Thank you for giving me the opportunity to speak today.

My name is Sarah O’Connell. I suffer from Long Covid.

Due to my cognitive symptoms, I am going to read my presentation to you.

I am here representing LCAI, Long Covid Advocacy Ireland, which is the only Long Covid Irish national patient advocacy organisation and Long Covid Kids, a UK-registered charity for whom I'm the representative for Ireland.

I’d like to share my family’s story with you. Then I’ll talk about the current approach to Covid, public awareness of Long Covid, the issues with Long Covid medical care, the financial and economic impact of Long Covid and the plight of healthcare workers, infected on the front line. Finally, I’ll address what we believe can be done to improve this situation.

My daughter Hayley, who is 12, and who also has Long Covid has joined me along with a small number of Long Covid patients. Many fellow Long Covid patients are housebound and bedbound and unable to be with us. For those of us well enough to be here, it's important to acknowledge the price that will be paid for our attendance.

The cost for me will likely be several days in bed recovering. However, I cannot stand by whilst the current attitude to Long Covid in Ireland continues.

Last November, almost a year ago now, Denis Naughton brought a motion before the Dail which passed unanimously. This motion promised to support Long Covid patients across the country - from a medical, social, and financial perspective. It both saddens and angers me to tell you today that since this motion passed, very little has changed. Long Covid patients continue to struggle with practically no support.

The WHO defines Long Covid, as the ‘continuation or development of new symptoms 3 months after the initial SARS-CoV-2 infection, with these symptoms lasting for at least 2 months with no other explanation’.

Over 200 symptoms have been reported, including profound exhaustion, weakness, post-exertional malaise or PEM (which is a worsening of symptoms following even minimal exertion), cognitive impairment, muscle, joint and nerve pain and sleep disturbance.

Crucially, the severity of the initial Covid infection doesn't matter when it comes to Long Covid. Someone who's hospitalised and ventilated may make a full recovery while someone with an extremely mild or even asymptomatic infection can go on to develop severe Long Covid symptoms.

Let me start by explaining how repeated Covid infections have affected my family.

Before the pandemic, my daughter had suffered from post viral ME but had improved alot regaining about 80% of her previous function. Following her first Covid infection, she developed Long Covid symptoms, and her previous recovery has been entirely undone. She attends school three days per week, and the impact of her illness on her education is a huge source of sadness for her. She is tired of feeling different.

My son, Jake, was previously healthy, he's 8 years old and has suffered from Long Covid since his first Covid infection in August 21, with a severe deterioration in his condition after his second infection and a further decline after his third. We keep hearing subsequent infections should be milder, but this is not the case for him. He gets worse every time.

My son attends school two to three half days per week. He suffers from profound exhaustion, widespread body weakness, muscle pain, headaches, insomnia, nausea and PEM. He now has coeliac disease triggered by covid. He has also been diagnosed with PANS as part of his Long Covid, which is paediatric acute-onset neuropsychiatric syndrome. It’s a condition caused by inflammation in the brain which triggers behavioural and psychological symptoms that include emotional dysregulation,,anxiety and OCD tendencies.

PANS can occur after any infection but at LCK, we’re seeing a significant number of children developing PANS following Covid.

Covid has completely and utterly obliterated our family life. We’ve to spend the majority of our time at home. At the weekend, Jake might have the energy for one small outing, an hour or two, the remainder of the weekend he then needs to rest. No sports, no charging around the garden, no playdates with his friends. I've lost my boy to this illness. There are nights I have to brush his teeth for him because he doesn't have the strength in his arms and when he cannot get to sleep due to the pains in his legs, when he cries and asks me when he will be better. I've no answer for him. I've no idea when he will recover, and no guarantee that he will.

It's a huge challenge trying to find time to attend my daughter's and my own medical appointments or even pick up groceries or medications when my son is in school so little and whilst my husband continues to try to work full time to provide us with an income.

