

Canadian Association of Psoriasis Patients

ANNUAL REPORT **2021-2022**

Letter from the Executive Director & Co-Chair

We envision a future where all people in Canada living with psoriatic disease are diagnosed, treated, supported and understood.

This year, CAPP reviewed and updated all the content on our website, <u>canadianpsoriasis.ca</u>. Through this process, we improved the information and made it available in both English and French. This project brought together many people in our community, and we are delighted to continue to provide new information that helps people live with psoriasis and psoriatic arthritis into the future.

We continued to foster a conversation on the impacts of psoriatic disease and intimacy. In 2021, the PsoIntimate campaign focused on the skin, in 2022 we looked at the impacts of psoriatic disease in the joints as well. We produced resources for our community about how to care for their body so that their intimate lives can flourish, less burdened by this disease.

In a special focus about the impact of psoriatic disease and other inflammatory conditions on women+, we heard how this disease impacts people's sexual lives, their family planning decisions, what they must deal with in order to be involved and successful parents, menopause, how they manage pain and mental health impacts, and how they pay for the medications they have been prescribed to manage their conditions. We shared these findings widely, with healthcare providers, private health plan specialists, and our community.

We also collaborated with others in the Canadian psoriatic disease community to improve our understanding of how they are impacted at work. This is the first year of a larger project where we work together to help patients in their workplace so keep in touch!

Our Studentship in Psoriatic Disease program awarded five studentships to undergraduate and medical students to further our understanding about how to better understand, treat, and manage the impacts of this disease. CAPP also helped to shape Canadian psoriasis research priorities and share new research with patients and their loved ones.

This has been a very busy year for our organization, and we sincerely thank all those who have given their time, energy and support to our work – and our community!

Sincerely,

Christian Boisvert-Huneault

Christian Bothers and

Co-Chair

Rachael Manion
Executive Director

Table of Contents

| Letter from the Executive Director & Co-Chair | 2 |
|------------------------------------------------------------------------------|--------------|
| About Us | 4 |
| Our Network | 4 |
| Awareness & Support | 5 |
| PsoIntimate 2021 | 5 |
| National Psoriatic Arthritis Awareness Day | 5 |
| Newsletters | |
| CAPP in the Community | 6 |
| Advocacy | |
| World Psoriasis Day 2021 IFPA: Be United Working It Out | 7 |
| Women's sexual and reproductive health | 10 |
| Final ReportInfographics | |
| Social media campaign | |
| Presentations | |
| Improving patients' access to new psoriasis & psoriatic arthritis treatments | |
| Public drug plans | 14 |
| Private drug plans | |
| Leadership | 16 |
| International Federation of Psoriasis Associations (IFPA) | 16 |
| International GPP Roundtable | 16 |
| Research | 17 |
| Studentships in Psoriatic Disease | 17 |
| Skin Investigation Network of Canada (SkIN Canada) | 18 |
| Psoriasis guidelines for clinical care | |
| Supporting patient engagement in psoriasis research in Canada | |
| Supporters | |
| Medical Advisory Board | |
| Board of Directors | |
| Sponsors | |
| JUUIJUI J | _ |

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 <u>psoriasis</u> and <u>psoriatic arthritis</u>. 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 <u>Studentships in Psoriatic Disease</u> program, which we launched in 2016, CAPP contributes to research on specific questions each year.

CAPP works in partnership with the <u>Canadian Skin Patient Alliance</u> 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

The second year of this campaign launched on Feb 7, 2022 and ran for 10 days (over Valentine's Day). This is an extension of PsoIntimate 2021, which focused on psoriasis, and included parallel resources related to psoriatic arthritis. This included updated website content on psoriatic arthritis (PsA) and Relationships and PsA and Fatigue.

We worked with two registered kinesiologists to develop a new downloadable resource on comfortable and enjoyable sex positions, which was made available on our website in both English and French.

We also worked with a certified sex therapist to develop two additional resources: an infographic with the answers to questions from the community about sex, intimacy, chronic pain / illness, and having a good relationship with your body; and guidance for healthcare providers and patients about talking about these issues as part of routine care. These were also available on our website in both English and French.

