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British Journal of Dermatology – Research Letter

Global Hidradenitis Suppurativa COVID-19 Registry: A Registry to Inform Data-Driven Management Practices

Haley B. Naik MD MHSc¹, Raed Alhusayen MBBS MSCE², John Frew MBBS MMed MSc^{3,33}, Sandra Guilbault⁴, John R. Ingram MD PhD⁵, Michelle A. Lowes MBBS PhD⁶, Angelo Marzano, Maia Paul MPH¹, Bente Villumsen, Christine A. Yannuzzi BA⁷.

Affiliations

¹ Department of Dermatology, University of California, San Francisco, CA

² Sunnybrook Research Institute, Dermatology Division, Department of Medicine, University of Toronto, Toronto, ON, Canada

³ Department of Dermatology, Liverpool Hospital, University of New South Wales, Sydney, Australia

⁴ Hope for HS

⁵ Department of Dermatology & Academic Wound Healing, Division of Infection and Immunity, Cardiff University, Cardiff, UK.

⁶ The Rockefeller University, New York, NY

⁷ No affiliation

Corresponding author:

Haley B. Naik, MD MHSc
Assistant Professor, Department of Dermatology
University of California, San Francisco
2340 Sutter Street, MC 0808
San Francisco, CA 94143-0808 USA
Phone 415-502-0433, Fax 415-476-6751
Email: Haley.Naik@ucsf.edu

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The management of hidradenitis suppurativa (HS), a chronic inflammatory skin disease, deserves special consideration in the context of the Coronavirus 2019 (COVID-19) pandemic. We would like to bring to your attention the development of the Global Hidradenitis Suppurativa COVID-19 Registry, a web-based registry developed to capture data on risks, clinical course, and outcomes of COVID-19 in HS patients. Caused by the virus SARS-CoV-2 (severe acute respiratory syndrome coronavirus-2), COVID-19 is an easily transmissible disease which, in its most severe form, is characterized by respiratory failure and multiple organ dysfunction triggered by a cytokine storm response that predominates in older adults and those with significant comorbidities¹. Although HS is not considered a specific risk factor for COVID-19 illness, individuals with HS are potentially at increased risk for severe COVID-19 illness and poor outcomes for several reasons.

First, although HS typically affects younger individuals, it is associated with diabetes and obesity, comorbidities which may predispose to more severe COVID-19 infections². Second, immunomodulating biologic agents such as TNF inhibitors, which are associated with increased infection risk, comprise the mainstay of therapy for moderate to severe HS and may put patients at increased risk of severe COVID-19 illness³. Third, HS disproportionately affects racial and ethnic minorities, and HS patients experience significant barriers to healthcare access under usual circumstances⁴. These data, in conjunction with limited healthcare resources during the COVID-19 pandemic and recent data demonstrating racial and ethnic disparities in COVID-19 transmission and management, suggest that disparities in care may disproportionately affect individuals with HS⁵⁻⁷. Given the time required to develop effective COVID-19 vaccination and treatment strategies, HS management in the context of COVID-19 will need to be grappled with

for the foreseeable future. However, whether HS and its treatments impact COVID-19 course and outcomes is unknown, and evidence is lacking to guide management recommendations.

Therefore, there is an urgent need for observational data to better understand risks, clinical course, and outcomes of COVID-19 in HS patients to guide evidence-based treatment guidelines and identify those at high risk for severe disease. The Global Hidradenitis Suppurativa COVID-19 Registry was launched by an international team of investigators and patient partners from the United States, Canada, United Kingdom, and Australia in collaboration with the U.S., Canadian and Asia-Pacific Hidradenitis Suppurativa Foundations, Hope for HS and Hidradenitis Suppurativa Warriors. This international pediatric and adult registry aims to identify predictors of COVID-19 outcomes in order to improve the care of HS patients. Wide participation and case reporting by healthcare providers and HS patients with suspected or confirmed COVID-19 infection is vital to the success of this endeavor. Cases can be reported at <https://hscovid.ucsf.edu>.

To inform HS management and maximally impact patient care in real-time, aggregate summary data will be regularly disseminated via the registry website and distributed through the HS foundations, patient support groups, and social media platforms. Although initial data from small numbers of reported cases must be cautiously interpreted, preliminary characterizations will provide important insights about predictors of outcomes and guide future analyses. Over time, the registry data will be analyzed for differences in disease severity and outcomes by sociodemographic features, and HS and COVID-19 characteristics and treatments. The potential benefit of immunomodulators in reducing COVID-19-triggered cytokine storm will also be examined.

To facilitate collaboration and comparative analyses across dermatologic diseases, the registry items have been harmonized with other international dermatology COVID-19 registries, and also account for the possibility of duplicate entry across registries.

The limitations of this registry include selection bias towards more severe cases as these individuals may be more likely to seek and receive care, particularly in the initial stages of the pandemic. Exposure misclassification due to limited testing may limit the number of identified COVID-19 infections. Cases may also be missed if dermatologists, who typically care for HS patients, are not informed of a patient's COVID-19 diagnosis, if patients with mild HS have not been diagnosed, or if deceased patients are not reported. The data are also subject to recall bias as they are collected retrospectively, and data entry may be slowed due to provider time constraints during the pandemic. Lastly, web-based registry studies tend to favor well-resourced nations and limit reporting from marginalized groups. Case entry by both healthcare providers and affected patients or their caregivers is one way to mitigate selection bias, limit reporting disparities, and maximize timely reporting. Direct outreach to HS specialists and information dissemination through varied international provider and patient outlets may further encourage diverse representation and strengthen generalizability.

Information from this database will provide timely and responsive real-world data where gaps in evidence exist, and over the longer term, offer improved understanding of predictors of severe outcomes in the HS population and guide evidence-based management recommendations.

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