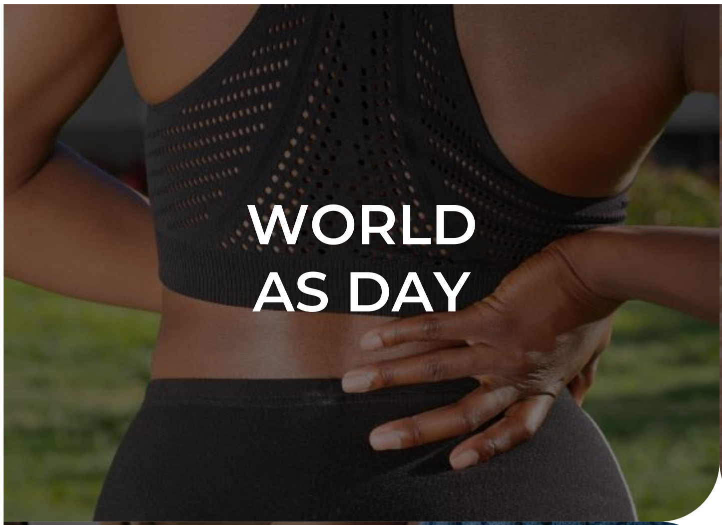
Electrify AS is more than a ride; it's a movement. Tyler's cross-country journey is a powerful tribute to resilience and community, raising awareness for a condition that is too often misunderstood and overlooked. His dedication reinforces the daily struggles of those living with SpA, while also inspiring hope, connection, and collective strength.

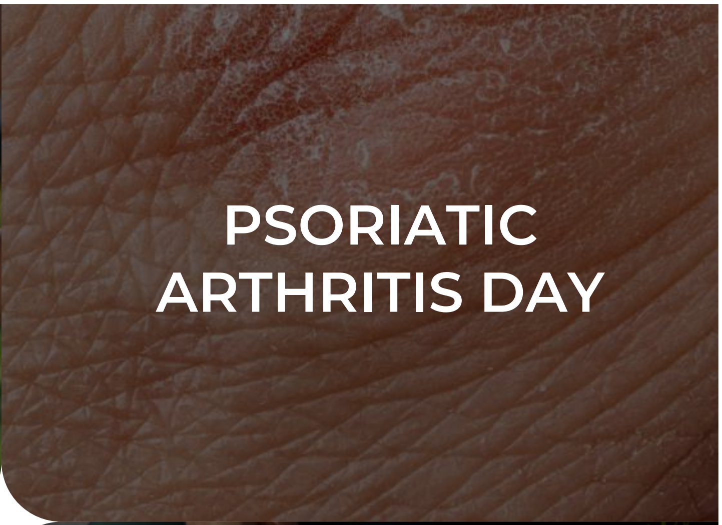
DRIVING CHANGE

CSA led four major awareness initiatives: World AS Day, Psoriatic Arthritis Day, Enteropathic Arthritis Day, and Arthritis Awareness Month. Each campaign reached Canadians from coast to coast via media content providing educational resources, webinars, and media engagement. These campaigns highlighted the early signs of disease, the impact of delayed diagnosis, and the importance of timely referral to specialists.

By broadening public understanding, supporting patients to self-advocate, and equipping healthcare providers with better tools, these awareness efforts directly drive down diagnostic delay by reaching more than 1 million Canadians.

TARGETED CAMPAIGNS ADVANCING TIMELY DIAGNOSIS





FEDERAL ELECTION ADVOCACY – KEEPING ARTHRITIS ON THE AGENDA

During the federal election, CSA joined the Arthritis Action Plan coalition to press all political parties to prioritize arthritis. Outreach to candidates and leaders emphasized that 6 million Canadians live with arthritis, more than diabetes, cancer, or heart disease combined, yet face long wait times, limited access to treatments, and inequities in care.

The coalition called for faster access to medications, innovative team-based models of care, and action on health inequities. Through this effort, CSA helped ensure arthritis remained firmly on the national political agenda.

OTTAWA ADVOCACY DAY - PUTTING A NATIONAL SPOTLIGHT ON ARTHRITIS

CSA joined patient organizations and health advocates in Ottawa, meeting with 20+ federal policymakers and elected officials. CSA led discussions highlighting arthritis as the leading cause of disability in Canada and the urgent need for equitable access to treatment.

Our impact was immediate. Following CSA's engagement, the federal health opposition sent a formal letter to the Minister of Health (February 2025) urging that arthritis medications receive the same level of access and support that diabetes already receives.

This outcome underscores CSA's growing influence and the power of sustained advocacy. It also reinforces our central message: arthritis deserves the same attention, recognition, and healthcare funding as diabetes, reflecting the millions of Canadians whose lives and futures are impacted by this disease.

PROVINCIAL ADVOCACY – DRIVING CHANGE IN BC

British Columbians with SpA face critical gaps in treatment options when compared to other provinces and territories in the country. In 2024, we took action, launching a national petition with 500+ signatures, hosting webinars with rheumatologist Dr. Jonathan Chan, and calling on the provincial government to expand treatment options and ensure equitable access for all. CSA also collaborated with Medicines Access Coalition BC to further drive urgency via advocacy outreach.

