



## **Canadian Skin Patient Alliance Annual Report**

July 1, 2018 - June 30, 2019

*~for patients, by patients~*

The Canadian Skin Patient Alliance is proud of the work that we accomplished this fiscal year to support our mission/vision and in line with our strategic priorities.

**Our vision:** *By 2022, Canadians living with dermatological conditions will have appropriate access to care and affordable treatments.*

**Our mission:** *To promote skin health and improve the quality of life of Canadians living with skin conditions, diseases and traumas.*

Of particular note, the Board of Directors approved the final version of the *Patient Charter for Canadians Living with Conditions, Diseases or Traumas Involving the Skin* after months of research, revisions and consultations. We were thrilled that the document was then endorsed by the Canadian Dermatology Association in the fall of 2018. The intent of the document is to educate and empower patients to take an active role in their care and treatment as well as to safeguard the respect of society, government and workplace as a result of their diagnosis. We look forward to evaluating the impact of this charter once the dissemination takes place over the coming months.

On the Advocacy side, the Board of Directors approved a position statement on the implementation of National Pharmacare. This document highlights the importance of “timely access to medications regardless of income, age, disease or postal code, so that no one is left behind.” Given the importance of this issue in the federal election, it was important for the Board to have a solid position on the issue.

We are proud of the work we do for the many Canadians living with skin diseases, conditions and traumas, often by supporting the work of our Affiliate Members.

Thank you to the many sponsors and volunteers who have worked with us throughout the year. We could not accomplish so much without your commitment and support for skin patients in Canada.

A handwritten signature in black ink, appearing to read "Munish Mohan".

Munish Mohan  
Chair  
Canadian Skin Patient Alliance

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

Kathryn Andrews-Clay  
Executive Director  
Canadian Skin Patient Alliance

## **Strategic Priority Area #1 - Support for Patients, Families and Affiliate Members: Increase our presence by creating greater brand awareness, strong networks for patients and families and mutually supportive relationships with Affiliate Members.**

In 2018-19, highlights include:

- Awarded two grants to Affiliate Members as part of our competitions held each spring and fall to help with marketing projects or campaigns. Congratulations to the winners of the Tanny Nadon Affiliate Members Grants in 2018-19:

Canadian Alopecia Areata Foundation (CANAAF) and, the Alberta Society of Melanoma



- Continued to work in partnership with the Canadian Association of Psoriasis Patients on projects and activities specifically focused on psoriasis and psoriatic arthritis, including several patient submissions to the Common Drug Review and the promotion of awareness days.



- Developed a new infographic template to highlight the work of each Affiliate Member to share at various events and online. To date, seven have been finalized and were introduced at the Canadian Dermatology Association conference in June.
- Reached out to the Affiliate Members on a monthly basis with news about our organization and other relevant information. We also highlight events and activities that they are doing as well on our social media platforms.
- Attended new national and international events this year as we continue to increase our presence, examples such as the Skin Inflammation and Psoriasis Network Congress in Paris, the Canadian Burn Conference in Toronto, Ontario and the Canadian Association of Physicians' Assistants conference in Victoria, B.C. And, we continue to host a booth at Primed which is focused on nurse practitioners, family physicians, and pharmacists and attended the Global Skin conference to represent Canada at this level.

## Strategic Priority Area #2 – Education: Empower patients and their families and Affiliate Members through knowledge, education and access to information.

In 2018-19, highlights include:

- Produced and distributed the “Canadian Skin” magazine to more than 11,500 people three times this year. The demand for this bilingual publication continues to grow with each publication. Topics covered this year included melanoma, neurofibromatosis, and ichthyosis.
- Participated in several on-line campaigns to promote HPV Awareness Week, World CIU Day, World Vitiligo Day, access to Clinical Trials, National Psoriatic Arthritis Awareness Day and World Psoriasis Day.
- Produced new bilingual resources for patients on biologics and added 4 new skin diseases to the website (dermatitis herpetiformis, porphyria, dermatomyositis and SJS/TEN) to ensure that we included the diseases of all of our Affiliate Members.
- Organized two forums on chronic idiopathic urticaria – one in Edmonton, Alberta and one in Ottawa, Ontario. One unintended benefit of these events was the ability to attract two new funders for the CSPA.
- Developed a new video on atopic dermatitis. This short video is meant to help the newly diagnosed with reliable information about the disease.
- Hosted two live social media events: an organic Twitter live with Dr. Harvey Lui on vitiligo and, a Facebook live event on hidradenitis suppurativa.
- Managed two successful social media platforms including Facebook and Twitter and started to use LinkedIn more regularly. (Please see the appendix for the social media report for the CSPA.)
- Attended the Canadian Dermatology Association in Calgary and shared the new Affiliate Member infographics at the booth. We received many positive comments from members who stopped at the booth to comment on the importance of the work that we are doing.