National Psoriatic Arthritis Awareness Day

This year we recognized the fourth National Psoriatic Arthritis (PsA) Awareness Day on October 19, 2021. For the first time we did not work in collaboration with other organizations, however many of them prepared their own campaigns.

CAPP took the opportunity to promote the "Baring It All Report" that was released a few weeks prior, with the Canadian Psoriasis Network, the Canadian Arthritis Patient Alliance and the Canadian Spondylitis Association. The report focused on the reproductive and sexual health of women living with psoriatic arthritis, as well as other inflammatory and rheumatic diseases. More information about this report is below.

Newsletters

In 2021-2022 CAPP continued to produce quarterly issues of the "PsoNewsworthy" newsletter. We began using a "featured article" to anchor the newsletter and included topics such as psoriasis and mental health and psoriasis and inflammation. We continued to feature our ongoing activities, share treatment updates and other news of interest to patients living with psoriatic disease. We also had two special eblasts announcing our new website refresh, and World Psoriasis Day activities. Each issue of the newsletter was distributed to close to 5,000 email subscribers.

CAPP in the Community

CAPP was delighted to be invited to share how CAPP supports patients living with psoriasis and psoriatic arthritis at the **Annual Psoriasis & Psoriatic Arthritis Patient Education Session** hosted by the Toronto Western Hospital Psoriatic Disease Clinic (October 3, 2021).

Advocacy

Strategic Priority

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

Living with psoriatic disease is not easy. CAPP advocates for optimal care and treatment for our community, and for improvements to the healthcare system that support improved diagnosis, treatment, and wraparound supports for patients.

World Psoriasis Day 2021

World Psoriasis Day 2021 (October 29) marked the second collaboration between the **Canadian Association of Psoriasis Patients** (CAPP), **Canadian Psoriasis Network** (CPN), and **Unmasking Psoriasis**, an awareness group in Saskatchewan. The groups launched Phase 1 of a three-year collaboration focused on psoriatic disease in the workplace.

IFPA: Be United

Drawing inspiration from the International Federation of Psoriasis Association's theme of #BeUnited for WPD 2021, CPN, CAPP and Unmasking Psoriasis are asking employers and policy makers to #BeUnited and support people with psoriatic disease in their work lives.

Working It Out

To gain a deeper understanding of the experiences of people with psoriatic disease in the workplace, through this collaboration we worked with a human resources consultant and disability advocate to develop a survey about the workplace experiences of the psoriatic disease community in Canada. The aim of the survey was to learn about the experiences of people living with these conditions and better understand their needs and priorities regarding accommodation in the workplace, access to private and public health benefits, and the impact of their health on their experiences at work.

The findings from this survey informed the report and tools launched in Phase 1 of this campaign and provides foundational knowledge and insights for Phases 2 and 3.

Asked to rank the relative importance of having information on a variety of workplace related topics, the following areas received top ranking among survey respondents:

- The type of workplace accommodations that might be useful
- Understanding what my employer can ask me about my health
- Understanding the steps involved in requesting and receiving workplace accommodation

Working it Out

A report on the experiences of people with psoriatic disease in the Canadian workplace

October 2021

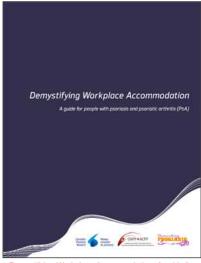




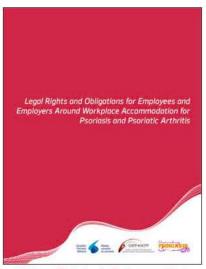




To address the needs identified by survey participants, we worked with an employment lawyer to develop three practical workplace tools that are enclosed in the *Working It Out* report and also available separately as standalone resources:



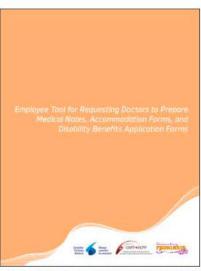
Demystifying Workplace Accommodation: A guide for people with psoriasis and psoriatic arthritis (PsA)



