

UCB VISION REPORT 2026

IMAGINE AN HS-FREE WORLD



Inspired by patients.
Driven by science.



At UCB, we imagine an HS-free world.

And we're taking steps to make it a reality.

UCB Vision Report: 2026 Progress and Commitment

In 2025, we made a commitment to the HS community. A commitment to Revolutionize Science, Redefine Care, and Restore Humanity, with a promise to hold ourselves accountable within these three core pillars of need.

This 2026 report captures our momentum to date on the goals we set out, spotlighting one key initiative within each pillar that we are proud to share with you. While these spotlights represent the exciting work we've been busy on from around the world, they are only a part of our broader efforts. We invite you to follow our social media channels to discover the many other initiatives currently in motion.

We hope you enjoy the read and join us as we continue to strive for an HS-free world.



If you'd like to read our 2025 report, you can check it out below

[VIEW 2025 REPORT](#)

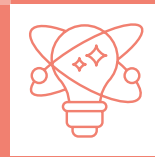
Our progress to date on our goals

We remain steadfast in our commitment to the goals identified for 2028:



Revolutionize Science

To advance community knowledge of HS and its pathways, triggers, and treatment, through science



GOAL 01

Explore at least 1 potential new pathway to target HS

GOAL PROGRESS



We are currently looking into a new pathway to target HS and look forward to sharing more by 2028

GOAL 02

Advance use of biomarkers to identify better and more personalized treatment options with at least 2 studies

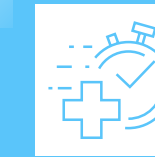
GOAL PROGRESS



One of our biomarker studies in collaboration with Stanford University has officially completed its patient recruitment phase and is now moving forward into analysis⁴

Redefine Care

To ensure earlier diagnosis and optimal treatment to reduce progression and control symptoms



GOAL 01

Reach 50,000 healthcare professionals worldwide with HS education

GOAL PROGRESS

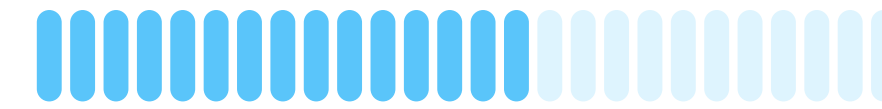


While we are quantifying the reach across our educational programs, we are excited that these programs are reaching as far as the Middle East, with training programs on surgical and imaging techniques in HS

GOAL 02

Publish at least 5 pieces of research on the impact of HS and importance of early advanced treatment

GOAL PROGRESS



Three new pieces of research have been published since the first report, including a study to validate a claims-based algorithm to identify patients with mild, moderate, or severe HS in the US⁵⁻⁷

Restore Humanity

To put an end to the shame, stigma, and inhumanity that currently surrounds HS patients and their treatment



GOAL 01

Amplify the work of at least 15 patient organizations around the world

GOAL PROGRESS



To date, we are actively collaborating with over 10 patient advocacy organizations worldwide, including HS Connect and ASENDHI in Spain, to support awareness and education initiatives for people living with HS¹⁻³

GOAL 02

Elicit actions from at least 3 health authorities worldwide to address HS health disparities

GOAL PROGRESS



We are making strides in reaching the underserved populations in HS through a multi stakeholder coalition to help transform the policy and access landscape for people living with HS⁸





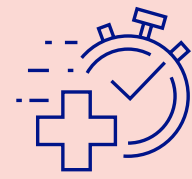
REVOLUTIONIZE SCIENCE



Precision medicine research has the potential to support earlier, more informed intervention by helping clinicians better identify patients at higher risk of progression and tailor care more effectively over time.



