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Committee on Social Affairs, Health and Sustainable Development

Minutes

of the hearing on “ “Long Covid” and access to the right of to health”

held in Lisbon on Friday, 13 September 2024

The Committee held a hearing with Mr Joan B Soriano, Medical Epidemiologist, Servicio de Neumología, Hospital Universitario de la Princesa – UAM, Madrid, Spain, and Ms Chantal Britt, Long Covid Europe (European network of Long Covid patient organisations).

Mr Moutquin, Chairperson of the Committee, recalled that at the Committee's meeting in Paris last June, Ms Leyte had presented her preliminary draft report on the deep and lasting impact of the Covid-19 pandemic and its aftermath, known as long Covid. At the time, some members stressed the difficulty of establishing a diagnosis and defining what is meant by "long Covid". The Committee therefore invited two experts to speak on the subject. Firstly, Mr Soriano, who has been working on the definition of Covid long within a WHO working group and will be presenting the results of his work in order to provide a better understanding of this Covid long disease. Secondly, Ms Britt will present the current state of recognition of this neuro-immunological disease and the challenges that exist.

Ms Leyte, the rapporteur, pointed out that the issue of "long Covid" concerns everyone. As a doctor, she observed that the Covid pandemic had affected all age groups, including children and adolescents, and had completely changed people lifestyles. Thousands of people were admitted to hospital and hundreds of thousands died. Economies were shaken, with employers and workers affected. The damage continues to this day: not only to health, with neurological and respiratory diseases, permanent fatigue and loss of smell, but also to everyday life and families. That was why it was important to hear from the experts on the subject to shed light on the report.

M. Soriano looked back over the last 5 years since Covid first appeared. It all began in December 2019, when the WHO bulletin for the Asia region indicated that there were 44 cases of pneumonia of unknown origin. The first information received in the West was a letter published in the journal *Science* from two journalists, in which they mentioned a limited outbreak which in a few weeks should have disappeared. Unfortunately, this did not happen, and there have been 14 million deaths from severe Covid and more than a billion infections worldwide. This pandemic has given rise to a great deal of research, and there are now more than 400 000 publications on the subject.

The pandemic has hit every country hard. Many medical staff and patients died as a result of the disease. While most patients recovered from severe Covid, 1 in 10 developed long-term symptoms ("long Covid"). This condition mainly affects people in their forties and fifties.

According to the journal *Nature Medicine*, around 400 million patients worldwide suffer from Long Covid, which is almost as many as the population of the European Union. Long Covid is a reality. However, like any new disease, it is difficult to define. A WHO working group, in which Mr Soriano took part, has been looking into this definition. It takes time to define a disease. In the 90s, it was not easy to define HIV. For some diseases it took 20 years. In the case of long Covid, there is very little hindsight, with only four years of work. To arrive at

¹ The minutes were approved and declassified by the Committee on Social Affairs, Health and Sustainable Development at its meeting on 6 December 2024.

a definition of long Covid, the Delphi method was used. All stakeholders were consulted: researchers, nurses, doctors, politicians and patients. The definition of Long Covid arrived at by the working group is as follows: "The post-Covid-19 state is defined as the state occurring in people with a history of infection by SARS-CoV-2, with or without laboratory confirmation, three months after the onset of Covid-19 and whose symptoms last at least two months. Symptoms of the post-Covid-19 state (such as fatigue, breathlessness, cognitive dysfunction, etc.) are persistent in nature and of recent onset, regardless of their number, intensity or severity, but are likely to appear in clusters. They have an impact on daily functioning and cannot be explained by another diagnosis". A separate definition should be considered for children. There are more than 200 symptoms associated with Covid long.

A fortnight ago, the Americans proposed a shorter definition saying that long Covid is an infection associated with a chronic health problem and after infection with the Covid virus, SARS-2, after three months, continues to evolve or becomes a progressive disease. And this affects one or more organs or gives rise to symptoms in one or more organs.

In 2024, there is still no threshold or biomarker to define what we mean by Covid long. Researchers are still working on it. In 2021, the NIH, the US National Institutes of Health, has decided to invest \$1 billion to study Covid long and its mechanisms. The European Union has committed €50 million. Not only have the Americans done so in 2021, but they have also systematically invested 1 billion dollars or more every year, and are much further ahead than Europe on the subject.