To get Jake medical care for his PANS, we had to visit an immunologist in London, the trip cost us around 3,000 euros, some of which we had to borrow. We are fortunate to be able to afford to go private. Many parents are not. But, the financial burden has been enormous.

When my son first became unwell we attended our GP and a neurologist, both of whom attributed his symptoms to psychological issues even after I explained that they had come on very suddenly right after his infection. I asked how a psychological issue would explain his muscle pain and overwhelming exhaustion, I was met with a blank look.

My son is missing out on a normal childhood. Last year for his birthday, we wanted to give him some sense of normality and had a party. He hid in his bedroom for most of the time as the noise of the other children was too much, sensitivity to noise being a common symptom.. He then suffered a crash for days afterwards. Any exertion of mental or physical energy can result in paralysing fatigue.

Despite how hard it is for us, others have it even worse. Many of the children in the LCK support group have been unwell since March 2020 and some haven't been able to attend school at all since. Many children are housebound, or even bedbound. Some children are confined to a wheelchair, and others suffer from daily seizures. One mother in Ireland who is a member of LCK, has two children with Long Covid, a third with diabetes triggered by Covid and HERSELF has Long Covid.

This is my personal story. But the challenges my family face are not unique. I'm here today to represent all those who are currently living with Long Covid, those who are contracting Covid in the latest wave and developing Long Covid as we speak and those who will develop it in the future. Because as long as Covid is spreading, the numbers affected by Long Covid will continue to grow.

Earlier this year, LCAI worked with HIQA to complete several reports on Long Covid. HIQA recognised that the only way to fully prevent Long Covid is to avoid getting Covid in the first place. But as a country, we are doing nothing to prevent infection.

In February 22, after removing mitigations, the message from the Taoiseach was that it should now be down to an individual's assessment of their own personal risk to determine if they should take precautions or not. This approach has been a dismal failure.

This messaging led people to assume incorrectly that Covid was now only a risk to those who were elderly or immunocompromised. This is not the case. As HIQA confirmed, Long Covid can affect people of any age. Most have no pre-existing conditions and were living extremely active lifestyles before becoming ill. 'Vax and relax' is not enough. Vaccination doesn't prevent transmission. Although vaccination slightly reduces the risk of Long Covid, many with Long Covid were fully vaccinated and boosted when they were infected. Many only developed Long Covid after their second, third or fourth infection.

Early in the pandemic, it was thought that Covid was spread only by droplet transmission. Despite the WHO later acknowledging the airborne nature of Covid and the necessity of layered mitigations including adequate ventilation and clean air, the government has not done enough to communicate this updated information to the public.

Our children are now exposed to repeated Covid infections. There are no mitigations in schools. Mechanical ventilation ENSURES THAT THE DAIL does not have air recirculating and yet, despite the Minister for Education's promise that millions were being made available to purchase HEPA units for classrooms, only a minority of classrooms in the country have these units in operation. Experts on ventilation including Orla Hegarty and John Wenger have highlighted this again and again. And have been ignored.

Similarly, with the removal of precautions in hospitals, anyone who needs to avoid Covid can no longer safely access healthcare. People with Long Covid risk being reinfected every time they visit their GP or even a Long Covid clinic. We believe the mask mandate for medical settings needs to be reinstated especially as hospital-acquired Covid infection makes up a significant proportion of all Covid cases.

This is a patient safety issue. LCAI was informed of one case where an elderly man attended the emergency department for a minor cut which needed stitching. There he caught Covid and died of it several weeks later.

As of today, there are no 'official' Irish statistics to quantify Long Covid. It took the HSE almost three years to commence the Fada study on which LCAI are providing PPI. but results are not yet available. The current Department of Health advice bizarrely is that there's no need to test if you have symptoms of Covid. As a result, many will not link a sudden decline in their health to the 'mild' viral infection they had a few months previously. Cases of Long Covid will be undercounted but more importantly, this will lead to delays in diagnoses and the provision of vital lifestyle advice necessary to help stabilise the condition.

