

Arthritis West Island Self Help Association

www.awishmontreal.org

In your community



37 years
Since 1987

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Arthritis West Island Self Help Association

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- Special Edition -

Joint Effort

Newsletter



PRESIDENT'S MESSAGE

I, Paulette Zielinski, have been volunteering for AWISH for over 27 years and became President in June 2006. AWISH is a non-profit organization that assists those dealing with arthritis and chronic pain in the West Island of Montreal and surrounding areas. Our mission is to provide Information, Education, and Support.

Arthritis is often thought to be a disease that only impacts the older generation; however this is not the case! Over the years I have been intrigued about the existence of Juvenile Idiopathic Arthritis and young adults who deal with arthritis.

To quote from Arthritis Society Canada: "Many people mistakenly think arthritis is just a disease of the elderly, but the statistics tell a different story. About three in 1,000 Canadian children have childhood arthritis (CA), which makes it more common than most chronic childhood diseases. You may have heard of the medical term "juvenile idiopathic arthritis" and wondered what it means. "Idiopathic" simply means "unknown". This word is used when other illnesses known to cause arthritis have been ruled out as the cause of a child's arthritis."

We hope that this Special Edition of our newsletter will provide new insights and helpful information to many. If you or someone you know deals with arthritis in babies, children and/or young adults, please reach out to AWISH as we would like to see what demand there is out there to be able to potentially offer additional classes and workshops geared towards the younger generation. If there is an interest, AWISH would be thrilled to organize and hold a special public event in the future with guest speakers (medical professionals) followed by Q&As with the audience. We would also invite community organizations to have information booths, of varying topics, offering numerous additional resources to the public.

This Special Edition of AWISH's quarterly newsletter Joint Effort is sponsored by <u>Kiwanis Lakeshore Montreal</u> – thank you!

Providing services to children & youth since 1958

"Our members are all volunteers who work to provide physical and financial help primarily to childrens' projects and also to seniors. We raise funds annually through a variety of events and initiatives."



www.lakeshorekiwanis.ca



AWISH – contact us today if you'd like to... **VOLUNTEER** | **DONATE** | **BECOME** A **MEMBER** \$25/year

CASSIE + FRIENDS

Cassie + Friends is the only charity in Canada dedicated 100% to the pediatric rheumatic disease community. Rooted in our four pillars, we champion research, education, connection & support for pediatric rheumatic diseases.

Working with patients, caregivers, healthcare professionals, researchers, and other friends, we've created a life-changing community to help kids and families face the ups and downs of life with a chronic condition – so that no child has to live in pain alone. We've shown what's possible, but there's lots more to do.

Page Source: www.cassieandfriends.ca

CASSIE'S STORY

When Cassie was diagnosed with JIA at just 22 months - a disease that would soon attack over 16 joints as well as her eyes - all her parents could think was, "What does my child's future hold?"

Overwhelmed by their new reality of joint injections, aggressive medications and daily pain, Cassie's family desperately searched for information and support. Instead, what they found was a heartbreaking gap in reliable resources and nowhere to meet other families who understood what they were going through.

In learning Cassie was just one of 24,000 affected kids in Canada, they decided to take action! Working with a handful of other families and their medical team, Cassie + Friends was launched to make sure no child, teen or parent ever has to feel alone again. Today, Cassie + Friends has raised over \$2.5 million to support kids and families all across Canada with research, educational events, youth and school programs, equipment/parent funds, advocacy and more.

Did you know that March is Juvenile Arthritis Awareness Month in Canada?

A WORD FROM MARISSA SANGERS

My name is Marissa Sangers. I am both a Juvenile Arthritis mom to my sweet daughter, who was diagnosed with Juvenile Arthritis at 3 years old, and the Youth and Family Engagement Coordinator at Cassie + Friends.

When my daughter was just 2 years old, she had a big swollen toe. We questioned it but thought it was just a break or bruise. We began to worry after a few days when [she] refused to walk on it without crying. Our local hospital thought it might have been a mild break, but didn't see anything on x-rays. I trusted my gut and knew it was something more. We went to the Children's Hospital in London, ON where they didn't give up until they knew exactly why our little one was experiencing so much pain. It took almost a year, multiple referrals and tests until finally a doctor said to us "this looks like Juvenile Arthritis."

We were shocked – and confused. My husband and I had never heard of JIA! Kids could get arthritis?! As the last 6 years have passed since this strange big toe – [our daughter] has tried more than 10 different medications, had multiple joint injections, daily physiotherapy, types of braces and supports and struggled with the physical and emotional tole of her condition. She now is taking daily medications and has to go for Biologic infusions at the Children's hospital every 4 weeks just to keep her pain under some sort of control – and it still isn't perfect.