International cooperation is therefore necessary. Traditional Chinese medicine, including acupuncture, can be used to help patients, and funding is needed. In Europe, one million patients suffer from Covid long, so this is a major medical challenge. Perhaps the systems are not yet ready to respond, but there is an urgent need to assess the situation and pool all our efforts.

The Chairperson thanked Mr Soriano for his presentation and suggested that we move on to the next speaker and then take questions. He then gave the floor to Ms Britt.

Ms Britt, who lives in Switzerland with a long Covid since March 2020, is a member of the Long Covid Europe network. This organisation, which is present in over 15 countries across Europe, brings together patients who have been living with Long Covid for years, as well as doctors, healthcare professionals and researchers. They are fighting for Long Covid to be recognised as a pathological physical condition affecting adults and children.

In the European Union, there is a 5% prevalence of long Covid, or 22.5 million people. This is equivalent to 400 million people worldwide. Within the European Union, another 2.5 million people live with chronic fatigue syndrome. In all, 25 million people live with these complications. This is equivalent to 6-7% of adults and 1% of children in the European Union. In economic terms, this is equivalent to 1% of GDP according to the OECD, or around €175 billion each year. Recovery and the trajectory of symptoms are highly variable, with frequent relapses.

The main challenges are multiple: a lack of evidence and data, a lack of established biomarkers, a lack of targeted funding, a lack of recognition of the physical origin of the disease, and a lack of skills and knowledge. Patients have different profiles. There is a lack of funding for research into women, the majority of whom are affected. Doctors find it very difficult to prescribe unlicensed treatments to relieve the symptoms (around 200) associated with Covid long. Many very specific symptoms are not the subject of specific research, and a large proportion of healthcare staff do not have sufficient skills or knowledge in relation to Covid long. With current knowledge, there's no way out. Very often, diagnoses are wrong, and prescriptions are therefore wrong, resulting in ineffective treatments that only make symptoms worse. This neglect has an impact on patients' lives (loss of work, inability to go to school, social isolation, lack of perspective).

So, what are the priorities from the patient's point of view? Only 1% of doctors treat Covid long. This means that transdisciplinary centres of expertise need to be set up to establish a correct diagnosis using current standards and tools. Unlicensed or off-label treatments combined with established drugs are also needed, and long-term support for patients, because many people suffer in silence. Germany, which is to invest \$250 million in healthcare research, appears to be a good example; the country is going to create a pioneering clinical trials platform to adapt existing treatments.

Biomedical research needs €500 million. There is a need for trans-disciplinary centres of expertise, awareness-raising campaigns, training programmes for healthcare staff, recognition of disability to make it easier to pay for accommodation in the workplace, but also in teaching at school. We also need public and private partnerships and international cooperation to develop biomarkers, diagnostics and treatments. One of the biggest scandals of recent years has been the neglect and malpractice of patients. One of the first approaches to be taken is to fund research to produce evidence and better tackle this disease. This would have positive consequences for patients and would help governments to be better prepared to deal with any future pandemics. If it is decided to live with Covid today, by no longer wearing a mask, by no longer protecting people, it is necessary to tackle Covid.

The Chairperson thanked Ms Britt and opened the floor for discussion.

Ms Leyte thanked Mr Soriano, who had helped the Committee to better understand the medical language and had shown how necessary it was to continue research in order to help patients. The figures presented on the number of people affected by Covid long in Europe were frightening. She thanked Ms Britt for her testimony, which helped to identify the problems. She wondered whether the stakeholders saw any possibility in the future of a doctor being able to cure or relieve the symptoms of Covid long? Are governments prepared for the next pandemic?