Legal Rights and Obligations for Employees and Employers

Around Workplace Accommodation for Psoriasis and

Psoriatic Arthritis



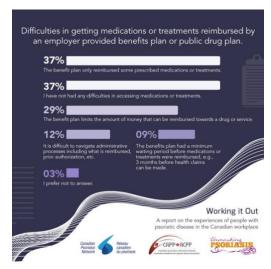
Employee Tool for Requesting Doctors to Prepare Medical

Notes, Accommodation Forms, and Disability Benefits

Application Forms

These resources were shared with our community via a social media campaign and through other media channels.





As well, we shared our findings and these resources with key audiences, namely **human** resources professionals, employers, and employment and social policy makers and influencers.

Media

- <u>Human Resources Professionals Association</u> (HRPA) blog on International Day for Persons with Disabilities featured the Working It Out report findings
- Radhika Panjwani, freelance writer with The Globe and Mail the article, <u>How are</u>
 workplaces supporting Canadian workers with disabilities?, was featured in The Globe
 and Mail's Careers newsletter on November 28, 2021
- Laurie Proulx, Talent Canada, <u>It's time for full workplace inclusion for people with disabilities</u> on December 3, 2021
- <u>CHIP 101.9</u> (a bilingual community radio station that serves the Pontiac County in Quebec and Renfrew County in Ontario)

Employers and private benefits providers

- <u>Centre for Research on Work Disability Policy</u> <u>Disability at Work in Canada</u> conference (December 2021)
- Benefits Canada Chronic Disease at Work conference (February 2022, sponsored by UCB Canada) see our presentation here
- The Centre for Research on Work Disability Policy (CRWDP) added these resources to their website to reach other people interested in these issues

Policy makers

- Provincial, territorial and federal human rights commissions
- Provincial, territorial and federal ministries of labour

We are grateful for the support of our sponsors: AbbVie, Janssen, Pfizer, UCB, Bausch Health, Sun Pharma, LEO Pharma, Novartis, Boehringer Ingelheim and Pierre Fabre Laboratories.

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 the **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.

BARING IT ALL:

Final report from a survey on reproductive and sexual health in women+ with inflammatory arthritis, rheumatic, and psoriatic diseases

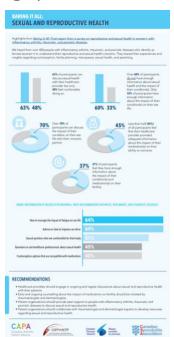








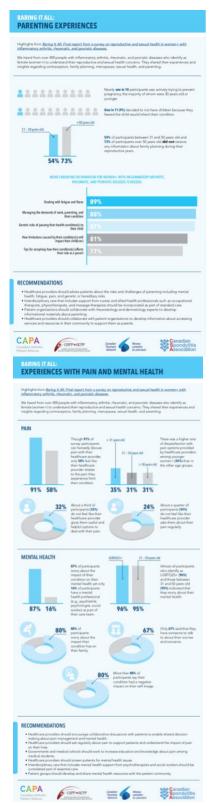
Infographics

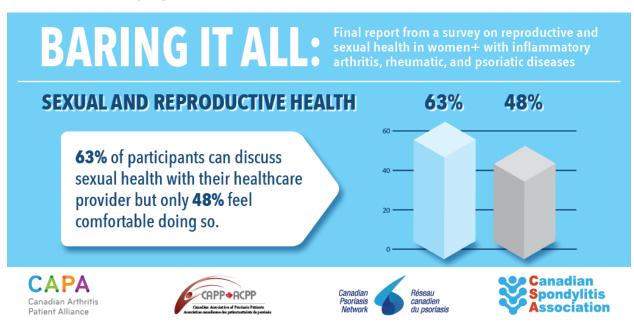




FAMILY PLANNING EXPERIENCES AND INFORMATION NEEDS 43% of participants had to switch the medizations they sale in pregnancy or brasilfecting. RECOMMENDATIONS CAPA Consider Agency Consider Agency Agency Agency Consider Agency Agency Agency Agency Consider Co BARING IT ALL: PAYING FOR MEDICATIONS Photos incurace through participans 46% These incurace through participans 30% on applict day appear have be provided with the day are more provided to the day are provided to the day a 15% 11% 9% 5% 2% MONTHLY OUT-OF-POCKET COSTS OF MEDICATION RECOMMENDATIONS

