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.[1] These bumps can become sores (or abscesses) that can leak and leave scars.[2] 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.[3,4]

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.[5]

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%)[5]
- The most discussed ongoing HS management strategies were dietary changes (47%), skincare products (26%) and clothing (12%)[5]

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.[5]

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

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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.

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