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**CANADIAN ARTHRITIS  
PATIENT ALLIANCE**

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**TAKE A PAIN CHECK  
FOUNDATION**

# **RHEUM FOR YOUR MIND**



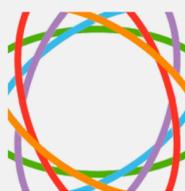
## **RESOURCE PACKAGE**

Day 1: October 14th

Day 2: October 28th

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**CAPA X TAPC**



**ONTARIO  
BRAIN  
INSTITUTE**



**CAPA**  
Canadian Arthritis  
Patient Alliance

Supported by the Ontario Brain Institute



# TABLE OF CONTENTS

**1**

What is Rheum for Your Mind?

**2**

About the Canadian Arthritis Patient Alliance

**3**

About Take a Pain Check Foundation

**4**

The Ontario Brain Institute and Their Resources

**5**

Speakers, Panelists, and Moderators

**8**

Immediate Help Resources

**9**

Resource Suggestions from the Speakers

**10**

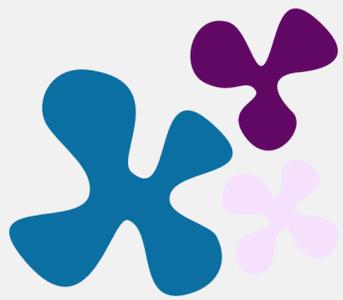
“Hurting Myself with Positivity” a TAPC Blog Post

**11**

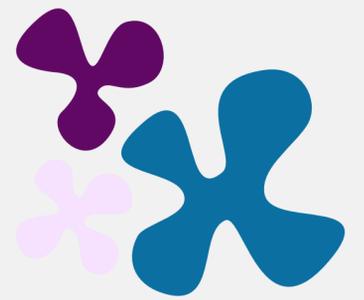
The TAPC Podcast

**12**

Daniel Kinchlea’s book + Brookie Zarb’s art



# WHAT IS RHEUM FOR YOUR MIND?



On Day One, youth and young adults have the opportunity to discover the latest insights and become experts on their own mental health and rheumatic diseases. learning valuable tools. Dr. Andrea Knight will share the latest research and clinical findings about the impact of rheumatic diseases on youth and young adults. Dr. Katie Birnie will share their knowledge and valuable tools about behaviour and pain. Patients will have the chance to engage in interactive art-focused exercises that encourage self-expression and identify coping strategies.

During Day Two, both youth and young adults and parents have the opportunity to further explore managing mental health. Social worker Pamela Jarvis will provide insights on options, opportunities and methods to help navigate getting help. After her presentation, there will be an interactive panel where experiences and perspectives will be shared by young adults with lived experience (Navya Juneja, Brookie Zarb), an adult with lived experience (Amanda Swartz) and a parent of a child living with a rare rheumatic disease (Chris Kinchlea). You will have the opportunity to ask the panelists questions. At the end of Day Two, you will participate in a dynamic workshop activity hackathon style where you can meet new people, work together to solve problems related to rheumatic diseases, and receive a virtual swag bag filled with helpful resources, including a digital journal.

These workshops are part of our Make Rheum for Youth project, we're excited to introduce Rheum for Your Mind and hope you can attend and learn with us.



# What is CAPA?

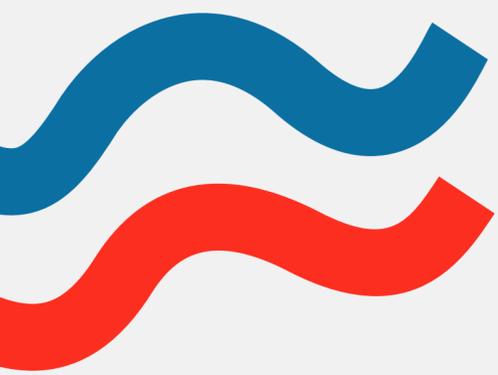
The Canadian Arthritis Patient Alliance (CAPA) works with various groups in the arthritis community to ensure the voice of people living with arthritis is heard and to bring up-to-date information on issues that affect the arthritis community. CAPA works with healthcare professionals, health organizations, clinicians, industry, health charities, researchers, and various levels of government to share patient perspectives and improve the quality of life and health care for people with arthritis.

They help Canadians people living with arthritis and their support groups understand more about their disease and have a voice in managing it.

