

Canadian Skin Patient Alliance

Annual Report 2020-2021



For patients, by patients.

Letter from the Chair and Executive Director

As an alliance, collaboration is at the heart of how we build a better future for all skin patients in Canada.

We were very fortunate this year to work closely with many wonderful organizations – new and established – on a variety of projects to improve care and treatment for skin patients. With several thousand skin, hair and nail conditions impacting people in Canada, it is critical that we work together and raise awareness of what skin patients need to live their lives to the fullest.

Historically, skin patients in Canada have remained silent and hidden, and as a result skin patients have poorer access to specialists, to treatments and to medications – all of which, if improved, would go a long way to improving the quality of life for millions of people in Canada, and would even save lives. CSPA's advocacy is a critical component to creating a better future for skin patients, whether through participating in patient input processes for specific new treatments or talking with policy makers about how processes can be better designed to reflect the needs of patients and caregivers.

We have broadened our support of skin research in Canada over the past year. With the CSPA's role in the Skin Investigation Network of Canada, we have a front row seat to new research initiatives being led across the country. This year saw the beginning of a grand project to list the Top 10 unanswered research questions for nine very different conditions. By encouraging skin patients to share their perspectives through surveys, discussions, social media engagement, and consultations, we are helping to improve care, treatment, and quality of life for those living with skin conditions in Canada.

On the eve of CSPA's 15th anniversary, the board of directors has embarked on a new strategic planning process that will set out how the organization will tackle tough challenges ahead. Through creativity, passion, skill, and the generosity of our community, we can raise the profile of skin patients and contribute to a more responsive healthcare system.

Sincerely,

Munish Mohan
Chair

Rachael Manion
Executive Director

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About Us

The Canadian Skin Patient Alliance (CSPA) is Canada's go-to resource for information regarding conditions that affect skin, hair, and nails.

The CSPA is a national non-profit organization. Our mission is to promote skin health and improve quality of life. To achieve this mission:

- 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, melanoma, and psoriasis.

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.

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.

Skin Patient Charter of Rights

The CSPA was awarded a Public Education Award (Not-for-Profit Category) by the [Canadian Dermatology Association](#) for the Skin Patient Charter.

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.

The Skin Patient Charter of Rights also received international attention this year. CSPA presented a poster on the Skin Patient Charter at the 9th Global Patient Congress (September 16 & 17, 2020) at the virtual exhibit booth of the [International Alliance of Patient Organizations](#), of which CSPA is a member.

Shed the Shame 2021

After the success of the Shed the Shame campaign in 2020, CSPA decided to make this an annual mental health awareness campaign. We chose to focus on the psychosocial aspect of living with a visible skin condition for broader appeal across the skin patient community.

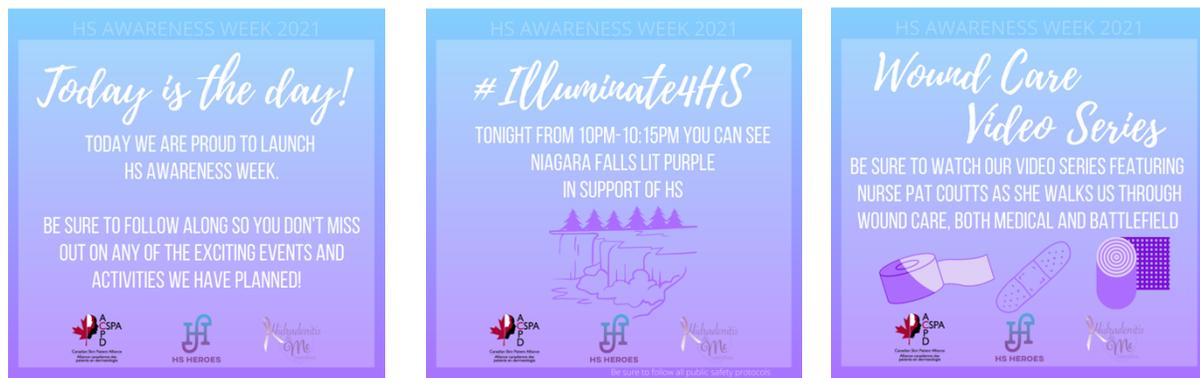
We worked with students from Ottawa's [Algonquin College](#) advertising program to develop the creative content for the campaign, which we launched on Bell Let's Talk Day. The campaign focused on bringing to light the whispers that a skin patient might hear and answering those "rumours". A tin can telephone concept was used.



