

Canadian Skin Patient Alliance

Annual Report 2016-17

This fiscal year marked the beginning of a special celebration for the Canadian Skin Patient Alliance – its 10th anniversary! This occasion was celebrated with several initiatives including the introduction of the CSPA's very first strategic plan, a special anniversary publication that included the history of the organization and a special anniversary logo.



Supporting Patients, Families and Affiliate Members

- The Affiliate Grant program was updated and renamed the Tanny Nadon Affiliate Grant. Tanny was an inaugural member of the CSPA Board of Directors and a founding member of the Alberta Society of Melanoma, which later became an Affiliate Member of the CSPA. Tanny passed away in 2016 and the CSPA Board agreed to name this grant in her honour.
- New focus has been initiated to identify to better support the needs of our Affiliate members. New resources have been added to oversee the growth and support of our Affiliate membership. Each Affiliate member has been contacted individually to discuss how we can work more collaboratively in a mutually supportive manner, as outlined in our strategic plan.
- The CSPA participated in a Patient Advisory Board meeting on Chronic Idiopathic Urticaria, in partnership with Novartis, to help identify the needs and raise awareness of this particular patient group. This was an important step in developing a plan to work with CIU patients across Canada.
- We partnered with Leo Pharma on a focus group project to identify issues related to topical adherence to medications. Issues identified included costs of medications, time to adhere properly and the impact on clothing/furniture.
- A student volunteered to do some research and draft a dermatology patient Bill of rights. The objective of this project is to empower patients to make the best choices for care and treatment and promote self-advocacy. This project is scheduled to be completed in the next fiscal year.

Congratulations to the winners of the Tanny Nadon Affiliate Grants in 2016-17:

Save Your Skin and the Canadian Burn Survivors Community



Education and Awareness

- The Canadian Skin magazine remains a popular publication. Three issues per year are published, in both official languages, and distributed to dermatology offices across Canada. The individual subscription list continues to grow after each publication as do the offers to write for the magazine – Dermatologists continue to request dozens of additional copies.
- The CSPA is proud to partner with the Canadian Dermatology Association to mark Melanoma Monday, the first Monday in May. We launched a patient survey developed by a melanoma survivor, dedicated the outside back cover of the Canadian Skin magazine to the day, developed social media posts and attended a reception on Parliament Hill.
- We marked Rare Disease Day (Feb. 28th) with social media posts, focused on two particular rare skin diseases: epidermolysis bullosa and ichthyosis.
- A significant project for the CSPA this year was the development of a national report of the patient experience living with Hidradenitis suppurativa. In partnership with AbbVie, we worked collaborative on this project with the HS Foundation as well as our affiliate, HS Aware. This collaboration ensured that a robust survey was created to collect the data for the report. Subsequently, the results of the survey were distributed in a variety of ways: a complete report, an infographic, patient summaries and a myth buster document. All of these were then loaded on an USB card to be distributed to health care professionals at a variety of conferences and opportunities for further distribution will continue to be identified.
- We added four new sections to the skin conditions and diseases section of the website: chronic idiopathic urticaria, hidradenitis suppurativa, scleroderma and psoriasis.
- The new and improved CSPA website was launched on October 28th. This was another significant project for the organization that ensures that our website is now up-to-date and mobile friendly to optimize our engagement with patients and their families.
- Another project this year focused on informing patients about what is involved in participating in a clinical trial and what they should consider if this is an option they are considering. This project also initiated a relationship with Probit Medical Research who is responsible for 90% of the recruitment for dermatological clinical trials in Canada.
- We continue to build our partnership with the Skin Research Group Consortium (McGill University). A student poster was accepted for their annual meeting and we participated in a panel discussion with other patient groups. We also continue to write letters of support for a variety of their grant applications.