This leads me to my next point - public awareness of Long Covid or the lack thereof. Long Covid is a hidden condition, underreported and misunderstood to the point that the national broadcaster RTE last night re-aired an episode of ‘How Long Will You Live’ promoting exercise Therapy for Long Covid. This approach has been robustly criticised by Long Covid experts as it can lead to permanent worsening of Long Covid symptoms. Letters to RTE from concerned doctors, occupational therapists and patients have fallen on deaf ears. Since the pandemic began, not only has there never been any national campaign from the Department of Health or the HSE to raise awareness around Long Covid, It has rarely ever even been mentioned.

We believe that the government and the HSE have a responsibility to communicate ALL of the risks of Covid 19 to the public. There has been a heavy focus on mortality and hospital and ICU admissions yet no mention of the impact of increased Covid cases in terms of morbidity. How can a person make an informed choice about whether to mask, whether to test, or whether to adopt clean air strategies, if they are unaware of how Covid spreads and the potential repercussions to their health of a Covid 19 infection?

With every batch of new Covid cases, new patients stumble into our world, all with a similar refrain ‘I'm young, I was healthy, why did no one tell me this could happen to me?’

The lack of awareness amongst the public has a huge impact on patients. Many patients report their family, friends and employers don't understand, think they're simply depressed, or exaggerating their symptoms. Imagine being suddenly severely ill, and not even having the support of your loved ones.

Many people don't understand that Long Covid patients are a vulnerable group, for whom re-infection can pose a considerable risk.And yet they aren't included as such in vaccine booster programmes.

A stigma has been allowed to develop around Long Covid. There’s a perception that Long Covid is simply a few mild lingering symptoms as opposed to a life-altering, debilitating condition which has tragically led to suicide in some cases.

It was amid much fanfare that the Minister for Health announced plans for the establishment of countrywide multidisciplinary Long Covid clinics in September 21 and the subsequent creation of an interim model of Care. Unfortunately, these clinics are not meeting the needs of Long Covid patients.

Several TDs have asked questions in the Dail about Long Covid services and supports. Unfortunately, they repeatedly continue to receive the same inadequate cut-and-paste response.

In April this year, LCAI participated in a Westminster Forum examining Long Covid in Ireland. Several clinic leads along with HSE representatives took part and assured us that Long Covid clinics were up and running and successfully treating patients. We challenged these assertions and emphasised the necessity for PPI in developing the clinics. Unfortunately, our concerns have not been acted upon.

There are six public Long Covid clinics in Ireland accepting referrals for adults. Three in Dublin, the others in Limerick, Galway, and Cork.

There are issues with both access and experience across the clinics. From an accessibility perspective, there are Long Covid patients who are entirely bedbound, unable to travel to receive care. Others are too far from a clinic to travel the distance required.

According to the Minister for Health, hospitals have been given substantial funding to provide Clinics. However, they often operate in a very limited capacity. For example, Limerick holds one clinic every second week seeing just six patients per month. There's a 7-month wait list. With one in 10 infections leading to Long Covid, this is grossly inadequate. There needs to be accountability regarding the funds that have been allocated to Long Covid.

Patients frequently report disappointment with the care they receive at clinics. Patients are often seen by the doctor only once on their first visit. The focus is on respiratory and cardiac issues. As most Long Covid patients have debilitating neurological symptoms, it's unacceptable that three and half years later, there is only one dedicated neurologist available for the whole country. Patients often report positive experiences with allied health professionals, however, there's no consistency around staffing of multidisciplinary teams. For example, Cork has an excellent psychologist supporting patients, but has no dedicated physio or OT. St. James has physio and OT but no dedicated psychologist.

There also seems to be confusion around the role of Long Covid clinics. One patient was discharged against his wishes despite worsening symptoms. He was told the role of the clinic was to rule out alternative diagnoses not to provide ongoing care. We're also concerned that patients who voluntarily stop attending the clinics, due to lack of benefit are presumed 'recovered' when they are anything but.