Parenting this has been especially challenging. There is so many times where I have been overwhelmed with information and questions on this journey. One late night and avid researching – I found Cassie + Friends. I knew that there had to be SOMEONE out there who understood what I was going through. I finally didn't feel alone...

Marissa Sangers

Youth + Family Engagement Coordinator (Cassie + Friends)

SLEEP AND PAIN: BREAKING THE VICIOUS CYCLE FOR A GOOD NIGHT'S REST



Author: Sheryl Guloy, PhD

President of Somnolence + Inc. <u>www.somnolenceplus.com</u>

Board Member, Somnolence Canada Foundation



For those living with arthritis, achieving a good night of sleep can be a challenge. Not only does poor sleep increase one's sensitivity to pain, but sleep deprivation and pain interact to form a vicious cycle of increasing inflammation for those living with arthritis. While medication has traditionally been used for arthritic pain management, growing support exists for the inclusion of non-pharmaceutical approaches, including sleep hygiene, to improve sleep in order to interrupt this cycle of inflammation and pain sensitivity.

Seven Sleep Hygiene Tips for All

Sleep hygiene is a set of practices used to promote good sleep. Some of these practices include:

- Maintaining a consistent sleep schedule, even on the weekends.
- Allowing sufficient time for sleep.
- Using the bedroom only for sleep.
- Keeping the bedroom cool and dark.
- Dimming lights in the evening.
- Turning off electronic devices at least one hour before bedtime.
- Drinking caffeine no later than six hours before bedtime.
- Drinking alcohol no later than four hours before bedtime.





Changing Sleep Needs

While sleep hygiene tips are good for all ages, they do need to be adapted for differences in age-related sleep needs. Here are the recommended hours of sleep for children, adolescents, and adults:

- Children (ages 6 to 12): 9 to 12 hours of sleep per night
- Adolescents (ages 13 to 18): 8 to 10 hours of sleep per night
- Adults (18 and older): 7 to 9 hours of sleep per night

The Challenge of Adolescent Sleep

In addition to age-related differences in sleep duration, changes in the timing of sleep also occur. Adolescents are particularly notorious for going to bed late, which negatively impacts the number of hours they sleep at night. While this may be related to poor sleep hygiene or the need for better time management, late bedtimes are primarily related to a biological shift in the internal clock or circadian rhythm at puberty.

For many adolescents and adults in their early twenties, this shift results in their not being able to obtain the recommended number of hours of sleep they need because their natural bedtimes tend to be quite late at night and they need to wake up early to go to school. Although those in post-secondary education may be able to schedule classes later in the day, this is not always possible. Moreover, those who work an early or 9-to-5 shift may also experience the same challenge. In fact, night owls of all ages may find sleep deprivation to be an ongoing issue as long as their sleep patterns are misaligned with school, work, and other commitments.



SLEEP AND PAIN: BREAKING THE VICIOUS CYCLE FOR A GOOD NIGHT'S REST

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What Can Be Done?

To advance bedtimes, strategies include:

- Exposure to morning sunlight.
- Eating breakfast soon after waking up.
- Engaging in physical activity earlier in the day.
- Limiting naps and caffeine consumption, particularly after 3 pm.
- Maintaining regular mealtimes and avoiding eating past 7 pm.



In sum, remember that good sleep is foundational to health and well-being. These strategies and tips promote good sleep. However, should sleep deprivation continue, consider consulting a healthcare provider, such as a sleep specialist, to explore further options.

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FORGE FITNESS OFFERS PATH TO HEALTHY LIVING

Author: Steve Henschel

Source: Niagara This Week - Welland - June 6, 2018

Four years ago, Zac Spinosa was in the darkest point of his life. On Monday he celebrated the opening of his own personal-training facility Forge Fitness.

The story of how the 21-year-old Welland resident got to the point of opening his own fitness space starts even before he hit rock bottom, though. It starts with an athletic, healthy Grade 10 Notre Dame student, a popular athlete who had it all from a high school perspective.

"I thought I was on top of the world," said Spinosa, who toward the end of Grade 10 started to get hives. He shrugged it off as an allergy and cut out some foods, hoping that would do the trick.

