

HS care has outgrown its standards

The pace of change in HS has begun to outrun the standards governing how the disease is diagnosed and treated.

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■ GUIDELINE TEXT ■ CLINICIAN SERIES ■ FROM THE HS FOUNDATION

THE NUMBERS BEHIND THE URGENCY

PREVALENCE

At least 1% of the U.S. population

Skin disease has historically been under-prioritized relative to its prevalence and its real impact on patients' lives.

PIPELINE

More than 40 therapies in clinical trials

The first HS treatments relied entirely on biologics repurposed from other indications. Today, developers pursue molecules designed for HS from the outset.

DELAY TO DIAGNOSIS

Seven to ten years

The window from a patient's first presentation to a confirmed diagnosis, and the most consequential statistic in HS care today.

WHY THIS IS THE MOMENT

Therapies for eczema and psoriasis brought sustained industry investment into a category treated, for a long time, as cosmetic rather than systemic. HS is now among the conditions benefiting from that shift. Just as significant as the volume of the pipeline is its nature, and it is the clearest available signal that the field has crossed from peripheral interest into sustained scientific investment.

THE DIAGNOSTIC GAP IS THE CENTRAL PROBLEM

The most consequential statistic in HS care today is the delay to diagnosis. The current window from a patient's first presentation to a confirmed diagnosis is seven to ten years. That number is both a clinical problem and a system problem. HS is progressive, and outcomes degrade as the disease advances untreated. Patients diagnosed late present with more severe disease, more comorbidities, and a narrower set of treatment options than patients identified early.

Patients with HS rarely begin in a dermatologist's office. They cycle through primary care, OB/GYN, urgent care, and emergency settings, often repeatedly, before the disease is named correctly. Each of those encounters is an opportunity for recognition, and at present, too few of them result in one.

WHERE CARE FRAGMENTS

HS is definitively managed in dermatology, but it is rarely encountered there first. Frontline clinicians outside dermatology are often the determining factor in whether a patient is identified, referred appropriately, and started on reasonable initial management, or whether they are sent home with an antibiotic course and a return visit several months later. The same patient, presenting with the same symptoms, can receive materially different care depending on which clinical setting they walk into.

The objective is not to make every clinician an HS specialist. That is neither realistic nor the goal. The objective is to give providers across specialties a shared, defensible reference for what HS looks like, when to refer, and what frontline treatment is appropriate while a patient moves toward specialist care.

WHAT THIS COSTS PAYERS

Without a clinical anchor, coverage decisions for HS therapies have been made against an evidence base that has shifted considerably in a short period. The downstream costs of delayed and inconsistent treatment, including hospitalizations, surgical interventions, and lost productivity, are absorbed across the system, often by the same payers whose upstream coverage decisions shaped the trajectory of care.

WHY GUIDELINES NOW

The HS Foundation, working with the Canadian HS Foundation, published the first HS treatment guidelines in 2019. At that point the FDA-approved therapeutic landscape consisted essentially of one drug. In 2023 the American Academy of Dermatology made the decision to fast-track HS in its guidelines development process, accelerating a workstream that typically operates on a longer cycle.

GUIDELINES AS INFRASTRUCTURE

Guidelines show us what we don't know yet. By documenting where the evidence supports a strong recommendation and where it doesn't, they make clear which questions the field still needs to answer. That clarity helps direct research priorities, at the foundation level, at NIH, and within industry, toward the gaps that most need closing. The next version of any guideline is shaped by what the current one exposes.

They are not a final statement on how HS should be treated. They are the operating layer the field has been working toward, and the starting point for the next set of questions.

FROM THE HS FOUNDATION

The guideline carries that idea in its own structure. Its Research Gaps section names where evidence is still needed, and the therapies it evaluated without reaching a recommendation are listed rather than dropped. See piece 10 of the clinician series.