



Canadian Skin Patient Alliance
Alliance canadienne des
patients en dermatologie

Canadian Skin Patient Alliance

Annual Report

2019-20

July 1, 2019 – June 30, 2020

Letter from the Chair & Executive Director

Mission

To promote skin health and improve the quality of life of Canadians living with skin conditions, diseases and traumas.

Vision

By 2022, Canadians living with conditions that affect the skin, hair and nails will have appropriate access to care and affordable treatments.

The Canadian Skin Patient Alliance (CSPA) is committed to improving the lives of people impacted by skin, hair and nail disorders. Through awareness, education, advocacy and supporting research, the CSPA continues to support people living with skin disorders.

This year, the COVID-19 pandemic created additional needs and brought to light existing gaps in health systems across Canada. The CSPA team responded promptly by providing answers to pressing questions from skin patients, including those using medications that made their immune systems more vulnerable, or who had challenges accessing their medication because of drug shortages.

We continued to provide new information on specific skin disorders on our website. This year, we also explored the impacts of living with hidradenitis suppurativa in an update to our initial baseline report about the disease, recognized several awareness days through social media campaigns, connected people living with ichthyosis, and worked with colleagues to improve timely cancer diagnoses and better support those living with rare dermatological diseases.

The CSPA is proud to amplify the voices of patients, through sharing patient perspectives with federal and provincial policy makers who are changing how patients can access medications, overseeing changes to drug pricing, and recommending whether drug plans should cover new medications through health technology assessments.

Looking to the future, the CSPA is proud to be actively supporting the inclusion of patients in dermatology research in Canada through its participation in the Skin Investigation Network of Canada (SkIN Canada). This network will support researchers and trainees to identify research of importance to patients and that improves health outcomes and patients' quality of life.

Munish Mohan
Chair

Rachael Manion
Executive Director

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Responding to COVID-19

No one has been left untouched by the COVID-19 pandemic. Rapid governmental responses across the country resulted in many changes to how patients were able to access and use healthcare services. To support skin patients in Canada, the CSPA developed a dedicated COVID-19 resource page on the website to help patients understand and navigate the impacts and risks of COVID-19. We also participated in roundtables and advocacy to bring patients' concerns to government.

COVID-19 resource page

We updated this information regularly in English and French and shared the site on our social media channels and directly with CSPA Affiliate Members and others.

Frequently Asked Questions. Working with our Medical Advisory Board, the CSPA provided answers to burning questions from our community, including implications of using medications that modified or suppressed the immune system.

Overview of changes to public drug plans in light of COVID-19. Information was available in English and French and not specific to skin conditions. CSPA shared this resource with other members of the Best Medicines Coalition, MedAccessBC and other collaborators and supporters so that it could be widely used as a resource.

Research into impact of COVID-19 on skin patient community. Information about a global registry of COVID-19 patients with psoriasis (PsoPROTECT), hidradenitis suppurativa (HS), atopic dermatitis, alopecia, and pediatric dermatology.

Affiliate Member resources. Information about resources provided by our Affiliate Members and other collaborators, including webinars and other materials.

Drug Shortages

Shortages of drugs began to emerge in the early days of the pandemic. The CSPA responded by creating an open questionnaire, promoted on social media channels, about patients' challenges accessing their medication.

This information was shared with the federal government. The CSPA participated in regular drug supply working group calls hosted by the Best Medicines Coalition. CSPA signed a letter on behalf of a group of organizations representing affected patients that called on the federal government to address the supply disruptions of this drug through a letter to international trade minister Mary Ng, who helped locate the active pharmaceutical ingredients to ensure supply could continue, and to federal Minister of Health Patty Hajdu.

Research

The CSPA also supported grant applications by clinical researchers about the impacts of the pandemic on skin patients.

Raising the Profile of Skin Patients

Strategic Priority Area 1

Increase our presence by creating greater brand awareness, strong networks for patients and families and mutually supportive relationships with Affiliate Members.

