

Canadian Skin Patient Alliance

Annual Report 2021-2022



Canadian Skin Patient Alliance
Alliance canadienne des
patients en dermatologie

Letter from the Chair and Executive Director

The Canadian Skin Patient Alliance strives to work across silos and bring stakeholders together to create a better future for skin patients.

The CSPA has helped to connect people throughout the skin patient community with one another to collectively imagine a better future for skin patients across Canada. Through our education and advocacy work, we continue to raise awareness about the impacts of living with skin, hair and nail conditions on people's lives.

Working with our colleagues at Affiliate Member and collaborating organizations, we have called for important changes in how treatments are made available to skin patients throughout the country. Participating in formal government consultations and supporting our colleagues who are driving policy change is critical to ensuring that skin patients become a priority for policy makers in Canada. This year, we have raised skin patients' concerns in consultations on a national rare disease drug strategy, potential models for national pharmacare, how drugs are priced and encouraged to be made available to people in Canada, addressing drug shortages, and other important issues like improving the skin cancer diagnosis process and ensuring there is good quality and consistently collected health data in our country.

Our role within the Skin Investigation Network of Canada (SkIN Canada) has provided a platform to shape and encourage skin research happening across Canada in the company of esteemed dermatologists, skin science researchers, trainees, and other patient organization leaders. This is an important time for skin patients, with a lot of promise for improved care and treatment of many conditions around the corner.

Our new strategic plan sets the stage for five years of energy, opportunity, passion and compassion at the CSPA. We continue to enjoy the support of our corporate sponsors, volunteers, the dermatology medical community, and our colleagues at other organizations dedicated to specific skin patient communities. We look forward to a brighter future for everyone in Canada impacted by skin, hair or nail conditions and to your continued support.

Sincerely,

Jeffrey Losch
Chair

Rachael Manion
Executive Director

Executive Summary

2021-2022 was a monumental year fuelled by ambition and achievement. Progress was made on the advocacy front, new strategic alliances were formed, and patient engagement increased following the launch of exciting public awareness and educational initiatives.

As part of the Canadian Skin Patient Alliance's (CSPA) strategic planning process, consultations were held with stakeholders to establish common themes across different groups. Based on a SOAR (strengths, opportunities, aspirations, results) framework, the process involved individual interviews with key informants, an online survey, and two focus group discussions. The combined feedback led to an amended vision and mission statement, and the development of the CSPA's five-year **Strategic Plan** comprised of four priorities:

1. Advocate
2. Educate
3. Raise our profile
4. Diversify funding

In response to patients' feedback on the rising cost of medications, the CSPA developed a new interactive tool called [Is My Prescription Covered?](#) available in English and in French, it serves to help everyone in Canada – regardless of their medical condition – better understand whether they can access, and benefit from, a public health insurance plan (i.e., drug coverage that is provided by governments across Canada) or a private plan.

The CSPA continued its ongoing collaborations with pharmaceutical companies, hospital drug access navigators, and others to establish a digital solution for private plans. It also hosted a meeting with the **pan-Canadian Pharmaceutical Alliance** (pCPA) to discuss its approach to negotiating drug prices on behalf of public drug plans.

Additionally, the CSPA shared input from skin patients as part of the health technology assessments for:

- Adtralza (tralokinumab) for atopic dermatitis, in collaboration with Eczéma Québec.
- Poteligeo (mogamulizumab) for cutaneous lymphoma, (mycosis fungoides / Sézary syndrome) in collaboration with Lymphoma Canada and Cutaneous Lymphoma Foundation (US).

On the collaborative front, the CSPA welcomed five new Affiliate Members. In spring 2021, it launched the **Affiliate Members Workplace**, an online platform to facilitate conversation and information-sharing. The CSPA also led workshops on best practices for collaborations with patient organizations.

The CSPA remains an active participant in discussions on a **national rare disease drug strategy** with Health Canada. To grow public awareness of dermatologic conditions, the CSPA worked with **Eczéma Québec** on both a survey and a report on atopic dermatitis for Eczema Awareness Month (November 2021). The CSPA also collaborated with the **Acne and Rosacea Society of Canada** on a similar survey and a report that shares the healthcare experiences of acne patients across the country. Currently, the CSPA represents Canada in the **Global Patient Initiative to Improve Eczema Care** (GPIIEC), a collective of 11 patient organizations in eight countries. Last spring, the CSPA marked International Day of the Family (May 15) with the release of an animated video titled, **How does eczema impact the entire family?**

The CSPA released five newsletters during 2021-2022 and expanded its website content on different skin conditions. It added new COVID-19 resources, an **interactive glossary** to help patients decipher dermatology-related jargon, and a **lexicon of eczema-related terminology** in **English** and in **French** for children.