We implemented a video element as well with a launch video that was created by students in the Algonquin College advertising program and was featured on our YouTube Channel. We provided a toolkit to our Affiliate Members so they could easily promote the campaign on their channels, and a [campaign page](#) was developed for the CSPA website with a call to action for people to share their stories about facing stigma in their own lives. The campaign reached over 90,000 on social media channels.

HS Awareness Week

CSPA led a successful HS Awareness Week campaign (June 7-13, 2021) in collaboration with [Hidradenitis & Me Support Group](#) and [HS Heroes](#). The three groups worked together to illuminate landmarks across Canada in purple to recognize HS. As well, throughout the week, together we shared a wound care video series that tackled specific issues faced by people with HS using medical supplies and “battlefield” materials that people usually have around the home, led by HS Heroes. Hidradenitis & Me hosted a cooking class with recipes people living with HS might find consistent with common dietary choices in the community. We were also fortunate to have 2 provinces and 8 cities issue proclamations declaring June 7-13 HS Awareness including Alberta, Newfoundland and Labrador, Toronto, and Ottawa.



Atopic Dermatitis Youth Art Contest

For Eczema Awareness month (November 2020) the CSPA hosted a youth art contest, asking Canadian youth to share their experiences, and draw how “eczema made them feel”. The contest had three aged categories: Primary, Intermediate and Senior, and a prize was awarded in each age group. Each winner received a cash prize of \$150 and the winning artwork for each age group was printed on the outside back cover of the Spring 2021 Issue of *Canadian Skin* and *À Pro peau* magazines, as well as featured on our website. We received close to 20 entries.

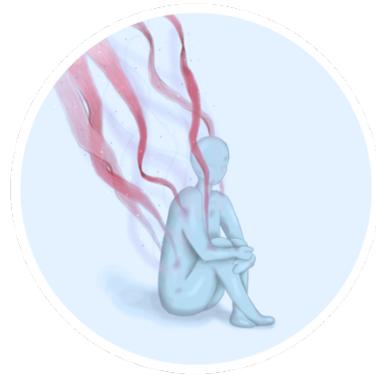
The winners in each category were:



Luke V - Primary



Victoria P – Intermediate



Majari M – Senior

The winners' artwork may also be featured on a tote bag or other marketing merchandise in the future.

Raising awareness in the community

In 2020-2021, we also supported Acne Awareness month, Craniofacial Acceptance month, World Patient Safety Day, Urticaria Day, Alopecia Awareness Month, World Mental Health Day, EB Awareness Week, National Pain Awareness Week, Rare Disease Day, World Lymphedema Day, Rosacea Awareness Month, National Nurses Day, and Pride month using our social channels.

The CSPA provided information to [Best Health](#) magazine about [cold sores](#) in October 2020.

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. CSPA is a proud supporter of the Skin Spectrum Summit, led by [Chronicle Companies](#), to discuss issues related to skin of colour and dermatology.

Education

The CSPA has focused on developing fully bilingual resources to best support skin patients and their caregivers across Canada, expanded our resources to include more hair, skin, and nail conditions, and developed content and resources that better reflect the diversity across Canada.

Canadian Skin magazine

The CSPA's official publication is our award-winning magazine, *Canadian Skin* (in French, it is called *À Propeau*). In October 2020, we launched our Fall 2020 issue, featuring articles on treating atopic dermatitis in children, psoriasis and HS during COVID-19, a close-up on pemphigus, and a guide to laser treatments.



In 2021, we refreshed our magazine both in print and redeveloped the digital version to be more interactive. We released the Spring 2021 issue on the CSPA website in English and French, with features on dermatology in northern communities, patch testing for contact dermatitis, a close-up on psoriasis, and raising the profile of skin patients through advocacy.

The CSPA also launched their Summer 2021 issue of *Canadian Skin*, featuring articles on talking to your dermatologist about respectful visits for Muslim patients, a close-up on hyperhidrosis, teledermatology in Canada, and sun protection and kids.

Information about skin conditions and diseases

We are working with the translator to complete translations of skin conditions and diseases so that each one listed in English is also available in French. A new section on **hyperhidrosis** was added in English and French to the CSPA website to complement the close-up section in the

Summer 2021 issue of *Canadian Skin* magazine. **Pyoderma gangrenosum** was also added to our website in French and in English. As well, the **nail fungus** section of the website was updated, and the CSPA endorsed an updated guide to nail fungus prepared by Bausch Health Canada, which was accompanied by a bilingual social media campaign to raise awareness and educate our audience on nail fungus infections.