Social Media Activities

- This year saw an increased focus in our social media activities in an effort to increase our reach and raise awareness of Canadians living with dermatological conditions. For the first time, we had a dedicated budget to be used for paid advertising, boosting of posts, and purchases of stock images and software to improve our Social media content.
- The social media committee met twice this year, once in person and once via teleconference. The committee reviewed the Social Media strategy and updated it to accurately reflect current practices.
- We were able to track statistics for the entire calendar year for the first time. We were able to grow our following significantly on both Facebook and Twitter. Our reach across all platforms was almost a half a million and our overall engagement rate was 4.27 (an average engagement rate on both Facebook and twitter is 0.5-1.0%). Social media posts focused on featuring our Affiliate Members, Awareness campaigns (ex. Alopecia, CIU, EB, Patient Solidarity Day, Rare Disease Day, National Volunteer Week, and HS awareness), promoting surveys for patient submissions, and highlighting other CSPA activities, including our 10th anniversary. Our most successful post was an educational post on Impetigo that had a reach of almost 20K and engagement of 900 which is an engagement rate of 4.7%.
- Our website is continuing to gain traffic and we increased by over 10,000 page views this year. Our appeal is to the first-time visitor with 77% of hits from first time visitors. We have been focusing on updating new content that will hopefully encourage the repeat visitor.
- We were successful in obtaining the administrator access to our Linked In page so that we can now focus on how to best use this page from an organization.
- The CSPA's Social Media Manager was accepted to the prestigious "HealtheVoices" workshop, sponsored by Janssen and took place in Chicago in April. She was selected from over 200 applications to spend three intensive days to build capacity in social media. Congratulations Helen!

Statistics for 2016-17

Overall Reach= 493,961
Facebook Followers = 3296 (increase of 28%)
Twitter Followers 619 (increased by 100)
89% of our followers are Canadian

Advocacy

- Several patient submissions (both for CADTH and for provincial formularies) were completed for a variety of skin conditions and diseases including hyperkeratotic actinic keratosis and psoriasis. We have also participated in the CADTH conference and webinars to keep up to date with advances in health technology assessments and the role of patient groups in this process. (Only three this fiscal year so I don't want to highlight the numbers!)
- In partnership with Janssen, we hosted two of three focus groups to better understand how dermatology patients feel about the introduction of biosimilars to the treatment landscape. The two meetings were held in Vancouver and Ottawa with a third one planned for Montreal in the upcoming fiscal year.
- The CSPA participated in several meetings organized by the Best Medicines Coalition, Health Canada, Innovative Medicines Canada etc. Topics ranged from the impact of biosimilars, pharmacare and issues related to private drug coverage.
- The CSPA also participated in several letter-writing campaigns to provincial decision-makers and the pCPA to advocate for new treatments for several diseases to be added to the provincial formularies. This is important work to meet our new vision "By 2022, Canadians living with dermatological conditions will have appropriate access to care and affordable treatments."
- The CSPA attended the HPV Awareness Week reception on Parliament Hill organized by the Federation of Medical Women of Canada. Peter Kent, conservative MP and throat cancer survivor (from the HPV virus) announced that HPV awareness week will take place from October 1-7 this year. Canada is gearing up to be the first country to eradicate the HPV virus with the vaccine.

Relationships with Other Organizations

The CSPA cannot do this important work alone! We are grateful to the following organizations for working with us, in a variety of ways, to achieve our mission:

- This year marked a positive evolution in the relationship with the Canadian Association of Psoriasis Patients (CAPP). Representatives of both the CSPA and CAPP came together to re-align the relationship from a subsidiary in nature to a true partnership. A funding agreement was introduced to outline human resource and financial responsibilities, communications strategies and potential areas of collaboration.
- We are grateful to the Canadian Dermatology Association for their continued financial support and collaborations on projects and events that take place throughout the year.



- We are proud to be members of:
 - ✓ Best Medicines Coalition
 - ✓ Canadian Organization for Rare Disorders
 - ✓ Canadian Society of Association Executives
 - ✓ International Alliance of Dermatology Patient Organizations
 - ✓ International Alliance of Patient Organizations
 - ✓ Volunteer Canada

Thank you for your support!

Volunteers are the backbone of our organization. The CSPA would like to thank the many people who contribute to the organization including the many authors of the Canadian Skin magazine, the members of the Board, the dermatologists who make up the Medical Advisory Board and the patients who keep us grounded to our mission and vision.

We are grateful for the funding and support from our pharmaceutical partners. We could not do any of this work without your valuable support. We are particularly grateful this year to our 10 “10th anniversary sponsors.”

Sponsors:

AbbVie
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 Roche
 WCD Legacy Fund

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