[WWW.ARTHRITISPATIENT.CA](http://WWW.ARTHRITISPATIENT.CA)

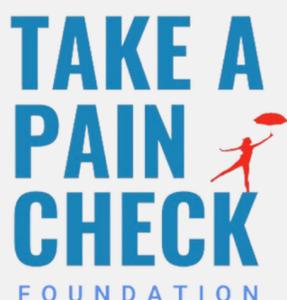
**CAPA**

Canadian Arthritis  
Patient Alliance

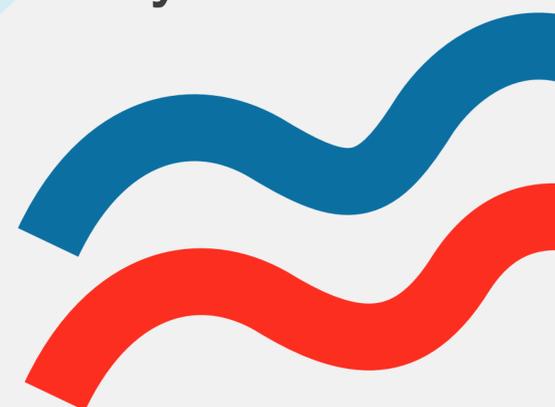


# WHAT IS TAKE A PAIN CHECK?

Take a Pain Check Foundation is a non-profit organization committed to the mission and vision of supporting youth and young adults with rheumatic diseases through social media, initiatives, advocacy, and raising awareness. Natasha hosts podcasts every other Sunday with guests engaging them in conversations about their chronic illness, their relationships, accomplishments, lifestyle, and much more. Guest speakers range from those living with rheumatic diseases, parents, friends, researchers, health professionals, and individuals who are making a difference in the rheumatic community. Take a Pain Check is currently changing the lives of individuals impacted with rheumatic diseases by creating a safe community. The goal is to empower youth to advocate for themselves, and to create a place where they feel understood.



[www.takeapaincheck.com](http://www.takeapaincheck.com)



Thank You to Our Sponsor

# ONTARIO BRAIN INSTITUTE

The Ontario Brain Institute is a provincially funded, not-for-profit organization that accelerates discovery and innovation, benefiting both patients and the economy.

Through our collaborative 'team science' approach between researchers, clinicians, industry, patients, and their advocates to foster discovery and deliver innovative products and services that improve the lives of those living with brain disorders.



## Research

Mobilizing Ontario's excellence in brain research through "Integrated Discovery"



## Brain-CODE

Taking brain research collaboration to a new level with advanced data management, sharing and analysis



## Commercialization

Engaging with industry to attract investments, build partnerships and support neuroscience technologies



## Care

Improving care and quality of life for those with brain disorders



ONTARIO  
BRAIN  
INSTITUTE

[WWW.BRAININSTITUTE.CA](http://WWW.BRAININSTITUTE.CA)

# Introduction of

# THE SPEAKERS



## Dr. Katie Birnie

Dr. Kathryn (Katie) Birnie is a Clinical Psychologist and Assistant Professor in the Departments of Anesthesiology, Perioperative, and Pain Medicine, and Community Health Sciences at the University of Calgary where she leads the Partnering For Pain program. She is the Associate Scientific Director of Solutions for Kids in Pain (SKIP), a national knowledge mobilization network working to improve evidence-based children's pain management through coordination and collaboration. Dr. Birnie joined Alberta Children's Hospital as a medical psychologist in 2018 when she primarily supported youth with rheumatological clinics and headache/migraine clinics. Since 2020, she continues to provide clinical care at ACH to youth with chronic pain through the Vi Riddell Children's Pain and Rehabilitation Program.

View Katie's talk here:  
<https://youtu.be/1txCHhx5UZ0?>



## Dr. Andrea Knight

Dr. Andrea Knight is a pediatric rheumatologist at the Hospital for Sick Children (SickKids) in Toronto, Canada. She obtained her medical degree from the Columbia College of Physicians & Surgeons in New York. She then completed her pediatric residency and pediatric rheumatology fellowship at The Children's Hospital of Philadelphia, and a Master of Science in Clinical Epidemiology from the University of Pennsylvania. She then returned to her home city of Toronto, to join the lupus care team at SickKids and continue her clinical research at the SickKids Research Institute. Dr. Knight conducts research with the goal of improving mental health and quality of life for young people with rheumatologic conditions. Her work focuses on understanding the mental health burden for these individuals, and developing strategies to improve mental health.

View Andrea's talk here:  
<https://youtu.be/fmokBCEfMRo?>



## Pamela Jarvis

Pamela Jarvis (she/her), is a registered social service worker within a multidisciplinary team at Arthritis Society Canada. Her role on that team is to provide mental health support, community resourcing, advocacy and working closely with her team to ensure each person with arthritis is heard, supported and empowered. She also works yearly at Camp Arthritis supporting 100+ kids at a 5-night camp targeted specifically for kids with arthritis. Pamela works with youth transitioning from pediatric to adult care rheumatology at McMaster. She has lived with JIA for over 40 years now so knows firsthand what living with this disease looks like, not only effects on her life but her family as well.