Skin Patient Charter of Rights

In 2019, the CSPA launched the Skin Patient Charter of Rights. The Skin Patient Charter sets out eight rights of all skin patients as they navigate the health system. This foundational document continues to help us support, educate and advocate on a variety of issues impacting skin patients in Canada. It has been shared with patients, dermatologists and other healthcare providers, and our Affiliate Members.

You have rights.

To live without fear.
Without discrimination.
With dignity and respect.

Rights protect us all.
Your skin protects you.
This charter protects you and your skin.

SKIN PATIENT CHARTER OF RIGHTS

canadianskin.ca/charter

- 1 Live without fear of discrimination due to the appearance of your skin;
- 2 Be acknowledged that living with a skin condition may have profound effects on overall well-being including physical, emotional, social and financial aspects, which can be just as significant as other diseases are to other patients;
- 3 Be entitled to societal, employment and government resources should your diagnosis have debilitating effects;
- 4 Receive comprehensive, evidence-based information about your skin condition, disease, or trauma including the expected impact on your health and available treatment options (including potential side-effects) as well as a prognosis;
- 5 Maintain your dignity, respect and absolute confidentiality during exams, procedures and treatments;
- 6 Access to counselling on lifestyle changes and preventive measures known to aid in the management of your disease, including physical activity, diet modification and the avoidance of triggers;
- 7 Discuss psychosocial concerns resulting from skin disease, and to receive information on coping strategies and referrals to mental health resources as needed; and
- 8 Be actively engaged in all treatment decisions as you are the ultimate decision-maker including modifications and additions to treatment plans as appropriate.

ENDORSED BY:

Canadian Dermatology Association
Association canadienne des dermatologues

SUPPORTED BY:

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An [article](#) drafted by Kathryn Andrews-Clay, Dr. Harvey Lui and Arunima Sivanand has been published in the *Journal of Cutaneous Medicine and Surgery*. Editor-in-Chief Kirk Barber provided open access to the article for two weeks to facilitate its circulation.

The CSPA was awarded the Canadian Dermatology Association's [Public Education Award](#) (Not-for-Profit Category) for the Skin Patient Charter in June 2020.

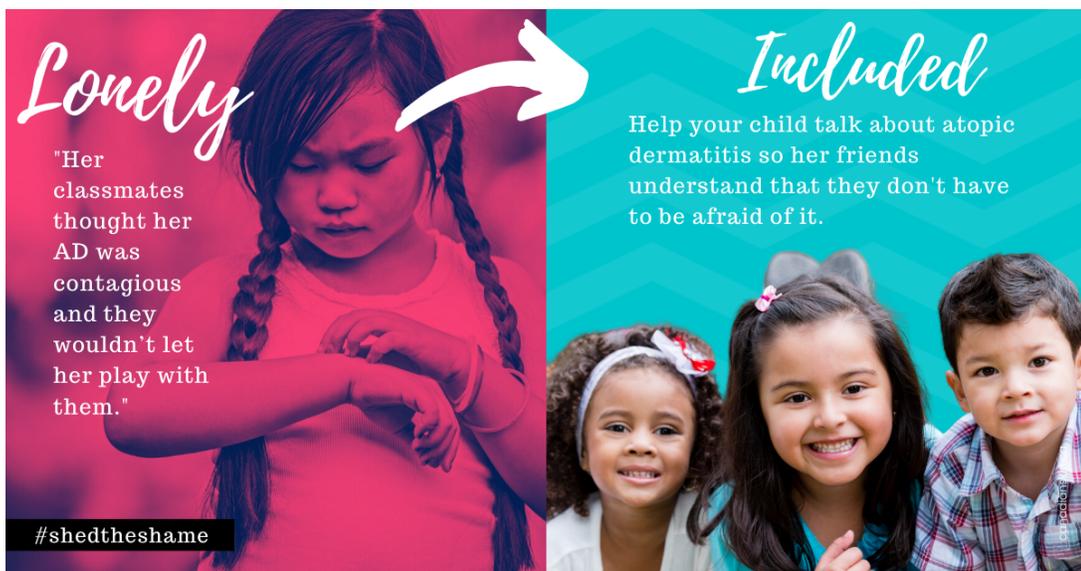
Awareness Campaigns

Social media campaigns were developed for HPV Awareness Week, World Atopic Eczema Day, Acne Awareness Month, Eczema Awareness Month, and HS Awareness Week.

