

FOR IMMEDIATE RELEASE

Women with Rheumatic and Psoriatic Diseases and Inflammatory Arthritis Share Experiences Discussing Reproductive and Sexual Health

Coalition of Stakeholder Groups to Collaborate on Development of Tools to Facilitate Important Dialogue

TORONTO & OTTAWA, ON – September 29: Significant numbers of Canadian women+ with chronic rheumatic, psoriatic disease and inflammatory arthritis say they need more information and support during different stages of life (including child-bearing years and menopause) in order to better manage their conditions and overall health.

Today the **Canadian Arthritis Patient Alliance (CAPA)**, the **Canadian Association of Psoriasis Patients (CAPP)**, the **Canadian Psoriasis Network (CPN)** and the **Canadian Spondylitis Association (CSA)** released findings from the ***Women’s Sexual and Reproductive Health Survey*** demonstrating that women+ have varying levels of comfort discussing reproductive and sexual health with their healthcare providers, romantic partners and support networks.

The four stakeholder groups advocate that without enhanced education, support and dialogue from HCPs, partners and support networks, there can be a number of inherent risks to the patient who may struggle to manage their condition. Honest, informative, two-way discussions about issues, such as the impact of medications on fertility/family planning; the risks and challenges of parenting with chronic disease and pain management, are necessary to empower women as they navigate their health concerns.

The onset and diagnosis of inflammatory arthritis, rheumatic and psoriatic diseases commonly affect people in the prime of their lives, most often between the ages of 30 and 50 for most rheumatic conditions and either between the ages of 15 and 30 or 50 and 60 for psoriasis. Often, these individuals have unique reproductive and sexual health concerns related to contraception, menopause, family planning, and parenting.

The full survey report and infographics are available on each organization’s website (included below) and demonstrates a general lack of information:

- More than 60% of survey participants indicated that they did not have enough information about sexual health and the impact of their condition(s).
- Less than 45% of survey participants felt that their healthcare providers provided adequate information about the impact of their medication(s) on their ability to conceive, with significant variation by region of Canada.
- Less than half (46%) of survey participants received counselling from a doctor about pregnancy risks and medication safety before considering pregnancy.
- 63% of survey participants had to switch the medications they were taking to ones that were safe to use during pregnancy or while breastfeeding.

- More than half of the women+ surveyed have experienced financial hardships associated with paying for their medications.
- 87% of survey participants worry about the impact of their condition on their mental health yet only 16% have a mental health professional as part of their care team.
- About a third of participants (32%) do not feel like their healthcare provider gives them useful and helpful options to deal with their pain.

The report makes four key recommendations:

1. Destigmatize reproductive and sexual health in women+ as its part of a holistic approach to patient care. We recommend that patients, healthcare providers, romantic partners and support networks raise these topics in conversation early and often.
2. Patient education resources must be available to women+ focused on how to communicate effectively about sexual health needs and concerns, how to navigate reproductive and sexual health at different life stages, the impact of medications on sexual and reproductive health and the role of mental health and wellbeing.
3. Specialists including rheumatologist and dermatologists should counsel patients about the impact of medications and treatments on reproductive and sexual health early in their disease journey in order for patients to make informed choices.
4. Researchers should consider the sex and gender impacts on access to care, medication safety, mental health, parenting and aging to ensure that women+ have the best evidence to inform decision-making.

Based on the findings from the survey, CAPA, CAPP, CPN and CSA are committed to developing tools and educational resources to raise awareness of the issues and facilitate dialogue about the reproductive and sexual health experiences and needs of women+ living with rheumatic, inflammatory and psoriatic diseases.

We appreciate the educational grant from UCB Canada to develop the survey and this report.

Quotes:

Canadian Arthritis Patient Alliance, Laurie Proulx, Volunteer Vice-President: “Planning for pregnancy is recognized as critical for people living with these chronic health conditions. We need to better support people to access information and care that supports optimal decision-making. This report sets an important foundation to inform the development of better supports as women+ navigate pregnancy and parenting with success.” www.arthritispatient.ca

- Ms. Proulx has lived with Juvenile Idiopathic Arthritis for 30 years, is a mom of two children and understands many of the challenges outlined in the report through first-hand experience.

Canadian Association of Psoriasis Patients, Rachael Manion, Executive Director: “Women+ living with rheumatic and psoriatic diseases and inflammatory arthritis need different types of information throughout their lives, including about contraception and family planning, parenting, menopause, how to access treatments, mental health and pain management. This collaboration explores what women+ are facing as they try to navigate these issues and the health systems across Canada, and how everyone can better support them.” <https://www.canadianpsoriasis.ca/en/>

Canadian Psoriasis Network, Antonella Scali, Executive Director: "Living with chronic conditions like inflammatory arthritis, rheumatic and psoriatic diseases can have a significant impact on mental health. Experiences with anxiety, depression and chronic pain are not uncommon and these issues can be particularly significant for women+ at different stages of their lives. The *Baring It All* report explores these experiences and provides insights and recommendations for how women+ with these conditions can be supported." <https://www.canadianpsoriasisnetwork.com>

Canadian Spondylitis Association, Wendy Gerhart, Executive Director: "Over half of the women+ surveyed have experienced significant financial hardships associated with paying for their medications. It is critical that governments and insurers reassess their policies looking through a gender-neutral lens to ensure inclusivity for all. It is essential that all Canadians have equitable and timely access to medications and do not suffer financial hardships in receiving the treatment they need to live full and productive lives." www.spondylitis.ca

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For more information and to speak with the organizations involved in this important project, please contact:

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