View Pamela's talk here:  
<https://youtu.be/pXPwoEsW1G4?>

# Introduction of

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# THE PANELISTS



## Amanda Swartz

Amanda Swartz had been living with Rheumatoid Arthritis for most of her life. She is now 43 and was diagnosed at 11, for good or bad she doesn't remember what it is like to live without arthritis. Arthritis has impacted every aspect of her life, from big decisions like her career and education to everyday things like what shoes she can wear.



## Chris Kinchlea

Chris is a writer, fundraiser, speaker, and advocate. She and her husband Will have two children: their son Daniel and daughter Gwen. Daniel has had a complicated auto-inflammatory journey and has been in and out of SickKids Toronto, and London Children's Hospital. Chris' passion for learning more and educating others about her son's condition led her to a career in fundraising at the London Children's Health Foundation and to start the Canadian Autoinflammatory Network.



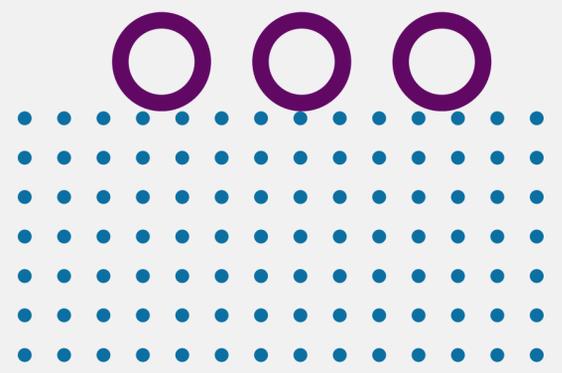
## Brookie Zarb

Brookie lives in Melbourne, Australia, and is an artist. She has experienced chronic pain since the age of 12, but only received a diagnosis of Psoriatic Arthritis at the age of 17. She also experienced non-epileptic seizures (PNES) since 2021 due to stress and anxiety levels when her physical health was at its worst. Now at the age of 19, Brookie has just completed a course in Allied Health Assistance (physiotherapy and occupational therapy) and works as a speech pathologist assistant.



## Navya Juneja

Navya is 19 years old, and lives with RA. She is currently a student at McMaster University in the Health Sciences program, pursuing a career in medicine. She is extremely passionate about health, fitness, and wellness, and actively incorporates it into her life in a multitude of ways - inspiring others to do so as well. She is determined to destigmatize rheumatic disease while simultaneously supporting paediatric patients as they navigate their diagnoses.



# SAY HI TO **OUR MODERATORS**



**Laurie Proulx**

Managing Director at the  
Canadian Arthritis Patient  
Alliance (CAPA)



**Natasha Trehan**

Executive Director at Take a  
Pain Check (TAPC)



**Isabel Dukes**

Youth Development  
Coordinator at CAPA and  
TAPC



**Brianne Chou**

Director of Operations at  
TAPC



# IMMEDIATE HELP RESOURCES

## Talk Suicide Canada

<https://talksuicide.ca/>

Canada wide 24/7 service available in English and French.

Call

**1.833.456.4566**

Text (4pm to midnight ET)

**45645**



## Kids Help Phone

<https://kidshelpphone.ca/>

Canada wide 24/7 service available in English and French.

Call

**1.800.668.6868**

Text (7pm to midnight ET)

<https://kidshelpphone.ca/live-chat-counselling/>



## 211 Ontario

<https://211ontario.ca/search/>

Ontario wide 24/7 service available in 150+ languages.

Has additional resources on many topics including disabilities.

Call or Text

**211**

Texting services available  
Mon. – Fri. 7am – 9pm



## Good2Talk

<https://good2talk.ca/>

Post-secondary students in Ontario and Nova Scotia. Call AND Text available 24/7.

Call

ON **1.866.925.5454**

NS **1.833.292.3698**

Text "TALK" to **686868**



## Canada's new crisis line – 988

<https://www.camh.ca/en/driving-change/988>

Canada wide 24/7 service. Suicide prevention services.

Call or Text, 24/7 Service

**988**

Available in English and French



## Outside of Canada? Find your helpline here

<https://childhelplineinternational.org/helplines/>

SCAN



# RESOURCE SUGGESTIONS FROM THE SPEAKERS

## “Make Rheum for Youth” Project by TAPC and CAPA

In September 2022, we launched a survey to better understand the needs of youth and young adults with rheumatic disease. Now, we are continuing this project and developing projects, resources, and programs to provide youth and young adults with necessary tools to thrive.

