

## BACKGROUNDER

### THE CANADIAN SKIN PATIENT ALLIANCE

The Canadian Skin Patient Alliance (CSPA) is a national not-for-profit organization that provides education, information, a supportive online community, and opportunities to create and join local support groups for all Canadian skin patients. The CSPA also provides physicians and researchers with access to patients and their concerns regarding skin health. The CSPA is a patient-centred organization serving patient needs to enhance care, to promote skin health and to find cures for Canadian skin patients. The CSPA also serves as a national umbrella organization for 14 disease-specific patient organizations. Each year, the CSPA publishes a research report comparing access to dermatological services and drugs in each province and territory. The organization was formed in 2007 by a group of patients, dermatologists and others with an interest in skin because—unlike for many diseases—there was limited support for skin patients. Since then, our network of individuals and affiliated groups has continued to grow.

The CSPA's work is based on 3 pillars:

- **Patient and family support** through education—in the form of this website, a quarterly magazine called *Canadian Skin*, online tools, education sessions and a **biannual conference**—and strategic alliances with affiliated groups and industry.
- **Advocacy for skin patients** that involves increasing awareness at Health Canada and the provincial/territorial ministries responsible for health about the issues around skin conditions and diseases and their impact on Canadian citizens. Our **2012 report card on the state of dermatological care in Canada** will soon be available online. Current issues include timely access to care, increasing the number of dermatologists, better access to medications and additional training for non-dermatologist physicians and nurses.
- **Research support** through involvement in research projects and by disseminating results through the website, magazine and in white papers. Visit the **Research section** of this site for more.

The CSPA believes that skin patients should have access to dermatological care within an acceptable wait time and regardless of where they live in Canada. Canadians seeking treatment for medical skin disorders should not have to wait longer than five weeks to see a dermatologist—the national median wait time reported in 2001. Although it is not possible for all dermatology services to be available within commuting distance of all Canadians, the CSPA believes that phototherapy—the mainstay of treatment for many medical skin conditions—should be available to every Canadian, either in a clinic or as an insured service at home for those Canadians who cannot access a clinic.

The CSPA's position on access to dermatological care is as follows;

- Medical procedures should be insured services for all patients with a medical skin disorder.
- All drugs that are considered the standard of care should be funded without restrictions.
- Patients with rare skin diseases should have access to a medication or medical procedures for which there is reasonable evidence of efficacy, regardless of its regulatory approval status.

The CSPA's affiliate members are:

- AboutFace: [www.aboutface.ca](http://www.aboutface.ca)
- Alberta Society of Melanoma: [www.melanoma.ca](http://www.melanoma.ca)
- Alliance Québécoise du Psoriasis: [www.psoriasisquebec.org](http://www.psoriasisquebec.org)
- Basal Cell Carcinoma Nevus Syndrome Life Support Network: [www.bccns.org](http://www.bccns.org)
- BC Lymphedema Association: [www.bclymph.org](http://www.bclymph.org)
- Canadian Alopecia Areata Foundation: [www.canaaf.org](http://www.canaaf.org)
- Canadian Burn Survivors Community: [www.canadianburnsurvivors.ca](http://www.canadianburnsurvivors.ca)
- Canadian Pemphigus and Phephigoid Foundation: [www.pemphigus.ca](http://www.pemphigus.ca)
- Cutaneous Lymphoma Foundation: [www.clfoundation.org](http://www.clfoundation.org)
- DEBRA Canada: [www.debracanada.org](http://www.debracanada.org)
- Eczema Society of Canada: [www.eczemahelp.ca](http://www.eczemahelp.ca)
- Hidradenitis Suppurativa Foundation: [www.hs-foundation.org](http://www.hs-foundation.org)
- Save Your Skin: [www.saveyourskin.ca](http://www.saveyourskin.ca)
- Scleroderma Association of British Columbia

For more information on the CSPA, please visit [www.canadianskin.ca](http://www.canadianskin.ca)