ELISA MAGGIOLI,
SENIOR DIRECTOR, NEW PRODUCT PLANNING
& RESEARCH LEAD, UCB



Biomarker research may one day enable meaningful change in HS care



2026 spotlight: Harnessing Biomarkers in HS

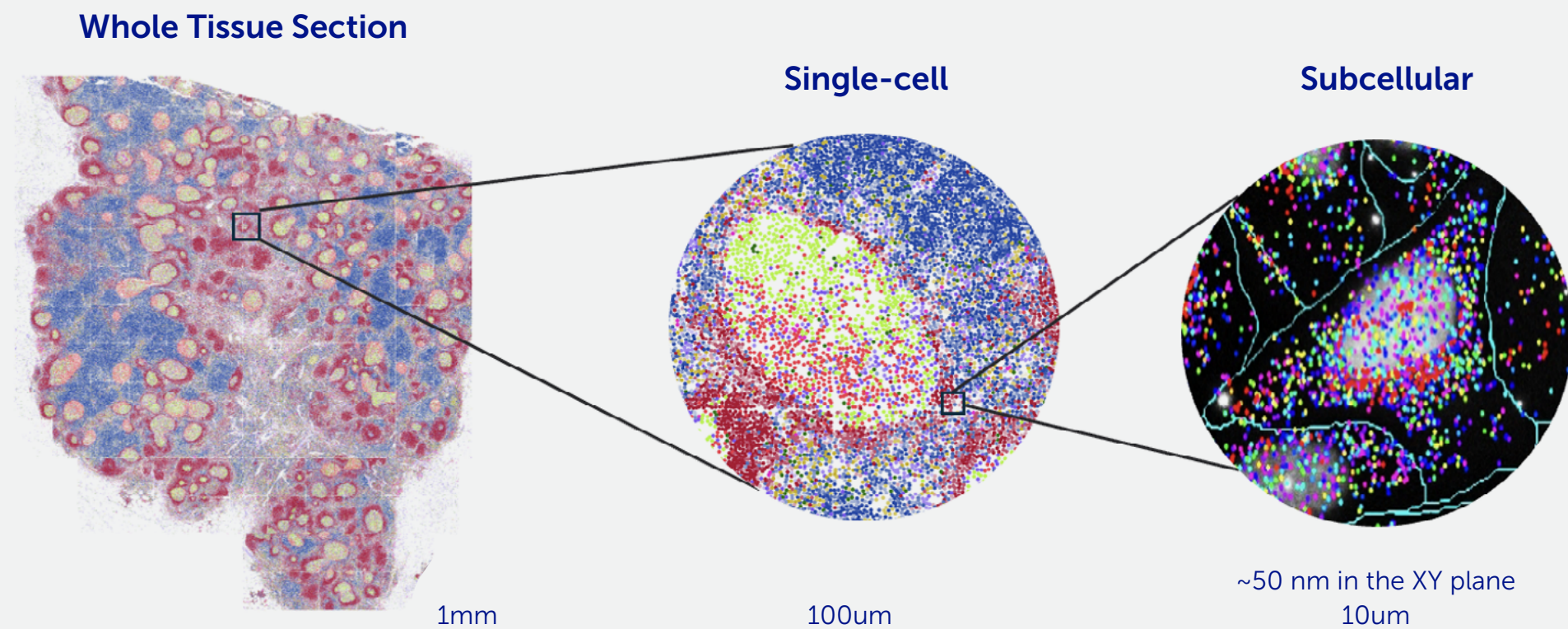
As part of our commitment to advance the use of novel biomarkers to identify better and more personalized treatment options, we are excited to announce that one of our biomarker studies has now completed its patient recruitment phase according to timelines.⁴

This study, executed in collaboration with a leading Stanford research team that combines clinical dermatology expertise with advanced molecular and computational technologies, will be investigating skin structural and biomolecular determinants of “fast” vs. “slow” HS progressors. Moving forward, the next phase will leverage cutting-edge, tissue spatial analysis of patients’ skin to uncover the biological pathways responsible for driving a more aggressive and faster progressing form of this debilitating disease.^{4,9,10}

In HS, being able to identify those patients who are likely to progress more quickly could support more timely treatment decisions, reduce cumulative inflammatory and tissue damage burden, and inform more ambitious treatment goals aligned with long-term quality of life.^{11,12}

We are hopeful that these types of scientific advances will then be translated into clinical awareness, education and updated standards of care. Biomarker research will one day enable us to create a bridge between “Revolutionize Science” and “Redefine Care”, taking insights from the clinic to enable meaningful change in day-to-day care.