Resources for skin patients

In addition to our magazine and information added about specific skin conditions, the CSPA has produced specific resources for skin patients and their loved ones.

The CSPA has updated our **COVID-19 page** with the latest information on the virus and vaccines as it relates to the skin patient community, addressing questions around COVID-19 and the risks for immunocompromised individuals, managing flares related to COVID-19 stress, and other questions that are important to the community.

A Top 10 Tips resource for treating **children and youth with atopic dermatitis** has been finalized for CSPA’s website in English and French and was also shared on CSPA’s social channels. This was developed to complement the magazine article in Fall 2020 on this topic.

Two new resources for Muslim skin patients were released in English and French during Ramadan (April 13 – May 12, 2021): **Wudu and Skin Care**, which discusses wudu-pattern xerosis (dry skin that can result from religious washing 5 times per day), and **Hijab and Hair Care**, which talks about the impacts on the hair from wearing a hijab (including traction alopecia) and ways to mitigate them. These were complemented by the article in the Summer 2021 issue of *Canadian Skin* magazine.

HIJAB AND HAIR CARE
By Zahra Niaz
Hair care specialist and dermatologist

Worries about hair loss are a common concern for women who cover their hair, such as those who wear the Hijab (religious attire worn by some Muslims). While the hijab itself does not cause hair loss, practices surrounding the hijab and covering of skin can create an environment of poor hair quality, excessive pressure and traction, all of which can contribute to excess hair loss.

NORMAL HAIR LOSS
While it may seem like you are losing too much hair from wearing the hijab, this may only seem excessive due to not shedding hair throughout the day. Hair loss of 50-100 strands a day can be considered normal [1], and this typically happens throughout the day. As one's hair may be tied under the hijab all day, hair loss may look significant upon removal, but this may well might be in the range of normal. Long-held styles, chokes or hair falling out or patchiness are all signs that you may be losing more hair than normal.

HAIR CARE PRACTICES
It is possible to engage in hair care practices that encourage hair loss. Tightly wrapped hair styles under the hijab may cause traction alopecia - a condition leading to hair loss where the hair is constantly pulled [2,3]. Traction alopecia is most common with frequent use of tightly wrapped braids, buns or pig tails [2]. To prevent traction alopecia, avoid tight or pulled hairstyles or styles that result in headaches or pain to your scalp. Traction alopecia, in its early stages, can be reversed with cessation of tight hair styles [3]. Consult a dermatologist to see what treatments may be suitable for you, particularly if you do not notice improvement at the site of traction alopecia within a few months of pain-free, gentler handling [3].

LONG-TERM HAIR LOSS
Hair loss can also be a sign of other health conditions or deficiencies. If you are concerned about excessive hair loss after following preventive methods, see your primary care provider or dermatologist. The two most common causes of hair loss are endocrine disorders, who known as male or female pattern baldness, and telogen effluvium. Androgenetic alopecia is related to an excess in hormones known as androgens [4]. This occurs without any other underlying diseases or deficiencies and is treated with blocking the actions of androgens. Telogen effluvium is caused by poor nutrition or situation (A stress, fever, surgery) that results in more hair follicles within the telogen phase (hair loss or 'shedding') [5]. Hair loss begins 8-12 weeks after the insult and continues within a few months without intervention [4]. Hair loss can however be caused by imbalances in hormones, such as with thyroid imbalances [6] or in blood or electrolyte imbalances [6]. Hair loss could also be due to deficiencies in nutrients, especially vitamin D. Vitamin D deficiency is thought to increase hair loss [7], and this is likely to be more prevalent in Muslim women wearing the hijab. Recent literature has demonstrated that Muslim women wearing the hijab are more likely to have a Vitamin D deficiency [8-9], likely due to reduced sun exposure to the sun.

RESTORE YOUR HAIR HEALTH
while wearing hijab
Dr. Shereen Khalil
Hair care specialist and dermatologist

While hijab itself does not damage your hair, many practices around the hijab may. The first step in restoring your hair health is identifying any underlying deficiencies or hormone imbalances (i.e., iron deficiency anemia, polycystic ovarian syndrome or thyroid dysfunction) and any practices that may be damaging your hair. Resolving these underlying issues is critical to both restoring and maintaining the health of your hair. If you are concerned about hair loss/ thinning, make an appointment with your family doctor to discuss potential bloodwork and possible assessment by a dermatologist.

