



# Canadian Association of Psoriasis Patients

**ANNUAL REPORT**

**2019-2020**

July 1, 2019 – June 30, 2020

## Letter from the Chair & Executive Director

---

The Canadian Association of Psoriasis Patients (CAPP) lives its mission of being a resource to people living with psoriasis and psoriatic arthritis and improving their quality of life. This year, we raised awareness about the impacts of psoriasis and psoriatic arthritis on the people who live with them. CAPP continued to add resources to and update the website and significantly increased communications with the patient community through its newsletters. We educated our community about adhering to topical therapies, expanded our resources related to Patient Support Programs, and increased awareness about the link between psoriasis and psoriatic arthritis.

Amplifying the patient voice, CAPP was actively advocating on a variety of issues affecting our community, including drug shortages, drug pricing, biosimilar policy, access to phototherapy and other treatments, and virtual dermatology care. We participated in several patient input submissions to ensure that decision makers were aware of the challenges faced by people impacted by psoriasis and psoriatic arthritis.

We envision a future where all people living with psoriatic disease are able to get the care and treatment they need. Our Studentship in Psoriatic Disease program awarded five studentships to undergraduate and health professional students to undertake research that will help expand our understanding of these diseases.

Our patient community is supported by a committed board of directors and medical advisor and we look forward to continuing to work together to advance our community's priorities.

Sincerely,



**Christian Boisvert-Huneault**

Co-Chair

Canadian Association of Psoriasis Patients



**Rachael Manion**

Executive Director

Canadian Association of Psoriasis Patients

# Table of Contents

---

<b>Letter from the Chair &amp; Executive Director .....</b>	<b>2</b>
<b>Table of Contents .....</b>	<b>3</b>
<b>Awareness &amp; Support .....</b>	<b>4</b>
<i>National Psoriatic Arthritis Awareness Day.....</i>	<i>4</i>
<i>World Psoriasis Day 2019.....</i>	<i>4</i>
<i>Newsletter.....</i>	<i>5</i>
<i>Patient Support Programs.....</i>	<i>5</i>
<i>Adherence to topical therapies.....</i>	<i>5</i>
<b>Advocacy.....</b>	<b>6</b>
<i>Drug shortages.....</i>	<i>6</i>
<i>Biosimilar policy .....</i>	<i>6</i>
<i>Providing patient input to support access to treatment.....</i>	<i>6</i>
<i>Psoriatic disease and national policy .....</i>	<i>6</i>
<i>Psoriatic disease and provincial policy .....</i>	<i>6</i>
<b>Leadership .....</b>	<b>7</b>
<i>International Federation of Psoriasis Associations .....</i>	<i>7</i>
<i>My Skin and Bones.....</i>	<i>7</i>
<i>Studentships in Psoriatic Disease .....</i>	<i>7</i>
<i>Research .....</i>	<i>8</i>
<b>Supporters .....</b>	<b>9</b>
<i>Board of Directors.....</i>	<i>9</i>
<i>Sponsors .....</i>	<i>9</i>

# Awareness & Support

Strategic Priority

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

This year, CAPP recognized National Psoriatic Arthritis Awareness Day and World Psoriasis Day to raise awareness about the impacts of these diseases on the people who live with them. As well, CAPP continued to update its website and significantly increased communications with the patient community through its newsletters.

## National Psoriatic Arthritis Awareness Day

To mark National Psoriatic Arthritis Awareness Day, CAPP held a Live Twitter session on October 17, 2019 in collaboration with the Arthritis Society, Canadian Arthritis Patient Alliance, Canadian Psoriasis Network, Arthritis Consumer Experts and the Canadian Spondylitis Association, which generated over 700,000 impressions.

Each organization also prepared their own social media campaigns for awareness day on October 19. CAPP's campaign for **#cdnPSAday** detailed the risk factors for developing psoriatic arthritis (PsA) and what people need to know if they suspect they may be at risk.



CAPP also participated in a live Facebook session in collaboration with the Canadian Spondylitis Association that featured rheumatologist Dr. Lihi Eder and again we focused on the connections between having psoriasis and developing psoriatic arthritis.

## World Psoriasis Day 2019

Every year, the International Federation of Psoriasis Associations (IFPA) establishes the theme for World Psoriasis Day. In 2019, it was Let's Get Connected, and CAPP's social media awareness campaign focused on the many connections with psoriasis, including mental health and psoriatic arthritis.





# Advocacy

Strategic Priority

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

This year, CAPP expanded its participation in national and provincial coalitions to enhance our ability to advocate for patients across Canada.

## Drug shortages

Many patients in Canada were unable to access hydroxychloroquine (HCQ), an older drug used to treat psoriatic arthritis (among other diseases) after it was touted as an effective treatment for COVID-19. CAPP worked with other patient organizations to gather information and convey updated information about shortages of this drug to Health Canada until the shortage was resolved and continues to monitor the impacts of the pandemic on patients' access to treatments.

## Biosimilar policy

Policy changes impacting how patients will be able to access biologic drugs have begun to roll out across the country. At a national level, CAPP participated in an online consultation by the Canadian Agency for Drugs and Technologies in Health (CADTH) about specific policy options. CAPP has also been active in conveying patient support for improved access to biologic drugs and concerns about the potential impacts of specific policies with public drug plans considering policy changes.

