

Canadian Skin Patient Alliance  

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Alliance canadienne des  
patients en dermatologie

# STRATEGIC PLAN

2022-27



# Executive Summary

The Canadian Skin Patient Alliance (CSPA) is a national non-profit organization dedicated to the education, support and advocacy of all Canadians living with skin, hair and nail conditions. CSPA advocates for the needs of patients in Canada and provides a wide range of educational and support resources.

In October 2021, the Canadian Skin Patient Alliance (CSPA) engaged consultants Leah Stephenson and Nicci Stein to conduct a strategic planning process for the organization. Using 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.

# Vision

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



# Mission

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



# 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.

# Methods

After initial meetings between the Executive Director, a long-time Board member, and the consultants, a Strategic Planning Committee was formed to oversee the process. The Committee was made up of the Executive Director and two Board members. The Strategic Planning Committee approved the work plan and timelines for the project.

The Strategic Planning process consisted of three phases.

- Phase 1: Gather information (consultations)
- Phase 2: Establish priorities (thematic analysis of the data)
- Phase 3: Validate and finalize (planning day; writing of final plan)

Consultations were conducted through three methods: individual key informant interviews, online surveys, and focus groups (one with staff and one with Board members).

## Key informant interviews

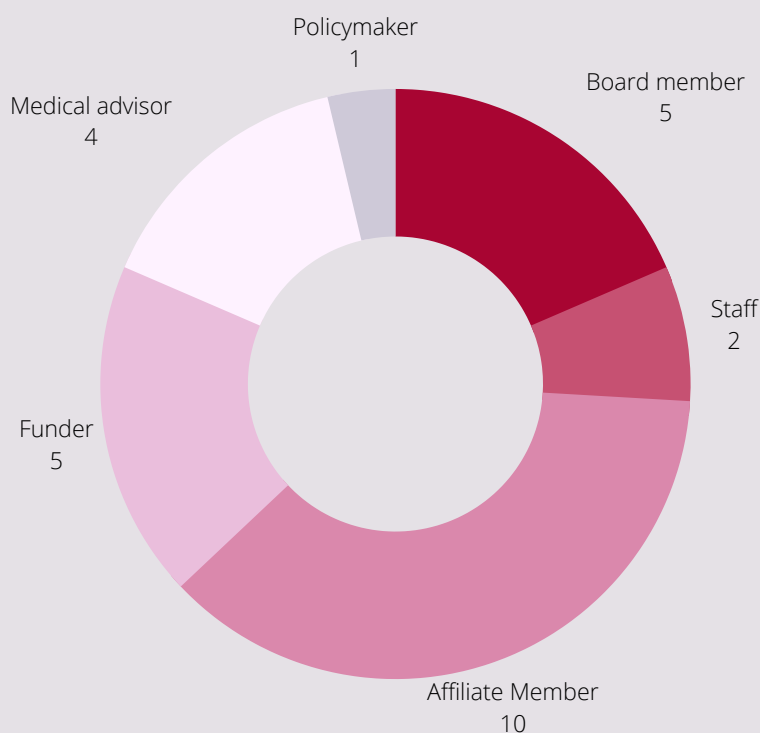
The Strategic Planning Committee provided a list of 12 people to interview. Interviewees had close and long-standing relationships with CSPA and had a good understanding of the organization. Interviews were conducted over a period of two months.

Seven individual interviews were conducted, representing a range of stakeholders. Of these seven interviewees, three were from Affiliate Member organizations, two were doctors who had long-term involvement in CSPA (one was a founder), one was a funder, and one was from a partner organization.

Interviews lasted between one and 1.5 hours and were guided by a set of questions developed by the consultants and Strategic Planning Committee.

### Online survey

An online survey was developed using the same set of questions as the interviews. The survey was made available in both English and French. Links to the surveys were circulated to Affiliate Members, partners, and other stakeholders. Thirty English and three French surveys were completed.



### Focus Groups

Two virtual focus groups were held using Zoom, one with five staff and the other with seven Board members. The same guiding questions were used to facilitate the discussions.

### Thematic Analysis

Once all elements of the consultation methods were completed, the qualitative data were compiled, and a thematic analysis was conducted to surface common themes across stakeholders and distinctions between stakeholders.

# Results

Consultation questions focused on the following key areas:

- The internal strengths of the organization., what CSPA excels at, and what makes it unique;
- Areas where CSPA might need to strengthen capacity to enhance impact;
- External opportunities that CSPA could leverage to enhance its goals; and
- External barriers that CSPA might face in pursuit of its goals.

CSPA also wanted to check in with stakeholders about its Vision and Mission statements and sought feedback about how they could be strengthened.