PART 1: PREVENTING FURTHER DAMAGE

Fabric Matters
Synthetic fabrics like nylon and polyester are more likely to cause friction and mechanical damage. These synthetic materials are also thought to generate an electrostatic charge that inhibits hair growth [1]. Natural fibers, like cotton, are gentler on the hair. Avoid a synthetic undercap when wearing a synthetic fabric.

Avoid the 'wash and wrap'
Hair that is more likely to be damaged by mechanical breakage, such as rubbing from harsh hijab fabrics [2]. Wrapping your hair so tightly in a bun and then putting on a hijab makes your hair strands more prone to breakage.

Let it loose
Keeping your hair tied up puts tension on your roots that if strong enough can even lead to hair loss [3]. When you come home, let your hair loose and massage your scalp. Gently massage the scalp to increase circulation to the hair and help release sebum - an oil that gives your hair its healthy sheen. Gently massage in men have strengthening been shown to increase hair thickness [4].

Change your part
Changing your hair part under your hijab can help avoid putting tension on the same areas. This helps avoid a condition known as traction alopecia which grows from repeated tension in the same area [5].

Get some Supplements
The role of supplements, in particular Vitamin D and Zinc, has been explored for treatment of hair loss. The role of Vitamin D deficiency in hair loss is not yet fully understood and based on data from animal models and observational studies [6-8]. However, vitamin D deficiency is common among healthy women, particularly those who live in more northern communities [7, 9]. Integrating Vitamin D into your diet (yogurt, milk, salmon and other foods) or taking a supplement may also help in certain populations. Ask your doctor about this. The role of Zinc supplementation has not been proven to help with hair loss [10].

RESTORE YOUR HAIR HEALTH
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PART 2: RESTORATION
A number of clinically proven treatments to restore hair loss exist. The use of topical **Minoxidil** and systemic **oral minoxidine** has great evidence for the treatment of androgenetic alopecia [3]. Many supplemental treatments have become popularized in the media. A summary of what is currently known about these treatments are below:

Biotin
Biotin is known as vitamin B7 or vitamin H, is a water-soluble vitamin that helps in the metabolism of fats and proteins. Biotin plays an important role in hair health and is found in many foods, like yeast and sweet potatoes. While biotin deficiency can lead to a red, itchy rash, a decreased blood pH and changes (over time) to brittle nails, a true and long-term deficiency from hair loss and thinning [2]. There is a clinical evidence for the advanced claim that biotin helps and stimulates hair growth in the absence of a biotin deficiency [4,6]. In addition, the risk of biotin treatment may outweigh the benefits, and treatment with biotin is known to interfere with certain medical investigations, such as thyroid immunoassays [5].

Ashwagandha
Ashwagandha, also known as Indian ginseng, is a plant in the nightshade family traditionally used for stress reduction and its anti-inflammatory properties [4]. It is used as an ingredient in several nutraceutical supplements. Evidence for nutraceutical supplements are often limited due to small sample sizes and limited diversity in clinical and cultural populations. While the therapeutic effects are not well understood, to date, no adverse events have been reported with use of ashwagandha extracts [7, 8].

Natural Hair Oils
The scalp has sebaceous glands that secrete an oily substance called sebum which lubricates the hair and contributes to the defense integrity and maintenance of healthy hair [9]. Specific grooming practices and normal hair weathering lead to a progressive loss of lipid production (a major component of sebum) contributing to a decrease in hair health through and breakage [9]. The rationale for hair oils, such as olive or argan, is that they will replace these lost lipids and improve hair integrity. A third competing argument is that the natural fat seal of hair and scalp is not able to increase the levels of lubricant fatty acids continuously over an 8-month period [12].

Platelet-Rich Plasma (PRP) Therapy
Platelet-Rich Plasma (PRP) therapy is a three-step medical regenerative treatment that uses a patient's own platelets to trigger natural hair growth [10]. The treatment begins with the patient's blood being drawn, processed and finally injected into the scalp, increasing blood supply to the hair follicles and thereby thickening or about [14]. PRP has been shown to be effective at increasing the number of hairs and overall hair density in patients with androgenetic alopecia (hair loss due to hormones called androgens) and is offered at cosmetic dermatology clinics [15-16]. While effective, PRP can cost for some at approximately \$1000 a treatment [11].

