

Press Release: Official launch of the first European Long COVID patient network

Heverlee, Belgium, 4 October 2021 - Today, more than 20 Long COVID patient associations from 17 different European countries officially launched **Long COVID Europe (LCE)**, a network run by Long COVID patient organisations. Across Europe, patients are struggling with the same issues; lack of awareness and recognition of Long COVID, inadequate and unequal access to care and rehabilitation, and a severe shortage of funding for research into therapeutic approaches. LCE addresses these issues by sharing resources with its members, jointly calling on governments to recognise Long COVID as a public health crisis within and beyond the COVID-19 pandemic.

Globally, more than 230 million people have already tested positive for SARS-CoV-2. In reality, many more have been infected. It is estimated that at least 10% of those infected continue to experience severely debilitating symptoms for longer than six months, ranging from post-viral fatigue and post-exertional symptom exacerbation to neuro-cognitive deficits, nervous system dysfunction, and chronic pain. For some patients, Long COVID also entails damage to vital organs. The World Health Organization (WHO) is due to publish the first clinical definition of Long COVID - referred to as the Post-Acute Sequelae of SARS-CoV-2 (PASC) - at the third WHO webinar on "Expanding our understanding of post COVID-19" on 6 October: <https://www.who.int/news-room/events/detail/2021/10/06/default-calendar/expanding-our-understanding-of-post-covid-19-condition-web-series-rehabilitation-care>.

In the meantime, patient associations are continuing to fight for the recognition of Long COVID as a physiological medical condition. Funding for research into the disease mechanisms and targeted treatments by governments remains scarce, and the establishment of safe and universally available rehabilitation approaches is urgently needed. Thanks to the efforts of patient advocacy groups in the United Kingdom (UK), the UK government developed an initial five-step plan during the summer of 2020. This has since been updated and includes, amongst other initiatives, establishing more than 80 Long COVID clinics. In other countries, such as Greece and Hungary, governments have yet to acknowledge the extent and severity of Long COVID and its implications for citizens affected.

Moving forward, LCE seeks to address the inequality and lack of management in its member countries and to pave the road for improved and adequate care for all Long COVID patients within the 53 countries in the WHO Europe region.

LCE is a registered non-profit organisation in Belgium. To contact LCE, please reach out via Mail to contact@longcovid europe.org or contact Chantal Britt (German, English, French: +41 76 588 0824) or Ann Li (Dutch, English, German: +32 494 435 879).