Highest-Plex Spatial Analysis with Subcellular Resolution



Source: Sirona Dx. Nanonstring CosMx. Available at: <https://sironadx.com/cosmx/>. Accessed: May 2026.

HS, hidradenitis suppurativa.



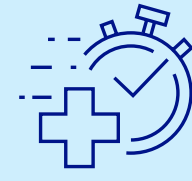


The true prevalence of HS is likely underestimated.

This study in Germany was conducted to show that there is a real burden and a real need to improve HS care that warrants greater attention from healthcare stakeholders.



LUIS MÖCKEL,
REAL-WORLD EVIDENCE TEAM LEAD, UCB



On average, deceased HS patients lost 20.5 to 25.9 years of their lives⁷

REDEFINE CARE



2026 spotlight: The human cost of HS

A deeper understanding of the true burden of HS is a powerful tool in the struggle for earlier diagnosis and treatment. When all healthcare stakeholders recognize the impact HS has on people's lives, it can lead to key steps forward in HS care.^{7,11,12}

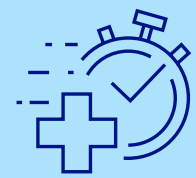
Driven by this need, we conducted a real-world study in Germany, analyzing health insurance claims from 4.1 million individuals, and performed a comparative analysis between the HS population and a matched healthy population to highlight the stark impact of HS on long-term outcomes. The study concluded that:⁷

- On average, deceased HS patients lost 20.5 to 25.9 years of their lives
- Roughly one-quarter of a patient's quality-adjusted life is lost every single year due to HS
- HS patients face a significantly higher prevalence of comorbidities, including depression, diabetes and obesity, and incur significantly higher healthcare costs (inpatient, outpatient and medication costs) compared to non-HS patients

Given the significant findings of this study, we are now exploring follow-up studies and developing new research questions to further generate evidence to show that an earlier diagnosis and optimal treatment are both a clinical and an economic necessity.

[READ THE FULL PAPER HERE](#)

HS, hidradenitis suppurativa.



Roughly one-quarter of a patient's quality-adjusted life is lost every single year due to HS⁷



DDG ORIGINAL ARTICLE

Burden of hidradenitis suppurativa in Germany: a retrospective claims data analysis and comparison with non-HS patients

Falk G. Bechara¹ | Sima Mehnik² | Tobias Müller³ | Hans-Dieter Pannasch⁴ | Romy Bley⁵ | Jonas Kramppe⁶ | Luis Möckel⁷

Summary The aim of this analysis was to assess the burden of hidradenitis suppurativa (HS) in Germany. **Background and Methods:** This was a retrospective German statutory health insurance claims data analysis covering the years 2020-2022 and 4.1 million individuals. An HS prevalence cohort and matched non-HS cohort representing the general population were analyzed regarding burden of disease indicators. An HS incidence cohort was analyzed regarding flare occurrences. **Results:** Adult HS patients showed a significantly higher prevalence of comorbidities including 3.38 (95% CI: 3.23-3.53), 3.65 (95% CI: 3.49-3.81), and 1.69 (95% CI: 1.58-1.82) for depression compared to matched non-HS individuals, respectively. HS patients aged ≥ 50 years had a 2.5-fold higher risk of death (HR 2.5; 95% CI: 1.8-3.4) compared to matched non-HS patients. The mean number of years of life lost ranged from 20.5 to 25.9 years during the period 2020-2022. Finally, 24.8% experienced at least one HS flare requiring medical treatment within 24 months following their initial HS diagnosis. **Conclusion:** The results of this analysis reveal that HS patients experience a substantial burden of disease compared to non-HS patients.

