



Canadian Association of Psoriasis Patients

ANNUAL REPORT
2020-2021

July 1, 2020 – June 30, 2021

Letter from the Executive Director & Co-Chair

We envision a future where all people in Canada living with psoriasis and psoriatic arthritis can get the care and treatment they need.

Growing knowledge about psoriasis and psoriatic arthritis has reinforced that the inflammation underlying these diseases impacts more than the skin and bones. Our Studentship in Psoriatic Disease program awarded four studentships to undergraduate and medical students to **further our understanding** about how to better understand, treat, and manage the impacts of this disease.

At an international level, the International Federation of Psoriasis Associations (IFPA) is embracing the language of “**psoriatic disease**” to capture these specific conditions and how this inflammation can increase risks of other conditions as well. When we met with Members of Parliament to talk with them about the impacts of the disease and how people were doing during the early days of the COVID-19 pandemic, we also educated them about how other organ systems in the body can be impacted and emphasized how important it is that people living with psoriatic disease receive optimal care and treatment to manage this inflammation.

With the great strides that have been made in psoriasis care and treatment over the previous decade since CAPP was first created, we began to **renew our website and digital resources** for the CAPP community. Although officially launched in July 2021, CAPP staff learned from patients throughout 2020-21 about how we could better educate people about psoriatic disease and how to manage living with psoriasis and psoriatic arthritis.

The launch of our PsoIntimate campaign about **psoriasis and intimacy** in February 2021 started a conversation about how these conditions impact one of the most important pieces of people’s lives. Looking at the visible and invisible impacts that psoriasis can have on people’s romantic relationships is the beginning of an ongoing – and long overdue – conversation in the psoriatic disease community.

We have deliberately broadened our network so that CAPP can better serve patients and their loved ones who are impacted by psoriatic disease. Solo and in collaboration with others, CAPP staff and board members give educational presentations, meet with government representatives, and participate in consultations to bring forward the perspectives of our community. **You are not alone.**

Sincerely,



Christian Boisvert-Huneault
Co-Chair



Rachael Manion
Executive Director

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About Us

Mission Statement

To be a resource for psoriatic patients and their families to advocate for improved patient care and quality of life.

Vision Statement

By 2023, Canadians living with psoriatic diseases will have equal access to best care and treatment.

The Canadian Association of Psoriasis Patients (CAPP) was formed in 2012 to serve people impacted by [psoriasis](#) and [psoriatic arthritis](#). CAPP's mission is to be a resource to these people by improving their quality of life, raising awareness, providing education, advocating for better access to care and treatments, and supporting research.

Each year, we recognize National Psoriatic Arthritis Awareness Day (October 19) and World Psoriasis Day (October 29) to bring awareness to the experiences of patients and caregivers. We provide educational materials about living with psoriasis and psoriatic arthritis, available [treatments](#), mental health impacts, comorbidities of these diseases and [resources for kids](#). All medical information is reviewed by experts before it is shared.

We have patients' best interests at the heart of what we do every day and actively advocate to the federal and provincial governments about difficulties patients face finding specialty care, accessing treatments, and unanswered questions that need to be researched. Through our successful [Studentships in Psoriatic Disease](#) program, which we launched in 2016, CAPP contributes to research on specific questions each year.

CAPP works in partnership with the [Canadian Skin Patient Alliance](#) to improve the health and quality of life for all Canadian psoriasis and psoriatic arthritis patients.

Our Network

CAPP is a proud member of the following associations.



Awareness & Support

Strategic Priority

Promote awareness and support for people living with psoriatic disease in Canada

CAPP always strives to promote improved access to care and treatment options as well as raising awareness of the experiences of both patient and caregivers affected by psoriatic disease. Through our awareness activities, educational resources, and support, we aim to empower the patient to make the best treatment choices for themselves in conjunction with their care team.

PsoIntimate 2021

This [awareness campaign](#) was launched on Valentine's Day (Sunday, February 14, 2021) and aimed to tackle the issues around psoriasis and intimacy. The campaign included new website content on [fatigue](#), [relationships](#) and [genital psoriasis](#). It also featured Q&A session with CAPP's Medical Advisor, Dr David Adam, that helped us produce a tip sheet for patient navigating relationships and intimacy while living with psoriatic disease.

The campaign was also featured in a special insert "[The Skin We're in](#)" which was published in the *Toronto Star* in May of 2021.