In 2002, the CSPA launched the **Shed the Shame** mental health campaign, along with a video series called **Reflections** to help deter the stigma of living with a visible skin condition. It also introduced the **Tanny Nadon Caregiver Award** in honour of the late founding member of the Alberta Society of Melanoma who was a devoted volunteer within the medical community and a past board member of the CSPA.

Table of Contents

Letter from the Chair and Executive Director.....	2
Executive Summary.....	3
CSPA’s Strategic Plan 2022-27	6
About Us	8
Advocacy	9
CSPA’s Advocacy Strategy	9
Helping skin patients navigate drug plans.....	9
Better access to treatments for skin patients.....	10
Improving cancer care.....	12
Health data that makes sense across the country.....	13
Advocating for specific skin patient communities in Canada	13
Raising Awareness	14
Shed the Shame 2022.....	14
Reflections: Skin patient stories	14
Tanny Nadon Caregiver Award	14
Raising awareness in the community.....	15
Diversity and inclusion: reflecting all skin patients	15
CSPA Newsletter: Beyond the Surface	15
Skin Patient Charter of Rights	16
Education	17
Canadian Skin magazine	17
Information about skin conditions and diseases	18
Resources for skin patients.....	18
Patient Engagement in Skin Research	19
Skin Investigation Network of Canada (SkIN Canada).....	19
Global Patient Initiative to Improve Eczema Care	21
Supporting Canadian skin research	21
Supporting CSPA’s Affiliate Members.....	22
Welcome to new Affiliate Members	22
CSPA Affiliate Member Private Communication Platform	23
CSPA Supporters.....	24
Dermatologist of the Year 2021.....	24
Medical Advisory Board.....	24
Board of Directors	25
Volunteers	25
CSPA Sponsors.....	26

CSPA's Strategic Plan 2022-27

In October 2021, the Canadian Skin Patient Alliance (CSPA) began the process to renew the organization's strategic plan.



Based on a SOAR framework (strengths, opportunities, aspirations, results), stakeholders were asked to identify CSPA's key strengths and assets, any external opportunities that exist for CSPA to leverage those strengths, what CSPA aspires to and desires to be in the future, and how success will be defined.

Consultations with stakeholders included individual interviews with key informants, an online survey in both official languages, and two focus group discussions – one with CSPA staff and one with Board members of the organisation. The same set of questions, developed using the SOAR framework, were used across all consultation methods.

The feedback gathered through the consultations was analysed to identify common themes across stakeholder groups as well as differences between stakeholder groups. At a planning day in March 2022, the CSPA Board and staff considered the feedback from the consultations and identified four strategic priorities to provide overall focus and direction for the work of the organisation over the next five years. They also updated CSPA's vision and mission.



2022-2027 Strategic Plan



Advocate

Advocate for the needs of people affected by skin, hair, and nail conditions, with a particular focus on access to treatments, healthcare systems strengthening, virtual care, and primary healthcare.



Educate

Educate the public and healthcare providers about mental health issues experienced by skin patients, including the impact of stigma and the reality of the severity of many skin conditions.



Raise our profile

Raise CSPA's profile with the public, healthcare providers, skin patients, and their caregivers.



Diversify funding

Diversify funding through the achievement of charitable status and building fundraising capacity.

About Us

The Canadian Skin Patient Alliance (CSPA) is a national non-profit organization that improves the health and wellbeing of people across Canada affected by skin, hair, and nail conditions through collaboration, advocacy, and education.

- We raise awareness about the impacts of skin conditions.
- We educate on a variety of issues affecting skin patients, their families, and caregivers.
- We advocate for best care & treatment options for all skin patients.
- We facilitate patient engagement in dermatological research.
- We support our [Affiliate Member](#) organizations who work with specific skin patient communities such as those living with acne, scleroderma, skin cancers, and psoriasis.

Mission

To improve the health and well-being of people across Canada affected by skin, hair, and nail conditions, through collaboration, advocacy and education.

Vision

A world where people affected by skin, hair and nail conditions live healthy and fulfilling lives.

Advocacy

Skin patients often stand in the shadows. At the CSPA, our advocacy shines a light on the impacts of living with a skin, hair or nail condition so that people who make decisions about skin patients' care, treatment and support better understand their experiences.

CSPA's Advocacy Strategy

In 2022, the CSPA developed its first advocacy strategy. This strategy is a living document that is updated regularly to best reflect how contexts change – sometimes, for the better. The advocacy strategy sets out the organization's priority actions to achieve our objectives.