Mr Soriano pointed out that nobody knows today whether an effective treatment for the long Covid will be found. However, he was certain that lessons could be learned from Covid. For example, in the 90s, with HIV/AIDS, all the patients died within a few weeks. Today, there are very few AIDS-related deaths in Europe, and none in Spain. Everything is under control thanks to antiretroviral treatment and triple therapy. In Asia, on the other hand, and in Africa, where treatment is not as accessible, AIDS is still a very serious problem. Looking at the example of cancers, certain types of cancer, such as pancreatic cancer or colon cancer, which were once death certificates, are now better treated and are becoming chronic diseases. There is no cure, but the disease can be controlled. So, it is important to target treatable symptoms. In the case of long Covid, some patients are short of breath, others are tired, others have half-hearted arrests. The most important symptoms need to be tackled, those that can already be treated, and from there, ensure that these patients are able to return to a normal life.

When it comes to preparing for the next pandemic, society and international medical systems are much better organised today, and politicians and policy advisers have a better grasp of this type of problem and its aftermath. It remains to be seen where the next pandemic will come from.

Ms Tanguy asked whether there are any plans to pool the data that countries can collect on this condition. In France, a law voted in 2022 recognised Covid long and set up a patient monitoring platform and dedicated care units. Pooling data would give a better understanding of this disease and facilitate access to care.

Mr Schennach thanked Ms Leyte and the two experts. He asked a question about medical research and the fact that it is not covered by social security. When Covid long is diagnosed, it is still very difficult to obtain reimbursement and compensation for loss of employment. This is particularly true for women, who find it all the more difficult to resume a normal life afterwards. There is a question about the link between Covid long and post-vaccination syndrome. The Federal Medical Committee in Germany now includes EMSFC and post-vaccination syndromes under the Covid long envelope. However, as we know, CFMS has existed for much longer. These are very different things, so it would be very important to separate them. Covid long is now a recognised reality, and some of those affected even suffer from disabilities. What can be done in practice today to reduce the impact of this condition on these people? We know that people who have been vaccinated are less likely to develop long-standing Covid. Do we still need to push for vaccination or booster shots to reduce the incidence a little?

Mr Amraoui congratulated Ms Leyte on her excellent report. He believed that patients' suffering was somehow silent. This made it difficult for individuals to get support. Would an awareness-raising campaign on Covid long be useful?

Ms Britt replied that as far as data was concerned, there have been several initiatives to try and gather data despite technical obstacles such as the use of different languages. From the point of view of research, we need to ask legislators for the possibility of harmonising them. We need disaggregated data, particularly on socio-economic aspects. Hospitals in Europe are not well equipped to deal with chronic diseases such as long-standing Covid, which require a major multidisciplinary effort. We need to do a better job of helping patients by concentrating the services they need.

As far as the effects of vaccination are concerned, research is ongoing. Vaccination has certainly saved lives, and patients should be encouraged to have booster doses. Even if 1 in 20 million vaccines administered have had a collateral effect, the benefits far outweigh the risks. Risks do exist, but for Covid long, 99.9% of effects are due to serious infection and not to vaccination.

When it comes to an awareness or communication campaign, we need to send out positive messages about health and medicine. Most of the people affected by Covid long are outside the health system, not receiving care or diagnosis. These people are outside the social security systems because they cannot prove that they are ill and have a physical health problem. That's why structures are needed to address their specific needs. This problem needs to be tackled urgently.

The Chairperson thanked the speakers and said that Ms Leyte's work would continue and that the report would be presented to the plenary session next January.

List of presence / *Liste de présence*

(The names of members who took part in the meetings are in bold / *Les noms des membres ayant pris part aux réunions sont en caractères gras*)

Chairperson / *Président*:

Mr Simon Moutquin	Belgium / <i>Belgique</i>
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Ms Danuta Jazłowiecka	Poland / <i>Pologne</i>
Mr Armen Gevorgyan	Armenia / <i>Arménie</i>
...	...