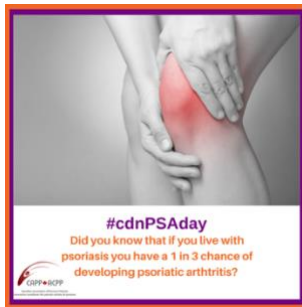


National Psoriatic Arthritis Awareness Day

For the third National Psoriatic Arthritis (PsA) Awareness Day on October 19, 2020, we once again worked with five other arthritis organizations to raise awareness.

The campaign featured having landmarks lit orange and purple. For example, we were successful in having the CN Tower (Toronto) lit up in support. We also embarked on a video series of patient testimonials on what makes them a PsA warrior.

CAPP launched an Instagram channel in celebration of National PsA Awareness Day, with a campaign on comorbidities and what to look for if you are at risk of PsA.



Newsletters

Throughout 2020-21, CAPP continued to produce quarterly issues of the “PsoNewsworthy” newsletter, as well as additional special issues on COVID-19 and the launch of the PsoIntimate campaign. A sign up for the newsletter feature was embedded into our website to prompt visitors to our site to sign up for the newsletter while they were there.

CAPP in the Community

CAPP’s Executive Director provided a brief overview of how CAPP supports patients living with psoriasis and psoriatic arthritis – and how patients can get involved – at the **Annual Psoriasis & Psoriatic Arthritis Patient Education Session** hosted by the Toronto Western Hospital Psoriatic Disease Clinic (October 25, 2020).

As part of a sponsored spread by AbbVie Canada about psoriasis, an issue of Chatelaine magazine (December 31, 2020) and online content included CAPP’s work. The digital campaign landing page is [Self-Love and Personal Care Landing Page](#) and the digital article is [The Impact of Psoriasis](#).

An advertorial was published [in Global Heroes digital](#) and in print magazines on June 12 about CAPP and directing people to the website and social channels.

Advocacy

Strategic Priority

Advocate on behalf of patients and their families living with psoriatic disease in Canada

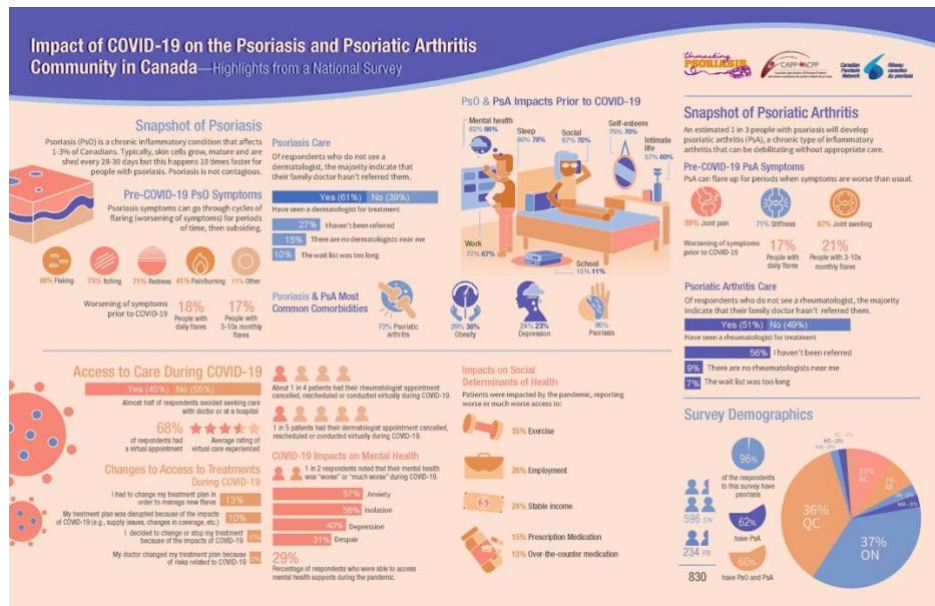
Whether you are trying to explain the impacts of your disease to your healthcare team, fill your prescription, get a new treatment option covered by insurance, explain to your family or friends what it's like living with psoriasis or psoriatic arthritis, or get supports in the workplace, we are here for you.

World Psoriasis Day 2020

In the fall of 2020, CAPP conducted a survey about the impacts of COVID-19 on the psoriasis and psoriatic arthritis community, in collaboration with the Canadian Psoriasis Network and an awareness group in Saskatchewan, Unmasking Psoriasis. The support from our community was incredible, with over 800 responses to the survey. We also held two virtual discussion groups to dive deeper into some of the themes that we uncovered from the survey:

- It is difficult to access **dermatological care** from a specialist across Canada
- There are many barriers to accessing **treatment**
- There is still much we do not yet understand about psoriasis and psoriatic arthritis

This infographic sets out the highlights of our survey results, including the fact that these diseases impact multiple aspects of people's lives. Many people experienced **changes to their treatment** plans since the onset of the pandemic. Most had a **virtual visit** with their healthcare provider during the pandemic, but there is a lot of room for improvement. Nearly half of survey respondents indicated that their **mental health** has worsened during the pandemic. We shared key findings from this survey through a week-long social media campaign.