Advocacy objectives

5. Promote skin health and improved quality of life for skin patients
6. Improve access to medical care for skin patients
7. Improve affordable and timely access to effective treatments for skin patients
8. Promote use of accurate information about skin diseases by policy- and decision-makers

Throughout this report, you will read about different initiatives that the CSPA has led or collaborated on to achieve these objectives, including surveys and publications, awareness campaigns, and resources that we have launched.

Helping skin patients navigate drug plans

Is My Prescription Covered? CSPA's drug coverage finder



We hear frequently from people who struggle to afford their medication. So, we built a tool that everyone can use to try and figure out if they can access public coverage – drug coverage that is provided by governments across Canada – or a private plan to help them cover the cost of their medication.

This interactive tool is available in French and in English and asks you a series of yes or no questions to help you figure out whether you're eligible for prescription drug coverage under any federal, provincial, or territorial plans. [Is My Prescription Covered?](#) was built not only for skin, hair, and nail patients, but for all people in Canada regardless of the medical condition that they may have. And for those who may not be eligible for any of the public (government-provided) drug plans available in Canada, we've also provided you with some possible ways of accessing private coverage that you may not have considered before, such as through a union or an alumni association.

As our country continues to look at **national pharmacare** as a solution to problems with paying for medication, we encourage you to see what is already available for you so that we can all put our heads together and develop something that will improve the current situation.

Faster insurance plan review of specialty drug coverage

The CSPA has been collaborating with private plan specialists, pharmaceutical companies, hospital drug access navigators, and others to establish a digital solution for private plans. This digital solution would enable private plans to more quickly review applications that require “prior authorization,” which is special advance permission required by these drug plans for drugs where certain criteria must be met. For patients who take biologics, biosimilars, other new treatments, or have been prescribed prescription medications for different reasons than they were approved, this initiative can help speed up the process. CSPA will continue to be involved in this initiative in 2022-23.

Better access to treatments for skin patients

More treatments for skin patients in Canada

Health Canada reviews drugs for safety and effectiveness before authorizing them to be used by (prescribed to) patients in Canada. Throughout 2021-22, several new treatments were authorized in Canada:

- Arazlo (tazarotene) for **acne vulgaris** (common acne)
- Cibinqo (abrocitinib) for **atopic dermatitis**

Once a drug is authorized in Canada, all public drug plans (and, increasingly, private drug plans) are reviewed in the context of other available treatments to determine whether they are effective

when compared with other treatments (clinical effectiveness and cost-effectiveness). As part of this process, patients and caregivers are asked for their input.

The CSPA also shared input from skin patients as part of the health technology assessments for:

- Adtralza (tralokinumab) for **atopic dermatitis** in collaboration with [Eczéma Québec](#).
- Poteligeo (mogamulizumab) for **cutaneous lymphoma** (mycosis fungoides / Sézary syndrome) in collaboration with [Lymphoma Canada](#) and [Cutaneous Lymphoma Foundation](#) (US).

Outside of these processes, there are sometimes opportunities to provide additional information to inform drug plans' decisions about whether to cover a specific drug.

- **Access to biologics in Quebec.** The CSPA provided feedback to Quebec's Institut national d'excellence en santé et en services sociaux (INESSS) about the importance of a flexible and updated approach to covering biologics in the province, including biosimilars. The Quebec government had implemented a biosimilar policy and restricted the use of manufacturer co-pay cards to help achieve its policy goals of saving money and increasing the use of biosimilar medications where they are available. This letter was supported by the [Canadian Association of Psoriasis Patients](#), the [Canadian Psoriasis Network](#) and [Hidradenitis & Me Support Group](#).
- **Negotiating public plan drug coverage.** The CSPA organized a meeting with the **pan-Canadian Pharmaceutical Alliance** (pCPA) Office to discuss their approach to negotiating drug prices on behalf of public drug plans and how they would like to work with patient organizations when it comes to addressing our concerns about delays in negotiations. We were joined by certain Affiliate Members who have had products go through negotiations with the pCPA or are likely to in the near future, including the [Canadian Association of Psoriasis Patients](#), [Canadian Psoriasis Network](#), [Acne & Rosacea Society of Canada](#), [Cutaneous Lymphoma Foundation](#) (US), and the [Chronic Urticaria Society](#).
- **National Advisory Committee on Immunization (NACI).** The NACI, which has come more into the public eye as an advisory body for COVID-19 vaccines, has been asked to consider the costs of immunizations as part of its recommendations. CSPA and other patient groups have signed on to a letter led by Save Your Skin Foundation questioning this policy approach and recommending (urging) NACI to have a formal patient input process as part of its process.