KEYWORDS HS, Germany, HS prevalence, mortality, QALY, Years of Life Lost

INTRODUCTION Hidradenitis suppurativa (HS) is a chronic, recurrent, inflammatory skin disease of the terminal hair follicle-gland apparatus resulting in formation of boils and abscesses. It represents a prevalent chronic inflammatory condition that can lead to disabling scars and scar tissue formation. Prevalence estimates of German statutory health insurance (SHI) claims data estimate that 0.24%-0.26% of the German population have been diagnosed with HS.¹ Nevertheless, it is known that there is a delay of up to 10 years between the onset of first symptoms and the confirmed HS diagnosis in Germany and patients are frequently diagnosed inaccurately.² Clinical signs of HS are painful, inflammatory lesions in the specific skin-rich regions of the body. In addition to chronic symptoms, HS patients frequently experience flares. An international flare at least monthly, including flares associated with substantial pain,^{3,4} is an Austrian patient cohort, the average numerical rating scale (NRS) for pain ranges from 1 to 10, increased from 2.2 during a flare-free period to 7.6 during a flare.⁵ Beyond pain, HS is associated with a high prevalence of comorbidities, including depression, diabetes and obesity.⁶⁻⁸ For example, Bechara et al. (2023) found that 25.2% of German HS

claims data analysis (prevalence, 0.23-0.29%; incidence, 0.01-0.02%).⁹ These differences may reflect variations in the study period, as our analysis covered 2020-2022, while prior studies examined data from 2010-2017.¹⁰ In addition, minor differences in the population structure between databases may have contributed to these variations. Nevertheless, it must be mentioned here, that the prevalence of HS in the dataset might be underestimated due to reasons such as frequent misdiagnosis, diagnostic failure or the avoiding of physician contacts by HS patients.¹¹ Our results confirm the substantial comorbidity burden associated with HS. The prevalence of depression among adult HS patients (20.0%-22.2%) was slightly higher than previously reported rates in German and UK studies (23.8%-26.1%),¹² and the relative risk (1.7-fold increase) aligns with prior findings.¹³ This is not unexpected given the substantial impact of hidradenitis suppurativa on quality of life and social participation.¹⁴ Diabetes and obesity are closely linked to each other and therefore, it is not surprising that both are significantly increased in HS patients (2.6 and 2.7 times) compared to non-HS patients. Our study revealed a prevalence of 14.2% to 15.9% for diabetes and 29.9% to 32.9% for obesity based on ICD-10 codes in HS patients. In comprehensive German health monitoring studies conducted by the Robert Koch Institute, the prevalence of self-reported diabetes and obesity in the general German population was 8.9% and 19.2%, respectively.^{15,16} An association between HS and diabetes is well known. The chronic inflammation stemming from HS has been shown to contribute to metabolic dysregulation, worsening of insulin resistance and glycemic control.¹⁷ In addition, a recently published study showed that a high genetic risk for HS is associated with an increased risk for diabetes,¹⁸ underlining that the link between HS and diabetes might be multifaceted. Alongside higher comorbidity rates, HS patients aged 50 years or older showed a numerically higher, non-significant risk of death compared to matched non-HS patients (Figure 1). The risk difference observed in this study (3.3%) is consistent with findings from a US-based electronic health records study reporting an excess mortality risk of 3.1 per 1,000 HS patients.¹⁹ Another indicator suggesting a higher risk of death among HS patients is the mean age of the prevalence cohort aged ≥ 50 years, which was 58.3 years in 2022. In contrast, the mean age of the overall German population aged ≥ 50 years in 2022 was 66.3 years.²⁰ The YLLs observed in our study (20.5-25.9 years per deceased patient) are comparable to findings from a Finnish study, which reported that HS patients died 14.7 years earlier than controls.²¹ Notably, the Finnish study identified alcohol-related diseases as a leading cause of death.²¹ In the present analysis, HS patients exhibited a 3.8-fold higher risk of nicotine dependence, coded as mental and behavioral disorders due to tobacco use. Previous studies have shown that mortality risk in HS is associated with factors such as smoking, sex, age, comorbidity burden (CVD) and cardiovascular diseases.^{11,22} In



2026 spotlight: The power of collective voices

At UCB, we understand that amplifying patient voices and building stronger community support must be an ongoing commitment to address the stigma, isolation and disparities in HS.

