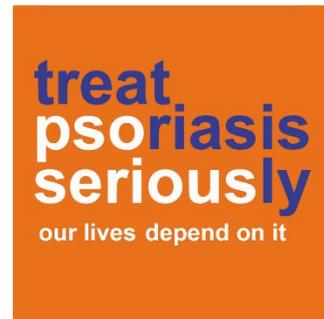




Canadian Association of Psoriasis Patients Annual Report July 1, 2018 – June 30, 2019

This has been an exceptional year for the Canadian Association of Psoriasis Patients! We completed the PsoSerious Report, led the first-ever National Psoriatic Arthritis Awareness Day in Canada and partnered on an award-winning “myskinandbones” awareness campaign!

The PsoSerious Report 2018: A Report on Access to Care and Treatment for Psoriasis Patients in Canada revealed the persistent barriers to treatment that Canadian psoriasis patients face including long wait times to see a dermatologist and unequal access to treatment options across the country. Working with five partner organizations, the objective of the National Psoriatic Arthritis Awareness Day was to educate about the link between psoriasis and psoriatic arthritis. On a similar line, “myskinandbones” used a variety of online and social media platforms to promote awareness between psoriasis and psoriatic arthritis even further.



We are proud of all of our accomplishments this year, including representing Canada at the International Federation of Psoriasis Patients (IFPA), celebrating World Psoriasis Day 2018 with our partners using the theme “PsoSerious”, continuing to fund studentships in psoriatic disease research and supporting many patients through social media campaigns and on an individual basis.

Sincerely,

A handwritten signature in black ink, appearing to read "Morris Manolson".

Dr. Morris Manolson
Co-Chair
Canadian Ass'n of Psoriasis Patients

A handwritten signature in black ink, appearing to read "K. Andrews-Clay".

Kathryn Andrews-Clay
Executive Director
Canadian Ass'n of Psoriasis Patients

Strategic Priority: Promote awareness and support for patients living with psoriatic diseases in Canada

Highlights for 2018-19:

- Working in collaboration with the Arthritis Society, Arthritis Consumer Experts, the Canadian Arthritis Patient Alliance, the Canadian Psoriasis Network, and the Canadian Spondylitis Association, the first National Psoriatic Arthritis Awareness Day was a great success! The hashtag #cdnPSADay garnered over 329,000 impressions and reached a potential 135,230 users.
- Promoted new sections of the CAPP website, especially the treatments available for patients living with psoriatic diseases including topicals, systemics and biologics. We developed infographics specifically to better understand the biologics/biosimilars class of treatment. We also added a new interactive section for pediatric psoriasis.
- We continued to share information about the link between psoriatic arthritis and psoriasis on the website and social media.
- Four bilingual newsletters were developed and distributed to our subscriber list and at a variety of conferences and events. Topics included the link to psoriatic arthritis, treatment options and common questions about psoriasis.
- We developed and managed a survey on topical treatments to better understand how and why psoriasis patients use topical treatments as well as their success using them. Concerns raised included the effectiveness of the product, out of pocket expenses and concerns about potential side effects.
- Managed two highly successful social media platforms including Facebook and Twitter for the organization. (Please see the appendix for the social media report for CAPP).

Strategic Priority: Advocate on behalf of patients and their families living with psoriatic diseases in Canada

Highlights for 2018-19:

- We completed several patient submissions for three new biologic drugs (cimzia, risankizumab, and tofacitinib) approved in Canada for the treatment of psoriasis and/or psoriatic arthritis for the Common Drug Review, the “INESSS” and BC Pharmacare “Your Voice.”
- The PsoSerious Report 2018: A Report on Access to Care and Treatment for Psoriasis Patients in Canada was distributed to decision makers across Canada to highlight the inequities for psoriasis patients. We are indebted to Celgene Canada for partnering with us to develop the microsite that focuses on this report.

- A meeting was held on World Psoriasis Day 2018 with Senior Advisors in the office of the Ontario Minister of Health and Long-Term Care. The focus was on the newly released PsoSerious report and how to improve the quality of life for Ontario patients living with psoriasis.
- As the Canadian member of the International Federation of Psoriasis Associations, we promote their international advocacy messages and participate in member meetings and events.
- Our British Columbia Board member, Simon Cheng, met with his Member of the Legislative Assembly to advocate for better access to dermatologists and treatments in this province.