CAPA
Constant Afficial
Control Afficial
Control





Presentations

We shared what people across Canada told us with policymakers and healthcare professionals:

- Canadian Agency for Drugs and Technologies in Health (CADTH) 2021 Symposium Poster
- Canadian Rheumatology Association 2022 Annual Scientific Meeting Poster
- Canadian Arthritis Research Conference 2022 <u>Psoriatic disease with joint involvement</u> and <u>becoming a parent</u> presentation
- Benefits Canada, *Chronic Disease at Work 2022*, <u>Recruiting and retaining women+ in the</u> workplace (sponsored by UCB Canada) presentation
- EULAR 2022 (Annual European Congress of Rheumatology) presentation Copenhagen,
 Denmark

TIPS FOR PRIVATE PLANS

Recruiting and retaining women+ with inflammatory arthritis, rheumatic and psoriatic diseases

INTRODUCTION

The onset and diagnosis of inflammatory arthritis, rheumatic and psoriatic diseases commonly affects people in the prime of their lives and brings up many reproductive and sexual health-related concerns related to contraception, family planning, parenting, menopause, pain and mental health.

The Canadian Arthritis Patient Alliance, Canadian Association of Psoriasis Patients, Canadian Psoriasis Network, and Canadian Spondylitis Association heard from over 400 women+ across Canada about gaps in private coverage. Here are tips for private plans to keep these women+ healthy and engaged in the workplace.

Awards

The collaboration was recognized by the Canadian Dermatology Association with a CDA Public Education Award in the Not-for-Profit category in 2022. CAPP's Executive Director, Rachael Manion, accepted the award on behalf of all four collaborating organizations.



Improving patients' access to new psoriasis & psoriatic arthritis treatments

Public drug plans

When a new drug for psoriasis or psoriatic arthritis comes to patients in Canada, before it can be added to a public drug plan, it must be reviewed in the context of other drugs available for these diseases. All government drug plans in Canada except for Quebec refer to the HTA done by the Canadian Agency for Drugs and Technologies in Health (CADTH). The Quebec government has its own health technology assessment (HTA), done by the Institut national d'excellence en santé et en services sociaux (INESSS). Some provinces (BC, Ontario) have their own HTA processes after 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). CAPP has provided patient input submissions for many new drugs:

- Bimelx (bimekizumab) for **psoriasis** (BC Your Voice). CAPP collaborated with the **Canadian Psoriasis Network**.
- Tremfya (guselkumab) for **psoriatic arthritis** (CADTH). CAPP collaborated with the **Canadian Psoriasis Network, Canadian Arthritis Patient Alliance, The Arthritis Society,** and **Creaky Joints** on a survey of patients with psoriatic arthritis to inform the submission.
- Ilumya (tildrakizumab) for **psoriasis** (INESSS). When Quebec's INESSS process recommended that the provincial health minister not include this new treatment option on the province's drug list, CAPP reached out to the health minister's office in collaboration with the **Canadian Psoriasis Network** to share key messages about the importance of new treatment options for people with psoriasis.

Since CAPP was founded, many new treatments have become available to patients in Canada for **psoriasis**. Government drug plans wanted to make sense of the treatment landscape as it has evolved over this same time period. CADTH reached out to CAPP when it conducted a new type of review intended to help decision-makers make sense of the treatment landscape. Specifically, they looked at all biologics available for **plaque psoriasis**. This was a new process for CADTH and CAPP was included in the review process in collaboration with the **Canadian Psoriasis Network**.

Through this advocacy, CAPP ensured that patients' perspectives helped to shape the information that was considered in the evaluation.