Now in its third year, the 2026 HS Patient Partnership Summit brought together 20 HS advocates from 14 different countries across the US, Canada, and Europe (including the UK, Italy, Greece and more), and 17 patient advocacy groups. Across 2 inspiring days, every session and interaction was anchored in:¹³

- **Connection:** Building and strengthening relationships between communities across the globe
- **Knowledge exchange:** Enabling sharing of insights, experiences and best practices
- **Co-creation to drive action:** Collaboratively exploring ideas to address unmet needs, identifying common priorities and future opportunities for global collaboration

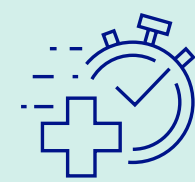
With the mantra of ‘by patients, for patients’, the Summit was more than an event; it was a call to action and a demonstration of what can be achieved through the power of global connection in patient advocacy.¹³

HS, hidradenitis suppurativa. UK, United Kingdom; US, United States.

RESTORE HUMANITY



Connection
-
Knowledge exchange
-
Co-creation



20 HS advocates
17 advocacy groups
from 14 countries



I leave the summit feeling empowered, heard and deeply motivated to continue our collaborative work. Thank you for creating a space where the patient’s voice truly matters.



PARTICIPANT AT THE 2026 HS PATIENT PARTNERSHIP SUMMIT, HS ADVOCATE





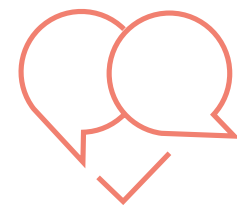
Shared HS disease awareness and educational materials at EWMA-DEWU, a conference on wound care in Germany¹⁴



Launch of a new scholarship program for HS patients and the caregivers



Seeing below the surface of HS lesions through medical ultrasound presentations



Under the Skin podcasts with specialized clinical content on earlier intervention and more¹⁵



Sponsored the Inflamed Sisters Thriving webinar via the **UCB HS Advocate Community Program**



2nd annual HS Summit in Atlanta, with over 100 patients, caregivers, advocacy leaders and HCPs¹⁶



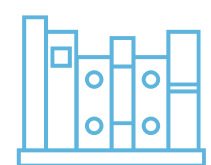
Supported HS Connect on their "Find Us" **patient activation at Times Square**³



A four-part video series on navigating HS and motherhood developed with medical experts and HS patients¹⁷



Real-world study published on the **economic burden of HS in Spain**⁵



Study published on a claims-based algorithm to identify HS severity⁶

Other key highlights

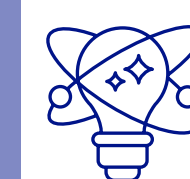


New HS clinical guidelines are in development by the American Academy of Dermatology in collaboration with the HS foundation¹⁸



HISTORIC is now moving into the implementation and validation phase of its Core Measures Set (i.e., HSiGA, HiSQoL mini)¹⁹

Exciting developments within the HS space



Growing scientific innovation with new molecules to target HS in clinical development²⁰



A new national HS multidisciplinary team is being established by the HS UK and Ireland Network (H-SKIN)²¹

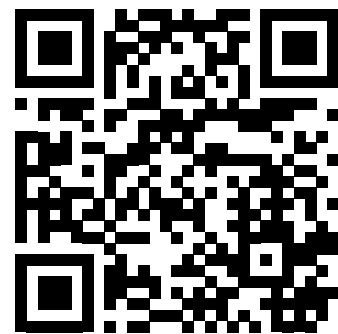
Thank you

Revolutionize Science.
Redefine Care.
Restore Humanity.

Our work in HS is driven by a belief that people deserve better – better science, better care, and better understanding. With that belief at the center, we will continue to push forward and create change that truly matters for the HS community. Thank you to all our partners in these efforts and **we look forward to sharing the next chapter of our progress in our 2027 Vision Report.**

To find out more about our exciting initiatives, follow us on:

 Instagram



 LinkedIn



If you'd like any more information about anything included within this report, then please contact:



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HS, hidradenitis suppurativa.

