

By patients, for patients: commemorating 10 years of the Canadian Skin Patient Alliance

Executive summary

Since its creation in 2007, the Canadian Skin Patient Alliance (CSPA) has worked to promote skin health and improve the quality of life of Canadians living with dermatological conditions. Throughout its successful history, the CSPA has been an organization run *by* patients, *for* patients, and as it moves into its second decade, it is well-positioned to meet the challenges and opportunities of the future.

Before the CSPA was created, Canadian skin patients were not represented by a single coalition. This made it exceedingly difficult for them to express their concerns, educate the public or advocate for change. The CSPA was intended to address that need, and with assistance from partners such as the Canadian Dermatology Industry Association (CDIA) and the Canadian Dermatology Association (CDA), it has worked to establish itself as an organization for all skin patients across Canada.

The early focus of the CSPA was much the same as it is now: information, education and advocacy. Through its website and projects such as its award-winning *Canadian Skin* magazine, the CSPA has worked to ensure that skin patients, their families and caregivers have access to the latest information on skin, nail and hair health. For years, however, the CSPA heard that patients were frustrated by a number of issues, including limited access to drugs, dermatologists and treatment options. It was the ground-breaking *Skin Deep: A Report Card on Access to Dermatologic Treatments and Care in Canada* (2012) that allowed the CSPA to advocate more effectively for skin patients and increase its credibility in the eyes of sponsors, government and physicians. The report provided a snapshot of dermatology in Canada in a meaningful, quantifiable way, establishing a platform for the CSPA to use in its work of ensuring that the specific issues facing skin patients in each province and territory received the attention that they deserved.

The CSPA has also worked hard to bring together the not-for-profit patient groups and organizations that deal with specific skin conditions and diseases. Together with its Affiliate Members, it has helped give the skin patient community a stronger, more unified voice, particularly through events such as the 2012 Skin Matters Conference and the 2015 International Dermatology Patient Organization Conference (IDPOC).

Moving forward, the CSPA remains committed to representing, educating and supporting Canadians who are living with skin diseases, conditions and traumas. Its accomplishments through its first 10 years have established a strong foundation for its continued success, and with the publication of its first-ever strategic plan in 2017, it will be prepared for another transformative decade.

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As the Canadian Skin Patient Alliance (CSPA) marks its 10th anniversary, it can look back on its accomplishments with pride. Throughout its work to promote skin health and improve the quality of life of Canadians living with dermatological conditions, the CSPA has remained an organization run *by* patients, *for* patients. It has advocated on behalf of all skin patients, provided education on a variety of issues affecting them, and supported Affiliate Members that deal with specific skin diseases, conditions and traumas. It has hosted two conferences, published groundbreaking publications and won several awards from the Canadian Dermatology Association (CDA) for its work—and that is only the beginning. After a decade of success, the CSPA is well-positioned to meet the challenges and opportunities of the next 10 years.

Establishing the CSPA

Given the far-reaching success of the CSPA, it might be difficult to imagine how different the skin disease landscape was in Canada over a decade ago, particularly for patients. While there were organizations devoted to individual skin diseases at that time, no one represented Canadian skin patients as a whole. As a result, they lacked a unified voice, which made it difficult for them to express their concerns, educate the public or advocate for change.

All of that began to change in December 2004, when the Canadian Institutes of Health Research (CIHR) sponsored a workshop on skin disease research in Canada. A collection of representatives from the Canadian dermatology community—including patients, clinicians, researchers, and representatives from industry and governmental organizations—gathered to discuss the creation of a national plan for skin disease research in Canada. Part of the agenda included a session on “establishing a skin disease patient coalition.”¹ By the end of the workshop, it was agreed that a coalition for skin patients should be established in order to “give patients a single voice and result in better education about skin disease and research for all stakeholders.”² The guiding principle of this new organization would be that “those affected by a decision should be involved in making that decision”—an approach that the CSPA still follows today.³

Over the following months, the basis of the new organization was established. Denis Morrice, former CEO of the Arthritis Society of Canada, was asked by the Canadian Dermatology Industry Association (CDIA) and the Canadian Dermatology Association (CDA) to lead the process. Working with a small group of contractors, Mr. Morrice began building relationships within the Canadian dermatology community, including industry partners. Funding was secured for the new organization, including a generous three-year commitment from the CDA, and a council of patient volunteers was recruited.