While there is currently no curative treatment for Long Covid, symptoms can and should be managed. Active symptom management can have an enormous impact on quality of life and level of functioning and yet the willingness to prescribe safe, well-established medications seems to vary greatly from clinic to clinic, with the vast majority of patients reporting they've been offered no medication at all to help to manage their symptoms

There is a risk that clinicians who've been assigned Long Covid patients have not been given the relevant training or dont have the experience. For many years ME (Myalgic Encephalomyelitis) which is also a post-acute viral illness was dismissed as psychological and not taught in medical schools.

Although ME has now been definitively proven through biomedical research to be physiological, these beliefs are held deeply by many doctors in Ireland, and it is perhaps with this scepticism and prejudice towards post-acute viral illnesses that they have met with Long Covid patients. Long Covid affects women more than men so there may also be a gender bias at play where women’s symptoms are mistakenly attributed to psychological causes.

We were extremely concerned to hear that a patient was told by the infectious disease consultant at a Long Covid clinic that they were unhappy that Long Covid had been placed under their service.

It is very clear that some of the doctors seeing Long Covid patients just don't want to be there. This is reflected in a complete lack of up-to-date knowledge, curiosity, and willingness to learn. Often, the patient at the clinic knows more about their condition than the doctor.

With the scale of the issues we are seeing at the clinics, the extremely limited hours that they're running, and the frequent lack of interest shown, it's hard to feel that the clinics are anything but a box-ticking exercise so that the government can be seen to be taking some action on Long Covid.

I would love to be able to tell you that the situation is better for paediatric Long Covid but as it stands, the HSE provides ZERO Long Covid services for children under 16. Minister Donnelly has advised that a GP can refer a child to a general paediatric consultant. However, the HSE when asked were unable to provide the name of ANY consultant who could address paediatric Long Covid.

This approach has been a disaster, and has led to many parents, children and young people being subjected to, in their own words, ‘traumatising’ medical appointments. Every parent in Ireland who contacts LCK tells us the same story; their child has a range of highly debilitating symptoms following Covid, they have been back and forth to the GP, standard blood tests are normal but their concerns aren't taken seriously. They are often told their child is anxious or stressed or avoiding school.

It often takes 12 to 24 months after the onset of Long Covid for a child to be seen by a paediatric consultant. In one case, we were informed by a parent that the consultant appeared to have some knowledge of post-acute viral illness, told them it would take time to recover and did provide validation of the child’s experience, but wouldn't take the patient on.

In all other cases where parents have been in touch with me as the charity rep, they have informed me that the consultant.

a) appeared to have no knowledge of Long Covid or post-acute viral illness in general, or

b) gave recommendations that contradicted international best practices regarding Long Covid such as being encouraged to exercise despite PEM or

c) were aware of Long Covid but thought that it was psychological.

I have yet to speak to ONE parent of a child with Long Covid in Ireland who felt that their child had received anything approaching adequate medical care.

Some examples of what parents have been told.

‘You are abusing your son if you don't have him in school full time’.

‘Your daughter just needs to drink more water and get fresh air’.

‘Your son and daughter are copying each other’ (in the case of one family where two children were suffering from Long Covid)

When asked why the government didn't feel it necessary to provide services for children they advised that Long Covid is rare in children and of short duration. Both are untrue. Long Covid in children appears to be thankfully less common than in adults but is by no means rare.

The conversation can be easily diverted by debating prevalence, however, prevalence is irrelevant to those affected. There ARE children with Long Covid in Ireland, they REQUIRE medical care now.

From a financial point of view, Long Covid patients around Ireland are drowning. Many have been forced to seek private medical care. Between doctors' fees, cost of medications, supplements, alternative therapies, and a lack of income, many are struggling to stay afloat with some even at risk of losing their homes. Long delays in diagnosis often create a block to obtaining social welfare.

Those delays and the lack of understanding of Long Covid also hamper employees in their negotiations with employers concerning reasonable accommodations. Working with an OT knowledgeable about Long Covid is crucial in developing an appropriate phased return to work, which may need to be slower with longer term accommodations. From reports, it would seem that although Long Covid was identified in 2020, social welfare officers have been given little or no direction on how to manage the tidal wave of applications for disability allowance and illness benefits.