The CSPA also recognized Bell Let's Talk Day, World Cancer Day, International Rare Disease Day, World Lymphedema Day, International Women's Day, Rosacea Awareness Month, World Melanoma Day, and Craniofacial Awareness Month.

Mental Health: #ShedTheShame

The CSPA launched its inaugural annual mental health campaign on Bell Let's Talk Day. From January 29 – February 12, 2020, the CSPA's social media campaign focused on the mental health impacts of atopic dermatitis, particularly on children and youth.



Outreach to Dermatologists

The CSPA was delighted to include information on its activities in the University of Toronto Division of Dermatology newsletter and the Canadian Dermatology Association. The CSPA also reached out to residents to introduce the organization.

Dermatologist of the Year 2019

Our annual program invites applications from Affiliate Members to recognize a dermatologist who has supported the skin patient community. In 2019, the CSPA recognized Dr. Eunice Chow for her compassion and dedication to improving skin cancer outcomes for her patients.

Providing Education and Support

Strategic Priority Area 2

Empower patients and their families and Affiliate Members through knowledge, education and access to information.

The CSPA continues to be an educational and support resource for the public and skin patient community.

Canadian Skin & À Propeau Magazines

This marked the 11th year of CSPA's official publications, *Canadian Skin* and *À Propeau* magazines that included features on ichthyosis, lymphedema, sunscreen, hypertrophic scars and keloids, human papillomavirus, hidradenitis suppurativa, scleroderma, lice & scabies, truncal acne, dermatitis herpetiformis, how to choose a sunscreen, and understanding the differences between creams, lotions and ointments, and how to work with your pharmacist and dermatologist for better health outcomes.

Expanding patient resources

- Information was added to our website about specific skin conditions:
 - Dermatitis herpetiformis
 - Epidermolysis bullosa
 - Neurofibromatosis
 - Shingles
 - Ichthyosis
- The CSPA produced a video about atopic dermatitis in [English](#) and [French](#).
- Information about the burden of nail fungus was shared in a televised interview with CTV News.
- A survey of patients' experiences with truncal acne was used as the foundation for a social media campaign to raise awareness of the impacts of living with this disorder.

HS Report: 2020 Update

In May 2020, CSPA released its new report, [Scarred for Life: 2020 Update – A National Report of Patients' Experiences Living with Hidradenitis Suppurativa](#), which describes patients' experiences as they seek a diagnosis, access care and treatments to manage their disease, and address the many significant burdens on their quality of life. The CSPA was supported by the hard work and dedication of volunteers Dr. Raed Alhusayen, Dr. Ilya Mukovozov, and Stephanie Carter (HS Heroes) to refine the survey and develop the report.

The report was featured in an [article](#) that raised awareness among health system leaders and the general public about the impacts of this disease on patients' lives.

The CSPA hosted webinars in English and French about the results of the report and shared information from the report throughout its HS Awareness Week digital awareness campaign. submitted a letter about significant gaps in pain management for HS and a copy of the report to the Canadian Pain Task Force as part of its consultation to develop a national approach to pain. As well, CSPA and the HS report team prepared posters for:

- UBC Skin Research Day
- CADTH Symposium 2020 (e-Poster gallery)
- Symposium on HS Advances 2020 (Montreal, October 2020)

Improving timely cancer diagnoses

As a member of the Interim Steering Committee of All.Can Canada, led by Affiliate Member Save Your Skin Foundation, the CSPA has contributed to a better understanding of how to improve the accuracy and timeliness of cancer diagnoses in Canada, including in melanoma.