With the support of a public affairs firm, CPN, CAPP and Unmasking Psoriasis organized a series of virtual meetings with federal MPs from across Canada, including members of the Standing Committee on Health. The goals of these meetings were to:

- Highlight the experiences and needs of people with psoriasis and psoriatic arthritis, including during the pandemic;
- Discuss the role of the federal government in supporting provinces to ensure access to care and effective and sustainable treatments for people with psoriasis and psoriatic arthritis; and
- Identifying the role of the federal government in research on skin diseases, including psoriasis.

We met with several Members of Parliament, some of whom held specific roles on House Committees.

Member of Parliament	Party	Riding / Roles
Carol Hugues	New Democratic Party	Algoma—Manitoulin—Kapusksasing, Ontario <i>Assistant Deputy Speaker and Deputy Chair of Committees of the Whole</i>
Chris d'Entremont	Conservative Party of Canada	West Nova, Nova Scotia <i>Member, Health Committee</i>
Darren Fisher	Liberal Party of Canada	Dartmouth—Cole Harbour, Nova Scotia <i>Parliamentary Secretary to the Minister of Health</i>
Helena Jaczek	Liberal Party of Canada	Markham—Stouffville, Ontario
Larry Maguire	Conservative Party of Canada	Brandon—Souris, Manitoba <i>Member, Health Committee</i>
James Maloney	Liberal Party of Canada	Etobicoke—Lakeshore, Ontario
Ron Mckinnon	Liberal Party of Canada	Coquitlam—Port Coquitlam, British Columbia <i>Chair, Health Committee</i>
Jamie Schmale	Conservative Party of Canada	Haliburton—Kawartha Lakes—Brock, Ontario <i>Member, Standing Committee on Human Resources, Skills and Social Development and the Status of Persons with Disabilities Committee</i>
Maninder Sidhu (staff)	Liberal Party of Canada	Brampton East, Ontario
Tony Van Bynen	Liberal Party of Canada	Newmarket—Aurora, Ontario <i>Member, Health Committee</i>
Adam Vaughan	Liberal Party of Canada	Spadina—Fort York, Ontario <i>Parliamentary Secretary to the Minister of Families, Children and Social Development (Housing)</i>
Kevin Waugh	Conservative Party of Canada	Saskatoon—Grasswood, Saskatchewan

The Canadian Dermatology Association recognized the important findings of this survey with a Public Education (Not-for-Profit) Award. In addition, we received an award from the Canadian Rheumatology Association for this project and were delighted to present our findings at the 2021 Canadian Arthritis Research Conference. CAPP was also pleased to present the findings from this project to those in the private health benefits industry through a MAPOL webinar sponsored by UCB Canada.

Improved health services for psoriatic disease patients

In 2021, CAPP collaborated with the Canadian Psoriasis Network to submit our [recommendations](#) to the federal government before it made its Budget 2021 decisions.

Improving patients' access to new psoriasis & psoriatic arthritis treatments

When a new drug for psoriasis or psoriatic arthritis comes to patients in Canada, it must be reviewed in the context of other drugs available for these diseases if the manufacturer wants it to be listed on a public drug formulary. The Quebec government has its own health technology assessment (HTA), done by the Institut national d'excellence en santé et en services sociaux (INESSS). All other government drug plans in Canada refer to the HTA done by the Canadian Agency for Drugs and Technologies in Health (CADTH).

As part of these processes, patients are invited to share their experiences living with the disease, how helpful they find existing [treatments](#), their treatment goals, and their experience with the new drug (if they have tried it) or their expectations of it (if they have not). Some provinces (BC, Ontario) have their own HTA processes. CAPP has provided patient input submissions for many new drugs:

- [Bimekizumab for treating plaque psoriasis](#) (INESSS, September 2021)
- [Bimekizumab for treating moderate to severe plaque psoriasis](#) (CADTH, September 2021)
- [Ilumya \(tildrakizumab\) for treatment of plaque psoriasis](#) (INESSS, February 2021)
- [Rinvoq \(upadacitinib\) for psoriatic arthritis](#) (INESSS, February 2021)
- [Rinvoq \(upadacitinib\) for psoriatic arthritis](#) (CADTH, January 2021)

In collaboration with the Canadian Skin Patient Alliance, CAPP provided recommendations and feedback regarding changes to **drug pricing** proposed by the Patented Medicine Prices Review Board (PMPRB).