Better access to more rare skin disease drugs

CSPA has been at the table for discussions on a **national rare disease drug strategy** with [Health Canada](#), fellow patient organizations via the [Best Medicines Coalition](#), and its membership in the [Canadian Organisation for Rare Disorders](#). We are also proud to continue to support the

international efforts of **Global Skin** to collect and analyze data about rare skin diseases through participation on the organization’s GRIDD Advisory Committee.

Clinical trials modernization

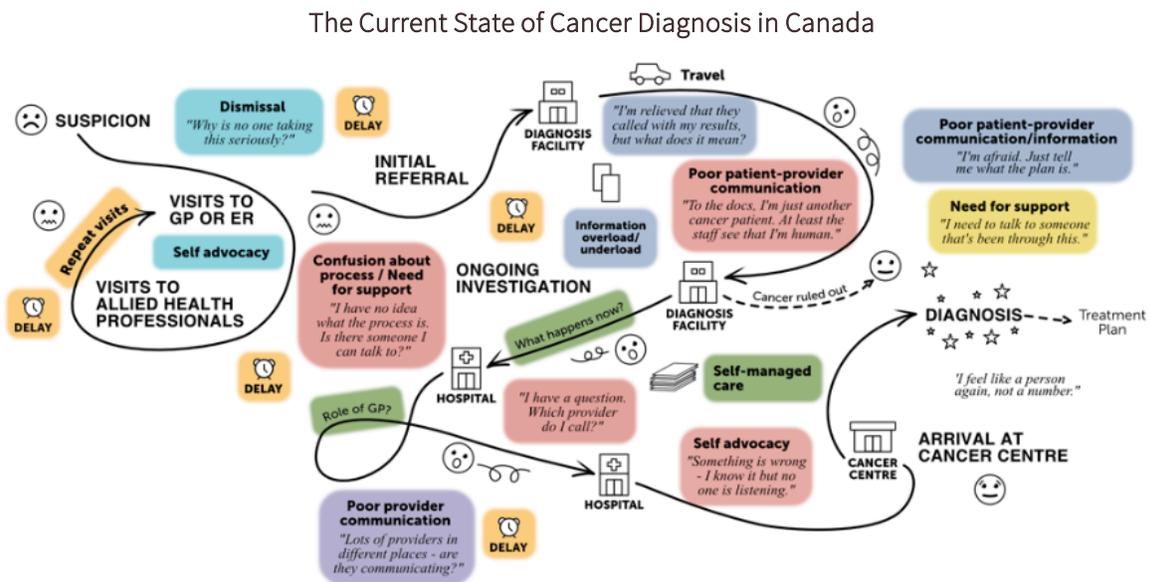
CSPA has signed on to a submission to Health Canada prepared by **Clinical Trials Ontario**, joining several other organizations’ support. Among the input, CSPA championed lay summaries being developed by all manufacturers within one year of the trial being completed, as is required in Europe. It is hoped that this would help communicate trial results to patients and, in particular, help patient organizations convey this information accurately and promptly.

Drug prices

The reforms to the Patented Medicine Prices Review Board (PMPRB) regulation of drug prices were implemented in part after much advocacy from the patient community, including CSPA. CSPA worked with colleagues through the **Best Medicines Coalition** to provide feedback and advocate on this issue.

Improving cancer care

The CSPA is proud to support the development and launch of a report on the challenges of getting a cancer diagnosis in Canada, led by **All.Can Canada** and CSPA Affiliate Member **Save Your Skin**.



Reference: *Optimizing Diagnosis in Canadian Cancer Care*, All.Can Canada, 2022. https://www.all-can.org/wp-content/uploads/2022/02/Optimizing-Diagnosis-in-Canadian-Cancer-Care_All.Can-Canada-Report-compressed.pdf

The report included information from melanoma and other cancer survivors and caregivers that inspired several recommendations on how to do better for people who suspect they may have cancer and are trying to get diagnosed.

Health data that makes sense across the country

We have joined other patient organizations in conversation with the Public Health Agency of Canada to share the perspectives of skin patients about their planned pan-Canadian health data strategy.

Advocating for specific skin patient communities in Canada

Acne

In collaboration with the [Acne & Rosacea Society of Canada](#), the CSPA launched a survey about acne patients' experiences with the healthcare system in Canada. Participants told us about the misconceptions that they encounter about acne, the often-devastating implications when they do not have optimal treatment, and how the condition impacts their mental health and participation in work, school and social life. A report of the findings will be launched in 2022-23.