OUR CALLS TO ACTION

Expand Treatment Options

Ensure Equitable Access to Treatment

500+

PUBLIC VOICES CALLING FOR URGENT REFORM

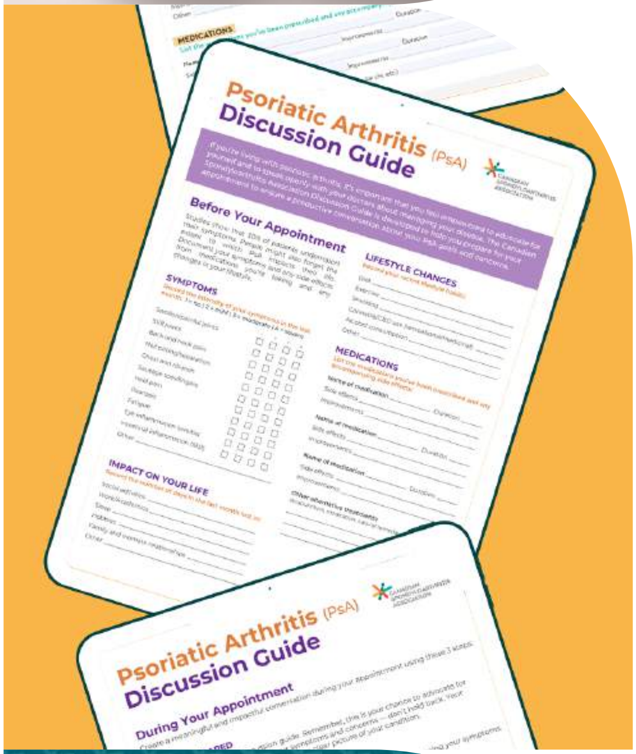
PATIENT VOICE SUBMISSION – JUVENILE IDIOPATHIC ARTHRITIS

In early 2025, CSA co-led a coalition submission to the BC Ministry of Health in support of approving a treatment for Juvenile Idiopathic Arthritis (JIA). Backed by 214 patient and caregiver testimonies, the submission highlighted the transformative impact of therapy options. CSA's leadership is pushing BC to ensure children and youth are not left behind in access to life-changing medications.

EXPANDING EDUCATION & SUPPORT THROUGH NEW WEBINARS AND RESOURCES

This year, we strengthened our commitment to empowering the SpA community by launching a suite of new and revised educational tools and support resources. We introduced four new Pain Management Journals designed to help individuals track their daily symptoms and engage in guided self-reflection.

We released a series of new webinars featuring expert insights and practical strategies, making valuable information more accessible to people living with SpA and their caregivers. To further support meaningful conversations between patients and healthcare providers, we revised our Psoriatic Arthritis (PsA) Discussion Guide, ensuring it reflects the latest clinical knowledge and patient needs.



These initiatives represent a significant step forward in expanding education, support, and self-advocacy within our community.

SARAH'S STORY: FROM PAIN TO EMPOWERMENT

For 3.5 years, Sarah lived with debilitating pain and no answers. Her persistence, and a referral to the right specialist, led to a diagnosis of Ankylosing Spondylitis, life-changing treatment, and renewed hope. Her journey reflects why CSA fights every day for earlier diagnosis and better care.

Sarah began experiencing low back pain in April 2019. What started as mild discomfort quickly became debilitating. Night after night, she'd wake up in pain, taking ibuprofen and stretching in hopes of falling back asleep, often without success.

Initially, Sarah dismissed her pain, attributing it to Accutane side effects, a new mattress, and poor work-from-home ergonomics. Like many, she assumed it was temporary.

But as her symptoms worsened, so did her quality of life. A once-competitive hockey goalie and full-time student, Sarah gained 40 pounds, experienced night sweats, exhaustion, and depression. When she finally sought medical help, her pain was dismissed as weight-related or hormonal. Still searching for answers, her family doctor ordered blood work and physiotherapy, which led to inconclusive results. It wasn't until she pushed for a rheumatologist referral, thanks to encouragement from her partner, that real progress began.

Her new rheumatologist listened, re-ordered better diagnostic tests, and finally diagnosed Sarah with

Sarah's advice to others:

"Give yourself grace"

Ankylosing Spondylitis after 3.5 years of suffering. The diagnosis also explained her chronic fatigue and posture issues she'd experienced for years.

Starting on a biologic medication gave her remarkable relief. She was able to return to the gym and play hockey again, but daily life still required adjustments. Some days, even a shower could drain her energy. She adopted the "spoon theory" to manage her day-to-day limits.

Sarah's workplace offered flexibility, but her romantic relationship didn't survive the toll of the illness. She entered a grieving phase, mourning the life she once had.

Then came another blow: nerve pain led to a diagnosis of CIDP, a rare side effect of her biologic. Forced to stop the medication, she relapsed until starting a new biologic. Slowly, her condition improved again.

Through it all, Sarah leaned on friends, family, and understanding coworkers. Her current partner met her at her worst and accepted her fully. The Canadian Spondyloarthritis Association's resources helped her explain her condition to others and advocate for herself.

Sarah's advice to others: Give yourself grace. Chronic illness is a roller coaster, emotionally and physically. She holds onto hope that future treatments will bring even more relief, and she's grateful for the people who stand by her side.

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OUR MISSION

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

OUR VISION

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