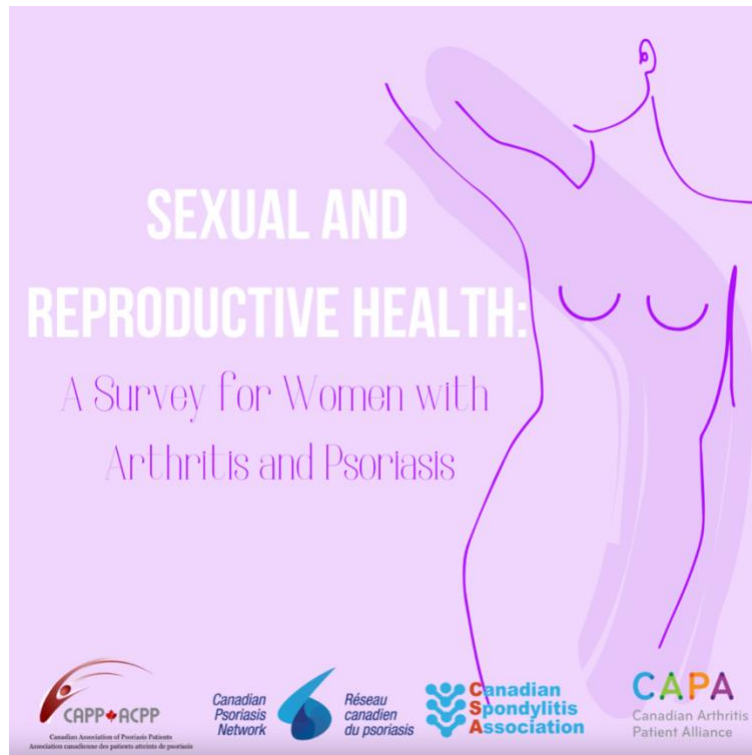
Although they are lesser-known forms of psoriasis, both palmoplantar psoriasis (PPP) and generalized pustular psoriasis (GPP) are rare diseases. To support people impacted by rare forms of psoriasis, CAPP contributed to the federal government's consultation on a new **rare disease drug strategy** as a member of the Best Medicines Coalition (read the [full submission](#)).

Women's sexual and reproductive health

People living with rheumatic and psoriatic diseases are often diagnosed in the prime of their lives when they need to consider a variety of health-related reproductive issues like contraception, sexual health, identity, and family planning goals. However, no broad and coordinated effort has been

taken to address the range of reproductive health issues across the life course for people living with rheumatic and psoriatic diseases.

To address this gap, CAPP collaborated with the Canadian Arthritis Patient Alliance (CAPA), Canadian Psoriasis Network (CPN) and Canadian Spondylitis Association (CSA) to develop a survey about the experiences of people who identify as women (women+) living with psoriatic and rheumatic diseases and inflammatory arthritis. The survey was launched on International Women's Day (March 8, 2021) and asked women about gaps in patient education, care, and treatment – and questions they had as a result of these gaps.



The survey had more than 400 participants, many of whom lived with **psoriatic arthritis** (38%) and **plaque psoriasis** (36%). A national report on survey findings was released as part of CAPP's recognition of Arthritis Awareness Month (September 2021) and National Psoriatic Arthritis Awareness Day (October 19, 2021).

Leadership

Strategic Priority

Be a trusted leader for people living with psoriatic disease in Canada

By ensuring that we continue to expand our community reach and be involved in initiatives that impact psoriatic patients and their networks, we raise our profile in the community and become a go-to resource. Providing robust, medically vetted information and resources ensure that we are a trusted source of information to our patients, their loved ones, and the psoriatic community as a whole.

Website Redesign

In 2020-21, CAPP embarked on a large-scale project to build a new, robust website ensuring that content was updated and covered the broad scope of psoriatic disease, not just psoriasis. A Website Renewal Committee was formed which included a board member with lived experience and a patient, ensuring that a patient focus was achieved and that we were offering a website that patients would revisit for current information. A website design was chosen, a content structure was planned, and content was drafted to refresh existing content and add new content, particularly on psoriatic arthritis. All content will be available in both official languages. The launch of the website, as well as a reworking of the treatments section, clinical trials section and expanding on the psoriatic arthritis section was planned for early in the following fiscal year.

International Federation of Psoriasis Associations (IFPA)

Throughout 2020-2021 CAPP helped to promote the **Psoriasis & Beyond Global Survey**, which was a large-scale international partnership between Novartis and IFPA to gather information on peoples' understanding of psoriatic disease. It also looked at the broader impacts, including comorbidities, quality of life and how patients talk to their doctors.

