LONG COVID MANIFESTO

Covid is not over. Each new variant brings with it a wave of long COVID. We are millions around the world - we exist. Long COVID unites us.

There is no cure for this systemic disease: at best, we have temporary fixes for some of the symptoms. This disease can affect anyone, regardless of age, social status or nationality; women are disproportionately affected, facing greater risk at work and often having their symptoms dismissed as psychological. Chronically ill and disabled people are at higher risk, and their health issues accumulate. Children also suffer, often in silence. But everyone is at risk, without any exception.

New cases emerge every day, as reinfections continue. 1 in 10 people at least : Long COVID cannot be written in the past tense, even though most institutions have chosen to erase and minimize the pandemic.

You likely know a close one suffering from it.

Even if you don't know it, you could be affected by it too: long COVID also means all the diseases that are induced by SARS-CoV-2 infection.

Five years in, we still do not know all the consequences of the pandemic. What we already know should be enough: some died in the acute phase, others later on, or slowly, from the chronic form of the disease and/or of the social death it brings along.

We have lost health, jobs, friends, family, social rights... New cases emerge every day. We can't manage it by ignoring it.

As of today, March 15, 2025, 5 years after the start of the pandemic, we are denouncing the lethal silence on the COVID epidemic still going on, and claim our rights.



I HAVE THE RIGHT TO TREATMENT AND CARE:

• Urgent clinical trials focused on the treatment of causes and mechanisms: thromboinflammation, viral persistence, dysimmunity.

• Recognition of the disease's severity, whatever shape it takes, and management of the risk of complications.

I want doctors to think about the risks of my persistent infection, my life expectancy, as for other chronic diseases.

• Biomarkers for diagnosis and monitoring treatment efficacy.

• Rapid, effective tests and preventive treatments to minimise the harm caused by the infection.

• Access to trained doctors and nurses, with coordinated, multidisciplinary care pathways and safe healthcare facilities that don't make us navigate aimlessly from one consultation to the next.

I live with long COVID, and I need to be able to be seen by healthcare staff that are committed to treating our illness more than silencing our complaints.

I HAVE THE RIGHT TO EFFECTIVE PREVENTION MEASURES (AND SO DO YOU) CLEAN AIR • We should all have the right to breathe clean air indoors, and wear high-quality masks in health care facilities. We don't want to risk our health anymore to access medical care. We also need a viable, robust healthcare system. • Our children, our friends, our loved ones and our carers all go to schools and other essential public spaces : this spaces must be safe, too. • Reliable, comprehensive and transparent epidemic monitoring enables us to adapt all these measures. • Easy access to preventive treatments for all. • End of the division of the population into vulnerable and invulnerable groups. • Extensive Covid information campaigns that take long COVID into account. INFORM The only way to avoid long COVID is not to have COVID. I can't afford to suffer from this disease. Can you? I HAVE THE RIGHT TO BE FREE FROM SOCIAL DEATH Social security coverage, sick leave and workplace accommodations must allow us to return to work, when possible, in decent and secure conditions. • An end to the stigma and dramatization of wearing FFP2 masks everywhere: LIVE we're all vulnerable to Long COVID.

• Disability rights and financial support, for survival until a treatment is available.

We can't wait another 5 years.

Without your knowledge, it is we, the persons living with Long Covid, with no financial resources, who are fighting for our rights to be recognized, for prevention, for research to progress. We should be able to focus on recovering just like any other sick person. And yet, we demand everyone's right to health, to safety, to a life without fear of the virus.

Time is running out. It happened to me, it happened to millions of people around the world, and it could happen to you tomorrow.

This is also what unites us. In the face of long COVID, let us be one.

