



Letter to the french president

June 28, 2023

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Mr President of the Republic,

2 MILLIONS OF PATIENTS AFFECTED BY Long Covid IN FRANCE SUFFER IN SILENCE WHILE YOUR GOVERNMENT LOOKS THE OTHER WAY

During your visit to Fontaine-le-Comte on 8 December 2022 as part of the Conseil national de la refondation en santé, you made a commitment to a patient affected by Long Covid to read our letter and answer our questions about government initiatives to support recognition, research and care for adults and children affected by this disease.

In the absence of any news from you, we took the initiative of renewing our request to the office of the Minister for Health and Prevention.

Long Covid patients from Poitiers, Nantes and Paris, members of the collective and the #AprèsJ20, the Long Covid France association, were due to be received on 5 May at 2pm by Mr Malczyk, Health Safety Advisor to Minister François Braun.

Less than 24 hours before, this meeting was cancelled due to "ministerial constraints". Despite requests to hold the meeting at another time during the day, the meeting was cancelled without taking into account the precarious situation of patients, for whom this meeting was very important after such a long waiting time, and which had required considerable human and logistical organisation.

Of course, other dates have been proposed and this meeting will take place on 24 May 2023 by videoconference, as several volunteers will no longer have the financial means to travel to Paris. A fund has been opened to enable them to attend this meeting on 5 May. However, it would have been preferable for them to attend the meeting in person, in order to engage in a face-to-face dialogue with the public on a crucial social issue - health, prevention and solidarity - that affects us all.

At a time when Long Covid seems to have been forgotten in the Ministry's priorities, the current situation of patients should unite us and encourage us to act collectively with greater ethical rigour, so that these millions of French people and their families, affected by this disabling illness, can live with dignity by benefiting from collective support tailored to all aspects of their lives. 3 years after the onset of this disease, concrete, useful, realistic and applicable public responses must be given by your government, in line with the principles of the law to modernise healthcare democracy promulgated on 26 January 2016, which involves including patients in the definition of healthcare provision throughout the country.

However, since the government reshuffle, the debate on Long Covid has changed, with unfavourable developments for adult and child patients with Long Covid. For example, Minister François Braun said a few days before your visit to Poitiers on 4 December 2022: "*I don't know if we can still call it a disease*". However, casting doubt on the very existence of the pathophysiological reality of this disease runs counter to scientific knowledge and the recognition of this pathology in Europe and in the world.

Nor do we understand why a series of actions carried out with the tireless efforts of patient associations and groups have not been successful:

- the Long Covid law was not applied,
- the care and support measures announced by Mr Véran have not been put in place, they are fragmented, inconsistent or unsuccessful,
- information on Long Covid is not updated or shared,
- research has been slowed by the lack of budget for 2023.

In order to justify the refusal of compensation and cover (ALD, MDPH in particular), you mentioned our volunteer uncertainties in the definition of diagnostic criteria. To date, the clinical picture of Long Covid has been documented by French and international bodies, and the state of health of patients is measurable. We are already seeing significant repercussions for the care of these patients, as a direct consequence of this public statement.

In addition, the Long Covid monitoring committee of the Ministry of Health and Prevention was repeatedly postponed, which is currently scheduled for 25 May and in which Mr Braun is due to take part. These postponements give the impression that recognition of Long Covid disease has been disinvested.

Not to mention the fact that when we write to you, or when our associations or members of parliament write to you, we only receive administrative responses. We are therefore seeing a decline in action in France, despite the fact that many patients are suffering the full impact of this situation and are faced with increasing insecurity and stigmatisation.

Our situation in France runs counter to the march of History. Since Long Covid was recognised by the World Health Organisation (WHO) in August 2020, a series of events has only served to underline the urgent need to invest in prevention programmes and care facilities.