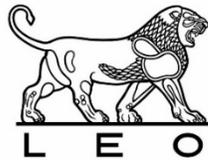
Strategic Priority: Be a trusted leader for patients living with psoriatic diseases in Canada

Highlights for 2018-19:

- After three years of funding, the CAPP Board of Directors evaluated the studentships program to decide whether or not to continue funding this project. Participants at the meeting included rheumatologists, funded students, Board members, and funders. Everyone agreed that it was a worthwhile investment and that the impacts were significant, including four pages of academic publications/presentations after only 2 years of funding (year 3 had not been collected yet.)
- CAPP managed another year of the “Studentships in Psoriatic Disease Research” and funded five more students, working in partnership with the Canadian Institutes of Health Research, Institute of Musculoskeletal Health and Arthritis, Eli Lilly and Janssen Canada. Topics included Investigating the Risk of Malignancy in Elderly Patients with Psoriasis and Three-Dimensional Body Imaging of Psoriatic Lesions.
- CAPP was pleased to introduce two new Board members this fiscal year. Welcome Holly and Kimberley! This is the first time that the CAPP Board has been at full capacity.
- “Myskinandbones” won the Canadian Dermatology Association Public Education award this year for raising awareness and changing public perception in a creative and engaging way. We are indebted to Novartis Canada for championing this project and providing an enormous amount of support to make it so successful.
- Dissemination of the “Journey to Stability” report continued with CPN Canada as we developed new infographics, presented posters at Conferences and sent the information to private sector payers.
- Participated in the Novartis Global Psoriasis Council, an international group of patient association representatives brought together to provide feedback into activities of the company and to share resources.
- Presented at the 6th Congress of the Skin Inflammation & Psoriasis International Network (SPIN) in Paris for the first time on how we involve patients in our work.

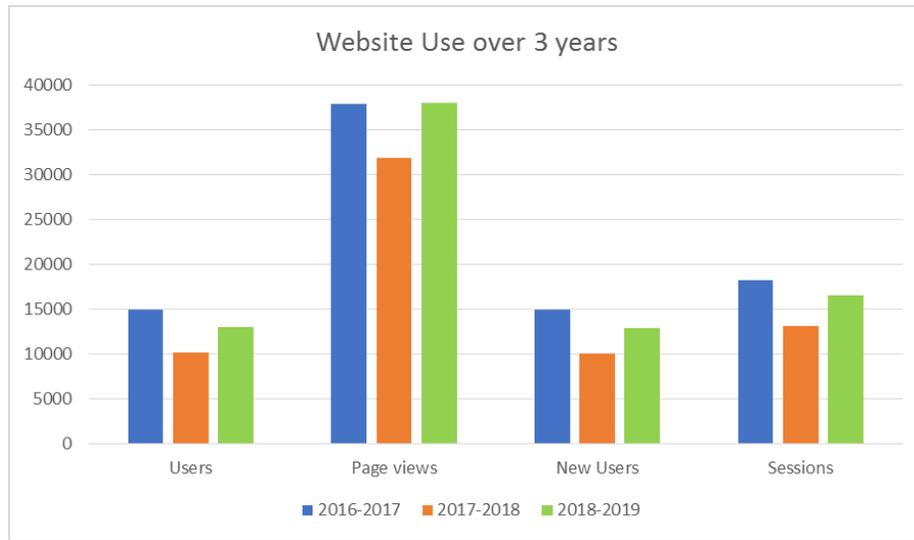
With Sincere Appreciation!

CAPP would like to thank our partners for their commitment to psoriatic patients in Canada and for helping us achieve our objectives for this year!