Hair Transplant
Hair transplant is a surgical procedure in which areas of your non-alopecic hair are used to fill areas with thinning or no hair [17]. It involves the removal and replacement of either individual hair follicles or an entire strip of scalp from affected areas [17]. Although the transplant has a high success rate, they are relatively costly at \$4,000 to \$10,000 depending on the area and type of the transplant.

Advocacy

For the CSPA, advocacy is simply about sharing skin patients' experiences and perspectives with those who make decisions. We believe that if our policymakers really could understand *what it feels like to live with a skin disease*, they could – and would – make decisions that would positively affect our lives.

COVID-19 & access to dermatology care

To better understand the challenges faced by the skin patient community during COVID-19, CSPA worked with Dr. Raed Alhusayen & Sheida Naderi-Azad at [Sunnybrook Research Institute](#) to report on the findings of a community survey. This was shared through CSPA's social channels and with our Affiliate Members, and a broad variety of skin patients participated in it. Skin diagnoses included alopecia, skin lymphoma, atopic dermatitis, psoriasis, hidradenitis suppurativa (HS), acne, melanoma, rosacea, and wart/molluscum.

The survey asked people about how they saw their care providers (in person or virtual) and what impacts they experienced from the pandemic, including mood changes, modified work, challenges accessing and affording medication, and changes to their treatments. [Impact of COVID-19 on Access to Care: A National Patient Survey](#) was published by the *Journal of Cutaneous Medicine and Surgery* in May 2021.

COVID-19 & cancer care

We were proud to participate in a conversation among cancer patient organizations who form the COVID-19 Cancer Task Force about the impact of COVID-19 on cancer care and how to reduce these impacts on patients. This is an ongoing conversation that has been led by [All.Can Canada](#) & the [Save Your Skin Foundation](#) (Affiliate Member).

Improved health services for skin patients

Leading up to the federal government's Budget 2021, the CSPA provided a pre-budget submission to the government, calling on it to provide funding to:

1. address the backlog in health systems across the country;
2. support the expansion of virtual dermatology and primary care; and
3. recognize the value of treatments for patients living with skin disorders that are delivered at home or in the community through different policies.

The CSPA also joined a group of cancer patient organizations calling on the federal government to increase the amount provided to provincial and territorial governments to support the health

systems considering the impacts of COVID-19. The federal government announced \$5B in funding for COVID-19 immunizations (\$1B) and a one-time increase in the Canada Health Transfer (\$4B).

Better access to treatments for skin patients

The way that treatments for rare skin diseases reach patients in Canada adds many hurdles. Health Canada has consulted with patients, including the CSPA, about how to improve this process through a **rare disease drug strategy**. We are also proud to support the work of [Global Skin](#) to collect data on rare skin diseases around the world, including in Canada.

When it comes to **drug prices**, the CSPA has actively and consistently advocated for access through affordability of treatments for skin conditions. We hear from patients who have trouble affording their prescriptions and are developing a tool to help you understand if you are covered when you have a prescription. When it comes to changing policy, the CSPA has urged the Patented Medicine Prices Review Board, which sets the price ceiling for patented medicines, to engage stakeholders meaningfully, including on how it evaluates changes it plans to make to how ceiling prices are set for these medicines in Canada.

We have also underscored the importance of meaningfully engaging patients in **health technology assessment**, supporting an initiative led by Affiliate Members [Save Your Skin Foundation](#) and [Canadian Psoriasis Network](#).

As new treatments are reviewed before governments decide whether to include them in their public drug plans, the CSPA draws on feedback from patients and caregivers about those treatments and how they might help address unmet needs. This year, we provided patient input about:

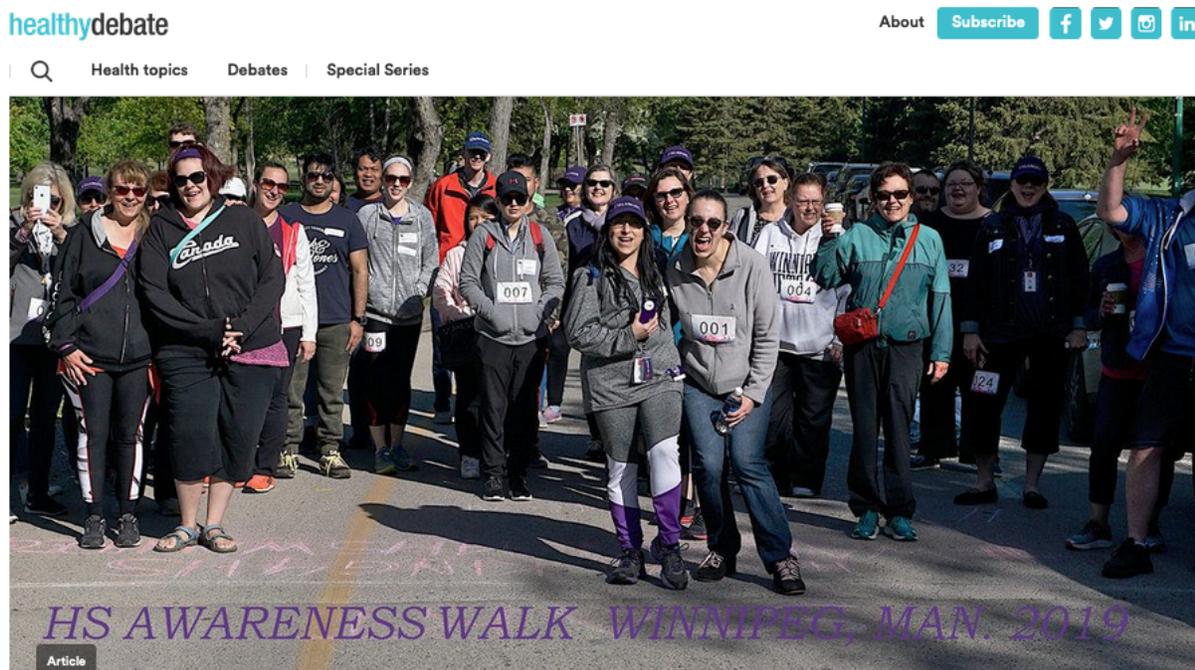
- Dupixent (dupilumab) for **atopic dermatitis** (12 years and up) in collaboration with [Eczéma Québec](#) (CADTH, INESSS)
- Rinvoq (upadacitinib) for **atopic dermatitis** (12 years and up) in collaboration with [Eczéma Québec](#) (CADTH, INESSS, BC Your Voice)
- Abrocitinib for **atopic dermatitis** (12 years and up) in collaboration with [Eczéma Québec](#) (CADTH, INESSS, BC Your Voice)
- Adtralza (tralokinumab) for **atopic dermatitis** (adults) in collaboration with [Eczéma Québec](#) (CADTH, INESSS, BC Your Voice)
- Ledaga (chloremethine hydrochloride) for **cutaneous T-cell lymphoma-mycosis fungoides type** (cTCL-MF) (adults) in collaboration with [Lymphoma Canada](#) & the [Cutaneous Lymphoma Foundation](#) (CADTH, INESSS)

The CSPA co-authored a [commentary](#) in the *Journal of Cutaneous Medicine and Surgery* on **biosimilar policy** that noted gaps in how skin patients access off-label biologics and whether biosimilars would also be available for those patients. It also looked at the role of Patient Support Programs offered by manufacturers and encouraged improved programs so that patients have access to similar resources regardless of which program they may use.

Advancing hidradenitis suppurativa (HS) report recommendations

In May 2020, the CSPA released [Scarred for Life: 2020 Update – A National Report of Patients’ Experiences Living with Hidradenitis Suppurativa](#), which included recommendations to improve the lives of people living with hidradenitis suppurativa (HS). The CSPA provided a [submission](#) to the Canadian Pain Task Force consultation on **pain management in Canada** that highlighted the findings of the 2020 HS Report – only 11% of respondents felt their pain was managed adequately.

To improve awareness about HS, CSPA worked with [Healthy Debate](#) to publish an [article](#) on the personal aspects of living with HS and the importance of getting diagnosed, which featured patients who discussed their lived experiences. We also shared a [poster](#) about our findings and copies of our report and HS resources at the Symposium on HS Advances (October 2020).



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..

