HS PROGRESS Registry: Real-World Patient Characteristics and Unmet Needs

Haley B. Naik,[1] Afsaneh Alavi,[2] Joerg Albrecht,[3] Maria A. Aleshin,[4] Marissa L. H. Baranowski,[5] Richard Flowers,[6] Noah Goldfarb,[7,8] Iltefat Hamzavi,[9] Kristen E. Holland,[10] Jennifer Hsiao,[11] Tarannum Jaleel,[12] Katrina Lee,[11] Hadar Lev-Tov,[13] Robert G. Micheletti,[14] Lauren A. V. Orenstein,[5] Gretchen M. Roth,[10] Christopher J. Sayed,[15] Angie Wan,[10] Robert Low,[16] Prajakta P. Masurkar,[16] Kajal Bhika,[16] Tae Oh,[16] Michelle A. Lowes[17]

[1]Department of Dermatology, University of California, San Francisco, CA, USA; [2]Department of Dermatology, Mayo Clinic, Rochester, MN, USA; [3]Cook County Health and Hospital Systems, Chicago, IL, USA; [4]Department of Dermatology, Stanford University School of Medicine, Redwood City, CA, USA; [5]Department of Dermatology, Emory University School of Medicine, Atlanta, GA, USA; [6]University of Virginia, Charlottesville, VA, USA; [7]Departments of Medicine and Dermatology, University of Minnesota, Minneapolis, MN, USA; [8]Departments of Medicine and Dermatology, Minneapolis VA Health Care System, Minneapolis, MN, USA; [9]Department of Dermatology, Henry Ford Hospital, Detroit, MI, USA; [10]Department of Dermatology, Medical College of Wisconsin, Milwaukee, WI, USA; [11]Department of Dermatology, Keck School of Medicine, University of Southern California, Los Angeles, CA, USA; [12]Department of Dermatology at the Duke University School of Medicine, Durham, NC, USA; [13]Dr. Phillip Frost Department of Dermatology and Cutaneous Surgery, University of Miami Miller School of Medicine, Miami, FL, USA; [14]Department of Dermatology, University of Pennsylvania, Philadelphia, PA, USA; [15]Department of Dermatology, University of North Carolina School of Medicine, Chapel Hill, NC, USA; [16]UCB, Smyrna, GA, USA; [17]The Rockefeller University, New York City, NY, USA

Objective

To describe baseline characteristics, quality of life, and treatment history of participants enrolled in HS PROGRESS.

Background

- Hidradenitis suppurativa (HS), a chronic, progressive inflammatory skin disease, can substantially impact quality of life (QOL) as well as physical and mental well-being.[1,2]
- HS remains understudied, which may contribute to the unmet needs and disparities in diagnosis and treatment among patients with HS.[1]
- HS PROGRESS is an ongoing United States prospective observational registry and biospecimen repository, developed to rigorously characterize an inclusive, longitudinal cohort.

Methods

- This prospective, longitudinal, observational cohort study comprehensively characterizes HS from clinical and biological perspectives.
- HS PROGRESS enrolls HS-diagnosed participants ≥1 year old.
- Participant surveys capture demographics, comorbidities, treatments, family history, as well as Dermatology Life Quality Index (DLQI), Hidradenitis Suppurativa QOL (HiSQOL), and skin pain (numeric rating scale) scores.
- Investigator surveys, completed by board-certified dermatologists with formal HS disease measurement training, include International Hidradenitis Suppurativa Severity Score System (IHS4), HS-Investigator Global Assessment (HS-IGA), HS-Physician Global Assessment (HS-PGA), and Hurley staging.
- Descriptive statistics are reported.

