

# Hidradenitis suppurativa (HS)

## Highlighting the Unmet Needs in HS

Hidradenitis suppurativa (HS) is a chronic, systemic and often painful skin disease that causes recurring boil-like lumps that may burst into open wounds and cause irreversible scarring, often in the most intimate parts of the body.<sup>1</sup> These bumps can become sores (or abscesses) that can leak and leave scars.<sup>2</sup> While not rare, HS is a condition that's rarely talked about, with some patients waiting an average of up to 10 years to receive a correct diagnosis, which can result in disease progression and may significantly impact their quality of life.<sup>3,4</sup>

## Living with HS: Understanding the Patient Perspective

In a social listening study\* designed to understand HS-related treatment patterns and management strategies, researchers analyzed social media content from patients in the United States, France, Germany, Italy, Spain and the UK between November 2019 and October 2021.<sup>5</sup>

The data visualization below illustrates key findings from 1,626 social posts, which indicated that:

- Pain was the most discussed ongoing symptom for HS patients (36%)<sup>5</sup>
- The most discussed ongoing HS management strategies were dietary changes (47%), skincare products (26%) and clothing (12%)<sup>5</sup>

Among social posts related to treatment, antibiotics (27%) and surgery (21%) were discussed most, while only 16% of posts focused on biologics, underscoring the significant unmet need for physicians to discuss the range of treatment options available for patients.<sup>5</sup>

## Beacons of Light: Jasmine's Story

Anyone who shares their HS story is a Beacon of positivity and hope. We worked with advocate, journalist and filmmaker, Jasmine IVANNA Espy, to create a powerful docuseries about Beacons in the HS community in order to shine a light on life with HS.

Watch as Jasmine reflects on her experience with HS, her relationship with her body and how she found her purpose.

*Jasmine, an HS patient, was compensated for her time.*

Novartis remains committed to working with and hearing from the HS community to normalize conversations around this disease and its daily impact. “Shine A Light On HS” is a multiyear disease education campaign focused on raising awareness of HS to address the unmet needs that exist for the HS community. On the [website](#), people living with HS can find tips, information, resources and places to find support and connections with others to make their journey a bit smoother. People can also hear stories from other Beacons featured in our docuseries.

\*A retrospective search was performed on social media platforms for public HS-related content posted from November 2019–October 2021 in the US and EU (France, Germany, Italy, Spain, UK).

## References

1. MedLine Plus. Hidradenitis suppurativa [online]. Available at: <https://medlineplus.gov/genetics/condition/hidradenitis-suppurativa/> [Last accessed: February 2024].
2. Napolitano M, Megna M, Timoshchuk E, et al. Hidradenitis suppurativa: from pathogenesis to diagnosis and treatment. *Clin Cosmet Investig Dermatol*. 2017 Apr 19;10:105-115. doi: 10.2147/CCID.S111019.
3. Kokolakis G, Wolk K, Schneider-Burrus S, et al. Delayed Diagnosis of Hidradenitis Suppurativa and Its Effect on Patients and Healthcare System. *Dermatology*. 2020;236:421-430.
4. Kimball AB, Okun MM, Williams DA, et al. Two phase 3 trials of adalimumab for hidradenitis suppurativa. *N Engl J Med*. 2016;375:422-434.
5. Sayed C, Martorell A, Alacron I, et al. Unmet needs in treatment options and management strategies in hidradenitis suppurativa: understanding the patient perspective through social media listening. Poster presented at: American Academy of Dermatology 2023 Annual Meeting, March 17-21, 2023, New Orleans, LA, USA.

---

**Source URL:** <https://www.novartis.com/us-en/patients-and-caregivers/diseases/hidradenitis-suppurativa-hs>

## List of links present in page

- <https://www.novartis.com/us-en/us-en/patients-and-caregivers/diseases/hidradenitis-suppurativa-hs>
- <https://www.shinealightonhs.com/>
- <https://medlineplus.gov/genetics/condition/hidradenitis-suppurativa/>