In February 2007, the newly formed and named Canadian Skin Patient Alliance held its inaugural meeting. With support from the CIHR Institute of Musculoskeletal Health and Arthritis (CIHR-IMHA), it launched its first website and began to pursue its mission: “to meet the needs of people with skin disease as those needs are identified by people with skin disease.”⁴

Finding focus, building a voice

The early focus of the CSPA was much the same as it is now: information, education and advocacy. In particular, the organization planned to advocate on issues such as patient access to therapies and healthcare providers who had dermatology-specific knowledge. The first CSPA website was the key to these early efforts. It allowed the organization to reach more people in a more efficient way, and it tapped into the growing trend of people turning to online sources for health information. Dermatologist members of the CDA reviewed the information presented on the website to ensure that it was both accurate and of the highest quality.

With the CSPA officially founded and established, Denis Morrice resigned as Executive Director in late 2007 and the organization elected its very first executive committee: Ken Downton (as the Chair), Allan Stordy, Charles Jago and Christine Janus (who became the organization's interim Executive Director). In keeping with the initial goals of the organization that were established during the CIHR workshop three years earlier, the mission of the CSPA was expanded to emphasize educating patients and the public by providing them with impartial information about skin, hair and nail conditions, diseases or trauma. To help with this, the website was revamped to incorporate additional medically reviewed material, making it the go-to resource for skin patients and other stakeholders in Canada.

Over the next two years, the CSPA continued to grow, strengthening its relationship with stakeholders and industry, and expanding the quality and reach of its services. In 2009, psoriasis information sessions also became a central part of the CSPA's activities, and a number of them were offered across Canada. In fact, it was the CSPA's attempts to reach more and more Canadian skin patients with high-quality educational resources that led to work in the second half of 2009 on the project that would be a cornerstone of its activities for years: the launch of its magazine, *Canadian Skin*.

Engaging skin patients

Created with the support of a grant from its founding sponsor, Abbott Canada, *Canadian Skin* was created to be a quarterly magazine that would provide skin patients with information on a range of topics related to skin conditions and diseases. In the first issue alone, there were articles on eczema, psoriasis, tattoos and workplace stress. Issues were distributed through dermatology and family doctor offices, the CSPA website and by a complimentary subscription, just as they are today.

Since its first issue in the spring of 2010, *Canadian Skin* has enjoyed great popularity, distributing an astounding 168,800 issues in its first year. It has released a total of 23 issues in both English and French, and a wide array of volunteer authors have contributed to its content: caregivers, dermatologists, general practitioners, medical students, nurses, skin patients and more. That diversity and scope over the years has helped the magazine maintain a dedicated and engaged readership.

CDA Public Education Awards received by the CSPA

2010: The CSPA website

2011: *Canadian Skin* magazine

2013: *Skin Deep: A Report Card on Access to Dermatologic Treatments and Care in Canada*

While the CSPA was enjoying great success with *Canadian Skin*, it continued its educational work around psoriasis. A new website provided information and tools for patients with psoriasis, including webinars (online videos for download or streaming) that featured the stories of actual psoriasis patients. Meanwhile, the newly launched Psoriasis Community Canada initiative—cosponsored by LEO Pharma and Janssen Pharmaceuticals—continued to provide the information sessions that had begun the previous year, offering 16 across Canada in 2010–2011. The sessions, which were conducted by leading dermatologists, highlighted the resources available to psoriasis patients and their families.

The CSPA also launched two special awards in 2011: the CSPA Pro-Patient Designation and the CSPA Dermatologist of the Year award. The Pro-Patient Designation was presented to dermatologists who had supported the CSPA, its staff or Affiliate Members through volunteer work, advocacy or education activities, and the Dermatologist of the Year award recognized a dermatologist who had made a significant contribution to the CSPA's efforts (or one of its Affiliate Members) in terms of time and support. Appropriately, the winner of the first Dermatologist of the Year award was Dr. Harvey Lui, who had been at the CIHR workshop in 2004 that led to the creation of the CSPA, and who had been a strong supporter of the organization during his time as President of the CDA. Dr. Lui continues to be a strong and valued supporter of the CSPA to this day.

While the CSPA's success during this time ensured that it was solidifying its place in the Canadian dermatology community, meaningful engagement with government bodies was proving elusive. To take that next step, what the CSPA needed was a prominent flagship campaign, something that would elevate the issues facing skin patients in the national consciousness. That breakthrough would come in 2012 with the CSPA's biggest project to date: *Skin Deep: A Report Card on Access to Dermatologic Treatments and Care in Canada*.