Results

- From April 2, 2025 to March 26, 2026, 660 participants were enrolled. Participants had a mean age of 39.8 years (N=657; range: 13.8–77.7 years) and 78.4% were female (N=523). The population included White (47.9%), Black or African American (40.0%), Asian (6.5%), and American Indian or Alaska Native (1.7%) patients; 17.2% of participants were Hispanic (N=522; **Table 1**).
- The median (interquartile range [IQR]) diagnosis delay (N=509) was 4 (1–10) years and, based on patient-reported symptom onset, the median (IQR) disease duration (N=517) was 15 (9–23) years (**Table 2**).
- The proportion of participants with mild disease, based on IHS4, was 42.3%, followed by 31.1% of participants with severe disease and 22.9% with moderate disease (**Table 2**). The proportions of participants with Hurley Stage I, Stage II, or Stage III disease were 24.5%, 46.1%, and 21.4%, respectively. (No Hurley Stage was recorded for 8.0%).
- At baseline, the mean (standard deviation [SD]; N=517) skin pain score was 4.1 (2.5). For worst level of skin pain in the last week, the mean (SD; N=520) was 4.6 (3.1), indicating moderate pain severity[3] (**Table 2**).
- The most prevalent comorbidities among participants (N=524) were anxiety (36.3%), depression (32.1%), and high blood pressure (25.2%; **Figure 1**).
- The health-related QOL of many participants was impacted by HS and skin-related disturbances (N=660): 37.6% of participants had "very severe" effects according to HiSQOL[2] and 35.5% had "very large"/"extremely large" effects as determined by DLQI[4] (**Figure 2**).
- At enrollment, almost half of participants were biologic-naïve (45.9%), while 17.6% and 36.5% had previously used 1 or ≥2 biologics, respectively (N=660; **Figure 3**). Of 284 participants with current biologic use and a Hurley Stage recorded, 20.8%, 45.8%, and 33.5% had Hurley Stage I, II, and III disease, respectively.

Tables and Figures

Table 1. Baseline demographics indicated a diverse cohort

n (%), unless otherwise specified	N=660
Age, years, mean (SD)[a]	39.8 (37.7)
Sex[b]	
Female	410 (78.4)
Male	113 (21.6)
Race[c]	
White	250 (47.9)
Black or African American	209 (40.0)
Asian	34 (6.5)
Declined to answer	20 (3.8)
American Indian or Alaska Native	9 (1.7)
Ethnicity[c]	
Hispanic	90 (17.2)
Non-Hispanic	432 (82.8)
Payer Channel[d]	
Commercial	37 (7.2)
Employer	296 (57.8)
Medicaid, CHIP, or government-assistance plan	94 (18.4)
Medicare	56 (10.9)
Military health care	5 (1.0)
Other	24 (4.7)
Income[e]	
≤$10,000	43 (8.5)
$10,001–15,000	27 (5.4)
$15,001–25,000	34 (6.8)
$25,001–40,000	42 (8.3)
$40,001–60,000	70 (13.9)
$60,001–80,000	75 (14.9)
$80,001–100,000	52 (10.3)
$100,001–120,000	36 (7.2)
$120,001–150,000	45 (8.9)
$150,001–180,000	20 (4.0)
$180,001–200,000	16 (3.2)
≥$200,001	43 (8.5)

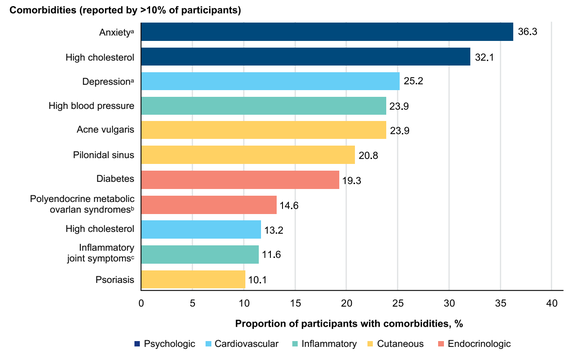
[a] N=657; **[b]** N=523; **[c]** N=522; **[d]** N=512; **[e]** N=503.

Table 2. Baseline disease characteristics indicated significant HS burden by validated measures

n (%), unless otherwise specified	N=660
Age at onset, years, median (IQR)[a]	18.0 (13.0–26.0)
Diagnosis delay, years, median (IQR)[b]	4.0 (1.0–10.0)
Disease duration, years, median (IQR)[c]	15.4 (8.9–23.3)
Number of days flaring in the last 4 weeks, median (IQR)[d]	6.0 (2.0–14.0)
Worst level of skin pain in the last week, mean (SD)[e,f]	4.6 (3.1)
Average level of skin pain, mean (SD)[c,e]	4.1 (2.5)
Hurley Stage	
I	162 (24.5)
II	304 (46.1)
III	141 (21.4)
No data	53 (8.0)
HS-PGA	
Clear	117 (17.7)
Minimal	32 (4.8)
Mild	171 (25.9)
Moderate	196 (29.7)
Severe	12 (1.8)
Very severe	112 (17.0)
No data	20 (3.0)
HS-IGA score (corresponding lesion count)[5]	
0 (0–1)	161 (24.4)
1 (2–5)	223 (33.8)
2 (6–10)	119 (18.0)
3 (11–15)	50 (7.6)
4 (16–20)	40 (6.1)
5 (>20)	47 (7.1)
No data	20 (3.0)
IHS4 categories[6]	
≤3 (mild)	279 (42.3)
4–10 (moderate)	151 (22.9)
≥11 (severe)	205 (31.1)
No data	25 (3.8)