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Arthritis West Island Self Help Association SEASONAL CALENDAR - WINTER 2025





For more information on our programs and activities, please contact us.

www.awishmontreal.org | 514-631-3288 | arthritis@awishmontreal.org





EXERCISE CLASSES – pre-registration is required

DORVAL

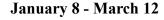
Sarto-Desnoyers Community Centre - 1335 Chem. Bord-du-Lac-Lakeshore

WEDNESDAY - MORNING

WEDNESDAY - AFTERNOON

11:00 am - 12:30 pm

1:00 pm - 2:30 pm



10 weeks | \$65 AWISH member | \$75 non-member

DDO

Sunnybrooke Chalet - 7 Rue Cadman

FRIDAY

January 24 - March 14

11:10 am - 12:40 pm

8 weeks

\$52 AWISH member | \$60 non-member

PIERREFONDS

Gerry-Robertson Community Centre - 9665 Blvd Gouin Ouest

TUESDAY

THURSDAY

10:30 am - 12:00 pm

10:30 am - 12:00 pm

January 7 - March 4 & March 18 January 9 -

January 9 - March 6 & March 20

10 weeks \mid \$65 AWISH member \mid \$75 non-member

Led by certified, professional fitness instructors. Well designed to meet individual needs and abilities. Joint and muscle-friendly whole-body exercises, including resistance, aerobics and stretching.

Some services are free for AWISH members, others may require a small fee. Full session payment is required – no exceptions - prior to start date. Contact us for cancellation policy, to register & for more information.



- Led by Health & Wellness Coach: Ariana Parolini -

5 weeks: April 1, 8, 15, 22, 29

Dealing with arthritis or chronic pain?

Tuesdays: 6:30 PM - 8:30 PM

Learn how to manage your pain by understanding it and developing strategies to live a better life through this workshop.

FREE for AWISH Members

Register with AWISH

or \$20 for non-members - join now for \$25/year!

Sarto-Desnoyers Community Centre - 1335 Chem. Bord-du-Lac-Lakeshore, Dorval

FORGE FITNESS OFFERS PATH TO HEALTHY LIVING

Continued from page 4



Soon his ankles became sore, then his wrists, eventually moving his arm would bring him to tears, even if he considered himself a tough guy. He was diagnosed with rheumatoid arthritis, a systemic auto-immune disease causing inflammation throughout the body. Spinosa needed crutches just to walk up the aisle to receive his junior athlete of the year award as Grade 10 wrapped up.

His symptoms worsened, and eventually his inflammation was so bad his parents and brother would have to help him bathe and dress.

Spinosa spiralled into depression, locking himself in his room, eating away the pain and distracting himself with

video games. His weight steadily rose until he was 275 pounds, a dramatic increase from the 190 pounds he weighed in at before his diagnosis. His grades slipped, everything seemed to be falling apart.

"Mentally and emotionally I was in the darkest space of my life," said Spinosa, who would live in that spiral of depression for another year and a half before a slight remission, and some coaxing from his father, got him on the treadmill for a light workout. He started off just walking at a slow pace.

He felt better, he got hooked on fitness. He dove into books and online articles on athletic training, dietary needs and pain management.

"I got addicted to health and wellness ... I expanded my knowledge and got really good at training myself," said Spinosa, who credits that addiction with his new-found lease on life. It has given him his mobility back, he's dropped down to 185 pounds, he jokes he is more healthy than he was before the arthritis diagnosis. He went from barely being able to walk to lifting 405 pounds off the ground in four short years. People noticed the transformation and he began sharing tips and tricks. A year ago he decided to make his passion a part-time career of sorts, renovating the storage room of his dad's bakery into the now-open 600-square-foot personal training space on Niagara Street. He had 19 hours of training booked before Forge Fitness even opened on Monday.

"My whole thing is being radically honest with people," said Spinosa, explaining his focus will be simple, a positive one-on-one training environment. He won't promise clients chiseled abs in eight weeks, or push miracle supplements. Instead he hopes to teach fitness as a skill, and like developing

"No one learns to knit overnight [...], fitness is the same way"

any skill it will be a journey. No one learns to knit overnight he said, fitness is the same way.

"It's going to be an intimate setting with no judgment," said Spinosa, adding he hopes to help his clients avoid some of the mistakes he made early in his fitness journey, be it impractical workouts from body building magazines or loading up on supplements. He said he will help with dietary info, he'll even go to the grocery store with clients. Most of all, he said, Spinosa will focus on what he described as the most overlooked benefit of getting one's self in fighting form.

"You can take a hold of your life and actually feel good mentally," said Spinosa.

What is juvenile idiopathic arthritis?

Juvenile idiopathic arthritis (JIA) is a general term covering all categories of chronic inflammatory joint diseases starting before the age of 16 years. (Source: www.canada.ca)

HOW IS CHILDHOOD ARTHRITIS DIAGNOSED?

