Overburdened:

A Preliminary Report on the Burden of Psoriatic Disease in Canada.

A Working it Out Scoping Review.







Background

Psoriasis (PsO) is a chronic, immune-mediated inflammatory skin disease presenting as welldefined silver, scaly plaques that can range from pink colour¹ to purplish or gray, depending on skin tone. Plaques most commonly occur on the trunk, the extensor surface of joints such as the knees and elbows, and on the scalp,¹ though they can occur anywhere on the body. PsO affects 1-3% of the general population, with women being diagnosed a decade earlier than men, on average.¹ Approximately one million Canadians live with the condition, with plaque psoriasis being the most common form.¹ Although there is currently no cure for the disease, there are many effective treatment options to control the disease.¹

Apart from affecting the skin, PsO patients often live with associated inflammatory diseases such as psoriatic arthritis (PsA), inflammatory bowel disease and inflammatory eye disease as well as other comorbidities such as hypertension, type 2 diabetes, metabolic syndrome, and depression.¹

There are many forms of PsO including plaque psoriasis, inverse psoriasis, guttate psoriasis, erythrodermic psoriasis, palmoplantar psoriasis, and generalized or localized pustular psoriasis.¹ Approximately one third of patients with PsO have psoriatic arthritis (PsA), a chronic, inflammatory arthritis that manifests in the joints, entheses, tendons, spine, skin, and nails. PsA can cause joint pain, joint stiffness, and irreversible joint damage,¹ without appropriate intervention. When referring to all sub-forms and manifestations of PsO collectively, this is known as "psoriatic disease" (PsD).

Individuals with PsD can experience many challenges that have large impacts on their quality of life. Struggles with body image and self-esteem can arise from stigma, shame, and embarrassment socially imposed on people with a visible condition. This can cause emotional difficulties, social difficulties, and mental health conditions such as anxiety and depression. Furthermore, symptoms such as itchiness, pain, discomfort, and joint stiffness can result in losses of productivity, absenteeism, or extended leave/disability in the workplace. Combined with the steep cost of medications and increased healthcare use, workplace impairment can have a massive impact on the financial well-being of individuals affected by PsD. PsD can also impact the families and loved ones of those affected by the disease, cause increased burden on the healthcare system, and have societal impacts in the context of productivity loss, healthcare consumption, and community resource use.

Burden of Psoriatic Disease – Preliminary Report

Given that the impacts of psoriatic disease are multi-faceted, it is of interest to examine the burden of PsD in various domains in the Canadian context, specifically: burden of PsD on individuals, on society, on families, and on healthcare systems.

As part of Phase 3 of <u>Working It Out</u>, a threeyear campaign focused on supporting people with PsD in the workplace, this preliminary report summarizes the dominant themes that emerged in the literature related to two domains – the burden of PsD on **individuals** and on **society**:

- Differential Experiences of Health-Related Quality of Life
- Patient-Reported Quality of Life, Health, and Functionality
- Comorbidities
- Special Areas
- Work Productivity
- Economic Burdens

Findings from grey literature are also summarized to provide additional insights and context to the literature.

A full review, which will include themes related to the burden of PsD on **families** and on **healthcare systems**, is currently underway.

Methodology

Study Design

As part of the <u>Working It Out</u> campaign, the Canadian Psoriasis Network (CPN), the Canadian Association of Psoriasis Patients (CAPP), and Unmasking Psoriasis (UP), an awareness group in Saskatchewan, are completing a scoping review (a type of literature review with rigorous methods) to help identify literature on the burden of PsD, specifically to Canadians. A protocol for this forthcoming scoping review has been registered in the Open Science Framework.

Search Strategy

The literature search was performed by a librarian scientist with over twenty years of experience. The search was broad as to capture burden in various domains of life: to patients, to families, to healthcare systems, and to society at large – including economic burdens. The search was applied to the following databases: MEDLINE, Cochrane (Cochrane Central Register of Controlled Trials, Cochrane Database of Systematic Reviews), Embase, JBI, PsycINFO. The literature searches were peer-reviewed by another librarian using the Peer Review of Electronic Search Strategies (PRESS) Checklist.² A sample search from MEDLINE is attached (Appendix 1).