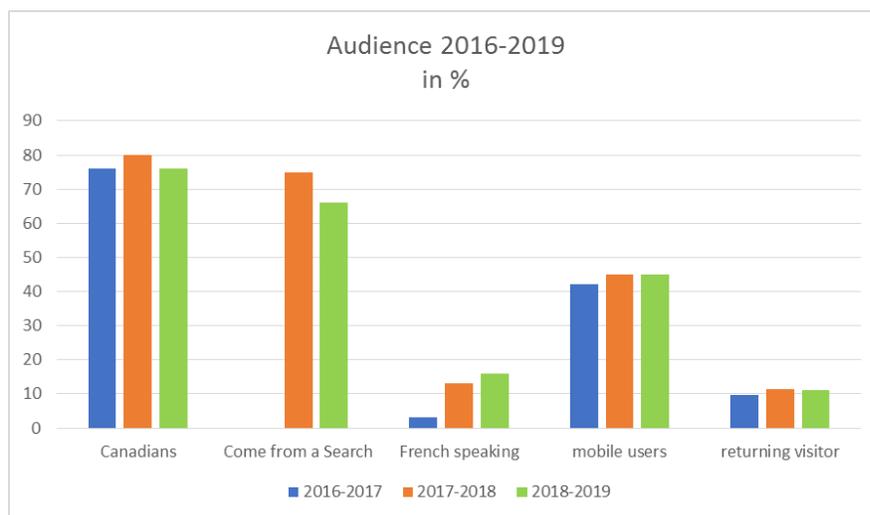


Appendix A: Social Media Report

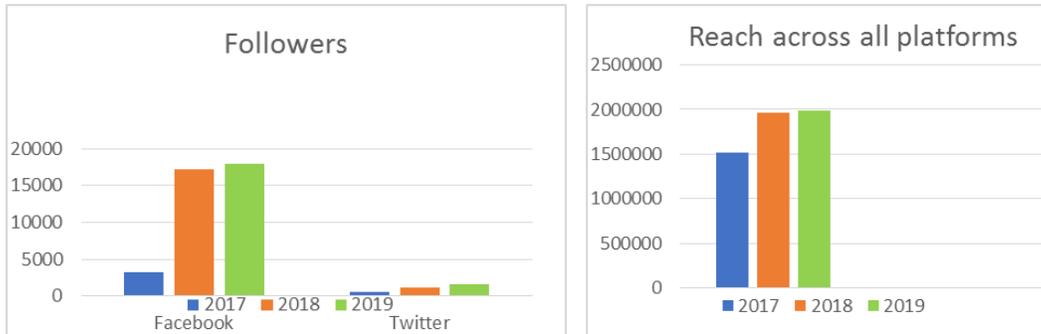
1. **Website:** The CAPP website gained some traffic and users this year so that we are now on par with the 2016-2017 fiscal year which was our goal for this year. The website has not had many changes made to it this year. This may be a priority, to look at ways to make the website more fluid in order to bring people back or attract new users. The landing pages in both languages were our most visited pages, followed by the page on clinical trials, the biologics treatment page, and the resource pages. However, if you combined all the hits to different sections in the “Treatment” section of the website, that section received almost 25% of our total website hits.



Audience: The website audience is 77% English speaking and 76% are Canadian. Given our mandate to support Canadian psoriatic patients and their families, we are definitely hitting that target. We also have visitors from the US (10%) and France (3.5%). While it is customary for most websites to have most of their visitors come to them on a mobile device (phone or tablet), the majority of our visitors are coming via desktop, which is surprising since 77% of our visitors are under the age of 44. We also see that the majority of our audience is male, which again the typical website has a higher percentage of females.



2. **Social Media:** Our social media channels continue to be our greatest assets in raising awareness and disseminating information. We already have a substantial Facebook following that continues to grow and a Twitter following that has tripled in two years, from 500 followers to well over 1,500. Our reach across all platforms was almost 2 million people.



Audience: Our social media followers are mostly female (78%) and Canadian, and surprisingly half of them are over the age of 55. Social Media posts focused on recruitment for patient events, trials and surveys, as well as focusing on our projects such as the Pso Serious report, the Journey to Stability report, and educational posts about living with psoriasis.

This year also saw us host a twitter chat using the #newdayforPsA in partnership with AbbVie and the Canadian Spondylitis Association. This event was also in celebration of the first National Psoriatic Arthritis Awareness Day. We also had an organic campaign to support this day and brought together all the Canadian patient organizations that work in the arthritis space. We hope to expand on this work next year as we continue with the #cdnPSAday hashtag in our activities this year.

Microsites: We had strong support from our sponsors in developing two microsites - myskinandbones.ca and psoserious.ca. Their paid promotions of these sites, for National Psoriatic Arthritis Awareness Day and World Psoriasis Day, helped with our reach and engagement.