

Highlighting the Unmet Needs in Hidradenitis Suppurativa (HS)

Living with Hidradenitis Suppurativa (HS): Understanding the Patient Perspective

Mar 16, 2023

Hidradenitis suppurativa (HS) is a chronic, or long-lasting, inflammatory skin condition with often painful bumps or boils that come and go, mostly on areas of the body where skin meets skin, like the groin, inner thighs, buttocks, under the breasts and in the armpits.¹⁻⁴ These bumps can lead to sores (or abscesses) that can leak and leave scars.^{1,3} While not rare, HS is a condition that's rarely talked about, with patients waiting an average of up to 10 years to receive a proper diagnosis.⁵

Unfortunately, for some patients, receiving a diagnosis takes even longer. Listen to Donna's story on living with HS - after first displaying symptoms at 13 years old, she describes the pain she experienced and the impact the disease had on her life and career. Ultimately, Donna embarked on a long journey to receive a proper diagnosis and find a dermatologist who could understand her needs and could help her find relief.

Too often, people living with HS can be suffering in silence through pain, stigma, shame and isolation; with few effective, long-lasting treatment options.⁶

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.^{7,8}

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%)^{7,8}
- The most discussed ongoing HS management strategies were dietary changes (47%), skincare products (26%) and clothing (12%)^{7,8}

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 new and effective treatments.^{7,8}

Novartis is committed to raising awareness of HS and working to address the unmet needs that exist for the HS community.

*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. 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.
2. Alikhan A, Sayed C, Alavi A, et al. North American clinical management guidelines for hidradenitis suppurativa: A publication from the United States and Canadian Hidradenitis Suppurativa Foundations. *J*

Am Acad Dermatol. 2019 Jul;81(1):91-101. doi: 10.1016/j.jaad.2019.02.068.

3. Sabat R, Jemec G, Matusiak L, et al. Hidradenitis suppurativa. *Nat Rev Dis Primers.* 2020;6(1):18. doi:10.1038/s41572-020-0149-1.
4. Fimmel S and Zouboulis C. Comorbidities of hidradenitis suppurativa (acne inversa). *Dermatoendocrinol.* 2010;2(1):9-16. doi:10.4161/derm.2.1.12490.
5. 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(5):421-430. doi: 10.1159/000508787.
6. Garg A, Neuren E, Cha D, et al. Evaluating patients' unmet needs in hidradenitis suppurativa: Results from the Global Survey Of Impact and Healthcare Needs (VOICE) Project. *J Am Acad Dermatol.* 2020; 82(2):366–376.
7. 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.
8. Kirby J, Martorell A, Sayed C, et al. Understanding the real-world patient journey and unmet needs of people with hidradenitis suppurativa through social media monitoring. Oral presentation presented at: 31st European Academy of Dermatology and Venereology (EADV) Congress, September 7-10, 2022, Milan, Italy.

Source URL: <https://qa1.novartis.us/us-en/news/highlighting-unmet-needs-hidradenitis-suppurativa-hs>

List of links present in page

1. <https://qa1.novartis.us/us-en/us-en/news/highlighting-unmet-needs-hidradenitis-suppurativa-hs>