SkIN Canada’s primary focus in 2020-21 was establishing the network and planning for the Priority Setting Initiative (PSI). The PSI is a project to create Top 10 lists of unanswered research questions important to skin patients & caregivers, clinicians, and researchers in Canada. The CSPA worked with other skin patient organizations in Canada to reach out to patients & caregivers and hear their priorities directly from them. At the end of this project, there will be a Top 10 list for nine specific conditions, which can influence research funders, researchers, and potentially even the pharmaceutical industry.

Inflammatory skin conditions	Non-melanoma skin cancers	Wound healing, skin fibrosis and regeneration
Atopic dermatitis Eczéma Québec Eczema Society of Canada	Basal cell carcinoma Squamous cell carcinoma Merkel cell carcinoma	Burns Canadian Burn Survivor Community
Hidradenitis suppurativa Hidradenitis & Me Support Group HS Heroes	Save Your Skin Foundation Melanoma Network of Canada	Chronic wounds
Psoriasis Canadian Association of Psoriasis Patients Canadian Psoriasis Network		Scars

The CSPA team has facilitated sessions with patients and caregivers to help researchers affiliated with Skin Canada get their feedback on research tools (for example, questionnaires) and plans in early stages of research.

CSPA remains committed to the growth of the network. From translating technical language into regular language, to advocating for more public skin research funding and raising the profile of skin research in the community, CSPA has been connecting the research network with patients, patient organizations, clinical experts, and industry.

skincanada.org
TAKE OUR SURVEY!

DO YOU HAVE EXPERIENCE WITH ONE OF THESE CONDITIONS?

- burns
- scars
- chronic wounds
- squamous cell carcinoma
- basal cell carcinoma
- Merkel cell carcinoma
- atopic dermatitis
- hidradenitis suppurativa
- psoriasis

Shine a Light on YOUR Unique Experiences and Help Shape Skin Research across Canada

A CSPA P D
Canadian Skin Patient Alliance
Alliance canadienne des patients en dermatologie

Skin Investigation Network of Canada
Réseau Canadien de Recherche sur la Peau

TAKE OUR SURVEY!

DO YOU HAVE EXPERIENCE WITH ONE OF THESE CONDITIONS?

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- chronic wounds
- squamous cell carcinoma
- basal cell carcinoma
- Merkel cell carcinoma
- atopic dermatitis
- hidradenitis suppurativa
- psoriasis

Tell Us: Which Unanswered Research Questions are Most Important to You?

Help Shape Skin Research Across Canada.

A CSPA P D
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Skin Investigation Network of Canada
Réseau Canadien de Recherche sur la Peau

At the SKIN Canada Trainee Bootcamp in November 2020, CSPA’s Executive Director moderated a fireside chat of three patients who had previously been patient research partners (i.e., part of a research team), including Latoya Palmer, founder of **Hidradenitis & Me**, Christian Boisvert-Huneault, **Canadian Association of Psoriasis Patients** Co-Chair, and a leader in patient engagement in research who lives with a rheumatology condition. They shared their diverse experiences to educate researchers about the possibilities of working with patients as part of the research team.

Letters of support for research projects

The CSPA continued to provide letters of support to researchers across Canada for their important skin research.

Supporting CSPA's Affiliate Members

The skin patient community is wide and diverse. Fostering the skin patient community is an important cornerstone of the CSPA's work. We support our Affiliate Member organizations who work with specific skin patient communities such as those living with acne, scleroderma, melanoma, and psoriasis.

The CSPA welcomed two new Affiliate Members:

1. HS Heroes
2. Tumour Foundation of BC



**Tumour
Foundation
of BC**

CSPA Affiliate Member Meeting

The Canadian Skin Patient Alliance held a virtual meeting of its Affiliate Members on November 12 & 13, 2020. The last meeting of Affiliate Members was held in 2017, when CSPA debuted its strategic plan.

The meeting was held by Zoom over two half-day sessions to enable participation from across the country. To inform our meeting agenda, we surveyed the Affiliate Members about the top challenges facing their communities and organizations.

The first day of the meeting was focused on discussions about challenges facing the distinct patient communities represented by Affiliate Members and to better understand collective priorities of the skin patient community. A virtual discussion and networking session was held following the first day session, at which CSPA was pleased to welcome funders of the Affiliate Members 2020 meeting.

There was consensus that the areas of focus and the efforts being undertaken by CSPA to date are valuable and well-aligned with the Affiliate Members' needs and priorities. Enhancing members' ability to communicate together, share opportunities, share promising and best practices, and speak with a unified skin patient voice are important and valuable.