Page Source: Arthritis Society Canada

Children with arthritis do not always complain of pain, so it may be difficult to tell if a child's joints are inflamed (red, swollen and warm to the touch). Sometimes the only initial clues to arthritis may be that the child is stiff when waking up or there is some difficulty using an arm or leg. In some cases, there may be no signs other than a swollen joint or some loss of movement. As a result, CA can be difficult to detect and may go unrecognized by even the most experienced physician. Your child's doctor will look carefully for any signs of joint swelling or loss of mobility, which indicate that the joints are inflamed.

Arthritis or its symptoms may be a result of many different illnesses, including infection, injury, allergic/drug reactions or other autoimmune diseases (such as thyroid disease, diabetes, inflammatory bowel disease or lupus). Since there is no single test to diagnose CA, tests to rule out other causes of joint pain and swelling must be done. Your child will likely have X-rays as well as urine and blood tests.

Once the diagnosis of CA has been confirmed, routine tests (such as blood tests, X-rays and eye examinations) will need to be repeated from time to time in order to follow the illness and assess the effects of any medication.

THE 7 MAJOR TYPES



Oligoarticular-Persistent Juvenile Arthritis:

- The most common and mildest form.
- If no more than four joints are involved beyond six months after diagnosis.



Oligoarticular-Extended Juvenile Arthritis:

- If four or fewer joints are involved within the first six months after the initial diagnosis, but the child develops arthritis in five or more different joints at any time during the course of the disease.

The rheumatoid factor (RH) is an antibody or protein produced by the immune system that can attack healthy tissue in your body such as the joints.



Polyarticular-Rheumatoid Factor Negative Juvenile Arthritis:

- Five or more joints involved within the first six months of diagnosis, but they do not test positive for rheumatoid factor (RF).
- Can begin at any age, and is more common in girls than in boys.



Polyarticular-Rheumatoid Factor Positive Juvenile Arthritis:

- Five or more joints involved within the first six months of diagnosis and test positive for a blood protein called rheumatoid factor (RF).



Systemic Juvenile Arthritis:

- Affects the body in a general way (ex: frequent fevers) and can affect not only the child's joints and skin, but also the internal organs.
- Can begin at any age and affects boys and girls equally.



Enthesitis-Related Arthritis:

- Inflammation both in their joints (arthritis) and in the spots where tendons attach or insert to bones (entheses).
- This is one of the few types of arthritis that may run in families.

"Articular" means relating to a joint.

"Oligoarticular" refers to a few (2-4) joints.

"Polyarticular" refers to many (5 or more) joints



Psoriatic Arthritis:

- The occurrence of arthritis with psoriasis, a skin disease that appears as a scaly red rash.
- Affects both boys and girls, and it can happen at any age.

COMMON TYPES OF JUVENILE ARTHRITIS

Source: Arthritis Foundation

• Juvenile idiopathic arthritis.

It is the most common form of juvenile arthritis (see page 7).

Juvenile myositis:

An inflammatory disease that causes muscle weakness. There are two types: Juvenile polymyositis and juvenile dermatomyositis, which also causes rash on the eyelids and knuckles.

• Juvenile lupus:

An autoimmune disease that can affect the joints, skin, internal organs (i.e. heart, kidneys, lungs) and other areas of the body. The most common form is systemic lupus erythematosus, or SLE.

• Juvenile scleroderma:

Scleroderma, which literally means "hard skin," describes a group of conditions that causes the skin to tighten and harden.

Vasculitis:

This type of disease causes inflammation of the blood-vessels, which can lead to heart complications. Kawasaki disease and Henoch-Schonlein purpura (HCP) are the most common kinds in kids and teens.

• Fibromyalgia:

A chronic pain syndrome that can cause widespread muscle pain and stiffness, along with fatigue, disrupted sleep and other symptoms. It is more common in girls but rarely diagnosed before puberty.

ARTHRITIS SOCIETY CANADA

offers numerous resources to help families live better with childhood arthritis

Source: Arthritis Society Canada



- <u>Taking Charge of Your JIA</u>: Online interactive resource helps youth 12-17 learn about juvenile idiopathic arthritis and steps they can take to help manage their condition.
- You, Your Child and Arthritis: This guide provides the information a parent/guardian needs to understand their child's disease and to feel comfortable caring for them. It also covers the different types of juvenile arthritis, current treatments and other important elements of treatment.
- <u>Childhood Arthritis Backpack Program:</u> the program delivers a backpack filled with information and tools to families of children ages 4-12 who have been newly diagnosed with arthritis or another rheumatic disease.
- <u>Summer Camps for Children with Arthritis:</u> Each summer, the Arthritis Society Canada runs camps across the country for children living with arthritis. Camping together with a common condition means that children feel understood and accepted. It allows them to be defined not by their disease, but by who they are.
- <u>Club Sunrise</u>: Provides children and youth aged 5-17 who are affected by arthritis or other rheumatic diseases an opportunity to come together online to participate in fun and interactive activities throughout the year. This program is free thanks to our amazing sponsors.
- <u>Childhood Arthritis Camps Travel Grant:</u> The Arthritis Society Canada offers grants of up to \$500.00 to help families participate and travel to an in-person camp.