## Providing patient input to support access to treatment

To support patient access to new treatments for psoriatic disease, CAPP provided patient input at the pan-Canadian (national) and provincial levels for new treatments this year:

- Duobrii (halobetasol propionate and tazarotene) for improving the signs and symptoms of moderate to severe psoriasis in adults (CADTH, INESSS, BC's Your Voice)
- Ilumya (tildrakizumab) for moderate to severe psoriasis (BC's Your Voice)
- Cimzia (certolizumab-pegol) for moderate to severe psoriasis in adults (INESSS, BC's Your Voice)

## Psoriatic disease and national policy

This year, CAPP participated in consultations on changes to federal drug pricing regulation in collaboration with its partner organization, the Canadian Skin Patient Alliance, and as a member of the Best Medicines Coalition.

## Psoriatic disease and provincial policy

In **Alberta**, CAPP supported advocacy to reinstate funding for phototherapy after the provincial government announced that it would place a cap on the number of office visits that a doctor can be paid for during a day. This specific policy would have significantly diminished access to phototherapy for psoriasis patients, and other patients with a photosensitive skin condition, and CAPP was glad to hear that it was reversed.

CAPP was a signatory to the Canadian Skin Patient Alliance's pre-budget submission to the **Ontario** government requesting funding for teledermatology, home phototherapy, and new treatments.

# Leadership

Strategic Priority

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

With a view to the future, CAPP has undertaken new projects to better support people living with psoriatic disease while ensuring that its signature studentships program has continued to thrive.

## International Federation of Psoriasis Associations

CAPP was delighted to attend the annual conference of the International Federation of Psoriasis Associations (IFPA) in Barcelona, Spain, in July 2019. At this event, CAPP staff connected with people living with psoriasis and representatives from other organizations serving the psoriasis community.

At that conference, IFPA changed its approach to meetings, introducing regional meetings for the first time. The first IFPA Pan-American regional meeting of the new schedule was scheduled to be held in Ottawa, Ontario, in April 2020 but was canceled in light of the COVID-19 pandemic.

## My Skin and Bones

In 2019-20, CAPP continued its partnership with Novartis Canada to raise awareness about the link between psoriasis and psoriatic arthritis through the [My Skin and Bones](#) campaign. These messages were shared on billboards, TV, YouTube, in magazines and via CAPP's communications to our community. This public service campaign won a Silver Leaf Award from the Canadian division of the International Association of Business Communicators.

## Studentships in Psoriatic Disease

The Studentships in Psoriatic Disease Studentships program provides funding for undergraduate and health professional students to complete summer research projects related to psoriatic diseases under the supervision of established investigators. This program encourages interest in psoriatic diseases among early career researchers, supports an environment that provides strong mentorship and contributes to general knowledge about psoriatic disease.

This year, CAPP received 15 applications and awarded five studentships with the support of our program funders AbbVie Canada, Bausch Health, UCB Canada, Janssen Canada and LEO Pharma Canada. Despite the impacts of COVID-19, the projects were able to go forward:

- **Andreea Damian** (Dr Lihi Eder, Women's College Research Institute, Toronto, ON), "Determining the incidence and risk factors for thromboembolic events in patients with psoriasis and psoriatic arthritis"
- **Amy Du** (Dr Robert Gniadecki, University Dermatology Centre University of Alberta, Edmonton), "Prediction of Psoriasis Clinical Outcomes Using Machine Learning"
- **Alexandra Finstad** (Dr Raed Alhusayen, Sunnybrook Research Institute, Toronto), "Trends in Psoriasis Care: A Population-Based Study"
- **Jacqueline Lai** (Dr Vinod Chandran, University Health Network Toronto Psoriatic Disease Research Program, Toronto), "Prognosis and Biomarker Studies in Psoriasis and Psoriatic Arthritis"
- **Yuliya Lytvyn** (Dr Jensen Yeung, University of Toronto, Sunnybrook Health Sciences Centre), "Efficacy and safety of brodalumab monotherapy (IL-17 receptor A inhibitor) in

the treatment of moderate to severe plaque psoriasis patients unsuccessfully treated with secukinumab and/or ixekizumab (selective IL-17A inhibitors): a retrospective study at the University of Toronto”

## Research

Our organization is dedicated to improving our collective understanding about psoriatic disease and we routinely support research projects and grant applications by clinicians and scientists.

To help identify the impacts of COVID-19 on people living with psoriasis and psoriatic arthritis, CAPP became the first Canadian organization to partner with the PsoPROTECT global registry of people living with psoriasis who have contracted COVID-19. We also supported gathering information about people’s experiences during the pandemic through PsoPROTECTMe, affiliated with the global registry.

CAPP provided letters of support for projects related to the safety of biologics in older adults and better understanding how to anticipate when someone with psoriasis will develop psoriatic arthritis.

## Supporters

---

CAPP would like to thank our supporters for their commitment to people living with psoriatic disease in Canada.

- **Patients** who share their experiences with us and guide the development of resources for our community
- Members of the **Board of Directors** who ensure that the voice of people living with psoriatic disease is reflected in our priorities, resources, and advocacy
- **Our medical advisor, Dr. David Adam**, who advises us and reviews CAPP's work for medical and scientific accuracy
- **Organizations** that partner and collaborate with us to serve our community

### Board of Directors

---

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

CAPP sincerely thanks **Brooks Harvey** for his dedication to the organization and the patients we serve during his tenure on the board of directors.

### Sponsors

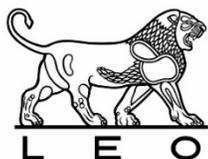
---

abbvie

AMGEN

BAUSCH+Health

janssen  
PHARMACEUTICAL COMPANIES  
OF JOHNSON-JOHNSON



NOVARTIS