Based on the Baring It All collaboration, CAPP worked with **MedAccessBC** to raise the topic of sex and gender analysis for reimbursement decisions (i.e., to learn more about whether / how the drug plan considers sex and gender in its decisions about whether to add a new drug to its formulary) at its November 2021 meeting with the BC division responsible for the public drug plans.

The National Advisory Committee on Immunization (NACI) has come more into the public eye as an advisory body for COVID-19 vaccines. It makes recommendations on immunizations available in the country, including those that are required for patients before starting on certain psoriasis or psoriatic arthritis treatments. NACI was asked by public payers to go beyond analyzing the clinical evidence about immunizations to also consider the costs of immunizations as part of its recommendations. CAPP supported the advocacy on this issue led by Save Your Skin Foundation that questioned this approach and urged NACI to have a formal patient input process as part of its process (like the HTA processes described above).

Private drug plans

When patients ask their drug plan to cover new treatments, they often have to do so through a specific process where they meet certain criteria. This type of process is called "prior authorization". CAPP has been part of an initiative that intends to **prior authorization process** used by private drug plans quicker and more transparent across plans. This project will continue in 2022-23.

Drug pricing

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

Leadership

Strategic Priority

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

By providing accurate and updated information and resources to the community, CAPP ensures that patients and their loved ones have a trusted source of information about their condition.

Website Redesign

In 2021-22 we began phase of the website refresh that built on the changes that were made the previous year. We evaluated content to see what needed to be expanded upon as well as adding new sections. Towards the end of the fiscal the sections were identified, writers were recruited to complete the sections, and review existing materials. The updates will be implemented into the next fiscal year, but will include a more robust psoriatic arthritis section, and new content on psoriasis and sleep, psoriasis and pregnancy, you and your rheumatologist. All content will be medically reviewed and translated.

We also began the process of updating the treatments sections of our website to be more thorough and up to date. WE worked with pharmacist to gather the information on the current treatment landscape for both psoriasis and psoriatic arthritis. All updates will be medically reviewed, translated, and implemented in the next fiscal year.

The clinical trials update was put on hold.

International Federation of Psoriasis Associations (IFPA)

CAPP continued to be Canada's representative at IFPA throughout 2021-2022.

CAPP's Communications Manager continued her work with IFPA's World Psoriasis Day and again participated as part of the WPD working group, which shaped the international events of World Psoriasis Day 2021. Leading up to World Psoriasis Day IFPA also launched new branding, a new website and announced new initiatives including the Ambassador program and the Accelerator program.

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. Our communications manager travelled to Amsterdam and participated in an advisory board meeting where we provided input on tools being developed by BI for GPP patients and then attended a multistakeholder GPP forum. There was also an exhibit of GPP activities by other patient organizations,

Research

Through supporting student awards and encouraging patient engagement in psoriatic disease research, we are helping shape a better future for our community.

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.

Each studentship application is reviewed by a patient or caregiver and two medical or scientific experts. This helps identify research questions that are important to patients and their loves ones. In 2021-22, CAPP expanded patient and caregiver engagement in the studentships program to include patient engagement in research training for studentship recipients.

This year, CAPP received 10 applications and awarded five studentships with the support of our program funders. CIHR's Institute of Musculoskeletal Health and Arthritis (IMHA) supported two studentships and the program was revised to reflect CIHR-IMHA's role as the "CAPP — CIHR-IMHA Studentships in Psoriatic Disease Research."

We appreciate the support of AbbVie, Boehringer Ingelheim, & LEO Pharma for this program and to help foster the future of psoriatic disease research in Canada.

| Abrahim Abduelmula | | |
|-----------------------|--|--|
| University of Western | | |
| Ontario | | |

Efficacy, Safety, and Treatment Alterations of a Fixed Combination Halobetasol Propionate and Tazarotene Lotion (Duobrii) For Moderate-To-Severe Plaque Psoriasis in Real-World Clinical

Practice: A Canadian Retrospective Study
Primary Supervisor: Dr. Melinda Gooderham
SKiN Health

Ahmed BagitUniversity of Toronto

Is Tildrakizumab (Ilumya) Safe and Effective In Treating Moderate-To-Severe Psoriasis In a Real-World Clinical Setting?

