

Brussels, 20th April 2020

Covid-19 and CF – Update

In order **to assess the impact** of this unprecedented health crisis on the CF community **both from the perspective of the patients and of the healthcare professionals, two surveys are being launched.**

The ECFS has set up an **ECFS-Covid-19 surveillance for healthcare professionals** to collect clinical information on people with CF in Europe that have been infected by Covid-19. The objective is **to identify the profiles at risk and to understand clinical courses and outcomes**, in order **to provide guidance to CF caregivers** in a timely manner and to **follow up on the long term impact of Covid-19** on people with CF.

Collaboration of all stakeholders, and especially the registries, is the key to epidemiologic global surveillance. The platforms of the CF registries are designed to collect and process this kind of data and data protection is covered by the Registries Informed consent. The aim is to aggregate all data in the European Patient Registry (ECFS-PR). Thus, national CF Registries are encouraged to carry out data collection within their country when possible and to pass the information onto the ECFS-PR. A procedure has been communicated to allow CF centres and clinicians from countries that do not have national registries to easily report individual cases of Covid-19 amongst CF patients directly to the ECFS-PR.

Broad participation and active contribution of all European CF centres is paramount to achieve this important project and we encourage patients and carers to discuss this protocol with their healthcare team.

In parallel, **European patients' organisations are launching a survey** under the umbrella of EURORDIS to **gather real-life information directly from patients with rare diseases**. CF Europe works closely with EURORDIS on this project, and will have direct access to the data filled in by the CF community. People with CF, their families and carers are invited to fill in the survey [online](#) to share their real-life experiences during the Covid-19 pandemic. The questionnaire is available in 23 languages and will give an overview on how Covid-19 impacts our community throughout Europe. We are confident that these **“patient-reported outcomes”** may be of great support not only to the CF community, but also in future **negotiations at the European level.**

Please do fill in the survey and share widely. The more and the sooner we get data, the better we can inform you and advocate on your behalf!