



Canadian Association of Psoriasis Patients
Association canadienne des patients atteints de psoriasis

Canadian Association of Psoriasis Patients Annual Report

2015-16

A significant donation set the tone for the year and set up the organization for success! CAPP was thrilled to be a recipient of a generous unrestricted donation from Pfizer Canada through its Psoriasis PACT (Partnership to Advance Care and Treatment.) This multidisciplinary group of health professionals from around the world are dedicated to elevating the standard of care for patients with moderate to severe plaque psoriasis. Canada is represented by Dr. Wayne Gulliver on the faculty of PACT.

The impact of this unrestricted donation is that CAPP had the opportunity to look beyond the project level and focus on the mission/vision of the organization. It gave us a sense of stability and the ability to be creative in our work.

World Psoriasis Day 2015 (Increase Education/Advocacy)

To mark World Psoriasis Day 2015, CAPP announced an innovative partnership to fund up to 10 studentships in the area of psoriatic disease research for the summer of 2016. In the end, 9 studentships were offered (with 6 being accepted) on topics such as “Do psoriasis patients who participate in clinical research differ from those who do not?” and “Safety and efficacy of Apremilast in the treatment of moderate to severe psoriasis.” (Please see the “Meet the Winners” for a complete list of projects.)



29 October - World Psoriasis Day

Pediatric Psoriasis Graphic Animation Video (Increase Education)

In an effort to raise awareness and reduce stigma for younger psoriasis patients, CAPP produced a short video, in both French and English, which was officially launched in June at the Canadian Dermatology Association Conference. This graphic animation video is targeted to help kids understand what it is like to live with psoriasis. Complete with a bilingual brochure, the video is being disseminated widely via social media channels and personal connections.

www.canadianpsoriasis.ca/kids

www.communaute-psoriasis.ca/enfants

136-2446 Bank St, Suite 383
Ottawa, ON K1V 1A8
Ph: (613) 440-4260
Toll: (877) 505-2772
Fax: (877) 294-1525

www.canadianpsoriasis.ca

Patient Advisory Board (Increase Advocacy)

CAPP was invited to develop a ground-breaking approach to inform the design of a Phase 3 clinical study on a new treatment for psoriasis. We put together a Patient Advisory Board that discussed the study in a focus group style to provide feedback on the design, consent form, marketing tools etc. This was a first for psoriasis patients in Canada!

Information Sessions, Psoriasis Clinics and Support Groups (Increase Patient/Family Support)

CAPP had the opportunity to host five Psoriasis information sessions across Canada (Montreal, Ottawa, Brandon, Winnipeg and Halifax.) Some of these sessions led to two psoriasis-specific clinics offered in Brandon and Winnipeg. The purpose of these clinics was to help patients who have been unable to secure a spot with a dermatologist in their area. Further, the information sessions also led to the start of a Psoriasis Support Group in Winnipeg. CAPP works closely with a dermatology nurse, who leads the session as a volunteer, to take care of the logistics and promotion of the sessions.

Subsequent Entry Biologics (SEBs) (Increase Advocacy/Education)

This continues to be a prevalent issue in the area of psoriasis. This year, CAPP informed patients about the issues around SEBs, contributed to several submissions about naming of SEBs, attended several meetings and webinars to get the most up-to-date information and we reviewed our position statement to ensure that it continued to reflect the issues as they evolve.

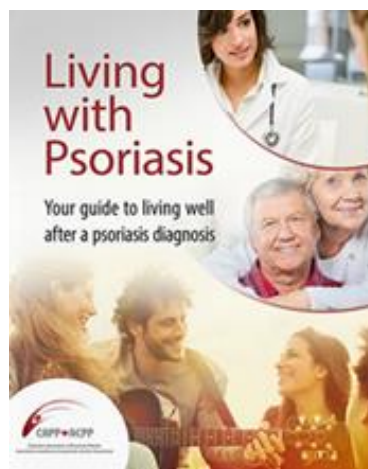
Communicating with Patients (Increase Education)

This year marked the introduction of an e-newsletter for patients as well as updates to the website, including a flipbook to consolidate much of the information about the disease, an updated slider and the translation of the materials on the site. An increased emphasis on social media posts and campaigns have helped us to secure a solid community of reach which is expected to continue to grow:

Facebook Followers = 1520 (increase of 224)

Twitter Followers = 545

Newsletter subscriptions = 93



Working with the Canadian Skin Patient Alliance (CSPA): Inaugural meeting of the Funding Partners (Organizational Processes)

CAPP had the opportunity to work closely with the CSPA on the first ever partner engagement meeting. 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 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.

Working with the Canadian Dermatology Association (CDA): Camp Liberté West (Organizational Processes)

CAPP had the opportunity to be represented at the inaugural Camp Liberté West by a Board member who spent time with the campers, sharing his psoriasis journey with them. It was a positive experience for all involved!

International Federation of Psoriasis Associations (IFPA) (Increase Advocacy/Education)

CAPP is proud to be the Canadian Representative of the International Federation of Psoriasis Associations (IFPA). This fiscal year, a staff and Board member attended the 4th World Psoriasis and Psoriatic Arthritis Conference in Stockholm in July 2015. Also, staff attended the General Assembly, member meeting and WPD 2016 Training meeting in Lisbon in June 2016. On October 29 each year, World Psoriasis Day is presented by IFPA, its member associations and support groups perform activities all over the world to raise awareness about psoriasis and give people with psoriasis the attention and consideration they deserve.



WHO Global Report on Psoriasis (Increase Advocacy)

This year marked the release of the **WHO Global Report on Psoriasis**. This is the first published report since member states recognized psoriasis as a serious non-communicable disease (NCD) in the World Health Assembly resolution WHA67.9. The resolution, passed in 2014, highlighted that many people in the world suffer needlessly from psoriasis due to incorrect or delayed diagnosis, inadequate treatment options and insufficient access to care, and because of social stigmatization. With Canadian Data noticeably absent in this Report, the recommendations for action are important to help CAPP appeal to the Canadian government to honour their commitment to the resolution they signed.

With Sincere Appreciation

CAPP is grateful to be working with a dedicated Board of Directors and staff. Thank you for all that you do for psoriasis patients in Canada!

We could not accomplish this work without the support and funding from our pharmaceutical industry partners. The funders for 2015-16 were: AbbVie, Celgene, Dermtek Pharma, Janssen, Leo, Merck Sorono, Pfizer and Novartis. We also thank CIHR-IMHA for their support of our studentship program.