Supporting patients with rare dermatological diseases

The CSPA was a member of Global Skin's Rare Derm Advisory Committee, which worked to better understand the international rare dermatological disease landscape around the world to improve supports for skin patients.

Connecting patients with ichthyosis

The CSPA was pleased to support the first ichthyosis patient forum held in Canada on July 20, 2019 in Toronto. The session was facilitated by CSPA board member Christine Butler.

Expanding Our Community of Reach

The number of people who interacted with the CSPA on social media channels increased. This year, CSPA launched its Instagram profile.



4,716 Followers

4,636 Likes



1,050 Followers



300 Followers

Leadership: Amplifying the Patient Voice

Strategic Priority Area 3

Lead as a respected voice, on key issues for skin patients and their families and Affiliate Members

The CSPA is part of a broad network of international, national and provincial organizations that advocate for better health outcomes and quality of life for patients.

Patient input submissions

The CSPA regularly participates in patient input submission processes for new dermatological treatments available in Canada. By providing patients' perspectives to these processes at the national and provincial levels, decision makers can better understand the burden of skin diseases and how new treatments can improve the lives of skin patients across the country.

This year, the CSPA provided patient input to the following processes:

- *Adcetris* (brentixumab / vedotin) for Primary Cutaneous Anaplastic Large Cell Lymphoma or CD30-expressing Mycosis Fungoides in collaboration with Lymphoma Canada (CADTH – pCODR)
- *Dupixent* (dupilumab) for atopic dermatitis in patients who are 12 years old and older (CADTH -CDR)
- *Duobrii* (halobetasol propionate / tazarotene) for moderate to severe plaque psoriasis in collaboration with the Canadian Association of Psoriasis Patients & Canadian Psoriasis Network (CADTH – CDR, Quebec's INESSS, BC's Your Voice)
- *Ilumya* (tildrakizumab) for plaque psoriasis (CADTH – CDR)
- *Cimzia* (certolizumab pegol) for psoriasis in collaboration with the Canadian Association of Psoriasis Patients & Canadian Psoriasis Network (BC's Your Voice)

Federal Policy

In advance of the October 2019 federal election, the CSPA prepared a [position statement on national pharmacare](#) to support patients who wanted to learn more about federal election candidates' positions on the issues.

In response to the federal Patented Drug Prices Review Board (PMPRB) consultation on draft guidelines to implement recent regulatory changes, the CSPA sent a [letter](#) outlining concerns that the proposed changes may reduce Canadian patients' access to breakthrough therapies in the future, noting that we are at what appears to be a turning point in the treatment of many disorders (e.g., psoriasis and atopic dermatitis). When the PMPRB announced it would lead a second consultation on revised proposed guidelines in the summer of 2020, the CSPA provided [input](#) and supported the submissions of the Best Medicines Coalition, a group of patient organizations, and MedAccessBC.

Provincial Policy

The CSPA sent letters to party leaders in Manitoba in advance of the provincial election, along with our election position statement.

In preparation for Ontario's Budget 2020, the CSPA sent a [submission](#) with specific recommendations for the annual provincial budget:

1. The Government of Ontario should expand access to specialist knowledge about skin conditions by **expanding access to teledermatology services**.
2. The Government of Ontario should **fund home narrowband-ultraviolet B (NB-UVB) phototherapy** for patients with photo-responsive conditions, including psoriasis, as recommended by Health Quality Ontario.
3. The Government of Ontario should **increase access to new and effective therapies** to improve skin patient outcomes, including take-home cancer drugs.

Research

Skin conditions are a leading cause of overall disability and death in Canada. The CSPA regularly supports research into skin, hair and nail diseases, conditions and traumas, including research into COVID-19, teledermatology, patient engagement, medical cannabis, ichthyosis, and psoriasis.