## **Strategic Priority Area #3 – Lead as a respective voice, on key issues for skin patients and their families and Affiliate Members**

In 2018-19, highlights include:

- Completed several patient submissions for the Common Drug Review for new treatments for psoriasis and atopic dermatitis. This includes submissions for the Canadian Agency for Drugs and Technologies in Health (CADTH), the Institut national d'excellence en santé et en services sociaux (INESSS) and BC Pharmacare.
- Organized a Partner Forum to discuss how we can all work better together to achieve our common goals of better health outcomes for skin patients. We were excited to have representatives from 10 companies in the room, as well as to have a keynote address from Dr. Bob Thirsk, who spoke about the importance of partnerships and collaborations to the success of his mission in space.
- Finalized a position statement on the implementation of National Pharmacare that is now posted on the website: <http://www.canadianskin.ca/advocacy/pharmacare> and we were involved in national consultations with the Advisory Committee as they developed their recommendations.
- Continued to distribute the election position statement on the importance of access to care and affordable treatments for patients living in Quebec, New Brunswick and Prince Edward Island where provincial elections were held this fiscal year. Follow-up took place with senior officials from Ontario.
- Welcomed two new members to the Board of Directors: Ivan Eggers (British Columbia) and Jeff Losch (Alberta).
- Participated in advocacy activities as a member of the Best Medicines Coalition (BMC), the Better Pharmacare Coalition (BPC) and the Canadian Organization for Rare Disorders (CORD) including discussions on pharmacare and PMPRB.

## ***With Sincere Appreciation***

The Canadian Skin Patient Alliance is grateful to the many people who contribute to the organization in so many ways:

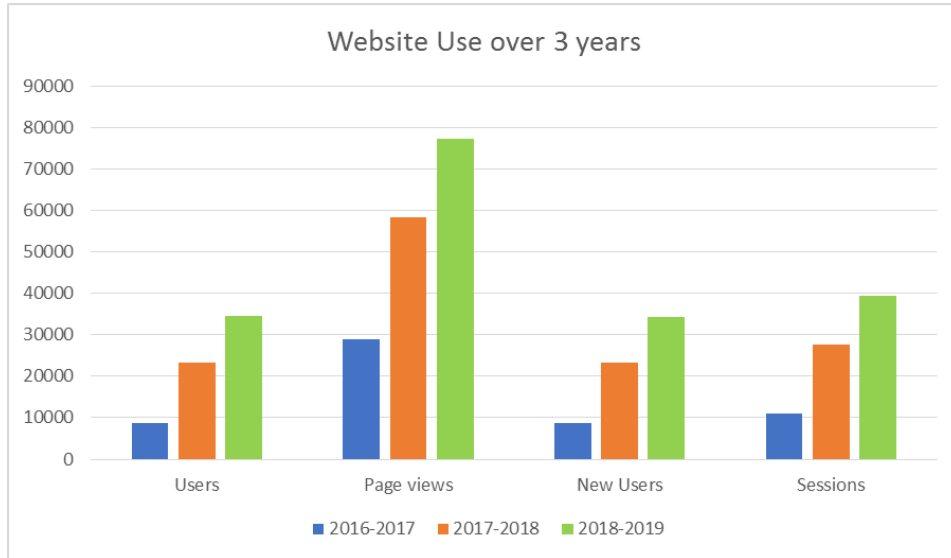
- The authors of the “Canadian Skin” magazine who contact us regularly with offers to contribute;
- The members of the Board of Directors and committees who ensure that we are on track in terms of governance and strategic direction of the organization;
- The dermatologists who review our many projects to ensure that they are medically accurate and help with special events;
- The staff and contractors who work tirelessly to make it all happen; and
- The patients who call us, share their stories, complete our surveys and continue to inspire us.