Inclusion/Exclusion Criteria for the Scoping Review

Literature would be included if:

- It is concerned with PsD (any type, sub-form, or associated conditions such as PsA);
- It speaks to burdens of PsD in one (or more) of the following domains: patients with PsD; family members of people with PsD; healthcare systems; society at large;
- 3. Study is either conducted in, or has findings that are attributable to, Canada;

- 4. No restrictions on study type;
- 5. No restrictions on publication date.

Literature would be excluded if:

1. Published in a language other than English or French.

Literature Screening

The literature was screened by a team established by CPN, CAPP, and UP. Every abstract which the literature search captured was reviewed by two reviewers independently. Each reviewer referred to the inclusion/exclusion criteria, and voted on whether to review the full-text of the abstract or not. This process is then repeated at the full-text stage where reviewers voted whether to include the article in the review. Critical information from these included articles was extracted by the two independent reviewers. If there was initial disagreements between reviewers regarding inclusion of an article, they met to resolve the matter through discussion.* This screening process was completed through the program, Covidence.³

Included Articles in this Preliminary Report

This preliminary report provides a summary of studies and other literature (e.g., commentaries) which were captured in our search in English about the burden of PsD in Canada in the "patients" and "broader society" domains. Upon its completion, the CPN, CAPP and UP plan to share the entirety of the scoping review which will be reported using the Preferred Reporting Items for Systematic Reviews extension for scoping reviews (PRISMA-ScR).⁴ The final review will include the remaining literature on the patient and society domains (e.g., articles still attributable to, but conducted out of Canada; abstracts) as well as PsD burden in the remaining domains: families and health systems and any French literature.



Differential Experiences of Health-Related Quality of Life

The literature revealed that PsD's impact on health-related Quality of Life (QoL), as measured through the Dermatology Life Quality Index (DLQI) (more details on this metric below), was worse for Black, Asian, and Hispanic/Latino individuals than for White individuals.⁵ This finding was evident regardless of severity of PsD, the treatment the patient was on, or other sociodemographic considerations.⁵

This raises questions about the impact that systemic racism, and other oppressive systems, may play on worsening PsD burden since racialization appears to have an impact on the burden of PsO on QoL even when disease stage/ severity are the same. Given that no studies emerged in this review that looked at the impacts of PsO on QoL for Indigenous individuals, this also suggests that there is a lack of research and knowledge about PsD in Indigenous populations.

Gender differences between men and women were noted, with women more likely to report lower functioning and QoL, while men were more likely to have axial involvement and radiographic joint damage in PsA.⁶ These differences indicate further research is needed into what differences in PsD burden may exist across genders, the extent of the differences, and the impacts of these differences.

Patient-Reported Quality of Life, Health, and Functionality

Impact of Daily Life and Quality of Life

Burdens of PsO range from minor to significant, with individuals expressing concerns about mobility, managing pain flares, and being concerned about how their condition impacts their families. Lack of understanding of one's PsO or disappointment with treatment options and progress can lead to isolation, worsened social stigma, a sense of hopelessness, and/or greater impact on daily activities.⁷ Moreover, some individuals discussed how PsO disrupted their daily life, and indicated it was challenging to "stay positive" while living with an "invisible disability."8 In one study, when people with PsO were asked to rank whether the disease posed a "problem" for their lives on a scale of 1-10, with 1 being "no problem at all" and 10 being a "very large problem." The mean score was 6.2 and one third describe PsO as posing a "substantial problem."9

In the context of PsA, over 95% (n=1,247)* of individuals with PsA surveyed reported having experienced musculoskeletal related symptoms within the last year.¹⁰ More than 75% of individuals with PsA said the disease impacted their daily activities, with 62% expressing concerns surrounding their work productivity, and more than half indicating the disease influenced their career path.¹⁰ This is similar to findings in the *Working It Out* survey on patient experiences in the workplace which found that more than half of survey respondents said that PsD impacted them negatively at work and that they had concerns about how PsD could impact their ability to stay employed.