Members / Membres	Country / Pays	Alternates / Remplaçant(e)s
Ms Jorida Tabaku	Albania / <i>Albanie</i>	Zz...
Ms Bernadeta Coma	Andorra / <i>Andorre</i>	Ms Susanna Vela
Mr Armen Gevorgyan	Armenia / <i>Arménie</i>	Ms Hripsime Grigoryan
Mr Franz Leonhard Essl	Austria / <i>Autriche</i>	Ms Agnes Sirkka Prammer
Mr Stefan Schennach	Austria / <i>Autriche</i>	Ms Doris Bures
Mr Bob De Brabandere	Belgium / <i>Belgique</i>	Ms Els Van Hoof
Mr Simon Moutquin	Belgium / <i>Belgique</i>	Ms Latifa Gahouchi
Ms Darijana Filipović	Bosnia and Herzegovina / <i>Bosnie-Herzégovine</i>	Mr Šemsudin Dedić
Mr Ivan Ivanov	Bulgaria / <i>Bulgarie</i>	Zz...
Ms Denitsa Sa cheva	Bulgaria / <i>Bulgarie</i>	Mr Vasil Pandov
Ms Zdravka Bušić	Croatia / <i>Croatie</i>	Ms Rada Borić
Ms Christiana Erotokritou	Cyprus / <i>Chypre</i>	Mr Constantinos Efstathiou
Ms Ivana Mádllová	Czechia / <i>Tchéquie</i>	Mr Aleš Juchelka
Ms Michaela Šebelová	Czechia / <i>Tchéquie</i>	Mr Ondřej Šimetka
Ms Camilla Fabricius	Denmark / <i>Danemark</i>	Ms Karin Liltorp
Ms Reili Rand	Estonia / <i>Estonie</i>	Zz...
Ms Minna Reijonen	Finland / <i>Finlande</i>	Ms Mira Nieminen
Ms Aude Luquet	France	Ms Nathalie Serre
Mr Alain Milon	France	Mr Alain Cadec
Ms Isabelle Santiago	France	Ms Mireille Clapot
Ms Anne Stambach-Terreoir	France	Ms Liliana Tanguy
Ms Eka Sepashvili	Georgia / <i>Géorgie</i>	Ms Ketevan Turazashvili
Ms Heike Engelhardt	Germany / <i>Allemagne</i>	Ms Franziska Kersten
Mr Andrej Hunko	Germany / <i>Allemagne</i>	Ms Catarina Dos Santos-Wintz
Mr Christian Petry	Germany / <i>Allemagne</i>	Ms Martina Stamm-Fibich
Mr Harald Weyel	Germany / <i>Allemagne</i>	Ms Katrin Staffler

Mr Ioannis Oikonomou	Greece / Grèce	Ms Maria Syrengela
Mr Georgios Stamatis	Greece / Grèce	Mr Alexis Tsipras
Ms Mónika Bartos	Hungary / Hongrie	Ms Katalin Csöbör
Ms Mónika Dunai	Hungary / Hongrie	Ms Zita Gurmai
Mr Bjarni Jónsson	Iceland / Islande	Ms Jódís Skúladóttir
Mr Joseph O'Reilly	Ireland / Irlande	Ms Reada Cronin
Ms Elena Bonetti	Italy / Italie	Mr Roberto Rosso
Ms Aurora Floridia	Italy / Italie	Mr Giuseppe De Cristofaro
Mr Alessandro Giglio Vigna	Italy / Italie	Mr Graziano Pizzimenti
Mr Stefano Maullu	Italy / Italie	Mr Francesco Zaffini
Mr Andris Bērziņš	Latvia / Lettonie	Mr Edmunds Cepurītis
Mr Peter Frick	Liechtenstein	Ms Franziska Hoop
Mr Kęstutis Masiulis	Lithuania / Lituanie	Ms Rasa Budbergytė
Ms Stéphanie Weydert	Luxembourg	Mr Paul Galles
Ms Romilda Zarb	Malta / Malte	Mr Joseph Beppe Fenech Adami
Mr Ion Groza	Republic of Moldova / République de Moldova	Ms Diana Caraman
Ms Christine Pasquier-Ciulla	Monaco	Ms Béatrice Fresko-Rolfo
Mr Miloš Konatar	Montenegro / Monténégro	Mr Boris Mugoša
Ms Saskia Kluit	Netherlands / Pays-Bas	Zz....
Ms Carla Moonen	Netherlands / Pays-Bas	Mr Theo Bovens
Ms Artina Qazimi	North Macedonia / Macédoine du Nord	Mr Vlado Misajlovski
Ms Lisa Marie Ness Klungland	Norway / Norvège	Ms Linda Hofstad Helleland
Ms Danuta Jazłowiecka	Poland / Pologne	Mr Mirosław Adam Orlński
Mr Jan Filip Libicki	Poland / Pologne	Ms Magdalena Biejat
Mr Ryszard Petru	Poland / Pologne	Mr Daniel Milewski
Zz....	Portugal	Zz....
Zz....	Portugal	Ms Jamila Madeira
Mr Andi-Lucian Cristea	Romania / Roumanie	Mr Ion Prioteasa
Ms Alina-Ştefania Gorghiu	Romania / Roumanie	Mr Cristian-Augustin Niculescu-Ţăgârlaş
Ms Diana Stoica	Romania / Roumanie	Ms Daniela Oteşanu
Ms Marica Montemaggi	San Marino / Saint-Marin	Mr Roberto Ciavatta
Ms Tatjana Pašić	Serbia / Serbie	Ms Jelena Milošević
Mr Vladimir Đorđević	Serbia / Serbie	Mr Predrag Marsenić
Ms Anna Záborská	Slovak Republic / République Slovaque	Mr Ľuboš Blaha
Mr Dean Premik	Slovenia / Slovénie	Ms Iva Dimic
Ms María Fernández	Spain / Espagne	Mr Alfonso Rodríguez

