



The coronavirus 2019 pandemic (COVID-19) has created a global public health emergency. New information suggests that some treatments used in patients with many forms of hair loss (alopecia) may result in better outcomes from COVID-19.

To research whether this is true, we have worked with a large network of alopecia specialists from across the globe to create a patient registry (SECURE-Alopecia), that has been endorsed by a number of national and international physician and patient organisations (<https://www.secure-derm.com/alopecia-partner-organisations>). This will allow collection of information about your hair condition, how COVID-19 affected you and whether the two are linked.

A number of similar registries have been developed for other conditions (e.g. eczema – SECURE-AD – <https://www.secure-derm.com/secure-ad-physician>; Inflammatory Bowel Disease SECURE-IBD – <https://covidibd.org>) and we have adopted the term SECURE, as we collect very similar information as these registries so we can combine data at a later stage. The acronym SECURE stands for Surveillance Epidemiology of Coronavirus Under Research Exclusion and is important as it describes that **we do not collect identifiable information**. The only data collected that relates to who you are is the country you live in, gender and year of birth.

Because of this focus on **anonymity**, a doctor will only get one chance to upload your information. As such we ask that if you have hair loss, whether on treatment or not, please ask your treating doctor to enter your information to the registry after there has been enough time for your COVID-19 to have passed – typically about 2 weeks. This will allow us to understand how quickly your symptoms resolved and the extent of the medical treatment needed to help you recover.

Data we are collecting includes details about your general health, your hair loss, medications and COVID-19 illness. All data will be entered into a database, specially designed for patient registries and accessed by doctors who register with us, using an online report form. Careful measures have been undertaken to ensure that the data which is recorded is **anonymous** by experts in data protection. The data itself will be stored on a secure, certified data centre.

Your **anonymised** information will be analysed to identify connections between your hair loss, treatment and response to COVID-19. We will be making information generally available when we have enough data to perform reliable analyses that have been reviewed by an international panel of experts and patient representatives. This will be shared on our website: <https://www.secure-derm.com/secure-alopecia> and using Twitter [@SecureAa](https://twitter.com/SecureAa).

If you are interested in participating and have had a confirmed diagnosis of COVID-19 (including if you had no symptoms) please contact your treating doctor to make them aware of this registry and arrange an appointment for data collection. Please bring details and records (if applicable) of your alopecia and COVID-19 illness with you.

This work has been kindly resourced and developed by an Irish charity, with experience of developing patient registries called National and International Skin Registry solutions (NISR).