PsA can present numerous impairments and limitations, though patients reported that access to certain environmental factors (e.g., medications, healthcare professionals, immediate family and their attitudes, friends and their attitudes) is helpful in maintaining participation in activities.¹¹ Despite these helpful factors, nearly 70% of individuals with PsA (n=887) reported a moderate to major impact on their mental health and more than half said the condition impacted their romantic relationships.¹⁰ Nearly 45% (n=556) reported that the disease had negative impacts on their relationships with family and friends, with one third of individuals indicating they had experienced social shaming over their condition.¹⁰

Differences emerged between patient and practitioner perspectives when evaluating QoL and ways to improve it. One study found that itch, symptom control, and skin clearance were reported as the top clinical goal for patients whereas practitioners rated "improving QOL" as the most important goal.¹²

An important approach to understanding the burden of chronic conditions, such as PsD is through validated questionnaires that ask patients questions about their lived experience and how living with PsD impacts their daily life. The following summaries provide insight into what several questionnaires used by PsD clinicians revealed about the burden of PsD.

Dermatology Life Quality Index (DLQI)

The Dermatology Life Quality Index (DLQI) is a questionnaire designed to measure healthrelated QoL in adult patients diagnosed with skin disease.¹³ According to Wasel et al., data collected using the DLQI suggest that the burden of PsD increases with the severity and extent of skin surface area affected; this results in a greater negative impact on patients' well-being.¹³

^{*}Please note that the exact numbers for subanalyses were not always shared and so these were calculated using the percentages shared in the papers' results of the total number of participants. Depending on how authors rounded, these numbers might differ by 1 or 2.

SF-36

The SF-36 is another questionnaire that measures health-related quality of life through eight scales: physical functioning, limitations due to physical health, bodily pain, general health, vitality, social functioning, limitations due to emotional challenges, and mental health.¹⁴ These eight domains all contribute to a physical component summary score and a mental component summary score, with a higher score indicating better QoL.¹⁴ The literature highlighted that the presence of PsA typically negatively impacts physical health more intensely than PsO alone.

Husted et al. found that in patients with PsA, comorbidities such as fibromyalgia, neurological disorders, and obesity were linked to decreases in physical component summary scores, and fibromyalgia and depression/anxiety were linked to decreases in mental component summary scores.¹⁴ These associations held true even after adjusting for disease-related and sociodemographic factors. Rosen et al. compared SF-36 scores in patients with PsO only and in patients with PsA. They found that the physical component summary score was higher in patients with just PsO, signifying higher QoL and less limitaitons in this domain compared to those who also had PsA. However, there was no difference in the mental summary score between the two groups.15

Health Assessment Questionnaire (HAQ)

The Health Assessment Questionnaire (HAQ) serves as a crucial measurement tool to comprehend self-reported health-related quality of life outcomes. The studies using this metric highlighted that PsA in particular poses negative impacts on health-related QoL.

In a study conducted by Rosen and colleagues, it was found that patients with PsA had HAQ scores that captured poorer health-related QoL compared to individuals with PsO alone.¹⁵ This is connected with the higher level of disability that is experienced due to the impact on the joints. Building upon these findings, Eder et al. (2013) further emphasized that women with PsA suffered from more severe functional limitations and reported a lower QoL compared to their male counterparts.⁶ Specifically, women with PsA scored higher on the HAQ, suggesting greater limitations in their daily physical functioning when compared to men.⁶

Female Sexual Function Index (FSFI)

The Female Sexual Function Index (FSFI) is a questionnaire used to understand sexual functioning in pre-and post-menopausal women.¹⁶ There is evidence that sexual functioning is negatively affected predominantly in women with PsA. In a comparative analysis, individuals with PsA have worse FSFI compared to healthy controls with score averages being 17.44/32 vs 25.49/32, respectively.¹⁶ Among a sample of 21 women who reported having sex in the most recent month, 52.2% of individuals with PsA had sexual dysfunction.¹⁶

Comorbidity

There is a high prevalence of comorbidity in individuals living with PsD. Among these common comorbid conditions are hypertension followed by obesity, diabetes, kidney disorders, and chronic obstructive pulmonary disease (COPD).¹⁷ Statically significant higher rates of hypertension (52.2% vs. 27.3%; P=0.027) and anxiety/depression (17.4% vs. 3.0%; p=0.048) were noted.¹⁷ The literature showed that comorbidities can also negatively impact work productivity amongst people with PsD,¹⁸ though these comorbid conditions do not necessarily result in additional PsD-related burden and can be independent sources of burden for the person.¹⁵

Special Areas

"Special areas" refer to areas of the body affected by PsD that are understood to be particularly burdensome.¹⁹ These "special areas" generally include: scalp, face, hands, intertriginous areas, genitals and nails. While this report did not capture comprehensive studies on special areas, we acknowledge that these areas have been identified as areas of high burden for people with PsD.