Mr José Latorre	Spain / <i>Espagne</i>	Ms Marta González Vázquez
Ms Carmen Leyte	Spain / <i>Espagne</i>	Ms Luz Martinez Seijo
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Mr Sevan Sivacioğlu	Türkiye	Ms Sena Nur Çelik Kanat
Ms Gökçe Gökçen	Türkiye	Mr Namık Tan
Mr Cemalettin Kani Torun	Türkiye	Mr Ali Fazıl Kasap
Ms Olena Khomenko	Ukraine	Ms Larysa Bilozir
Ms Yuliia Ovchynnykova	Ukraine	Mr Andrii Lopushanskyi
Ms Lesia Zaburanna	Ukraine	Mr Rostyslav Tistyk
Ms Kate Osamor	United Kingdom / <i>Royaume-Uni</i>	Zz...
Ms Sally-Ann Hart	United Kingdom / <i>Royaume-Uni</i>	Mr Richard Bacon
Lord Don Touhig	United Kingdom / <i>Royaume-Uni</i>	Ms Ruth Jones
Ms Sheryll Murray	United Kingdom / <i>Royaume-Uni</i>	Zz...

Partners for Democracy / Partenaires pour la Démocratie

Mr / M. Allal Amraoui, Morocco / *Maroc*

Mr / M. Hassan Arif, Morocco / *Maroc*

Other parliamentarians present / Autres parlementaires présents

Ms / Mme Edite Estrela, Chairperson of the Network of Contact Parliamentarians for a healthy environment / *Présidente du Réseau des parlementaires de référence pour l'environnement sain*, Portugal

Mr / M. Paulo Moniz, PACE member, Portugal

Ms/ Mme Regina Bastos, former MEP, Portugal

Mr / M. Yunus Emre, PACE member, Türkiye

Experts / Expert-es

Mr / M. Joan B Soriano, Medical Epidemiologist, Servicio de Neumología, Hospital Universitario de la Princesa / *Médecin épidémiologiste, Département de pneumologie, Hôpital Universitaire de la Princesa* – UAM, Madrid, Spain / *Espagne*

Ms / Mme Chantal Britt, Long Covid Europe (European Network of Long Covid patient organisations / *Réseau européen d'associations de patients touchés par la Covid longue*) – online / *en ligne*

Mr / M. Willy Bergogné, Director / *Directeur*, Save the Children Europe

Ms / Mme Claire Nicolet and/et Mr Jason Rizzo, Doctors without borders / *Médecins sans frontières* – online / *en ligne*

Mr / M. David Wightwick, Executive Director / *Directeur exécutif*, UK-Med

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Ms / Mme Despina Chatzivassiliou-Tsovilis, Secretary General of PACE / *Secrétaire générale de l'APCE*

Ms / Mme Louise Barton, Director of Committees / *Directrice des commissions*

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Ms / Mme Xenia Birioukova Assistant/ Assistante

Ms / Mme Özgü Tan Assistant/ Assistante