Atopic dermatitis (Eczema)

For Eczema Awareness Month (November 2021), the CSPA collaborated with [Eczéma Québec](#) to launch a survey asking patients about their experiences accessing care and treatment in Canada. People told us about getting a diagnosis, their concerns about topical corticosteroid use, how they access treatments and the impacts on their mental health and lives. A report of the findings will be launched in 2022-23.

On International Day of the Family (May 15, 2022), CSPA released an animated video about the burden of atopic dermatitis on the family when a child lives with the condition, [How does eczema impact the entire family?](#)

Raising Awareness

Too many skin patients suffer in silence. CSPA highlights the impacts of skin conditions in nationwide awareness campaigns. The goal of these campaigns is to create and share information that will lead to better understanding, earlier diagnosis, improved health outcomes and quality of life.

Shed the Shame 2022

Shed the Shame is a mental health campaign aimed at helping to shed the stigma of living with a visible skin condition. This year, we were joined by Dr. Dayna Lee-Baggley, a registered clinical psychologist who specializes in living with a chronic illness, with a video series featuring her answers to questions from the skin patient community on how to manage the psychosocial impacts of living with a visible skin condition.

The campaign launched on Bell Let's Talk Day (January 26, 2022). We posed questions from the skin patient community to Dr. Lee-Baggley. She addressed questions on managing feelings such as anger, guilt, and worry as well as managing staring, building a village of support, and dating and relationships.

Reflections: Skin patient stories

This year, the CSPA launched a video series called Reflections. The first [video](#) featured Christine Butler talking about her life with **ichthyosis**, a rare genetic skin condition. Ichthyosis is characterized by skin that appears as dry, thickened, and scaly. Christine reflected on the challenges she has faced in her life, and the impact that support from her family and friends has made. Christine is a dedicated CSPA volunteer and the Co-Chair of the CSPA's Board of Directors.

Tanny Nadon Caregiver Award

Tanny Nadon (1941-2016) was a dedicated, caring and compassionate volunteer for several cancer-related community organizations. She was also a founding member of the Alberta Society of Melanoma. As a former director of CSPA, Tanny was an innovative leader who worked hard behind the scenes and helped to shape the organization in its formative years. Tanny has been missed by many since she passed away in 2016. Her legacy as a selfless volunteer in the areas of patient advocacy and mentorship lives on and continues to inspire us all!



This year, we launched this caregiver award in honour of her memory and the example she set for us all. The award recognizes those who go above and beyond in their role of caregiver to an individual impacted by a skin, hair or nail condition.



The first recipient was Hazel Booth. Hazel has gone above and beyond in her support of her sibling, John Hart, a burn survivor. John nominated Hazel. [Watch the video](#) where the siblings speak about their special relationship and how Hazel remains inspired to support her brother on our YouTube channel.

Raising awareness in the community

There are many awareness activities in the CSPA calendar. Our community is broad and diverse, reflecting people who live with more than 3,000 skin, hair and nail conditions. In 2021-22, we recognized over 21 awareness days, 5 awareness weeks and 9 awareness months on our social channels.

We also helped to spotlight awareness activities from our Affiliate Members including the [Canadian Alopecia Areata Foundation](#), [Eczéma Québec](#), [AboutFace](#), [Neurofibromatosis Ontario](#), [Tumour Foundation of BC](#), [Camp Liberté](#), [Hidradenitis and Me Support Group](#), [HS Heroes](#), [Acne and Rosacea Society of Canada](#), and the [Canadian Burn Survivors Community](#). We also highlighted all our Affiliate Members on National Best Friend Day.

Diversity and inclusion: reflecting all skin patients

Dermatology has historically focused on fairer skin types and the dermatology community is working hard to address the gaps in care, treatment, and research for people with skin of colour. At the CSPA, we ensure that information about skin, hair and nail conditions includes descriptions of all skin tones. We also work with contributors to develop additional content that helps to close these gaps.

CSPA Newsletter: Beyond the Surface

The CSPA released five newsletters during 2021-22. These newsletters help keep the skin patient community informed about policy changes, awareness campaigns, the work of the CSPA and how they can support the organization.

