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

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Conflicts of interest:

HBN has received grant support from AbbVie, consulting fees from 23andme, advisory board fees from Invitrogen Biovitrum, and is a board member of the U.S. Hidradenitis Suppurativa Foundation. RA has received fees for participating in advisory boards for AbbVie and Janssen, consulting fees from Eli Lilly and Hidramed solutions, and is President of the Canadian Hidradenitis Suppurativa Foundation. JRI has received fees for participating in advisory boards for Viela Bio and Kymera Therapeutics and consulting fees from UCB Pharma and Novartis. He received travel expenses and a speaker's honorarium from UCB Pharma. MAL has received fees for participating in advisory boards for AbbVie, Janssen, Viela Bio, and consulting fees from Incyte, BSN, XBiotech, Kymera, and Almirall, and is Vice President of the U.S. Hidradenitis Suppurativa Foundation. MP has no COI to report. SG has received compensation for patient advisory board from Boehringer Ingelheim and is a board member of the US HS Foundation and Hope for HS. BV has received compensation for patient advisory board from Boehringer Ingelheim and consulting fee for UCB and is the President of Patientforeningen HS Danmark. JF, AVM and CAY have no COI to report.

The management of hidradenitis suppurativa (HS), a chronic inflammatory skin disease, deserves special consideration in the context of the Coronavirus 2019 (COVID-19) pandemic. A new Global Hidradenitis Suppurativa COVID-19 Registry has been 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 comorbidities[1].

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 infections[2]. 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 illness[3]. Third, HS disproportionately affects racial and ethnic minorities, and HS patients experience significant barriers to healthcare access under usual circumstances[4]. 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, management and outcomes, suggest that disparities in care may disproportionately affect individuals with HS[5-7].

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. As evidence is lacking to guide management recommendations, there is an urgent need for observational data to better understand risks, clinical course, and outcomes of COVID-19 in HS patients. 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, Australia, Italy and Denmark 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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