



September 22, 2020

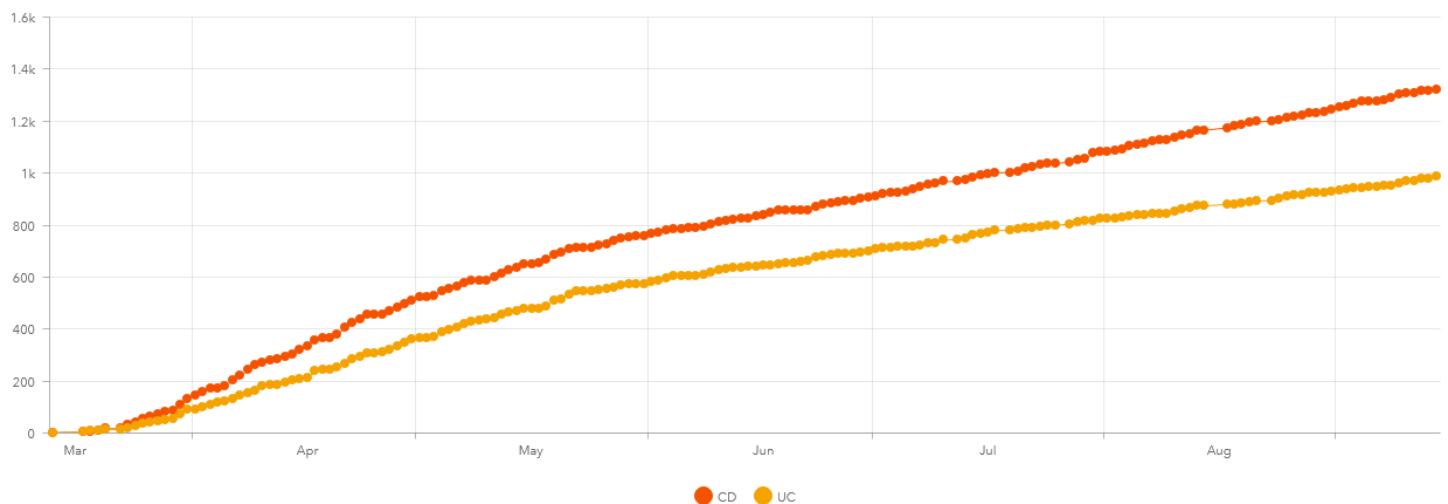
Re: SECURE-IBD COVID-19 update #16

Dear Colleagues,

We hope this newsletter finds you safe and well. As of September 19, 2020, there have been 2,364 COVID-19 cases in IBD patients reported in SECURE-IBD. Overall, the number of cases reported to the registry continues to steadily increase, in large part due to cases reported from Russia, Brazil and Belgium. While our data continue to provide reassurance regarding the safety of anti-TNF, we need more data to understand the safety of biologics, small molecules, and other therapies in the context of COVID-19. Robust global participation will be critical to addressing this urgent unmet need. **We need your help more than ever.**

We are excited to announce that later this fall we will be implementing a process to facilitate the sharing of de-identified SECURE-IBD data with qualified investigators in the spirit of fostering collaborative research. Lastly, we are working on strategies to study intermediate- and long-term outcomes of COVID-19 as these are starting to emerge in “long-haulers”.

**Please continue to spread the word about SECURE-IBD to all of your colleagues, locally, nationally, and internationally!**



Interactive web-based map: <http://covidibd.org/map/>

You may download flyers translated into 17 languages at <https://covidibd.org/press/>

### Frequently Asked Questions

**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?** We encourage **all IBD providers to report all cases of confirmed COVID-19** in 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), Dr. Manasi Agrawal (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), the Asian Organization for Crohn's & Colitis, and the Pan American Crohn's and Colitis Organisation (PANCCO). We also acknowledge the promotional support of many local/regional societies and pharmaceutical companies as detailed on [www.covidibd.org](http://www.covidibd.org).



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.

Follow us on Twitter: @SecureIBD

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 and Manasi**

#### **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