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:



SUPPORTED BY:



Skin Patient Charter of Rights

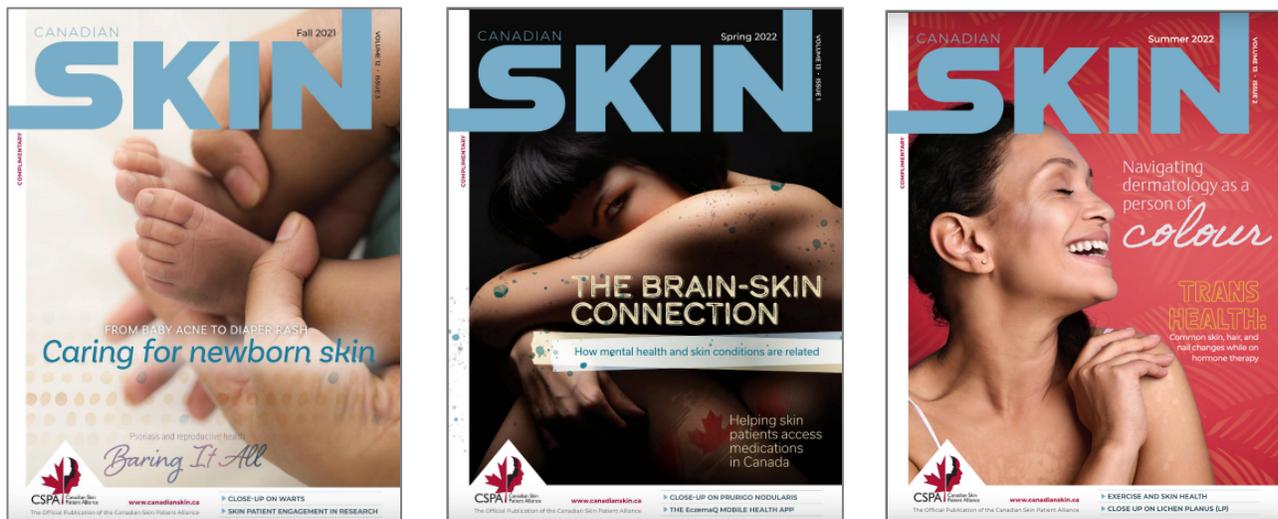
We continue to share the Skin Patient Charter at conferences and events throughout Canada. Its eight rights inform our projects and initiatives, from mental health and self-empowerment through to education, information and advocacy.

Education

It is vital that people in Canada understand skin, hair and nail conditions: how they develop, whether they can be prevented, how to treat them, and where to find support and resources. Our bilingual resources aim to educate and help raise awareness about the experiences of skin patients across Canada.

Canadian Skin magazine

The CSPA's official publication is our award-winning magazine, *Canadian Skin* (in French, it is called *À Propeau*).



The Fall 2021 issue featured articles on caring for **newborn skin**, **psoriasis** & sexual and reproductive health, how patients can help shape **skin research** as a part of the research team, a close-up on **warts**, and information for kids on how to spot **burn hazards** in the Family Focus section.

In Spring 2022, the magazine featured articles on mental health and skin health; CSPA's *Is My Prescription Covered?* tool; and Eczema Quebec's new patient self-management app for **atopic dermatitis**. The close-up was on **prurigo nodularis** and the Family Focus section explained how **vaccines** work.

The Summer 2022 issue featured articles on exercising with a skin condition, complementing the Family Focus section on **sweating**. Other features include skin health for people transitioning from male to female, and dermatology for darker skin types, and a close-up on **lichen planus**.

A special congratulations from CSPA to Priya Dhir on her public education award from the Canadian Dermatology Association for her article on dermatitis herpetiformis (“celiac disease of the skin”) in the Spring 2021 issue of *Canadian Skin*.

Information about skin conditions and diseases

This year, we revamped the information available on our website about **warts, psoriasis, and nail fungus** and added information about **HPV**.

Resources for skin patients

COVID-19

In October 2021, we added new COVID-19 resources to help answer questions patients may still have around the safety of the vaccine for people who are immunocompromised, for children, and those who are pregnant or breastfeeding.

Glossary of dermatology terms

We understand that medical jargon isn’t always the easiest to understand, and when you’re speaking with your doctors or looking into treatments there can be a sea of unfamiliar words, so we’ve broken down some of the most used ones to help you to better understand your condition. Check out the [interactive glossary](#) on our website.

Animated video: How does eczema impact the entire family?



In May 2022, we released *How does eczema impact the entire family?* This short animation helps people better understand the family burden of disease of atopic dermatitis. The video was produced in [English](#) and in [French](#) and they are the most viewed videos on our YouTube channel.

Eczema Resources for Kids

We created a glossary of eczema-related words to accompany the Family Focus section on eczema and compiled them into a resource for kids to help them to better understand the condition. This was produced in [English](#) and in [French](#).

Patient Engagement in Skin Research

Through supporting skin research initiatives in Canada, we are helping create a brighter future for skin patients in Canada.

