



Re: Coronavirus and IBD reporting registry

Dear Colleagues,

Given the interest in the emerging and evolving coronavirus (COVID-19) epidemic and the questions regarding how this will impact patients with IBD, many of whom may be undergoing treatment with immune suppression, we have established a secure, online, de-identified Personal Health Identifier (PHI)-free reporting registry.

All IBD clinicians worldwide are highly encouraged to report ALL cases of COVID-19 in their IBD patients, regardless of severity (including asymptomatic patients detected through public health screening). Reporting a case to this Surveillance Epidemiology of Coronavirus) Under Research Exclusion (SECURE)-IBD registry should take approximately 5 minutes.. Please report only confirmed COVID-19 cases, and report after sufficient time has passed to observe the disease course through resolution of acute illness and/or death.

With the collaboration of our entire IBD community, we will rapidly be able to define the impact of COVID-19 on patients with IBD and how factors such as age, comorbidities, and IBD treatments impact COVID outcomes.

Key points:

1. This is an international effort—we are counting on robust participation and collaboration.
2. We will provide regularly updated information about reported cases on the project website, www.covidibd.org, including numbers of cases by country, number of cases by treatment, etc. so the entire IBD community has access to these data.
3. The registry contains only de-identified data, in accordance with [HIPAA Safe Harbor De-Identification standards](#).
4. The UNC-Chapel Hill Office for Human Research Ethics has determined that storage and analysis of de-identified data does not constitute human subjects research as defined under federal regulations [45 CFR 46.102 and 21 CFR 56.102] and does not require IRB approval.

We hope you will actively contribute to this voluntary reporting system. Through broadscale participation and collaboration, we will be able to answer these very pressing questions for our IBD patients and their caregivers.

3/16/2020 Update

Two cases of COVID-19 have been reported to the registry so far:

United States: A 35 yo female with Crohn's disease on budesonide. This patient was hospitalized but did not require ventilator support.

Spain: A 24 yo female with ulcerative colitis on vedolizumab. This patient did not require hospitalization.

To report a case of coronavirus, [click here](#) or visit www.covidibd.org. If you have any questions, please reach out to COVID.IBD@unc.edu

Sincerely,

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