

Long Covid SOS organise historical meeting with the WHO

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We have heard your message about long covid and we will act, says WHO

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A few weeks ago, we wrote a BMJ Opinion piece about the long term impacts of Covid and called for patients' experiences of Long Covid to be included in any initiatives to explore the experience of "long-haulers." This opinion piece foregrounded a video called "message in a bottle" made by the LongCovidSOS patient group, which caught the attention of the World Health Organisation's covid-19 response team. The LongCovidSOS team were then invited to organise a meeting. This opportunity to present the existing evidence and highlight patients' experiences of having Long Covid took place on Friday 21 August 2020. The meeting was attended by Maria Van Kerkhove, (WHO Covid Technical Lead) and Janet Diaz (WHO Head of Clinical Care) from the central WHO team.

At the meeting, two of us, Clare Rayner and Amali Lokugamage, both doctors who are experiencing long term impacts of covid-19, discussed their perspective of having Long Covid.

Why patient led evidence matters

When Long Covid SOS was invited to a meeting by the WHO, we knew straight away that there was a need to present firm evidence and robust statistics in order to be taken seriously. To help them achieve this, Hannah Davis of Patient-Led Research presented the findings of a report on the main characteristics of Long Covid, based on a detailed survey of members of the Body Politic Slack support group and other covid-19 support groups. The picture she gave was one of a complex illness which consistently affects young and fit people, presents a multitude of symptoms across the cardiovascular, neurological, respiratory, and gastrointestinal systems, and afflicts patients with cyclical relapses. The research was also cited in a recent BMJ piece on guidelines for GPs on how to care for long haulers. Frances Simpson, the mother of two children who have had covid-19 presented on the experiences of other parents whose children have had Long Covid, based on information from patient support groups.

Listening to patients with Long Covid is key

In the final part of the discussion we heard from Pauline Oustric from the French campaigning group #AprèsJ20. Pauline spoke about active support groups and campaigning initiatives across Europe that have emerged in the wake of the first wave of the pandemic. In her talk Pauline asked for recognition, research, and rehabilitation, the three pillars of all Long Covid campaigning. She also asked for better communication and called for the WHO and national governments to warn populations of the risks of Long Covid, as a matter of urgency. Encouragingly, France has already responded to this plea with a short public information film about a young people's experiences.

Covid-19 is a new disease and the long-term effects have taken the research and medical communities by surprise. We strongly believe that it is only by listening to peoples' experiences carefully and compassionately that solutions will be found.

They gave us hope

At the end it became apparent that Dr. Tedros Adhanom Ghebreyesus had been listening in the side lines. He suddenly appeared, to summarise at the end, thanked us each by name, and re-quoted part of our presentation where Amali had said "with patient-led research and patient-led activism, it appears that patients are writing the first textbook on Long Covid."

He said touchingly that he wanted the audience to know: we have watched your film, received the "message in the bottle," we have received your "SOS." We have heard loud and clear that Long Covid needs recognition, guidelines, research and ongoing patient input and narratives, to shape the WHO response from here on.

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The original article can be viewed here in full <https://blogs.bmj.com/bmj/2020/09/03/we-have-heard-your-message-about-long-covid-and-we-will-act-says-who>

You can read a press release about this meeting [here](#) (from page 3) and also Dr Tedros' [tweet](#):

"I joined an inspiring meeting with #COVID19 patient groups. My colleague @mvankerkhove contacted these great advocates who strive to increase research, rehabilitation and recognition for people suffering long-term effects of the virus. @WHO is committed to supporting their goals"