<https://arthritispatient.ca/capa-news/how-does-having-a-rheumatic-disease-affect-young-people/>

## BounceBack Ontario

BounceBack® is a free online skill-building program managed by CMHA. It is designed to help adults and youth 15+ manage low mood, depression, anxiety, stress or worry.

<https://bouncebackontario.ca/>

## Anxiety Canada

Their mission is to reduce the barrier of anxiety. They offer trusted resources and programs to help people better understand and manage anxiety.

<https://www.anxietycanada.com/>

## The Comfort Ability

The Comfort Ability Program helps kids, teens, parents and caregivers learn how to better manage recurring functional symptoms such as chronic pain. Offering workshops, health chats, newsletters, and other resources.

<https://www.thecomfortability.com/>

## SickKids Mental Health Learning Hub

Learn how to support your mental health and well-being and how to recognize and manage various mental health conditions, with multimedia resources including articles, animations and guided meditations.

<https://teens.aboutkidshealth.ca/mentalhealth>

## Canadian Mental Health Association

Canada wide organization that promotes mental health and supports people recovering from mental illness. Provides free mental health support.

<https://cmha.ca/>

## Power Over Pain

The Power Over Pain Portal provides access to a range of free resources, courses, and peer support.

<https://www.popyouth.ca/>



# HURTING MYSELF WITH POSITIVITY

A TAPC Blog Post

By Isabella Boles

“I constantly felt that I needed to be a role model, and my story was perfect to bring one to life. But does a role model have this much sadness and hurt inside them?”

Read the full Blog Post here:

<https://www.takeapaincheck.com/post/hurting-myself-with-positivity>



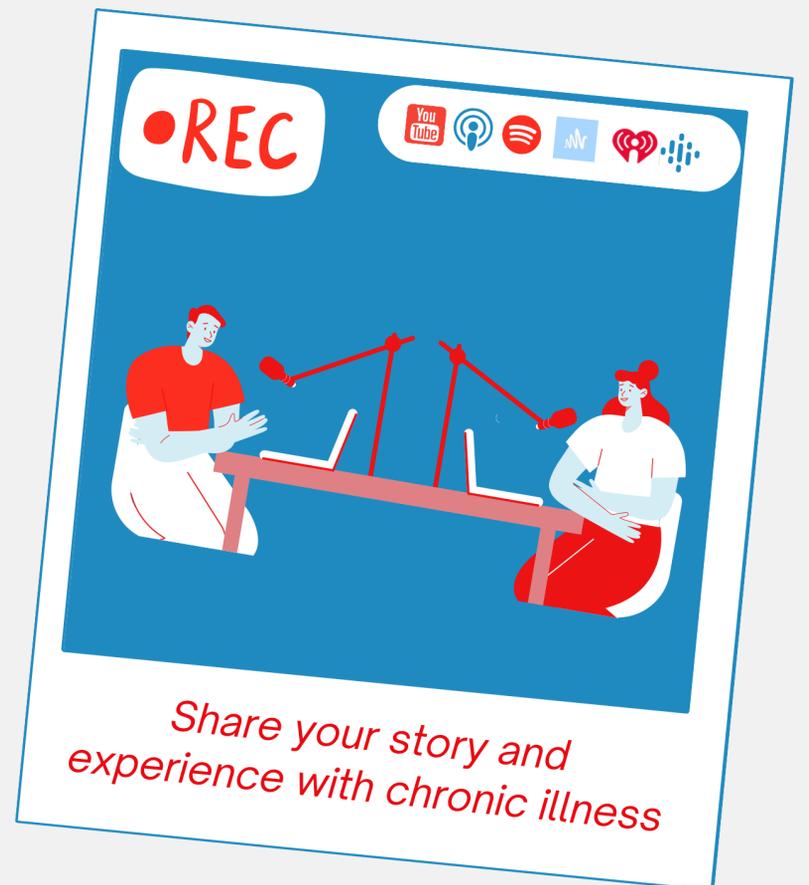
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# THE TAKE A PAIN CHECK Podcast

## TAKE A PAIN CHECK Podcast



Take a Pain Check's podcast, hosted by Natasha Trehan, engages guests in conversations about their experience with chronic illness, their relationships, accomplishments, lifestyle, and much more. TAPC brings guests with a wide variety of perspectives and experiences, ranging from youth with rheumatic disease to actresses, rheumatologists, Olympians, and youth and their family and friends who all have a direct or indirect connection to a rheumatic disease. Podcast Guests are categorized in three groups.