**Thank you to our 2018-19 sponsors for believing in the importance of our vision and mission:**

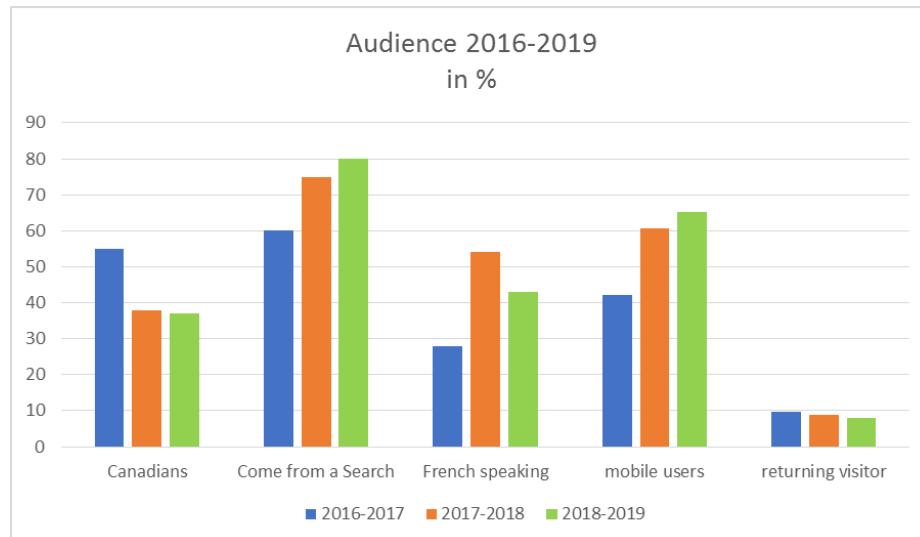


## Appendix A: Social Media Report

1. **Website:** We continued to see a growth in website traffic with an increase of almost 20,000 page hits. The audience still tends to be new first time users but that number is also increasing. This is likely due to the promotion of our website on social media, new content including a resource section for each skin condition, a link to types of treatments and 5 new skin conditions.

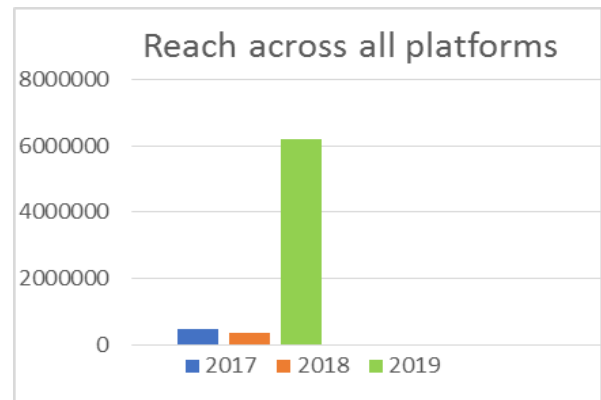
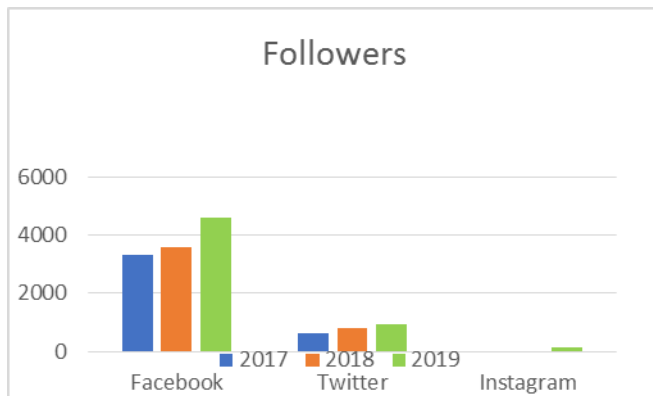


**Audience:** With an increased focus on translating content, it is not surprising that our audience continues to have a large number of French speakers (almost 40% Canadian, with the remainder coming from the US and France). We continue to see the benefit of being mobile responsive as the majority of our users visit our site on a mobile device. 80% of website traffic comes from an organic search, followed by someone using a bookmark or typing our website indirectly. Despite increased social media links to our website, this type of link only accounts for 1.5% of our traffic.



2. **Social Media:** Our social media platforms are still our greatest tool for raising awareness and reaching Canadians living with skin conditions, diseases and traumas. The Facebook page has grown by over 1,000 followers this past fiscal year and we continue to slowly grow our Twitter following. With the acquisition of Instagram by Facebook, we have organically reached an audience there and have already acquired 118 Followers. We will explore this platform along with the LinkedIn site which currently has 24 followers. With the Instagram acquisition our reach grew excessively in the second half of the year, with over 6 Million people reached. Any paid promotion on Facebook is now also run on Instagram, and with the nature of Instagram being a more “public” forum” and their broader use of hashtags, our reach grew exponentially.

Social Media posts focused on highlighting the work of our Affiliate Members, promoting events and activities, awareness campaigns such as Clinical Trials and National Eczema Awareness Month, and highlighting other Awareness days and events. We also hosted a live Facebook event on CIU, a Twitter Chat on Vitiligo and another Facebook live event for HS Awareness week.



**Audience:** Our Social media audience tends to be middle-aged English Speaking women. Over 90% of our social media audience is Canadian – this excludes the reach we gained with the Instagram acquisition.