This literature review found that nail involvement is not only correlated with poorer outcomes, but also might be of particular concern to Canadians with PsD. In a comparative analysis between Americans and Canadians living with PsO, Richette and colleagues found that while musculoskeletal or skin manifestations were comparable, nail involvement was more commonly reported by Canadians.²⁰ Nail involvement, which can place a heavy burden on individuals with PsD, can also be an indicator of more severe disease. An expert panel asserted that nail involvement has social implications, worsened pain, and negative impacts on activities of daily life (e.g., buttoning clothes or opening bottles) along with social concerns.²¹

Work Productivity

Across several studies, it was reported that PsD can impact career choice for those diagnosed from a younger age and PsD symptom flares can impact work productivity.

Thirty-eight percent of participants reported that their career choice and the process of acquiring employment were impacted by their PsD diagnosis.²² Of the same cohort of 81 patients, 28% reported accommodations including altering job description and responsibilities.²² Work attendance can be impacted with nearly 20% of individuals with PsD needing to miss one or more full days of work and nearly 30% one or more partial work days in the previous two weeks.¹⁸ While one third of individuals with PsD reported lost work productivity, the mean loss was quite small, with <5% lost productivity being measured.¹⁸ Chan and colleagues estimated a loss of 2.2 hours per week of work due to PsD.²² Work impairment was another theme in the identified literature. As many as 14% of individuals with PsD reported they worked fewer hours than they desired because of the impact of their PsD.¹⁸

Work productivity losses were reported to be lower in patients with PsA who are taking biologics and/or disease-modifying anti-rheumatic drugs (DMARDs), suggesting that when individuals taking these medications experience work productivity losses, it is likely due to the high disease severity rather than these therapeutics themselves.¹⁸ This is further supported by the fact that erosive disease (more severe disease leading to breaking down of bone and joints) in patients with PsA is independently associated with workplace-related disability.¹⁸ Education status, self-reported flexibility with working schedule, and self-reported supports within the workplace were all protective factors against lost work productivity.¹⁸

Economic Burdens

The literature found that PsO severity is correlated with unemployment, income, and income loss.

There appears to be an inverse relationship between PsO severity and income where those with moderate and severe PsO had much lower reported incomes than those with milder PsO.²³ This also extended to employment, with greater unemployment reported amongst those with more severe PsO.²³ The use of biologics increased with income from 4% of individuals in the lowest income bracket taking biologics compared to 14% of individuals with the highest income bracket.²³ This trend of biologic use was highly correlated with income and healthcare insurance coverage.²³

PsO severity was higher amongst those with lower healthcare insurance coverage, with 43.6% (65/149) of those with severe PsO having full coverage healthcare insurance and 68.4% (13/19) of those with mild disease having full healthcare insurance coverage.²³ The authors posited that this is likely strongly connected to the significantly lower employment and incomes rates among those with severe PsO; 42.2% (8/19) of those with mild disease earned an income in the top quintile compared with only 13.4% (20/149) of those with severe PsO.²³

Chan et al. reported that individuals with PsO experienced an average \$2,270.84 CAD annual loss of income due to PsO. This would be equivalent to \$3,352.19 CAD <u>in today's dollar</u> value.²² These findings emphasize the importance of income and disability supports and improved sick-day policies. The cumulative estimated loss of income due to PsO was reported as \$749 million CAD annually which would be more than \$1.1 billion CAD <u>today</u>, indicating that lost work productivity due to PsO not only impacts individuals with PsO, but it has serious implications for the broader economy and society as well.²²

Grey Literature Findings

While not part of the formal search strategy for the scoping review, several pieces of grey literature that speak to PsD burden are summarized below to add further insights and context to this preliminary report.

Working It Out is a collaboration between the Canadian Psoriasis Network (CPN), the Canadian Association of Psoriasis Patients (CAPP), and Unmasking Psoriasis. In 2021, *Working It Out* released findings from *Working It Out: A Report* on the Experiences of People with Psoriatic Disease in the Canadian Workplace which concluded that individuals with PsD needed more support navigating their disease and necessary accommodations in the workplace.²⁴ Phase 2 of the project was released in 2022, and included a white paper that analyzed federal public employment and disability policies that affected individuals living with PsD.²⁴

<u>The Journey to Stability Survey</u> is a collaboration between CPN and CAPP focused on understanding the lived experiences of people with PsD and as they manage their disease. This report found that the top five attributes most affected by PsD reported by patients were: lack of self-esteem; interrupted sleep; anxiety; depression; and avoidance of intimacy. These findings are in keeping with several themes identified in our review to date.

