



Long Covid Alert

June 28, 2023

Document produced by Association #ApresJ20

Find out more about Covid long on our website
apresj20.fr
and follow us on social networks



Subject: LONG COVID ALERT

28 June 2023

Dear Sir/Madam,

In France, **2 million adults** have Long COVID, several hundred thousands of whom suffer from a severe form (figures from the *Agence nationale de Santé publique* or *Santé publique France*, a public body under the authority of the French Ministry of Health), and **34 million people in Europe** (figures from the World Health Organisation WHO).

“Sick human beings” whose lives have been turned upside down, confronted by a society that often doubts the reality of this disease due to a lack of information and awareness-raising initiatives. Long COVID is now recognised and defined internationally (WHO), in Europe (European Parliament) and in France (Haute Autorité de Santé). The symptoms are multiple, serious and extremely incapacitating: brain fog, dyspnoea (breathing problems), neurological problems, cardio-thoracic pain, extreme fatigue, coagulation problems, etc.

3 years after the onset of this disease, people suffering from Long COVID are calling for official recognition of this disease by the French public authorities and for access to appropriate care in the hope of a cure.

So, without waiting any longer, we must now :

- provide resources for **research** into the pathophysiology of Long COVID (how the virus acts), its epidemiology (why a particular person is affected) and research into treatments for this disease,
- **recognise** this disease so that patients, some of whom are no longer able to work, attend school or continue their studies, can benefit from social protection, avoid losing their place in the world of work and education, and combat their impoverishment,
- **train** healthcare professionals to identify patients, support them towards multidisciplinary, coordinated, long-term care and **communicate** about Long COVID at the national level.

In France, our patient association, #ApresJ20, was created 3 years ago. Here's where we are today:

- **The President of the Republic** is aware of our case; he was questioned once again in 2022 by a patient ([Questions to the President of the Republic during a visit to Poitiers \(December 2022\)](#)), then in May 2023 he was alerted by a letter from our association "#ApresJ20, Association Long COVID France", a letter to which there has been no response to date, [Letter to the french president](#), [Testimony from Vinciane](#)
- On 25 May 2023, **the Minister for Health and Prevention** chaired a meeting of experts, advisers, doctors and patients' associations. Concrete proposals were to be made by 28 June 2023, but to date, there has been no response,
- **French parliamentarians** have been informed, and many have relayed our requests to the Minister of Health. In return: observations, promises, and compassion, but nothing concrete from the government.

A law was passed in 2022, but the implementing decree has still not been published. [Law of 24 January 2022 aimed at creating a referral and management platform for chronic covid-19 patients](#).

It is our duty to alert as many people as possible to the situation of the 2 million patients affected by Long COVID in France who are suffering in silence.

This silence, particularly on the part of the public authorities, is inexplicable given the suffering of sufferers, both adults and children, who are not diagnosed and whose doctors are ill-informed. This disease remains poorly understood, despite the fact that it is particularly well-supported scientifically. The fact that it is not taken into account in our public health policies is unacceptable. Patients cannot put up with this unfair and abnormal situation any longer.

We are asking you to work alongside us to ensure that the rights of patients with Long COVID in France are heard.

Help us to give the 2 million adults affected by Long COVID back their dignity as patients.
Help us to give a future to the thousands of children and teenagers affected by paediatric Long COVID.
Help us at your level by supporting us and **by calling on the President of the French Republic and the members of his government** by sending them this letter [Courrier Appel Citoyen PresidentRepublique](#) to the addresses you will find in this table. [Mailing list Presidency 28 June 2023](#)
Help us to give a voice to the millions of adults, children and teenagers with Long COVID so that they can finally find hope of living with dignity with this disease in France!

Respectfully,

Association ApresJ20 Covid Long France

Long COVID info: apresj20.fr

Calendar and patient testimonials

8th of December 2022 President of the Republic, Emmanuel Macron: video oral commitment to a patient https://youtu.be/nzl_5f47GUc

15th of March 2022 Olivier Véran, Minister for Solidarity and Health: communication on the need to put in place a national action plan to support COVID patients long <https://www.dailymotion.com/video/x89ravg>

In October 2022, Tedros Adhanom Ghebreyesus, General Director of the WHO, urged the countries of the world to launch "immediate" and "sustained" programmes to combat this "devastating disease". <https://www.theguardian.com/society/2022/oct/12/long-COVID-who-tedros-adhanom-ghebreyesus>

In March 2023 European Parliament: conclusions and recommendations of the European Parliament on the long COVID of March 2023 ([report on](#) the conclusions on pages 8 and 9). Impact of long COVID on economies is estimated at an economic cost of USD 3.7 trillion (over 5 years) and GBP 2.5 trillion (per year) respectively in the United States and the United Kingdom. No assessment in France.

In May 2023, Tedros Adhanom Ghebreyesus, Director-General of the WHO made a speech recalling that the impact of the long COVID was serious. "The worst thing a country can do now is to let its guard down, dismantle the systems it has built or send a message to its people that COVID-19 is nothing to worry about".

<https://twitter.com/apresj20/status/1654531442364252189>

In May 2023, the G7 health ministers meeting in Japan decided, at Germany's instigation, to make Long COVID a G7 priority and to launch a research initiative for Long COVID sufferers to invest in new therapies and better care. Federal Minister Karl Lauterbach (SPD), in contrast to France, is investing in **prevention, communication and the weekly dissemination of** news and scientific discoveries about COVID Long.

In May 2023, Dominique Martin, national medical advisor on COVID long: "There is a physiological, pathological reality, and there are symptoms. It's a real disease and it's a chronic disease. https://twitter.com/Assur_Maladie/status/1656940357613940737

In June 2023, the European Parliament's Special Committee on the COVID-19 pandemic adopted a recommendation for the development of an EU strategy to combat "long COVID". <https://www.europarl.europa.eu/news/fr/press-room/20230612IPR96901/les-deputes-tirent-les-lecons-de-la-crise-de-la-COVID-19>

France Inter's poignant podcast, which *"gives a voice to those for whom nothing is over, those who are still exhausted and barely walking, all the "long COVIDs", those who thought they would get through the pandemic like a cold and who are still fighting with their bodies"*.

<https://www.radiofrance.fr/franceinter/podcasts/le-telephone-sonne/le-telephone-sonne-du-mardi-09-mai-2023-4281782>

Florent (Florent Long COVIDbedridden 24h/24h without solution) Vinciane Testimonial

Other testimonials on the Association's website: <https://www.apresj20.fr/temoignages>