Skin Investigation Network of Canada (SkIN Canada)

Funded with a three-year network catalyst grant from the federal Canadian Institutes of Health Research – Institute of Musculoskeletal Health and Arthritis (CIHR-IMHA), the [Skin Investigation Network of Canada](#) (SkIN Canada) was established in 2020 to improve how skin researchers in Canada collaborate and support future generations of skin researchers.

The CSPA is embedded in the research network, with a formal role to foster patient engagement in skin research in Canada. Specifically, the CSPA's Executive Director is a **Co-director of the network** and member of the Executive Committee, which ensures that patient perspectives are incorporated throughout network activities. The Executive Director is also the **Chair of the Patient Advisory Council**, which is a formal committee of the network composed of Patient Research Partners.

Priority Setting Initiative: Top 10 Research Questions

This year, SkIN Canada completed its Priority Setting Initiative. Through this project, the community of patients, caregivers, clinicians and researchers determined the Top 10 Research Questions for nine specific conditions. CSPA and participating Affiliate Members shared these infographics with our communities. Publication of related manuscripts in academic journals is underway through SkIN Canada so that clinicians and researchers are informed about these priorities from the skin patient community in Canada.

CSPA wishes to thank our Affiliate Member colleagues & collaborators who helped us reach more patients and caregivers for this project.

[Canadian Association of Psoriasis Patients](#)
[Canadian Burn Survivors Community](#)
[Canadian Psoriasis Network](#)

Eczéma Québec
Eczema Society of Canada
Hidradenitis & Me Support Group
HS Heroes
Save Your Skin Foundation

And a special thank you to everyone who completed the surveys and participated in the workshops!



Team development grants

SKIN Canada also put out a call for applications for small team development grants (\$25,000) to further the research questions identified in the Top 10 lists project. CSPA was delighted to facilitate connections between interested patients, patient organizations and researchers as part of its role with SKIN Canada.

Presentations

The CSPA Executive Director led workshops for network members to better understand how to work with patient organizations in its research and moderated a discussion with a person living with scars about her experiences and what researchers should know.

Global Patient Initiative to Improve Eczema Care

The Initiative is a global collaboration to establish a common “yardstick” to assess the responsiveness of health systems to the needs of **eczema** patients and their caregivers, and to identify opportunities for improvement. The **Global Patient Initiative to Improve Eczema Care** (GPIIEC) is led by [Global Parents for Eczema Research](#) (US) and CSPA is representing Canada.

GPIIEC released a global report card of eczema patient care in eight countries: Australia, Canada, Denmark, France, Italy, Germany, United States, and the United Kingdom. Findings were submitted to academic journals for publication so that patients’ feedback could more easily reach clinicians and researchers.

Eczema is a chronic relapsing inflammatory skin condition that impacts approximately 15% to 20% of children and 1% to 3% of adults globally, resulting in a significant patient burden and high demand on health care systems. A global survey by the GPIIEC that received over 3,200 responses found that patients in every country, and particularly those who live with moderate-to-severe eczema, are struggling to achieve long-term control of their eczema symptoms and report limited satisfaction with current treatments. Moderate-to-severe eczema is complex and chronic, demanding a high degree of patient involvement in ongoing symptom management. However, training for this role is minimal and patient input into treatment decisions is lacking in almost every country surveyed. Interestingly, shared decision-making, defined as asking patients and caregivers about their priorities during a medical visit, was predictive of symptom control. This finding suggests that such involvement may improve medical care and outcomes and serves as a target for improvement for health systems in each country.

Learn more about it on GPER’s [podcast](#), **Episode 19: Let’s get real: Why are eczema patients struggling worldwide?** This project will continue in 2022-23.

Supporting Canadian skin research

Whether for a clinical trial network to conduct **burns** research, better understanding sun protection practices to avoid **skin cancers**, helping **morphea** researchers learn from patients as they set up a patient registry, or including skin patients in research on **medications and breastfeeding**, the CSPA continues to support skin research taking place in Canada.

Supporting CSPA's Affiliate Members

Collaboration is the cornerstone of our alliance. We strive to support our Affiliate Member organizations who work with specific skin patient communities – such as those living with acne, eczema, hidradenitis suppurativa, melanoma, and psoriasis – to thrive.

