



# **Pregnancy & Parenting with Arthritis**

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AHPA Pre-Course  
February 27, 2019



@ProulxLaurie

# Who is CAPA?

- Virtual, patient-driven, volunteer national arthritis advocacy organization
- CAPA is about: education, awareness, collaboration & advocacy

*“Those affected by the decision must be involved in making the decision”*

[www.arthritispatient.ca](http://www.arthritispatient.ca)



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# About me



- Diagnosed with Juvenile Rheumatoid Arthritis at 14
- Affected all aspects of life – school, career, family, pregnancy, parenting, work...

# Why the focus on pregnancy & parenting?

- Women are consistently more likely than men to report a diagnosis of arthritis<sup>1</sup>
- Many women with inflammatory arthritis of reproductive age

Few resources exist to help people with arthritis navigate these important, life-changing decisions

# Phase 1 - Survey

- ✓ Survey of people living with arthritis and network of support to identify information needs
- ✓ ~150 survey responses

## Top 5 issues

1. Medication safety
2. Disease management
3. Handling fatigue & flares
4. Physical care of children
5. Impact on children

# Phase 2 – Educational resource

- ✓ Educational resource developed
- ✓ Medical review by rheumatologist and occupational therapist / researchers



Dr. Evelyne Vinet  
(McGill University, Montreal,  
Canada)

Dr. Catherine Backman  
(University of British Columbia,  
Vancouver, Canada)

[www.arthritispatient.ca/pregnancy-parenting](http://www.arthritispatient.ca/pregnancy-parenting)

# Resource topics: Pregnancy



- Fertility and Family Planning
- Talking to your Partner about Parenting
- Medication use during Pregnancy & Breastfeeding
- Managing Arthritis during Pregnancy
- Labour and Delivery
- Pregnancy Resources

# Resource topics: Parenting



- Physical Care of Children
- Dealing with Fatigue and Flares
- Impact on Children
- Parenting Resources



# Medication safety

- Emphasizes planning
- Approach for assessing safety & FDA labelling
- Questions to guide decision-making around meds

Unfortunately, with some of the newer medications **there was no black and white answer** for me as to how long to stay on them for and when pregnant. In the end I had to make decisions that I could live with. It was difficult to not have solid research behind some of these decisions that needed to be made.



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# Disease management

- Impact of pregnancy on arthritis
- Plan for arthritis flares

During my first pregnancy my arthritis went to **remission**. I thought it was almost guaranteed to do the same during my second pregnancy but it was the **complete opposite**. I wish I had been better prepared mentally for the fact that my arthritis may not go away as it did with my first.



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# Handling fatigue and flares

- It's OK to put yourself first
- Sleep when the baby sleeps

**Super moms do not exist**

so if you are feeling too fatigued or too sore to go to play centres, it's ok to stay home. There will be another day to go out when you feel up to it.



# Physical care of children

- Life hacks for common challenges
  - Picking up & carrying children
  - Car seats
  - Bathing
  - Dressing
  - Buying baby equipment
  - Childproofing

Even though **my hands and wrists are badly deformed**, I found my way to do everything for them. And most of all, hold them close and give them that unconditional love. In return, I received their unconditional love



# Impact on children

- Arthritis can bring positive AND negative
- Educate your children

My now almost 4-year-old has a **compassion and understanding** that many adults lack, she understands some people need to rest more because their bodies are fighting an invisible battle. She asks with curiosity rather than judgement. The struggles are well worth the rewards!













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# Twitter chat #arthritisparent

## The #ArthritisParent Influencers

### Top 10 by Mentions

	@ProulxLaurie	61
	@CAPA_Arthritis	58
	@MariahForward	39
	@cath_back	33
	@maryadevera	31
	@MotherToBaby	27
	@Somayyyeh	21
	@DrCCChambers	20
	@nicole_tsao	16
	@CreakyJoints	15



Tweet











### Top 10 by Tweets

	@CAPA_Arthritis	81
	@ProulxLaurie	46
	@DrCCChambers	37
	@MariahForward	31
	@Somayyyeh	24
	@MotherToBaby	20
	@anetto	19
	@cath_back	18
	@JAParkerPhD	15
	@CreakyJoints	10



Tweet

### Top 10 by Impressions

	@DrCCChambers	304.4K
	@anetto	179.4K
	@CreakyJoints	112.3K
	@CAPA_Arthritis	67.3K
	@MariahForward	53.0K
	@Somayyyeh	36.6K
	@MotherToBaby	28.9K
	@ProulxLaurie	26.2K
	@cath_back	20.4K
	@NatriceR	14.4K



Tweet

## The Numbers

897.073K Impressions

340 Tweets

28 Participants

14 Avg Tweets/Hour

12 Avg Tweets/Participant

 Tweet

 Like

Twitter data from the #ArthritisParent hashtag from Tue, September 25th 2018, 8:20PM to Wed, September 26th 2018, 8:20PM (America/New\_York).

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# Supporting activities

- Partnering with other organizations



- Partnering with researchers
  - Dr. Mary Abigail da Vera – poster #13
  - Dr. Evelyne Vinet – poster #110
  - Dr. Catherine Backman



# Closing remarks



*With these hands*

By: Karen Miller

Let's provide  
encouragement and  
support to patients and  
their families

[www.arthritispatient.ca/pregnancy-parenting](http://www.arthritispatient.ca/pregnancy-parenting)

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