Primary Supervisor: Dr. Jensen Yeung

Sunnybrook Health Science Centre & Women's College Hospital

Hani Choksi McMaster University Identifying Small Molecules that Measure Disease Activity in Patients with Psoriasis

Primary Supervisor: Dr. Vinod Chandran

Krembil Research Institute, Toronto Western Hospital

Richie Jeremian Epigenetic Aging Studies of Psoriatic Disease

McGill University Primary Supervisor: Dr. Carolyn Jack

Research Institute – McGill University Health Centre (RI-MUHC)

Wenhui (Wendy) Yu

The Economic Burden of Psoriatic Arthritis

University of Ottawa Primary Supervisor: Dr. Dafna Gladman

Toronto Psoriatic Disease Research Program

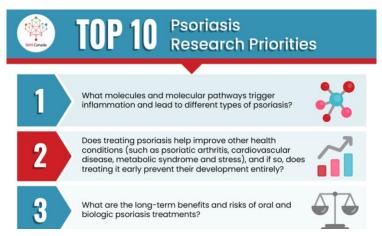
Toronto Western Hospital

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.

Former CAPP Co-Chair, Dr. Morris Manolson, is a Patient Research Partner of the network and serves on SkIN Canada's Steering Committee. He brings his lived experiences of psoriatic disease to the work of the network.

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. CAPP representatives attended the workshop for SkIN Canada's Priority Setting Initiative — Top 10 Psoriasis Research Questions. These were published in the summer of 2022 on the website of our collaborator, the **Canadian Skin Patient Alliance**, and shared with the CAPP community directly. CAPP is proud to work in collaboration with SkIN Canada on this important work and hopes that researchers and the organizations that invest more in answering questions that matter to patients.



Psoriasis guidelines for clinical care

New guidelines were released by the Dermatology Association of Ontario (DAO) about the <u>Use of Systemic Therapies for Treatment of Psoriasis in People Living with Controlled HIV</u>. Previously, the immune systems of these patients were considered very complex and the patients often went without psoriasis treatment. CAPP is hopeful that these new guidelines will help to provide healthcare professionals with the guidance and confidence to help treat people living with HIV and psoriasis.

Supporting patient engagement in psoriasis research in Canada

CAPP has provided letters of support for research about **biomarkers to detect psoriatic arthritis**, two of which have received funding. This project can improve our general understanding of how to diagnose psoriatic arthritis.

The national research funder, Canadian Institutes of Health Research – Institute for Musculoskeletal Health and Arthritis (CIHR-IMHA) has added CAPP to its website as a patient organization involved in research (in English and French). We look forward to continuing to be a resource for researchers who want to include patients' perspectives in their projects.

Supporters

We all benefit from the contributions of people in our community who want to improve the lives of people with psoriatic disease in Canada. We sincerely appreciate all the patients, caregivers, volunteers, collaborators and sponsors who have worked with us this year.

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 | Dr Yvette Miller-Monthrope | Dr Maxwell Sauder |
|------------------------------|----------------------------|-------------------|
| Dermatologist | Dermatologist | Dermatologist |

Board of Directors

Morris ManolsonCo-ChairChristian Boisvert-HuneaultCo-Chair

Kimberly Seguin Secretary / Co-Chair

Holly Rockbrune Treasurer
Kimberley Hanson Secretary
Simon Cheng Director
Reena Ruparelia Director
Amanda Shanks Director

CAPP welcomed Kimberley Hanson to the board of directors in 2021. We appreciate all the time, energy and skills that Morris Manolson and Amanda Shanks brought to the organization as board members.

Sponsors

We sincerely thank our sponsors for their generous support of our initiatives this year.

Your support makes it possible for CAPP to raise awareness, educate, advocate and support psoriatic disease research so that our community can look forward to a better tomorrow.





















Canadian Association of Psoriasis Patients G303-851 Industrial Ave Ottawa, ON. K1G 4L3

613-224-4266 877-505-2772 www.canadianpsoriasis.ca info@canadianpsoriasis.ca