



Canadian Skin Patient Alliance
Alliance canadienne des
patients en dermatologie

Canadian Skin Patient Alliance Annual Report

July 1, 2017- June 30, 2018

~for patients, by patients~

This proved to be an exceptional year for the Canadian Skin Patient Alliance as it was the first year implementing our new Strategic Plan. We made significant progress in meeting our strategic objectives, particularly in the areas of increasing our visibility, defining our community of reach and educating patients and their families.

The Board of Directors took the initiative to develop an election position statement, which was sent to the major party leaders prior to the June 2018 Ontario provincial election, to advocate for better access to affordable care and treatment for skin patients in that province. This was, of course, in addition to the many patient submissions completed this year for the Common Drug Review process run by the Canadian Agency for Drugs and Technologies in Health (CADTH.)

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.*

We are proud of the work we do for the many Canadians living with skin diseases, conditions and traumas and we are happy to be more connected to our 22 Affiliate Members. After a productive meeting with Affiliate Members, we have increased our communications with them, developed tools and resources to support their work and are proud to share their accomplishments and activities.

Thank you to the many sponsors who have worked with us throughout the year. We could not do this important work without your dedication and support for skin patients in Canada.

Munish Mohan
Chair
Canadian Skin Patient Alliance

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 2017-18, the Canadian Skin Patient Alliance:

- Clarified and implemented its role and that of its Affiliate Members. A successful face-to-face meeting was held to build on the current relationships with the Affiliate Members and to develop stronger relationships for a more effective and efficient skin patient voice in Canada. Since the meeting, ideas to work better together were implemented, monthly communiques were sent out, the role of the sub-committee was clarified and the Affiliate Grant program was strengthened.

*Congratulations to the winners of the Tanny Nadon Affiliate Members Grants in 2017-18:
Canadian Skin Cancer Foundation and the Scleroderma Society of Canada*



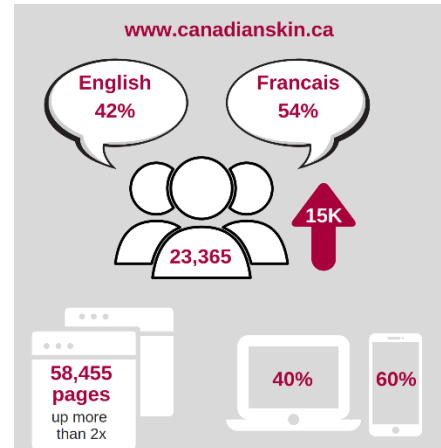
- Increased our presence and visibility by participating at a variety of new forums including the World Congress of Pediatric Dermatology, the Family Medicine Forum, the Symposium on Hidradenitis Suppurativa Advances and the Primed Toronto Conference, among others. The impact of this has been an increased number of health care professionals and other professionals requesting our tools and resources to share with their patients, an increased social media presence and new opportunities to advance our mission.
- Strengthened our relationships on an international level as a member of the International Association of Derm Patient Organizations, the Coalition of Skin Diseases and the International Alliance of Patient Organizations. Helen Crawford presented to the International Association of Derm Patient Organizations on two occasions to share her knowledge and expertise in the area of social media.
- Worked with the Skin Research Group and the Canadian Institutes of Health Research Institute of Musculoskeletal Health and Arthritis to encourage research in the area of skin diseases, conditions and traumas. We completed several letters of support for prominent skin researchers in Canada and we participated in an application for a large grant looking to create a research network for burn victims.
- Continued to work in partnership with the Canadian Association of Psoriasis Patients on projects and activities specifically focused on psoriasis and psoriatic arthritis.



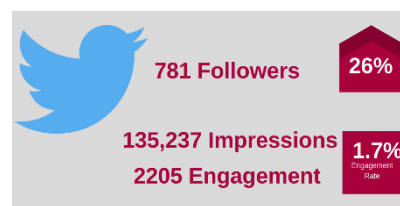
Strategic Priority Area #2 – Education: Empower patients and their families and Affiliate Members through knowledge, education and access to information.

In 2017-18, the Canadian Skin Patient Alliance:

- Built on our successful website by increasing the visits by 15,000 over the previous year. This includes an increase of 54% of French speaking visitors as we strive to translate all of our information. These same visitors viewed more than 58,000 pages, which is up more than 50%. And with our mobile friendly site, more than 60% viewed the website from their smartphone. We also added several new disease areas to the website including impetigo, scleroderma and atopic dermatitis.



- Continued to produce and distribute a high-quality magazine, “Canadian Skin” that reaches over 11,000 people three times per year. A new look and feel has a welcoming look and engages with patients in quizzes and contests. Topics covered this year include rosacea, actinic keratosis and Lyme disease.
- Increased our presence on both Facebook and Twitter. We also hosted two successful live tweet sessions on hidradenitis suppurativa, a new forum for this organization.



- Participated in several on-line campaigns to promote HPV Awareness Week, World CIU Day, Patient Solidarity Day and World Psoriasis Day.
- Completed a national report on the patient experience living with Atopic Dermatitis (AD). This significant document has been instrumental in developing additional tools and resources on this topic, increasing awareness of the challenges of living with AD and informing a patient submission for this disease.
- Initiated a new social media platform for the CSPA: <https://www.linkedin.com/company/canadianskin/>. Although this is a new asset for us, it is starting to show results with the health care community and other professionals.
- Won the Canadian Dermatology Association Public Education Award for our project on *Scarred for Life: A National Report of the Patient Experience living with Hidradenitis Suppurativa*.



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

In 2017-18, the Canadian Skin Patient Alliance:

- Completed patient submissions for the Common Drug Review for seven new treatments for psoriasis, atopic dermatitis and impetigo. 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.
- Revamped our Fundraising sub-committee to be the Advocacy and Fundraising sub-committee. New volunteers were recruited to help add a variety of perspectives to the topic.
- Participated in several consultations on high-level issues that could affect skin patients. These include consultations on the proposed changes to the Patented Medicine Prices Review Board and the implementation of Pharmacare.
- Developed an election position statement on the importance of access to care and affordable treatments for Ontario patients living with conditions that affect the skin, hair and nails. This document was sent to party leaders prior to the provincial election. Issues included long wait times to see a dermatologist, difficulty accessing treatments that are not covered on the provincial formulary and a prolonged process to access the correct medication for the severity of their disease. This process will be repeated prior to each upcoming provincial election and followed up with a request to meet with the new Minister of Health in each province.
- 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).
- Continued to work with a Danish company that distributes a smallpox vaccine for contra-indicated populations, such as skin patients living with compromised immune systems, in the event of a smallpox outbreak from bioterrorism.



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 on the Medical Advisory Board who vet 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 2017-18 sponsors for believing in our work:

