



Canadian Skin Patient Alliance

Annual Report
2015-16

It has been truly an exceptional year for the CSPA! It was a year full of opportunities and changes as well as new, unique projects in the following areas:

Education and Social Media

- The **Canadian Skin Magazine** continues to be the cornerstone of the organization's work. Published three times per year in both official languages, this year we increased the distribution of the magazine to general practitioners and initiated a pilot to circulate the magazine to emergency rooms/health clinics across Canada. By the end of this fiscal year, the number of magazines distributed reached 25,625 per edition. We would like to thank Dr. Searles and Dr. Bourcier for their continued support as they volunteer their time as medical advisors to review all of the content of the magazines.
- For the first time, the CSPA developed and implemented a **Social Media Strategy** to help inform and streamline our social media activities in a proactive way. The goals are to increase our reach and engagement with skin patients on all platforms currently being used and to provide consistent content and messaging throughout the year. The reach is being monitored and quarterly reports highlight what has worked successfully.
- The CSPA completed a **Melanoma Environmental Scan** project in partnership with the Melanoma Network of Canada and Save Your Skin Foundation. The purpose of this project was to identify what currently exists for melanoma patients in Canada and what is needed moving forward. The report concluded that there are many resources available but a portal is required to ensure that the information is accessible to patients. The results were discussed at a Roundtable meeting hosted by Save Your Skin Foundation at the Melanoma National Conference in February 2016 and they continue to use the results of the project to inform their work.
- A **Forum** on Chronic Idiopathic Urticaria (CIU) was held in Dartmouth Nova Scotia in April 2016 in partnership with the Atlantic Canada CIU Group. Dr. Gena Lacuesta delivered an excellent presentation from an allergist's perspective. All of the evaluations were positive and the participants are hoping for more forums such as this one. Many of them stated that this was the first time they had met someone else with the disease so they left feeling supported and less alone!

Social Media Stats

Facebook – 259,266 total engagement

Twitter – 517 followers (almost 100 new this fiscal year!)

Website – 18,876 page views from 5,559 unique users.

- The CSPA was also invited to present at a meeting of patients living with hidradenitis suppurativa (HS) in October 2015. The purpose of this meeting was to gain insight into HS **patient journeys** and experiences living with HS; to identify specific needs patients with HS require in terms of services, resources and educational tools; and to review tools and platforms for creating disease awareness. Again, many of the patients stated that they had never met anyone else living with HS so it was comforting to them to not feel so alone in their journey.

Advocacy

- SEBs (**subsequent entry biologics**) continued to be a priority for us this year. We have informed patients about SEBs and worked with many groups to better understand the evolving issues as new SEBs continue to be approved in Canada. For dermatology patients, only one SEB is available to them however many more are in the process of being introduced to market. We are monitoring for adverse events as there is a concern that stable patients on biologics may be switched for non-medical reasons.
- We reviewed the organization's **position statement** on SEBs to ensure that it is current and relevant for dermatology patients. We also provided input to Health Canada's Guidance Document on Information and Submission Requirements for Subsequent Entry Biologics, through the Best Medicines Coalition.
- The CSPA's role continues to mature as we develop **patient submissions** for the common drug review as well as provincial health technology assessments (BC, Quebec and Ontario.) One was particularly significant as we developed a joint submission with the Arthritis Society of Canada. It was focused on psoriatic arthritis, and by working together, the submission was very robust and reflected the disease from the perspectives of both the skin and joints.
- We were invited to provide input into **clinical practice guidelines** for acne, rosacea and pressure ulcers. There are often many treatment options available to physicians for all skin conditions so the clinical practice guidelines provide evidence-based information to support the decision-making process in patient care.
- The CSPA **endorsed several campaigns** this fiscal year including a letter to the Ministry of Health and Long Term Care in Ontario sent by the CanCertainty campaign. The organization sees an opportunity to support efficiencies and urges the Ontario government to go further with cancer drugs towards a complete overhaul, including oral medications for melanoma. We also endorsed a letter written to the Biologics and Genetic Therapies Directorate at Health Canada by the Alliance for Safe Biologic Medicines Health Canada is about to start a consultation to review its guidelines for the approval of biosimilar medicines.