[a] N=519; **[b]** N=509; **[c]** N=517; **[d]** N=493; **[e]** numerical rating scale with a range of 1–10 was used to quantify skin pain; **[f]** N=520.

Figure 1. Substantial comorbidity burden was observed (N=524)



[a] Diagnosed by a medical professional; **[b]** Proportion of female patients (N=410); **[c]** Patient-reported joint pain or stiffness that is worse in the morning and worse with inactivity.

Figure 2. Profound dermatologic and HS-related QOL impairment is reported at baseline (N=660)

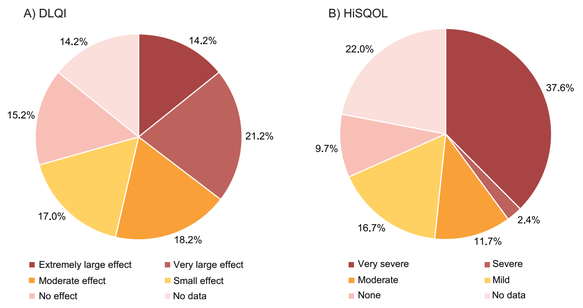
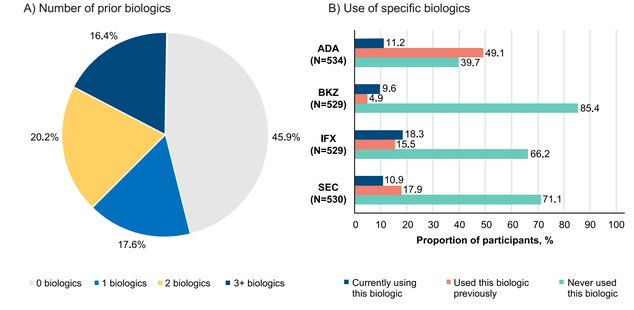


Figure 3. Nearly half of participants had never received biologic therapy prior to enrollment (N=660)



Conclusions

HS PROGRESS captures a diverse, real-world HS population spanning the full spectrum of HS severity.

Comorbidity burden was high in the present population at enrollment, across psychologic, inflammatory, and cardiometabolic domains, reinforcing HS as a systemic disease with impact extending beyond the skin.

Despite substantial disease burden at enrollment, almost half the population in the present analysis was biologic-naive. Over one-third had received ≥2 prior biologics, suggesting a persistent need for durable treatment options and highlighting ongoing treatment gaps.

The degree of health-related QOL impairment in the population illustrates the life-altering nature of HS, supporting the need to consider earlier clinical intervention.

Plain Language Summary

Why was this study needed?

- Hidradenitis suppurativa (HS) is a chronic skin disease that can worsen over time, affecting general health and lowering quality of life.
- More research is needed to better understand the impact of HS on people with the condition, and how it is treated. This could help to find ways to improve care.

What did this study show?

- On average, people with HS joining this study had waited several years for their HS diagnosis.
- When they joined, people in the group tended to have moderate skin pain. The effects of HS on the skin and quality of life varied from person to person, ranging from mild to severe.
- Though the study showed that HS had a wide impact on this group, when people joined almost half had never received a biologic drug.

Why is this important?

- The life-changing effects of HS for people in this study could suggest that medical care is needed at an earlier stage.

Abbreviations

ADA: adalimumab; **BKZ:** bimekizumab; **CHIP:** Children's Health Insurance Program; **DLQI:** Dermatology Life Quality Index; **HISQOL:** Hidradenitis Suppurativa QOL; **HS:** hidradenitis suppurativa; **HS-IGA:** HS-Investigator Global Assessment; **HS-PGA:** HS-Physician Global Assessment; **IFX:** infliximab; **IHS4:** International Hidradenitis Suppurativa Severity Score System; **IQR:** interquartile range; **QOL:** quality of life; **SD:** standard deviation; **SEC:** secukinumab; **US:** United States.

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University of California San Francisco

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