



April 16, 2020

Dear CHSF members,

I am writing to inform you about the launch of the [Global HS COVID-19 Registry](#).

The mission of this international collaborative effort is to improve the care of hidradenitis suppurativa patients during the COVID-19 global crisis by capturing data on risks, treatments and outcomes of pediatric and adult COVID-19-infected HS patients. Our plan is to regularly share updated aggregate data with the HS community via the study website in order to help inform the care of HS patients.

The success and impact of this collaborative effort depends heavily on everyone's active participation. Please participate enthusiastically and feel free to disseminate widely to anyone you know who cares for HS patients.

The case report form should be completed by a healthcare provider and takes about 5-7 minutes to complete.

HS patients who currently have or have had COVID-19 may also participate by visiting the study [website](#).

Please report only confirmed or suspected COVID-19 cases a minimum of 7 days after COVID-19 diagnosis and ideally after sufficient time has passed to observe disease course through resolution of acute illness or death.

The database collects only de-identified data in accordance with HIPAA Safe Harbor De-Identification standards. As this is a surveillance study with the aim to improve HS patient care, the UCSF IRB has determined that this is *not human subjects research*, and does not require IRB approval (IRB determination is available on the study [website](#)). We anticipate that U.S. entities will generally recognize our existing IRB determination and should not need additional approvals, however, IRB procedures around the world vary so we are encouraging people to contact their local IRB to determine if there are any questions about need for IRB review/approval. The UCSF IRB determination should cover providers in private practice.

Please direct any questions to hscovid@ucsf.edu.

Thank you all for all that you are doing to care for your patients in this challenging time. We hope this tool will help us all take better care of our HS patients.

Sincerely,

Raed Alhusayen
President, Canadian Hidradenitis Suppurativa Foundation