Skin Deep and national exposure

From its years spent speaking with patients and other members of the Canadian dermatology community, the CSPA knew that patients were frustrated by a number of issues, including limited access to drugs, dermatologists and treatment options. What the CSPA lacked, however, was *data*—the hard information to support those patient stories. In fact, no one had that information: it had never been gathered, and without it, it was nearly impossible for the CSPA to provide a snapshot of dermatology in Canada in a meaningful, quantifiable way.

Skin Deep attempted to change that. The product of extensive research by the CSPA and an independent researcher, the study was an objective look at how publicly funded health systems were performing in relation to the expectations of patients. As Allan Stordy, CSPA President at the time, explains in the opening of *Skin Deep*:

This Report Card was born out of a need for us—the patients—to understand where the gaps are in access to care across the country. We have a sense that there are problems, but this report sets out a platform from which we, the CSPA, can advocate for patients where it is needed most. This is the first time Canadian skin patients have organized as a collective group to try to effect change.⁵

The result, the CSPA hoped, was “a tool [for] the many ... who have a stake in the care of Canadian skin patients ... to help make their conversations with governments more focused and productive.”

Overall, *Skin Deep* looked at four measures:

- access to medications
- access to medical procedures
- access to dermatologist care
- improvements to access.

The report presented the results across Canada, comparing the provinces and territories on the respective indicators. The goal, however, was not to be adversarial; rather, it was to collaborate with everyone involved. In fact, both doctors and the provinces and territories themselves were asked to validate the data to ensure it was correct before *Skin Deep* was published.

The release of *Skin Deep* was a significant event. Many of the provinces and territories expressed their approval, thanking the CSPA for being included in the process. The CDA’s Dr. Gordon Searles, President of the Association at the time and the current Chair of the CSPA Medical Advisory Board, noted that “we have been calling on governments to address the shrinking dermatology workforce for several years now, and I’m glad to see the CSPA take a stand on these issues on behalf of Canadians, because we will all ultimately suffer if this is not addressed.”⁶

Just as importantly, *Skin Deep* gave the CSPA the data it needed to advocate more effectively for skin patients, and it increased its credibility in the eyes of sponsors, government and physicians. This, in turn, helped the organization pursue its work of ensuring that the issues facing skin patients received the attention that they deserved.

An umbrella organization for all skin diseases

While the creation and launch of *Skin Deep* was a watershed moment for the CSPA in 2012, it was not its only notable achievement that year. Two other events occurred that had a significant effect on the CSPA: the creation of the Canadian Association of Psoriasis Patients (CAPP) and the 2012 skin patient conference, Skin Matters.

Even before its creation in 2007, the CSPA had always been envisioned as a “coalition” of skin patients, an umbrella organization that welcomed all organizations dealing with skin disease without focusing too heavily on any one condition. For the first five years of its existence, however, psoriasis had been prominent in the CSPA’s education and advocacy activities, and it became clear that a separate psoriasis patient organization was needed. The benefits were substantial: a separate organization for psoriasis patients would allow the CSPA to continue being an umbrella organization as had been intended, and it also would clarify advocacy and messaging related to skin diseases, allowing the CSPA to speak for skin patients as a whole while the new organization represented psoriasis patients in particular. The majority of psoriasis patients were in favour of a separate psoriasis organization, and in 2012, CAPP was created as a subsidiary of the CSPA.

Also in 2012, the CSPA hosted Skin Matters, Canada’s first-ever skin patient conference. Held in Toronto, Skin Matters was attended by more than 200 patients and 24 exhibitors. It featured 58

sessions on topics ranging from alternative medicine to sexuality, as well as breakout sessions that gave participants a chance to discuss specific diseases. The entire three-day event was a success and greatly enjoyed by attendees.

Consolidating gains and building on achievements

Throughout 2013 and 2014, the CSPA continued to build on its achievements. Thanks to the increased credibility and visibility provided by the *Skin Deep* report card, the CSPA secured meetings with representatives from the federal government and several provinces to discuss key issues around skin cancer, including issues of early detection, access to care, and treatment and prevention. It also joined other organizations in successfully advocating for enhanced tanning bed legislation in multiple provinces, and it participated in collaborations such as the Best Medicines Coalition, the Coalition of Skin Diseases and the Canadian Delegation to the World Health Organization.

