



Canadian Skin Patient Alliance  
Alliance canadienne des  
patients en dermatologie

*for patients, by patients*

**VIA EMAIL: [cptfsecretariatsecretariatgtcsld@canada.ca](mailto:cptfsecretariatsecretariatgtcsld@canada.ca)**

May 27, 2020

Dear Members of the Canadian Pain Task Force,

Today, the CSPA is launching its report [\*Scarred for Life: 2020 Update – A National Report of Patients’ Experiences Living with Hidradenitis Suppurativa\*](#). A copy of the report is attached, along with the French version of our Executive Summary and Recommendations.

Hidradenitis suppurativa (HS) is a devastating inflammatory skin disease that produces discharge and a foul odor from many acute and chronic lesions. Up to 4% of Canadians live with HS. The painful lesions that are characteristic of HS appear in the skin folds, which makes activity and wearing comfortable clothing very challenging. It is often mistaken for boils, ingrown hair, a skin infection, generally poor hygiene, or a sexually transmitted infection.

This report provides an update to our baseline survey in 2017. We received 537 responses to the survey this year, 73 of which were from Canada. The HS community has seen some gains since our baseline report on the disease in 2017 – for instance, the median time to diagnosis has decreased from 9 years to 7 years. However, nearly all patients experienced some degree of pain daily, and, on average, moderate pain (5.3 out of 10 vs. 5 out of 10 in 2017).

Section VI (pp. 37-38) of the report focuses on HS patients’ experiences with pain management, and reflects the responses of HS patients around the globe. Most patients still do not have a successful pain management regimen. Only 11% of all respondents consider their pain to be very well-controlled, down from 19% in 2017. An additional 46% think their pain is poorly controlled, indicating that there is much room for improvement in helping patients manage this symptom. In 2017, 51% of respondents indicated that they manage their pain on their own without the help of a healthcare provider. In 2020, we saw some improvement in this figure, with 44% managing their pain without medical involvement. Given the significant amount of pain that accompanies this condition, it is troubling that such a large proportion of patients are self-managing. Less than 5% of HS patients have the help of a pain specialist to manage their pain. Many patients commented on the difficulty of accessing prescriptions for effective pain medications from their HCPs, reporting that they were often made to feel that they were exaggerating this symptom and/or were only seeking medication to feed an addiction.

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The CSPA has identified 11 recommendations to healthcare and providers and policy makers that will improve awareness about HS and care and management of the disease and the lives of HS patients. Two of the recommendations stemming from this report focus on better supporting pain management for HS:

- **Recommendation 5:** Expedite access to procedures. Those that are suffering from emergent symptoms involving discharge and excruciating pain should be able to access office-based procedures and surgical interventions (including those requiring operating room time) in a timely manner.
  - *This recommendation notes the important role of the federal government in supporting better access to needed procedures that get at the root cause of pain in HS across Canada.*
- **Recommendation 9:** Integrate a pain management discussion into every interaction with patients with HS. People with HS are experiencing pain on a daily basis, making it very important to create a pain control regimen so as to impact quality of life as little as possible. This should become standard practice as recommended in the North American clinical management guidelines for HS. Access to pain medications can often be very challenging for patients, due to heightened awareness of their addiction potential. It is important for family physicians to screen patients for pain, for patients to be able to quickly access pain specialists, and for HCPs to work together with patients to explore methods of pain management that are safe and effective, and be able to address the significant levels of pain that accompany HS.
  - *A national approach to managing pain should recognize the need of patients living with skin diseases including HS to have better access to pain management, including pain specialists and medications that alleviate the significant burden of living in pain every day.*

It is important to note that more than 4 out of 5 survey respondents reported that their condition had a negative impact on their work performance, their social lives, and their ability to be intimate with a partner. Optimal pain management would go a long way to improving the lives of patients with HS every day.

I would be pleased to discuss the report and our findings with you. Please do not hesitate to reach out if you have any questions.

Thank you for your important work.

Sincerely,  
Rachael Manion  
Executive Director