CAPP's Communications Manager continued her work with IFPA's World Psoriasis Day working group, which shaped the international events of World Psoriasis Day 2020, with the theme #BeUnited.

International GPP Roundtable

CAPP was delighted to participate in an international discussion with people living with generalized pustular psoriasis (GPP) that was hosted by Boehringer Ingelheim.

Research

Through supporting student awards and encouraging patient engagement in research in psoriatic disease, we are helping shape a better future for people living with psoriasis and psoriatic arthritis in Canada.

Studentships in Psoriatic Disease

The purpose of this funding opportunity is to provide undergraduate and health professional students with opportunities to undertake research projects related to psoriatic diseases with established investigators in an environment that provides strong mentorship. We encourage applications from across Canada.

In 2020-21, CAPP expanded patient and caregiver engagement in the studentships program: each application was reviewed by a patient or caregiver. Their review received equal weight to that of each of the two medical / scientific reviewers of each application in determining the awards.

This year, CAPP received 12 applications and awarded four studentships with the support of our program funders AbbVie Canada, LEO Pharma Canada, Sun Pharma & UCB Canada.

Dhruv Sharma
McMaster University

Prognosis and Biomarker Studies in Psoriasis and Psoriatic Arthritis

Primary Supervisor: Dr. Vinod Chandran
University of Toronto
Toronto Western Hospital, University Health Network

Farhan Mahmood
University of Ottawa

A Clinical Trial Assessing the Efficacy of Topical Cannabis in Treating Psoriasis

Primary Supervisor: Dr. Mark G. Kirchhof
University of Ottawa
The Ottawa Hospital

Nadia Kashetsky
Memorial University

Evaluating the Efficacy and Safety of Narrowband Ultraviolet-B Phototherapy Cumulative Doses: A Retrospective Cohort Study at the Vancouver Skin Care Center

Primary Supervisor: Dr. Sunil Kalia
University of British Columbia
Vancouver Skin Care Centre, Psoriasis & Phototherapy Clinic

Yuliya Lytvyn
University of Toronto

Is risankizumab treatment effective and safe in patients with moderate to severe plaque psoriasis that were unsuccessfully treated with guselkumab? A retrospective study at the University of Toronto

Primary Supervisor: Dr. Jensen Yeung
University of Toronto
Sunnybrook Health Sciences Centre

Skin Investigation Network of Canada (SkIN Canada)

CAPP was proud to partner with the Skin Investigation Network of Canada (SkIN Canada) to reach patients and caregivers so they could share their top unanswered psoriasis research questions. SkIN Canada is a research network funded by the Canadian Institutes of Health Research – Institute of Musculoskeletal Health and Arthritis (CIHR-IMHA) to catalyze skin research infrastructure across Canada.

CAPP Co-Chair, Dr. Morris Manolson, is a Patient Research Partner of the network and serves on SkIN Canada's Steering Committee.

Its first project, the Priority Setting Initiative, identified psoriasis as an area in need of research that is important to patients and caregivers, as well as clinicians and researchers in Canada.



Psoriasis guidelines for clinical care

The Dermatology Association of Ontario (DAO) asked CAPP to help gather input regarding a Patient Needs Assessment Survey for patients and caregivers. This follows a needs assessment survey that was sent to Canadian and international dermatologists to define priority topics in the guidelines that the association will produce. CAPP also supported the DAO by sharing this assessment with the community for their direct input into priority topics.

Letters of Support

CAPP provided letters of support for projects related to the underlying genomics and related analyses of psoriatic disease, as well as management of flares and the impacts of diet on psoriatic arthritis.

Supporters

We would like to thank our supporters for their commitment to people living with psoriatic disease in Canada. We appreciate the time and effort of patients and caregivers who share their experiences with us and guide the development of resources for our community. It is a pleasure working with our organizational partners and collaborators to serve our community.

Medical Advisory Board

The Canadian Association of Psoriasis Patients wishes to thank our medical advisors for their expertise, time, and compassion for patients who need support throughout their experiences with psoriasis.

Dr. David Adam, Chair
Dermatologist

Dr Yvette Miller-Monthrope
Dermatologist

Dr Maxwell Sauder
Dermatologist

Board of Directors

Morris Manolson	Co-Chair
Christian Boisvert-Huneault	Co-Chair
Kimberly Seguin	Secretary
Holly Rockbrune	Treasurer
Simon Cheng	Director
Reena Ruparelia	Director
Amanda Shanks	Director

We were pleased to welcome Amanda Shanks to the CAPP Board of Directors at the 2020 Annual General Meeting.

Sponsors

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