References: **1.** The Health Policy Partnership. Call to action: improving the lives of people with hidradenitis suppurativa (HS). Available at: <https://www.healthpolicypartnership.com/app/uploads/Call-to-action-improving-the-lives-of-people-with-hidradenitis-suppurativa.pdf>. Accessed: May 2026. **2.** UCB. HS Patient Resources. Available at: <https://ucbsuisse.ch/en/patients>. Accessed: May 2026. **3.** UCB. From Bandages to Bravery: HS Patients Command Times Square in Unforgettable Event. Available at: <https://www.ucb-usa.com/stories-media/UCB-U-S-News/detail/article/bandages-bravery-hs-patients-command-times-square>. Accessed: May 2026. **4.** UCB Data on File. 2026. Structural and Molecular Determinants of Early HS Progression. p1–14. **5.** Vilarrasa E, et al. *Dermatol Ther (Heidelb)*. 2026;16(3):1739–56. **6.** Schneeweiss MC, et al. *Clin Epidemiol*. 2025;17:935–44. **7.** Bechara FG, et al. *J Dtsch Dermatol Ges*. 2026;1–11. **8.** UCB. Putting People First to Create a More Sustainable Healthcare System. Available at: <https://www.ucb-usa.com/stories-media/UCB-U-S-News/detail/article/putting-people-first-create-more-sustainable-healthcare>. Accessed: May 2026. **9.** UCB. The Art of Being Data-Enabled: UCB's Approach to Delivering Innovative Patient Solutions. Available at: <https://www.ucb.com/about-ucb/magazine/detail/article/the-art-of-being-data-enabled-ucb-s-approach-to-delivering-innovative-patient-solutions>. Accessed: May 2026. **10.** Sirona Dx. Nanonstring CosMx. Available at: <https://sironadx.com/cosmx/>. Accessed: May 2026. **11.** Martorell A, et al. *Am J Clin Dermatol*. 2026;27:217–26. **12.** Sabat R, et al. *Lancet*. 2025;405(10476):420–38. **13.** UCB. 2026 HS Patient Partnership Summit: deepening our commitment to the HS community. Available at: <https://www.ucb.com/solutions/magazine/detail/article/2026-hs-patient-partnership-summit-deepening-our-commitment-to-the-hs-community>. Accessed: May 2026. **14.** LinkedIn. UCB Deutschland. Available at: https://de.linkedin.com/posts/ucb-deutschland_ucb-bei-ewma-dewu-2026-in-bremen-activity-7461050557936599041-1Go0. Accessed: May 2026. **15.** UCB. UCB go 'Under the Skin' with new hidradenitis suppurativa (HS) podcast. Available at: <https://www.ucb.com/about-ucb/magazine/detail/article/ucb-go-under-the-skin-with-new-hidradenitis-suppurativa-hs-podcast>. Accessed: May 2026. **16.** UCB. Beyond Awareness: Uniting for a Brighter Future at the HS Summit. Available at: <https://www.ucb-usa.com/stories-media/UCB-U-S-News/detail/article/beyond-awareness-uniting-brighter-future-hs-summit>. Accessed: May 2026. **17.** UCB. Navigating Hidradenitis Suppurativa and Motherhood. Available at: <https://www.ucb.com/solutions/diseases/hidradenitis-suppurativa/Navigating-Hidradenitis-Suppurativa-and-Motherhood>. Accessed: May 2026. **18.** HS Foundation. News. Available at: <https://www.hs-foundation.org/news>. Accessed: May 2026. **19.** HiSTORIC. Hidradenitis Suppurativa Core Outcomes Set International Collaboration. Available at: <https://www.c3outcomes.org/historic>. Accessed: May 2026. **20.** Charrow A, et al. *J Am Acad Dermatol*. 2024;91:S27–S30. **21.** Wainman HE, et al. *Clin Exp Dermatol*. 2026;llag132.