<u>Baring it All</u> is a collaboration between CPN, CAPP, the Canadian Spondyloarthritis Association and the Canadian Arthritis Patient Alliance focused on understanding the experiences and sexual and reproductive health needs of women+ who live with inflammatory arthritis, rheumatic, and psoriatic diseases.

Optimizing care for patients with pustular psoriasis. Research Report and Summary from National Policy Roundtable (September 2022) explores generalized pustular psoriasis, a rare, chronic form of psoriasis and its nuanced challenges including the potential for severely diminished quality of life, reduced productivity, stigma, and risk of shortened life expectancy from disease.

Conclusions

It is apparent from this preliminary report that PsD poses significant burdens to patients and to broader society. This report reiterates concerns about the disproportionate burdens faced by groups that have been traditionally marginalized by healthcare systems. Furthermore, there is concern that burdens compound on one another with worsened disease status being connected with lower work productivity and lower income. While worsened disease severity can contribute to these work-related burdens, it is important to explore how this relationship can be bi-directional. For instance, with poorer income comes greater barriers to accessing care, medicines, and other treatments and supports, which in turn leads to worsened disease progression.

In the next iteration of this report, it will be important to explore how PsD impacts families and healthcare system to better understand the overall impacts of PsD on society at large.

Acknowledgements

This resource was developed by Catherine Stratton, PhD Student in Epidemiology, University of Toronto, Dalla Lana School of Public Health and Wenhui (Wendy) Yu, M.D. Candidate at the University of Ottawa with support from Darshana Seeburruth, M.D. Candidate.

Thank you to Jessie McGowan, PhD, Health Information Consultant, for providing guidance and support in developing the methodology for this literature review.

Thank you as well to our Medical Advisory Committee for their review of the search protocol and findings:

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We appreciate the unrestricted educational grants and sponsorships from multiple funders to develop this report: Pfizer, Arcutis, Janssen, Amgen, AbbVie, Boehringer Ingelheim, Bausch Health Canada, and LEO.

About Working It Out

Working It Out is a collaboration between the <u>Canadian Psoriasis Network (CPN)</u>, the <u>Canadian</u> <u>Association of Psoriasis Patients (CAPP)</u>, and <u>Unmasking Psoriasis</u>. In 2021, <u>Working It Out</u> released findings from Working It Out: A Report on the Experiences of People with Psoriatic Disease in the Canadian Workplace that concluded that individuals with psoriatic disease were not receiving sufficient accommodations in the workplace.²⁵ Phase 2 of the project was released in 2022, and included a white paper that analyzed federal public employment and disability policies that affected individuals living with psoriatic disease.²⁵

As part of the broader <u>Working It Out</u> project, which explores the experiences of people with psoriatic disease in the workplace, this preliminary report provides a summary about the burden of psoriatic disease in Canada through the lens of impacts on patients and on the healthcare system. It is intended to be the first iteration of a broader scoping review, which will include the impact of psoriatic disease on other domains such as families and health systems.

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Appendix 1 MEDLINE Scoping review of burden of psoriatic disease (psoriasis + psoriatic arthritis) in Canada

Search strategies – June 9, 2023

Database: Ovid MEDLINE(R) ALL <1946 to June 08, 2023>

Search Strategy:

