SECURE-Psoriasis: A de-identified registry of psoriasis patients diagnosed with COVID-19

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SECURE-Psoriasis: A de-identified registry of psoriasis patients diagnosed with COVID-19

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Given the interest in the emerging and evolving coronavirus (COVID-19) epidemic and the questions regarding how this will impact patients with psoriasis, many of whom may be undergoing treatment with immune suppression, we have created a secure, online, de-identified Personal Health Identifier (PHI)-free reporting registry for psoriasis patients who have been diagnosed with COVID-19 (Surveillance Epidemiology of Coronavirus Under Research Exclusion in Psoriasis [SECURE-Psoriasis]). We encourage clinicians who treat psoriasis patients worldwide to report all cases of COVID-19 in their psoriasis patients, regardless of severity (including asymptomatic patients detected through public health screening and those with mild or subclinical illness). Reporting a case to the SECURE-Psoriasis registry will take five minutes or less, and no patient-identifying information will be requested or recorded.

We are committed to collaboration, transparency, and rapid data sharing with the international pediatric and adult psoriasis community. By working across borders, we will rapidly be able to define the impact of COVID-19 on patients with psoriasis and explore how factors such as age, comorbidities, and psoriasis treatments impact COVID outcomes.

This is an international effort—we are counting on robust participation and collaboration. On the project website, covidpso.org, we will provide regularly updated summary information about reported cases, including numbers of cases by country and number of cases by treatment, so that the entire psoriasis community will have access to these data. The registry contains only de-identified data, in accordance with HIPAA Safe Harbor De-Identification standards. The Wake Forest School of Medicine Institutional Review Board 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].

We hope that those in clinical contact with psoriasis patients will actively contribute to this voluntary reporting system. Through broad-scale participation and collaboration, we will be able to answer pressing questions for our psoriasis patients and their caregivers. Only confirmed COVID-19 cases should be reported, and only after a minimum of 7 days from COVID diagnosis and after sufficient time has passed to observe the disease course through resolution of acute illness or death.

We find ourselves in an unprecedented situation and, truly, we are all in this together.

SECURE-PSORIASIS is produced in collaboration with SECURE-IBD, a database to monitor and report on outcomes of COVID-19 in IBD patients. SECURE-IBD is 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) at the Icahn School of Medicine at Mount Sinai, New York.