Affiliate Members shared that CSPA helps present a unified skin patient voice while appreciating how different skin patients experience their conditions differently.

There was consensus that mental health unites us all. COVID has really exacerbated and highlighted this. Skin conditions and burns cause stigma, internalized discrimination, and shame, contributing to poor mental health. There was consensus to continue and expand the annual #ShedTheShame mental health awareness campaign to cover more types of skin conditions. Diversity and inclusion are important and different members are looking for support in how to improve their ability to engage and support diverse members of their communities.

Affiliate Members also shared their desire to have a new platform to connect with one another and create communities of practice among skin patient organizations.

The second day of the meeting focused on capacity building in the areas of social media and fundraising. We also held a debrief of advocacy and awareness discussions from the first day of the meeting.

There were 18 attendees across 13 organizations over the two-day meeting:

- Acne and Rosacea Society
- BC Lymphedema Association
- Camp Liberté Society
- Canadian Alopecia Areata Foundation (CANAAF)
- Canadian Burn Survivor Community
- Canadian Psoriasis Network
- Eczema Society of Canada
- Hidradenitis & Me Support Group
- HS Heroes
- Melanoma Network of Canada
- Save Your Skin Foundation
- Scleroderma Manitoba
- Stevens Johnson Syndrome Canada

Tanny Nadon Affiliate Members Grants

The Tanny Nadon Affiliate Member Grant (2015-2021) was created by CSPA to support educational activities of our Affiliate Members. Eligible projects included, but were not limited to, websites, pamphlets, newsletters and endeavours that served to raise visibility or awareness. Tanny Nadon was an inaugural member of the CSPA Board of Directors and a founding member of the Alberta Society of Melanoma, (that has since merged with Affiliate Member, Save Your Skin Foundation).

October 2020	Canadian Alopecia Areata Foundation (CANAAF)
April 2021	Hidradenitis & Me Support Group
	Canadian Psoriasis Network

Congratulations to all recipients of the Tanny Nadon Affiliate Member Grant!

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 2020

The Canadian Skin Patient Alliance recognizes **Dr Raed Alhusayen** for his:

- 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 Alhusayen's leadership in the development of [Scarred for Life: 2020 Update – A National Report of Patients' Experiences Living with Hidradenitis Suppurativa](#) and sharing our findings to fellow dermatologists & patients.

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)

Dr. Isabelle Delorme (Quebec)

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)

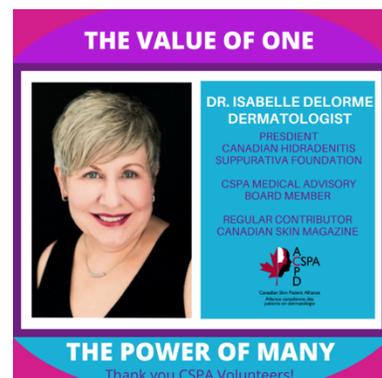
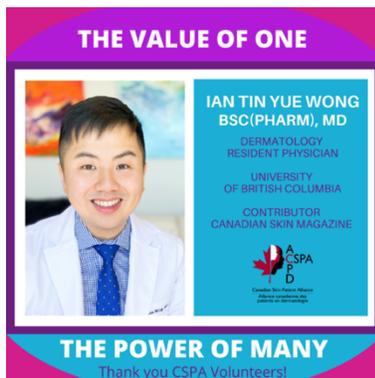
Board of Directors

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.

Munish Mohan	Chair
Julie Powers	Co-Chair (2020)
Jeff Losch	Co-Chair (2021)
Tochi Omoloye	Treasurer
Hansi Peiris	Secretary (2020)
Barbara-Anne Hodge	Secretary (2021)
Sandy Burton	Director
Christine Butler	Director
Ivan Eggers	Director
Shiamala Paramasivam	Director
Chris Peralta	Director (2021)
Thomas Dornoy	Director (2021)

Volunteers

CSPA is proud to have a team of approximately 70 volunteers. Their sharing of professional and personal experiences helps CSPA deliver educational materials and respond to patients' and caregivers' questions and concerns.

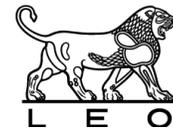


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**Alliance canadienne des
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Canadian Skin Patient Alliance
111 – 223 Colonnade Rd South
Ottawa, ON. K2E 7K3

613-224-4266 | 877-505-2772 | info@canadianskin.ca