For example:

- On 15th of March 2022, the French Minister for Solidarity and Health, Olivier Véran, announced the need for a national action plan to support patients.
- In October 2022, Tedros Adhanom Ghebreyesus, Director-General of the World Health Organisation (WHO), urged the world's countries to launch "immediate" and "sustained" programmes to combat this "devastating disease".
- In March 2023, the conclusions and recommendations of the workshop held at the European Parliament on Long Covid emphasised the importance of investing in research and patient care (see [report on the conclusions on pages 8 and 9](#)).
- In May 2023, Tedros Adhanom Ghebreyesus, Director-General of the World Health Organisation (WHO), gave a speech reminding us that the impact of 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 Covid19 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 in order 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 Long Covid.

Mr Chairman, our demands are not new and we already have solutions: they were clearly identified in the Long Covid roadmap of 13 April 2022. Unfortunately, we can see that this action plan, in which we participated, has not been implemented, and that the situation of patients with Covid Long continues to deteriorate.

(FR) Mr President, every day is a new test to avoid the precariousness of our lives, whether professionally, socially or even medically, simply because we are affected by Long Covid in a European country, France, which does not provide the means to support patients suffering from this invisible but disabling illness.

Not to act would be a nonsense, an obstacle to collective action whose conclusions are unequivocal and which no one can ignore. The fact is that:

- This disease is clearly recognised and defined both internationally by the World Health Organisation (WHO) and by the Haute Autorité de Santé (HAS) in France,
- There is an abundance of national and international scientific literature providing a better understanding of the causes and pathophysiological mechanisms, even though there is as of now no specific treatment for Long Covid.
- Long Covid will have and is already having a major impact on our economies (> 1% of US GDP - *Brookings data*). The European Parliament estimates the economic cost to the United States and the United Kingdom at USD 3.7 trillion (over 5 years) and GBP 2.5 billion (per year) respectively (see the European report mentioned above). No assessment has been made in France.

Today, despite the government's answers to numerous parliamentary questions on the implementation of Long Covid schemes, we are still waiting for a real and effective French policy on the management and prevention of Long Covid:

- with multi-disciplinary, coordinated, tailored care pathways and real long-term care monitoring,
- backed up by appropriate resources for scientific research (pathophysiological causes and treatments),
- taking into account what patients have to say and base the policy on their own experience,
- allowing all the people affected with this disease, adults, adolescents and children to benefit from the same protective framework,
- Putting into place national prevention campaigns to prevent new infections, as it is the case in other countries.

https://twitter.com/Ecole_Oubliee/status/1659649986802360329?t=UqdreSwU0BQzb8nfuCVqWQ&s=31

We would remind you that SARS-CoV-2 infections still lead to Long Covid disease. Added to this are re-infections with the virus, which in some cases worsen the lives of patients already suffering from Long Covid. Some patients, despite their condition, do not benefit from protection or preventive and curative drug treatments like those at risk. We believe that these measures could form part of a broader programme to protect the population. As the European Parliament has emphasised, this pandemic crisis is an opportunity to anticipate future health and climate disasters while respecting our democratic principles. It could be a lever for action to anticipate the challenges that lie ahead and support, from now on, a cultural transformation based on crisis prevention rather than crisis management. Our role as patient representatives is therefore to sound the alarm about this situation on a massive scale, so that our experience supports the promises of a new approach to healthcare, based on democratic and ethical values of dignity, respect and inclusion for patients.

We will submit this letter to Minister Braun at the committee meeting on 25 May 2023. We will send it by e-mail the next day to your Health Safety advisor and to the Minister attached to the Minister for Health and Prevention, responsible for Territorial Organisation and the Health Professions.

Mr President of the Republic, we would really appreciate it if you could give us your position and commitment by formulating concrete responses on these various points before 28 June 2023.

There is now an urgent need to respond to the 2 million patients with long-standing Covid who have been waiting for too long, even though they have the right to be informed, to have a reliable diagnosis and to be treated.

If you fail to provide a realistic and practical response by this date, patients and we will be obliged to send this letter to the public and institutional bodies that are listening to us (in particular the G7 health ministers and French and European parliamentarians), as well as to associations and the media.

We can't imagine such a situation, but it would be 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 while your government looks the other way. It will no longer be possible to say that we didn't know and that it wasn't possible to act.

Yours respectfully,

Members of the Poitiers collective and the #ApresJ20 Association Long Covid
France - 25 May 2023