Skin Investigation Network of Canada

Canadian researchers have made substantial contributions to address the heavy burden of skin disease, but much of the work is conducted in relative isolation by a dispersed community of scientists and clinicians. The creation of the Skin Investigation Network of Canada (SKIN Canada) will expand the critical mass of skin research expertise, create new collaborations, and enhance skin health through innovation. We have brought together patients and an interdisciplinary team of leading researchers and clinicians across the country who are tackling the mechanistic, clinical, health systems, and population health questions for a broad range of skin conditions.

SKIN Canada Disease Areas of Focus

There are three disease areas that the network will focus on. However, we expect that connections made among patients and researchers through SKIN Canada may also lead to interesting research questions and additional projects outside of these three disease areas of focus.

1. Inflammatory skin conditions
2. Wound healing, skin fibrosis and regeneration
3. Skin cancer

The Executive Director of the CSPA is the Chair of the Patient Advisory Council and a member of the Executive and other committees for the network. Through these roles, the CSPA will recruit, train and support patients as research partners throughout the committees and working groups of the network.

The CSPA has been actively recruiting Patient Research Partners for the network and developing related policies.

Affiliate Members & Global Collaborators

The CSPA continues to strengthen and expand its relationship with other organizations that represent patients with specific skin disorders.

Affiliate Members

This year, the CSPA worked with Affiliate Members to articulate the benefits of collaborating on expanding communities of reach, sharing information and resources, advocating and supporting organizational success. Through this process, the CSPA deepened its understanding of the needs of Affiliate Members in preparation for the upcoming Affiliate Members Meeting in November 2020.

The CSPA was pleased to welcome three new Affiliate Members this year:

- Scleroderma Manitoba
- Hidradenitis & Me Support Group
- Société Camp Liberté Society

The **Tanny Nadon Affiliate Member Grant** was awarded to

- Canadian Burn Survivors Community (October 2019)
- DEBRA Canada (April 2020)

Global Collaborators

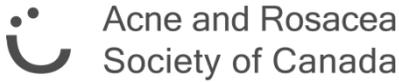
We are pleased to welcome four new Global Collaborators this year:

- National Organization for Albinism and Hypopigmentation (NOAH)
- Skin Sri Lanka
- Foundation for Ichthyosis and Related Skin Types (FIRST)
- HS Connect

CSPA's Affiliate Members



ABOUT FACE



Canadian Skin Patient Alliance
Alliance canadienne des patients en dermatologie

for patients, by patients

Supporters

The Canadian Skin Patient Alliance is grateful to the many people who strengthen the organization through their passion, time and expertise:

- **Patients** who share with us their stories and continue to inspire us
- Members of the **Board of Directors and committees** who ensure that our priorities reflect those of the communities we serve, and our organization remains resilient
- **Dermatologists** who review and contribute to our many projects
- **Affiliate Member** and **Global Collaborator** organizations that help us support and elevate the profile of skin patients
- **Organizations** that partner and collaborate with us to serve our community
- **Authors** of articles and columns in the *Canadian Skin* magazine
- **Staff and contractors** who bring it all together

CSPA Board of Directors

Munish Mohan	Chair
Julie Powers	Co-Chair
Audrey Santo-Domingo	Treasurer
Hansi Peiris	Secretary
Shiamala Paramasivam	Director
Christine Butler	Director
Jeffrey Losch	Director
Ivan Eggers	Director
Sandy Burton	Director

The CSPA thanks **Audrey Santo-Domingo, Marianne Welsh, and Felix Kongyuy** for their contributions and support to the organization and our patient community.

2019-20 Sponsors

Thank you for your support of the CSPA and our community.

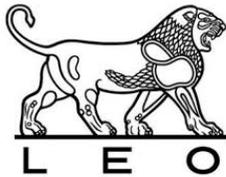
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