

Pregnancy & Parenting with Arthritis

Laurie Proulx AHPA Pre-Course February 27, 2019

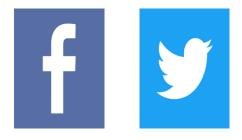


Who is CAPA?

- 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





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 arthritis¹

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



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.





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.





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

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!





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



@DrCChambers 20



@nicole tsao 16



@CreakyJoints 15



Top 10 by Tweets



@CAPA Arthritis 81



@ProulxLaurie 46



@DrCChambers 37



@MariahForward 31



@Somayyyeh 24



@MotherToBaby 20



@anetto 19



@cath back 18



@JAParkerPhD 15



@CreakyJoints 10



Top 10 by Impressions



@DrCChambers 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



The Numbers

897.073K Impressions



340 Tweets

28 Participants

14 Avg Tweets/Hour

12 Avg Tweets/Participant





hashtag from Tue. September 25th 2018. 8:20PM to Wed, September 26th 2018, 8:20PM (America/New York).



symplur



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



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

With these hands
By: Karen Miller

www.arthritispatient.ca/pregnancy-parenting