Patient Submissions

2013-14 = 4

2014-15 = 6

2015-16 = 11

Supporting the Affiliate Members

- The CSPA introduced a new category of Affiliate Members called “**Global Collaborators**” to reflect the fact that these organizations are different than Affiliate members, with their own rights and responsibilities. The advantages to this addition are to offer Canadian skin patients a link to support, not yet available in Canada; to open the door to the creation of a Canadian chapter in Canada and more support for Canadian skin patients; and to provide learning/networking opportunities, from these outside organisations, to the CSPA and its Affiliate Members.
- The CSPA recognizes the importance of regular **communications** to the Affiliate Members and started to develop short, timely and accessible newsletters. Two were sent out this fiscal year. We received positive feedback about the value of this type of communications tool.
- We also worked diligently with a new organization that was just starting up and **HS Aware** ultimately became the 22nd Affiliate Member of the CSPA in 2015-16.
- As an **umbrella organization** for the Affiliate Members, the CSPA has been increasing their presence on our website so that they are easily accessible to patients. And we continue to feature one Affiliate Member in each issue of the Canadian Skin magazine to ensure that patients are aware of the disease-specific organizations available to them for support.

Congratulations to the two winners of the **Affiliate grants** in 2015-16:
Canadian Skin Cancer Foundation and the Scleroderma Association of BC.



Other related priorities and work:

- The subsidiary organization of the CSPA is the **Canadian Association of Psoriasis Patients (CAPP)** and it continues to thrive. This fiscal year saw a significant amount of work in research partnerships, the development of awareness tools such as a video on pediatric psoriasis, co-hosting information sessions across Canada and supporting patient advisory functions.

- The CSPA collaborated with CAPP to hold an **inaugural meeting of the funding partners** in November 2015. The purpose of this meeting was to bring all of the funders in one room to discuss current and upcoming priorities for both the CSPA and CAPP. With more than 12 partners in the room, it was an excellent opportunity to share the plans and priorities for both organizations as well as to discuss synergies and potential collaborations for the future. A patient kicked off the meeting with an inspiring story of how a small project funded by one of the partners had a significant impact on her life. The feedback was extremely positive and helped partners to understand some of our realities and challenges.
- The Executive Committee and Board of Directors spent a significant amount of time reviewing and approving **financial, human resources and Board policies**. Although the focus of this work is administrative, it was essential work to build the foundation of a strong organization moving forward.
- We are grateful to the members of the **Medical Advisory Board** who support the work of the CSPA by ensuring that information provided to patients is medically sound. The members for 2015-16 are: Dr. Gordon Searles(Chair), Dr. Charles Lynde, Dr. Kirk Barber, Dr. Danielle Marcoux, Dr. Marc Bourcier, Dr. Yves Poulin, Dr. Anatoli Freiman, Dr. Cheryl Rosen, Dr. Nicole Hawkins and Dr. Jack Toole.
- Congratulations to Dr. Jeff Donovan who was chosen as “**Dermatologist of the Year**” in June 2015 for his work and commitment with one of the Affiliate Members, the Canadian Alopecia and Areata Foundation (CANAAF.)

We are proud to be **members** of:

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| ✓ Best Medicines Coalition | ✓ International Alliance of Dermatology Patient Organizations |
| ✓ Canadian Organization for Rare Disorders | ✓ International Alliance of Patient Organizations and |
| ✓ Canadian Society of Association Executives | ✓ Volunteer Canada |



With sincere appreciation

The CSPA could not be successful without the **commitment and support** of so many people, including the members of the Board, staff, volunteers, contractors and partners. Thank you for working towards our common goal of an improved quality of life for Canadians living with dermatological conditions.



We are grateful for the **support and funding** from our pharmaceutical industry partners. We could not carry out this important work without you! This also includes in-kind support received to attend the Advocacy Boot Camp and the IAPO Global Patients Congress, for translation services and the donation of goods. Partners for 2015-16 were: AbbVie, Celgene, Galderma, Janssen, Leo, Merck and Novartis.

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of dermatology

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We are also grateful to the Canadian Dermatology Association for their continued financial support and **collaborations** on projects and events that take place throughout the year.