VARIOUS ORGANIZATIONS AND HEALTH RESOURCES

AWISH

Arthritis West Island Self-Help Association (West Island of Montreal & surrounding areas) www.awishmontreal.org | 514-631-3288 | arthritis@awishmontreal.org

Cassie + Friends www.cassieandfriends.ca

Arthritis Research Canada www.arthritisresearch.ca

Arthritis Society Canada

www.arthritis.ca

WIAIH www.wiaih.qc.ca **Kiwanis Lakeshore Montreal**

www.lakeshorekiwanis.ca

Click here for a collection of **Various Youth Resources**

Government of Canada

www.canada.ca/en/public-health/services/publications/diseases-conditions/juvenile-idiopathic-arthritis

Shriners Children's Canada (Pediatric Specialty Care in Canada)

www.shrinerschildrens.org/en/locations/canada

JGH: Jewish General Hospital - Rheumatology www.igh.ca/care-services/rheumatology

MCH: Montreal Children's Hospital - Rheumatology www.montrealchildrenshospital.ca/clinics/rheumatology

MUHC: McGill University Health Centre - Division of Rheumatology

www.muhc.ca/med-rheumatology/profile/division-rheumatology

Clinic Locations: Glen site – Royal Victoria Hospital | Montreal General Hospital | Lachine Hospital

McGill - Faculty of Medicine and Health Sciences - Division of Rheumatology

www.mcgill.ca/rheumatology/clinics www.mcgill.ca/rheumatology/faculty

> Clinic Locations: Montreal Neurological Institute Montreal Children's Hospital | Montreal General Hospital Royal Victoria Hospital | Jewish General Hospital

Montreal West Island Integrated University Health and Social Services Centre - Musculoskeletal Clinic

www.ciusss-ouestmtl.gouv.qc.ca/en/care-and-services/specialized-services/musculoskeletal-clinic

AWISH MEDICAL PARTNERS

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Dr. Elizabeth M. Hazel, OLY, MDCM, FRCPC, MM, Division Director, Rheumatology, MUHC, Assistant Dean, PGME, CBME, Associate Professor of Medicine, Division of Rheumatology McGill University; Director of Young Adult with Rheumatic Disease (YARD) Clinic: 514-934-1934 ext. 42437

It is estimated that as many as 25,000 Canadian children aged 18 and under live with a form of arthritis.

Source: Arthritis Society Canada

WORDS OF WISDOM

My advice is, never do tomorrow what you can do today. Procrastination is the thief of time

Source: Charles Dickens, David Copperfield

COMMUNITY CALL TO ACTION - VOLUNTEERS & SUPPORT NEEDED

AWISH is looking for volunteers

Our charity is particularly in need of skilled individuals willing to take leading roles in:

- Fundraising & donor relations (find & bring on new partners/supporters, fundraising ideas, etc)
- Community outreach (find events/groups/locations for AWISH to give presentations and/or to have an information booth; aid with these events/gathering in numerous ways – help us help others!)
- Member relations (help increase membership only \$25/year every member's contribution counts!)
- Assisting with adding to our offered services (help us find someone qualified to run a Yoga/Chair Yoga exercise class + AWISH is open to other ideas for increasing social activities that can be offered such as other types of exercise classes, various workshops & more.)

Volunteering is a fulfilling experience that helps the community – your small gesture has great impact!

AWISH looks forward to hearing from you!

www.awishmontreal.org | 514-631-3288 | arthritis@awishmontreal.org

MANY THANKS TO OUR SUPPORTERS!

It is with their continued support that AWISH is able to better serve the community. Please contact us today to find out how you can help.









The Dr. J. David & Doris Roger Family Fund









membres

AWISH

members





Gregory Kelley Député/MNA Jacques-Cartier



Monsef Derraji Député/MNA Nelligan



Député/MNA Marquette



Enrico Ciccone Brigitte Garceau Député/MNA Robert-Baldwin



COMMUNITY FUND

Jardins Dorval Gardens





Héritage anonyme

Joint Effort is a quarterly publication. All articles, at times translated and edited, are presented for your information and do not necessarily reflect the opinion of AWISH. We recommend you consult your doctor if you have any questions about diagnosis or treatment.