Welcome to new Affiliate Members

The CSPA welcomed five new Affiliate Members in 2021-22:

1. **Chronic Urticaria Society** (Quebec City, QC)
This organization is a group of specialists, and patients with chronic urticaria, that aims to improve the health and quality of life of people dealing with chronic urticaria across Canada.
2. **Eczéma Québec** (Montreal, QC)
This organization was created as a branch of the McGill University Hospital Network Center of Excellence for Atopic Dermatitis to connect patients and healthcare practitioners and build resources based on international best-practice guidelines.
3. **Mamingwey Burn Society** (Winnipeg, MB).
This organization supports **burn survivors**, their families and caregivers, burn unit staff and firefighters in Manitoba and the surrounding area.
4. **Lymphedema Association of Ontario** (Toronto, ON)
This organization promotes lymphedema education, prevention, treatment and quality of life for those with the condition.
5. **Scleroderma Atlantic** (Halifax, NS)
This organization is committed to enriching the lives of people living with scleroderma through education, awareness, patient support, and advocacy for patient wellness.

CSPA Affiliate Member Private Communication Platform



The CSPA Affiliate Members Workplace is an online platform like Facebook is a private space where collaboration, conversation and information sharing happen between CSPA and Affiliate Member organizations. CSPA launched the platform in summer 2021 in response to Affiliate Members' expressed desire for a means of collaborating with each other. Through Workplace, we host a monthly "Let's Chat" series of topic-specific or open discussion gatherings. CSPA and Affiliate Members regularly post about happenings, resources, opportunities, challenges and successes. Many postings generate follow-up comments and conversations.

At present there are 22 Workplace account holders representing 20 Affiliate Member organizations. Workplace insights show that over the last year 184 posts were created by 22 people with 279 comments made by 26 people.

CSPA Supporters

The CSPA depends on the contributions of volunteers, funders, medical advisors, students, patients, and caregivers to deliver programs and continue to raise the profile of skin conditions.

Dermatologist of the Year 2021

The Canadian Skin Patient Alliance recognizes
Dr Yuka Asai for her:

- Compassionate concern for patients' welfare and happiness
- Commitment to community service and quality patient care
- Positive effect on others, and
- Outstanding patient care



In particular, the CSPA appreciates Dr Asai's leadership to develop important information about several different skin conditions, including **warts, HPV, and lichen planus**.

Medical Advisory Board

The CSPA is proud to have some of Canada's most experienced and respected dermatologists sit as members of our Medical Advisory Board. This board serves to review all medical content prior to publishing, be it on this website, in our award-winning *Canadian Skin Magazine*, or in individual responses to patients.

Dr. Gordon Searles, Chair (Alberta)

Dr. Kirk Barber (Alberta)

Dr. Marc Bourcier (New Brunswick)

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Dr. Anatoli Frieman (Ontario)

Dr. Nicole Hawkins (Alberta)

Dr. Charles Lynde (Ontario)

Dr. Danielle Marcoux (Quebec)

Dr. Jaggi Rao (Alberta)

Dr. Cheryl Rosen (Ontario)

Dr. Jack Toole (Manitoba)

Dr. Raed Alhusayen (Ontario)

Board of Directors

The CSPA Board of Directors is composed of patients, caregivers, skin health professionals, and educators.

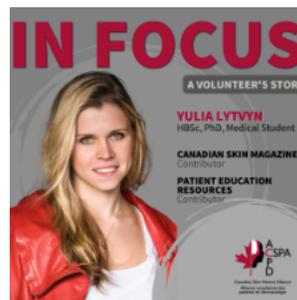
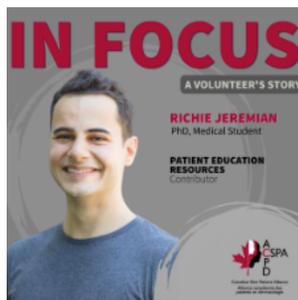
The CSPA thanks the board of directors for their thoughtful guidance and oversight.

Jeff Losch	Chair
Christine Butler	Co-Chair
Tochi Omoloye	Treasurer
Barbara-Anne Hodge	Secretary
Sandy Burton	Director
Ivan Eggers	Director
Chris Peralta	Director
Thomas Dornoy	Director
Nadia Kashetsky	Director (2022)

The CSPA thanks former board members **Munish Mohan** (Chair), **Sandy Burton**, and **Shiamala Paramasivan** for sharing their time, energy and expertise to benefit the skin patient community.

Volunteers

CSPA is fortunate to have long-term volunteers who serve on our boards and committees, who advise our staff and who contribute to the creation and review of our public reports, online content, educational resources and more. Each year, new student volunteers come forward to offer their skills and services. The CSPA team has been working toward improving and streamlining its processes regarding volunteer postings and volunteer onboarding.



CSPA has begun to recognize its volunteers year-round. In addition to the spring National Volunteer Week spotlights, written bios of volunteers are featured through CSPA's new "In Focus" series, a collection of written volunteer profiles that are promoted on social media and added to the volunteer webpage.

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Canadian Skin Patient Alliance
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