- 1. exp Psoriasis/
- 2. (pustulosis or psorias* or guttate or pustular or erythrodermic).tw,kf.
- 3. 1 or 2
- 4. Economics/ or "Costs and Cost Analysis"/ or Economics, Nursing/ or Economics, Medical/ or Economics, Pharmaceutical/ or exp Economics, Hospital/ or Economics, Dental/ or exp "Fees and Charges"/ or exp Budgets/ or ec.fs.
- 5. (budget* or economic* or cost or costs or costly or costing or price or prices or pricing or pharmacoeconomic* or pharmaco-economic* or expenditure or expenditures or expense or expenses or financial or finance or finances or financed).ti,kf.
- 6. (economic* or cost or costs or costly or costing or price or prices or pricing or pharmacoeconomic* or pharmaco-economic* or expenditure or expenditures or expense or expenses or financial or finance or finances or financed).ab. /freq=2
- 7. (cost* adj2 (effective* or utilit* or benefit* or minimi* or analy* or outcome or outcomes)).ab,kf.
- 8. (value adj2 (money or monetary)).ti,ab,kf.
- 9. (markov or monte carlo).ti,ab,kf.
- 10. exp models, economic/ or markov chains/ or monte carlo method/ or economic model*.ab,kf.
- 11. ("burden adj2 disease*" or disease cost* or illness burden* or BOD).tw,kf.
- 12. exp "Cost of Illness"/
- 13. exp Quality of Life/ or "Value of Life"/ or exp *health status indicators/
- 14. ("quality of Life" or QOL or qaly or daly or HRQOL or "psychological Well-Being" or SF-36 or SF36 or SF6 or SF6 or SF8 or SF-8 or SF12 or SF-12 or SF20 or SF-20 or Newcastle or hql or hqol or h qol or hrqol or hrqol or pqol or qls or eq or euroqol or euro qol or eq5d or eq 5d or euroqual or euro qual or "nottingham health profile" or "duke health profile" or "sickness impact profile" or "disability adjusted life" or "willingness to pay" or "functional status questionnaire" or "dartmouth coop functional health assessment*").tw,kf.
- 15. (((social adj2 cost*) or societal) adj2 cost*).tw,kf.

16. or/4-15

17.3 and 16

18.17 or (burden adj4 psorias*).tw,kf.

- 19. exp Canada/ or (canadian* or canada* or canadien* or british columbia* or vancouver* or (Victoria* not Australia*) or alberta* or calgary* or edmonton* or saskatchewan* or regina* or saskatoon* or manitoba* or winnipeg* or ontario* or toronto* or ottawa* or McMaster or thunder bay* or London Health Science* or University of Western Ontario or Western University or (Queen* adj University) or quebec* or montreal* or McGill or new brunswick* or Moncton* or Fredericton* or prince edward island* or Charlottetown* or nova scotia* or Halifax* or Dalhousie or labrador* or newfoundland* or ((St or Saint) adj John*) or memorial university or nunavut* or lqaluit* or northwest territor* or Yellowknife* or yukon* or Whitehorse* or first nation* or metis or inuk or innu or autochtone). ti,ab,hw,kf,jw.
- 20. (canadian* or canada* or canadien* or british columbia* or vancouver* or (Victoria* not Australia*) or alberta* or calgary* or edmonton* or saskatchewan* or regina* or saskatoon* or manitoba* or winnipeg* or ontario* or toronto* or ottawa* or hamilton* or thunder bay* or quebec* or montreal* or new brunswick* or Moncton* or Fredericton* or prince edward island* or Charlottetown* or nova scotia* or Halifax* or labrador* or newfoundland* or ((St or Saint) adj John*) or memorial university or nunavut* or Iqaluit* or northwest territor* or Yellowknife* or yukon* or Whitehorse* or first nation* or metis or inuk or innu or autochtone).ia,in.
- 21. ((Hamilton not ((Hamilton adj New Zealand) or ((Chedoke or Hamilton or McMaster) adj4 (equation? or index* or inventor* or norwood or scale?)))) or (Hamilton adj Ontari*)).ti,ab,hw,kf,jw.
- 22. London not (UK or "U.K." or United Kingdom* or GB or "G.B." or england or britain or british)).ia,in.

23. or/19-22

24.18 and 23

About the Canadian Psoriasis Network (CPN)

CPN is a national not-for-profit organization with a mission to enhance the quality of life of people with psoriasis and psoriatic arthritis. We do this in part by providing current information on research and treatment options and by working with others to build awareness and advocacy about the complexity of these conditions.

www.canadianpsoriasisnetwork.com

About the Canadian Association of Psoriasis Patients (CAPP)

CAPP is a national not-for-profit organization that was formed to better serve the needs of people living with psoriasis and psoriatic arthritis in Canada. We raise awareness about the burden of psoriatic disease, provide education, support research into psoriatic disease and advocate on behalf of our community.

www.canadianpsoriasis.ca

About Unmasking Psoriasis

Unmasking Psoriasis is a Saskatchewan-based awareness group looking to educate employers and the public. We support patients with psoriasis through education and changing the way we think of psoriasis.

www.unmaskingpsoriasis.org