## Strengths and Uniqueness

The convening role - connecting, supporting, advocating and educating is central to CSPA. The organisation uses a range of opportunities and tools to support skin patients. Being able to bring together many different groups under one umbrella to support, learn from each other, and advocate together is what sets CSPA apart. Without CSPA playing this role, the various Affiliate Member organizations would lack a way to effectively network, share best practices, and advocate for common issues.

In terms of advocacy, CSPA acts as the national skin patient voice interacting with policy makers. Advocacy efforts are supported by excellent tools including reports and infographics. This is an important role, and CSPA is strong in this area. CSPA has a presence at tables where patient voices need to be heard and opens the door to dermatologists and other influential people/organisations.

Educational tools and information are developed by CSPA, particularly for skin conditions where no patient organisation exists. CSPA is “data driven” and produces high quality, evidence-based reports. Materials, website, and resources are all “top notch”.

Cultivating relationships with a range of different stakeholders (e.g., pharma, government, dermatologists, patients), collaboration is a centrally defining feature as CSPA co-develops and collaborates in everything they do. Their credibility with dermatologists and researchers makes them well-positioned from a patient perspective.

The ability to operate with both breadth and depth is highly valued across stakeholders as a way of bringing better health outcomes for patients. CSPA effectively navigates through a complex landscape to focus on what’s important. CSPA’s mandate includes 3,000 skin conditions, over 1,000 of which are rare. This leads CSPA to be invited to many different tables where they interact with other networks and organizations active in the healthcare field. They are sought out because of this unique role.

The organization has a “stellar reputation”, is well-respected, and held in high regard. They are credible and well established. Strong leadership from the Executive Director who is described as very accessible, responsive, extremely strategic, and thoughtful. The organizational culture makes it open and accessible for Affiliate Members and they are always willing to help. Staff are described as being wonderful, knowledgeable, engaging, encouraging, service-oriented with a high level of professionalism.

### **Areas to strengthen to enhance impact**

Strengthen the CSPA’s profile and brand and increase awareness to increase CSPA’s reach and impact. Target audiences would be dermatologists, other relevant healthcare professionals, skin patients, and the public.



Clearly define and articulate CSPA's identity and role to capture the essence and central purpose of the organization. While the breadth and range of the skin conditions included in the organization's mandate is one of its greatest strengths, this also poses challenges. Maintaining a balance between attention given to the different skin conditions and deciding how to prioritize activities is key.

Strengthen capacity in fundraising and funding diversification, including applying for charitable status. This also offers opportunities to engage supporters in different ways. Diversifying funding would also reduce reliance on industry funders. Without adequate funding, the organization is limited in its ability to pursue its goals.

Increased staffing will be needed to expand programming. Staff are currently working at maximum capacity.

### External opportunities that could help CSPA realise its goals

Continue putting the patient voice front and centre in all CSPA activities and decisions, which provides opportunities for future growth and development. It defines the organization's role and purpose.

Opportunities for research exist now that CIHR requires integrated teams on all grant projects. There are current opportunities to increase the visibility of patients and the patient voice in research priorities and projects. Combining efforts with other patient groups may offer opportunities in research and drug policy. There is no Canadian research chair in dermatology and medical advisors felt there was a need for patients to also advocate for this.

Healthcare systems strengthening, post-COVID-19, is an opportunity as there is a greater awareness of the gaps and deficiencies in the healthcare system and the need to build a better system into the future. These endeavours benefit CSPA and offer opportunities for advocacy and improving skin patient health outcomes.

The pandemic has also shone a light on mental health issues in general, thus opening the door to a greater understanding of the mental health impacts of skin conditions. The lack of understanding of the serious impact that skin conditions can have on a patient's quality of life is a major challenge.

COVID has also highlighted the pros and cons and potential expanded use of virtual healthcare. The greater availability, accessibility, and effectiveness of various forms of virtual care are particularly important for rural, remote, and more isolated patients.

Affiliate Members appreciate the opportunities presented to CSPA by being engaged in the global skin movement and helping Affiliate Members feel connected to issues on a global level and engage in broader advocacy initiatives.

There is an opportunity to build a stronger relationship with the Canadian Dermatology Association (CDA).

Upcoming new treatments for some skin conditions offer quality-of-life improvements for patients and the need for advocacy related to ensuring patient access to new treatments.

During the planning day, Board and staff members considered the feedback gained through the consultations and participated in a number of strategic prioritisation exercises. The following four areas emerged as top strategic priorities for CSPA over the next five-year period.

CSPA also decided to take the opportunity to check in with stakeholders about the organization's Vision and Mission statements. Participants at the Planning Day considered the feedback received through the consultations and discussed revised versions.



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