Guidelines are a first step

The publication is a milestone, and the beginning of an effort rather than the end of one. Three things have to happen next.

Haley B. Naik, MD, MHSc
President, HS Foundation and Guidelines Workgroup Co-chair; Associate Professor of Dermatology, UCSF

GUIDELINE TEXT · CLINICIAN SERIES · FROM THE HS FOUNDATION

EIGHTEEN YEARS OF CHANGE

I started caring for patients with hidradenitis suppurativa during my residency training, before there were any FDA-approved therapies. The patients who came to our clinic had often spent years searching for a diagnosis. Even once they had one, the treatment options available to us were limited.

For the vast majority of the two centuries since HS was first described, there were no approved therapies. Today there are three, and several more promising agents are advancing through the pipeline. Awareness has expanded and research funding has increased. The patient voice has appropriately risen and demanded more from science and medicine.

WHAT THE GUIDELINES WORK INVOLVED

The workgroup reviewed every available piece of published literature on every therapeutic option for HS. Recommendations were weighed not only on efficacy and safety, but also based on access, cost, and whether a given therapy was more appropriate for some patient subgroups than others.

It became clear that for many important aspects of HS care, the evidence was insufficient to support a recommendation. Pain management, wound care and dressing selection, and diet modification are areas patients often ask about and providers need more guidance on. Those gaps are now formally part of the guidelines themselves, in a dedicated Research Priorities section.

WHAT SHE WISHES MORE CLINICIANS UNDERSTOOD

If I could change one thing about how HS is treated today, it would be to ensure timely intervention with systemic therapy. This painful and disfiguring condition impacts life trajectory through school and work absences, work productivity, income attainment and social isolation.

We have three FDA-approved therapies for moderate to severe HS, but there is no clear definition of what moderate HS looks like. Moderate HS has many faces. It looks like scarring and tunnel development. It also looks like patients in excruciating, sustained pain with impaired quality of life and limited function. When clinicians see these signs, we should be considering systemic treatment.

Dermatologists already know how to do this because we exercise these skills when we manage acne. The moment we see the first hint of scarring, we are ready to prescribe isotretinoin, because early intervention prevents permanent irreversible damage.

The right time to offer systemic therapy for HS is, almost without exception, earlier than when it is being offered today.

NAIK, IN THE NEW HS GUIDELINES, THE DERMATOLOGIST

WHAT THE GUIDELINE SAYS ABOUT DOCUMENTING SEVERITY

HS recommendations specific to moderate to severe HS should not be interpreted as requirements for documenting HS severity using specific measures before patients should access HS treatments.

JOINT AAD AND HSF GUIDELINES, DEFINITION

WHY THAT SITS ALONGSIDE HER POINT

FROM THE HS FOUNDATION

Dr. Naik argues for acting on clinical signs rather than waiting. The guideline, separately, removes severity documentation as a precondition for access. The two are not the same statement, and together they remove two different reasons to delay.

THREE THINGS THAT HAVE TO HAPPEN NEXT

ONE

Access

FDA approval does not guarantee that patients can access a therapy. Coverage decisions, prior authorization, step therapy and the broader machinery of how care reaches patients all sit downstream of the guidelines.

TWO

Research

The Research Priorities section is, in effect, an invitation. For investigators, foundations, NIH program officers and industry partners, it is a roadmap to where work can make a difference.

THREE

Maintenance

The therapeutic pipeline is full, and several new therapies are expected to reach FDA approval. The AAD has a defined process for amending published guidelines, and the workgroup has begun applying it.

WHAT THE GUIDELINES WILL DO

They will offer clinicians a clear picture of what the evidence supports in HS care today. They will provide payers with an evidence-based reference for coverage decisions. They will give patients a more consistent and high-quality experience across the specialties they encounter. They will also outline the work that is left to do.

THE ASK

For clinicians, treat HS in a timely and confident manner, advocating for the care patients need with the backing of evidence and the AAD and HSF. For researchers, industry and the foundations supporting this work, use the Research Priorities section as the agenda for the next several years. The work ahead is to make sure what is written reaches the people who need it.

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