

Brussels, 10<sup>th</sup> April 2020

## Covid-19 and CF – Update

CF Europe continues to work closely with the European Cystic Fibrosis Society (ECFS) and the wider CF community in order to monitor how this exceptional situation impacts people with CF and their families.

The international scientific community is mobilised to organise the sound and thorough collection of reliable clinical data in order to evaluate the long-term impact of the pandemic on our community. The **ECFS patient registry (ECFSPR)** is working hard under the umbrella of the **ECFS to implement a straightforward yet efficient online protocol to allow clinicians to report cases of Covid-19** amongst their CF patients in a systematic fashion. What patients and carers can do is **inform their healthcare team** of this protocol and of the importance of collecting data on how the Covid-19 virus impacts the life of people with CF.

Although the long-term effects and the extend of them cannot be estimated at this point, scientists are already gathering first pieces of evidence to understand how this virus behaves. It has been widely communicated that people suffering from other illnesses are at higher risk when contracting Covid-19. A new article published by a **Chinese team studied the potential correlations between Covid-19 severity and a range of different conditions**. The objective was to identify the population that may require extra care. A **lay summary** of their findings is available on the European Lung Foundation (ELF) website [here](#).

Furthermore, at the instigation of the UK CF Trust, several countries are currently collaborating to put together a **case study presenting the first reported cases of Covid-19 amongst the European CF population**. The aim is to provide an early picture of the situation, a scientific basis that can be built upon and could support clinicians in the analysis of the risk for patients with CF.

In parallel, in collaboration with the European Organisation for Rare Diseases (EURORDIS) and with the proactive input of patients' representatives, **a survey will be soon launched aimed at people with a rare disease – and notably CF – and their families**. The objective is **to gather real-life experiences** in these unprecedented times in the form of **“patient-reported outcomes”**. We hope this information may support not only the CF community, but may also serve as leverage in future negotiations at the European level.

We realise that these are challenging times rising all sorts of interrogations and concerns, especially for people already dealing with CF in their everyday life. **Prof. Tobias Welte**, past president of the European Respiratory Society (ERS), **gives some insightful answers about the Covid-19 pandemic** in an interview published by ELF [here](#). And to keep up during this difficult time, **Dr Samantha Phillips**, co-chair of the CF psychology and social work committee at the UK CF Trust, **shares some tips and tricks** you may find helpful **to manage anxiety** around Covid-19.