Alongside this high-level advocacy, the CSPA continued to use the media in its other campaigns. Coverage of skin disease-related topics appeared in mainstream print media, and CSPA board members and staff gave interviews on radio and TV. Like many other organizations, the CSPA embraced social media at this time, with Facebook featuring eight campaigns on different issues, such as access to medication. Meanwhile, the website remained an important source of educational material for skin patients and their families, and *Canadian Skin*, which was now being published three times a year and sponsored by AbbVie, was still in-demand among dermatologists and patients.

The work of the CSPA as an umbrella organization grew during this time, with the number of Affiliate Members expanding to 21 by the end of 2014. In order to promote advocacy efforts and ensure mutual sustainability, the CSPA helped those organizations—particularly the smaller or newer ones—pursue their activities and expand their reach.

The International Dermatology Patient Organization Conference

In 2010, Dr. Harvey Lui of the CDA asked if the CSPA would be interested in adding a patient component to the CDA's bid to host the 2015 World Congress of Dermatology (WCD). The CSPA Board of Directors agreed, and the CDA bid was eventually successful. Over time, that patient component of the WCD 2015 grew to become a conference in its own right, a gathering for the world skin patient community that would be held within the larger WCD event. When it was finally held in Vancouver in June 2015, that gathering—the International Dermatology Patient Organization Conference (IDPOC)—was the first of its kind.

Featuring representatives from 25 countries, IDPOC 2015 offered “three days of skill-building workshops ... dedicated to helping patient organization leaders reach and serve our patients better.”⁷ The goal was to bring patient leaders together with their peers, professionals in the field, and industry in order for them to collaborate, network, and share ideas and best practices. The hope was that it would not only form an international alliance of dermatology organizations, but that patients would increasingly be seen as important allies in the dermatology community.

The success of IDPOC 2015 solidified the CSPA's reputation as a leader among world dermatology patient organizations, showcasing the organization's expertise and experience, and giving it an important opportunity to network with other organizations.

The present and future

After the success of the past decade, where should the CSPA go next? In 2017, the CSPA will publish its first-ever strategic plan to try to answer this very important question.

Several ongoing CSPA activities, however, will remain central to the organization. Since 2014, the CSPA has been playing a significant role in the Common Drug Review (CDR), which "conducts thorough and objective evaluations of the clinical, economic, and patient evidence on drugs ... to provide reimbursement recommendations and advice to Canada's federal, provincial, and territorial public drug plans, with the exception of Quebec."⁸ By collecting and submitting balanced and impartial accounts of patient experiences with new treatments, the CSPA is able to provide valuable information to the health technology assessment phase of approval that reflects the patient perspective of the new treatment option.

Similarly, the CSPA has been advocating on behalf of patients with regard to a new type of treatment called subsequent entry biologics (SEBs), which is now available to dermatology patients. The organization is collaborating with both government and industry to ensure that the needs of patients are embedded in decisions being made about SEBs. It also works to educate patients when it comes to SEBs and their use, and it will continue to do so as these treatment options—and the policy around them—develop.

Despite its growth and success over the past 10 years, the CSPA remains an organization *for* patients, *by* patients. As we look ahead to the next 10 years, one thing is certain: the CSPA's primary goal will continue to be to represent, educate and support Canadians living with skin diseases, conditions and traumas.

¹ Canadian Institutes of Health Research (CIHR). *Excerpts from the CIHR Institute of Musculoskeletal Health and Arthritis Skin Priority Workshop Report*. Ottawa: CIHR; 2004, p. 1.

² *Excerpts*, p. 19.

³ *Excerpts*, p. 20.

⁴ Canadian Skin Patient Alliance (CSPA). *Canadian Skin Patient Alliance Business Plan: April 1 2007 to March 31 2008* (2007), slide 6 (internal Power Point document).

⁵ *Skin Deep: A Report Card on Access to Dermatologic Treatments and Care in Canada* (Ottawa: CSPA, 2012), p. i (available from <http://www.canadianskin.ca/en/advocacy>).

⁶ The Canadian Skin Patient Alliance [website], *Reports and Papers* (available from <http://www.canadianskin.ca/index.php/en/29-english/publications-media/reports-and-papers>).

⁷ IDPOC 2015 [website] (available from <http://globalskin.org/idpoc/>).

⁸ Canadian Agency for Drugs and Technologies in Health [website], *CADTH Common Drug Review (CDR)* (available from <https://www.cadth.ca/about-cadth/what-we-do/products-services/cdr>).