



March 31, 2020

Re: SECURE-IBD COVID-19 weekly update #4

Dear Colleagues,

On behalf of SECURE-IBD, we hope that you and your families are safe and healthy. We are providing this weekly update as part of our commitment to collaboration, transparency, and rapid data sharing. By working across borders, we have already taken a big first step in defining the impact of COVID-19 on patients with IBD and learning how factors such as age, comorbidities, and IBD treatments impact COVID outcomes. We are happy to share these emerging data with you. Please also visit [www.covidibd.org](http://www.covidibd.org) on a regular basis as things are changing so fast and information will be updated frequently.

Remember, we also need your help! Please be sure to report all cases of confirmed COVID-19 in IBD patients, regardless of severity. Reporting a case should take less than 5 minutes. Cases should be reported after a minimum of 7 days and sufficient time has passed to observe the disease course through resolution of acute illness or death. And, please spread the word about SECURE-IBD to all of your colleagues, locally, nationally, and internationally.

**March 30, 2020 Data Update.** A total of 164 COVID-19 cases have been reported as of March 30<sup>th</sup> (93 CD, 66 UC, 2 IBDU). We have received reports from 24 different countries. Thirty-eight patients have been hospitalized and 8 patients have died. The overall mortality ratio among reported cases is approximately 5%. Most deaths have been in elderly patients. More information including a breakdown of cases by age, gender, geography, disease type, and medication use is available at [www.covidibd.org](http://www.covidibd.org). See the Updates and Data tab. A word of caution: it remains too early to draw any conclusions. Going forward we will be updating the website with new data every Monday, Wednesday and Friday.

**Update on erroneously reported death.** We were notified that the patient death reported last week (a 25 year old man from Asia) was a data entry error. The reporter contacted us to correct the entry which is now updated. To prevent future errors, we have added a warning message to the Case Report Form and reporters will now be required to complete to verify accuracy of any reported death. In the spirit of collaboration and transparency, we will continue to update in real time but are also concomitantly ensuring data quality.

**Data visualization interactive map.** We would like to thank Drs. Gil Kaplan, Siew Ng, and Richard Geary who have helped create a visualization of the SECURE-IBD data that will be updated at same interval as the website. The map creation was funded by IOIBD.

**Creation of Advisory Committee.** To help champion and advise on this project, we have formed an advisory committee representing every continent and diverse clinical backgrounds. This committee will assist in continuing to publicize this project and give input on data interpretation and future directions. Membership is noted below.

**Acknowledgement of Reporters.** All those who report cases to SECURE-IBD will be acknowledged on the website and in any resulting publications from this project. Thanks again to all those who have taken the time to report cases during this incredibly challenging time!

**What is SECURE-IBD?** Surveillance Epidemiology of Coronavirus) Under Research Exclusion (SECURE-IBD) is an international, pediatric and adult registry to monitor and report on outcomes of COVID-19 occurring in IBD patients. The registry contains only de-identified data, in accordance with [HIPAA Safe Harbor De-Identification standards](#). 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.

**How can a provider report a case?** All IBD clinicians worldwide are **highly encouraged** to report ALL cases of COVID-19 in their IBD patients, regardless of severity. Reporting should take at most 5 minutes. Please report only confirmed COVID-19 cases, and report after a minimum of 7 days from COVID diagnosis and sufficient time has passed to observe the disease course through resolution of acute illness or death. **To report a case of coronavirus, click [here](#)**

**Who is organizing this project?** This project is being led by Drs. Michael Kappelman (Pediatric Gastroenterologist) and Erica Brenner (Pediatric Gastroenterology fellow) at the University of North Carolina at Chapel Hill and Dr. Ryan Ungaro (Gastroenterologist) and Dr. Jean-Frederic Colombel (Gastroenterologist) at the Icahn School of Medicine at Mount Sinai, New York.

**Are there any partnering organizations/societies?** Official partners include the Crohn's & Colitis Foundation, the International Organization for the Study of IBD (IOIBD), the North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition (NASPGHAN), the European Crohn's and Colitis Organisation (ECCO), and the Asian Organization for Crohn's & Colitis.



European  
Crohn's and Colitis  
Organisation



Please visit us at [www.covidibd.org](http://www.covidibd.org) for updated information or to report a case.

If you have any questions, please reach out to [COVID.IBD@unc.edu](mailto:COVID.IBD@unc.edu).

**Through worldwide collaboration, we can make a large difference!**

**Best,**

**Mike, Erica, Jean-Fred and Ryan**

#### **Advisory Committee Members**

North America: Jim Lewis and Gil Kaplan

Nursing and Advanced Practitioners: Michele Kissous-Hunt

Europe: Walter Reinisch and Jean-Francois Rahier

Asia: Siew Ng

S. America: Flavio Steinwurz

Australia/New Zealand: Richard Gearry

Industry: Irene Modesto

IOIBD: Marischka Konings