<https://www.takeapaincheck.com/podcast>

### Lived Experience

Lived Experience share their stories and journey on the podcast, these guests represent a variety of rheumatic diseases, including JIA, Lupus, Sjögren's, and more. Some of the important topics discussed include mental health, social support, lifestyle, workplace accessibility, school accommodations, navigating their chronic illness, and more.

### Family & Friends

These conditions also have an effect on the loved ones of those experiencing the condition. We provide valuable insights and support for these individuals by addressing the concerns, challenges, and questions of family and friends. We aim to create a holistic platform that offers more comprehensive information and assistance for everyone.

### Research & Medical

Our podcast features two essential categories of experts: research and medical professionals. Our Research experts provide insights into the new and latest discoveries and breakthroughs in arthritis and other rheumatic diseases, while medical experts offer practical guidance and support for diagnosis, treatment, and patient care.

**Visit our website for more information on our podcast and how to become a guest!**

**You can listen to the pocast on YouTube, Spotify, Apple Podcasts, and iHeartRadio!**

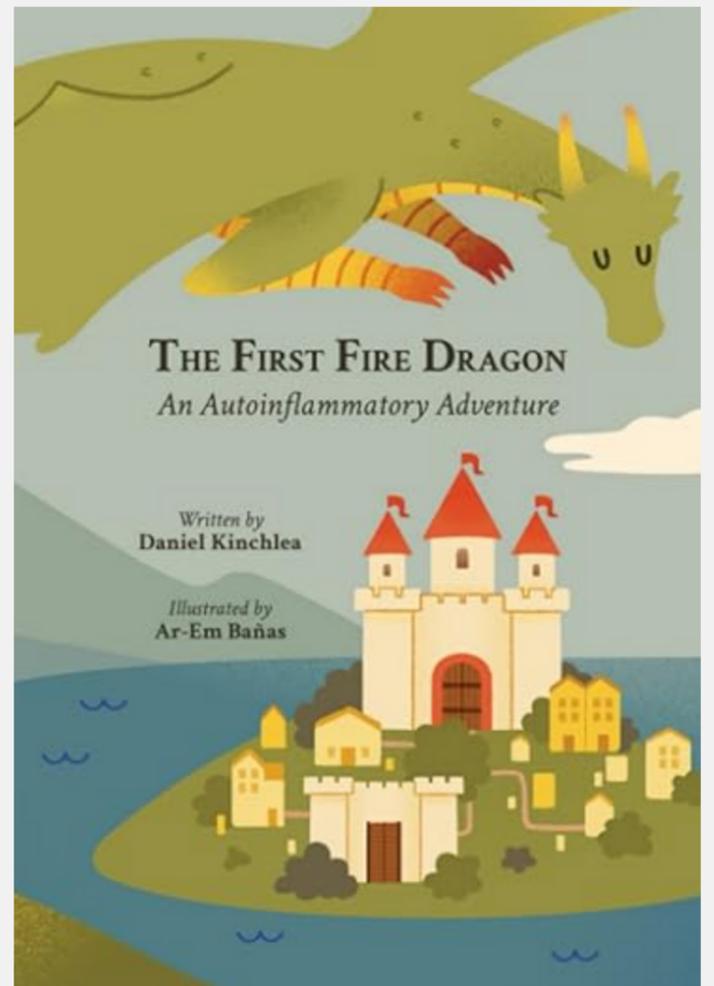
# Daniel Kinchlea's Book

## Our Panelist, Chris Kinchlea's son!

This children's story is based on the life of the author, Daniel Kinchlea—a 9-year-old boy with a rare autoinflammatory disease. Daniel has struggled with symptoms of prolonged fevers, rashes, systemic arthritis, lung disease, and more. Early in Daniel's journey, finding proper access to the right kind of specialized healthcare was a struggle, and concerns for his health were often dismissed. Now that he has proper care, he wished to bring recognition and awareness to these rare rheumatological diseases.

Read more about their story here:  
<https://www.firstfiredragon.com/>

Order the book here:  
<https://a.co/d/7ESebpc>



# Brookie Zarb's Art

## One of Our Panelists!



Check out her Instagram art page here!  
[www.instagram.com/art.by\\_brookie](https://www.instagram.com/art.by_brookie)



# CONTACT US



@capa\_arthritis

@takeapaincheck\_



Canadian Arthritis Patient Alliance

Take a Pain Check



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info@takeapaincheck.com



www.arthritispatient.ca

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