Instead, severely ill patients are having to fight tooth and nail to obtain their payment. Many patients have been rejected even on appeal with social welfare officers stating that Long Covid is not a disability.

We're also concerned about the proposed Green Paper Disability Reform. The proposed new payment seems strikingly similar to the "Work Capacity Assessments" in the UK. Those reforms were described by the UN as a 'human catastrophe', with the UK government said to be culpable of 'grave and systemic violations' of disabled people's human rights.

As many in the medical establishment don't have an adequate understanding of Long Covid, clinicians who do not understand PEM may categorize people with Long Covid as having a higher capacity to work than they do. Just because someone with Long Covid can do something one day doesn't mean they can do it every day.

The enormous economic cost of Long Covid is rarely mentioned. Up until now, the cost has been largely borne by the individuals and their families.

But if Long Covid is allowed to continue to grow, the cost will inevitably increasingly impact upon the state through increased healthcare costs, increased welfare claims and decreased tax returns.

The global economic cost of Long Covid is estimated at $21 trillion dollars. Long Covid predominantly affects young, working-aged people. We are decimating our workforce. Long Covid affects more women than men. Women in this age demographic often have dual caring responsibilities, looking after young children and elderly parents. Unable to perform these tasks, there's a gaping hole left to fill.

Finally, I wish to speak to the plight of a group of healthcare workers. This group of people went to work in the early days of the pandemic when everyone else was told to shelter at home. Some volunteered to be deployed to take care of Covid patients as they were young, fit and healthy and the messaging at the time was that this cohort had little to fear. These were our ‘healthcare heroes’ the people the government thanked effusively and clapped for in those early terrifying days.

They were exposed to Covid without any protection from vaccines or in many cases adequate PPE. And they simply failed to recover. They've still not recovered three-plus years later. They want their old lives back, they want to be able to go back to work, to raise their kids, to participate in life again. But they can't. Their lives have been ruined by Long Covid. Initially placed on the Special Leave with Pay Scheme, they've had to fight over and over, quite literally from their sick beds to continue to be paid when this original scheme ended.

The current extension expires on October 31st. The issue will be heard at the Labour Court on the 27th. They were promised new schemes to cover the illnesses they contracted on the frontline, but they've yet to materialise.

These people are left in limbo, enquiries passed around from the Department of Health to the Department of Social Welfare to the Department of Public Expenditure, and Reform like a humiliating game of pass the parcel.

No department wants to take responsibility, nobody is taking care of the people who put their health on the line to care for us, saving many many lives, during the early days of the pandemic. They've paid a very steep price. They have lost everything, and the very least this government can do is to continue to provide support MORE MEANINGFUL THAN APPLAUSE by guaranteeing these ‘Healthcare Heroes’ their pay until they recover, or until treatment is developed which allows them to return to work.

So what can be done? Our recommendations are that:-

1. Urgent action is taken to reduce the spread of Covid. The government needs to provide the public with accurate up-to-date information as to how Covid spreads, including that it’s airborne, the importance of clean air and how people can adopt layered mitigations to minimise their risk of infection without relying solely on vaccination.
2. The Department of Health and the HSE be tasked with creating awareness of Long Covid. The public need to know the true face of Long Covid, how severe it can be and how widespread the condition is. Then and only then can they make an informed decision as to their personal risk
3. The interim model of care and the service provided at clinics be urgently reviewed and informed by proper PPI. We are more than willing to engage to help shape these clinics into what patients need. Specialist paediatric clinics need to be established and additional training given to GPs to help accurately diagnose and manage Long Covid.

4. Long Covid be examined from a financial perspective, both to the individuals affected and on a national level. Supports must be put in place to help people access illness/disability benefits as efficiently as possible.
5. And finally, the small group of healthcare workers I spoke about previously are treated fairly and looked after by this government during their recovery.

Thank you for listening.