

# LONG COVID KIDS

OPEN LETTER  
14 July 2024

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## CHILDREN AND YOUNG PEOPLE WITH LONG COVID DISMAYED THAT UK C-19 INQUIRY REFUSES TO RECOGNISE THEM IN CHILDREN AND YOUNG PEOPLE'S MODULE

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The Chair of the Covid 19 Inquiry has indicated that she intends to refuse the application of [Long Covid Kids](#) ('LCK') and Long Covid Kids Scotland<sup>1</sup> ('LCKS') to be core participants in Module 8 of the Covid 19 Inquiry investigating the impact of the pandemic on children and young people.

The charities directly represent approximately 11,000 children and families suffering from Long Covid. The decision means that they are closed out of the Inquiry process: they will not have the right to review relevant documents, ask questions of witnesses or make submissions in an opening and closing statement to the Inquiry. This is the only module dedicated to investigating the impact of the pandemic on children and young people and yet children and young people with Long Covid will not be represented.

Children and young people with Long Covid suffered the dual burden of the social, education disruptions and loss of learning that all children suffered as well as long-term injury to their health. For many children and young people with Long Covid those impacts persist to date, resulting in chronic illness, substantial and long term impairment.

It is essential that their voices and experiences are represented at the Inquiry. Their status as core participants will ensure that the Inquiry fully understands the perspective of children and young people with Long Covid in the course of the investigations in Module 8. If the Inquiry proceeds without LCK and LCKS present, there is a clear risk that the impact of Long Covid on children and young people will not be properly and fully explored.

Their members are now calling for the Inquiry to review this decision.

### **Parents and Carers of Children and Young People with Long Covid**

#### **Diane Fisher (parent of child with Long Covid)**

*"LCK has fought for us since 2020, they understand the struggles experienced by children suffering with long covid, and their families, better than any other organisation. They stand out as a beacon of hope, support and information in an otherwise disappointing and distressing quagmire of gaslighting, denial and ignorance from medical, educational and political bodies. They will know the right questions to ask to help the inquiry understand how our children have been so badly let down."*

#### **Becky O'Connor (parent of child with Long Covid)**

*"My 12-year old son has been diagnosed with long covid this year, after an infection in March 2024, long after the Government decided the risk had passed. His sporty, academic and sociable life has been turned upside down in a matter of months. This is a direct result of public*

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<sup>1</sup> Charities registered in England & Wales 1196170 and Scotland SCO52424.

health policy failure. In being denied a core role in this Inquiry, it feels as though the experience of my child, and countless others who have been and will continue to be affected by repeated and avoidable failures, does not matter.”

**Kerry Simpson (parent of child with Long Covid)**

*“This inquiry was our opportunity to have our and our children’s voices heard, acknowledged and hopefully used to learn lessons for the future. With LCK being the primary portal to convey so many of our voices, their being denied a vital role in the inquiry, is appalling! What message does this send my child about how much her life, her voice and her well-being matters”*

**Katie Antill (parent of child with Long Covid)**

*“My son has had long covid for two and a half years, getting Covid just two months after starting secondary school. I would like to tell his story and ask questions to the Inquiry as I feel he and others like him are being completely forgotten about. The education and health system is ignoring their needs. Their futures are being written off and politicians and policy makers just don’t seem to care.”*

**Leila, (parent of child with Long Covid)**

*“So much of the current focus and rhetoric is on the way that lockdowns affected children. What about the children who have been harmed by the virus itself? Don’t the children who are still suffering from debilitating Long Covid symptoms deserve to be heard? To be given the opportunity to ask questions about why schools were not made safer by proven measures such as air filters? To ask why punitive Department of Education attendance policies encourage the continued spread of Covid in schools, whilst continuing to punish those who are already sick? These children’s lives have shrunk. My 14 year old watches his friends play sport, socialise, go to school, do Duke of Edinburgh and wonders when he will be well enough to ‘get back to normal’. I would like to know the date that Eton installed its HEPA filters.”*

**Anonymous (parent of child with Long Covid)**

*“My daughter believes that she has been forgotten by society, every reinfection is debilitating, she doesn’t want to live anymore as she doesn’t believe anything will change. We keep reminding her that the Inquiry is listening and will make recommendations, that there is hope for her future. Long Covid Kids are her voice. What do I tell her now?”*

**Simon Craner (parent of child with Long Covid)**

*“The children most affected by Long Covid (aside from those that have tragically died) are those now tens of thousands disabled by Long Covid. My own child has been disabled by Long Covid for several years and may remain so after several school caught reinfections. Not representing the children most harmed by the virus is an appalling disservice to them and adds to the growing impression that the children disabled with Long Covid are being intentionally ignored. Long Covid Kids charity is a lifeline for these children and they must not be excluded from the Inquiry.”*

**Children and Young People with Long Covid**

**EB, age 16:**

*“It’s like everyone’s talking about the grown-ups who got sick, but what about us? We got sick too, and sometimes it feels like it’s never going away. The grown-ups are talking about what happened with Covid, but they’re not asking us how it feels. Is that fair? The Long Covid Kids charity is like our team, fighting so we can be heard. They should be part of the inquiry too, so everyone knows what it’s like for kids like me.”*

**TS, age 11:**

*“I was sent in to school two years ago when covid was going through my class because I was told that children didn’t get that ill from covid but I got very ill. I was in lots of pain but some of*

*the doctors I saw told my mum and dad that I was making it up and made me walk but I couldn't even stand up. I haven't been to school for two years. I can't do all the things I did before like playing football and I have lost my friends. I don't think it's fair that children won't get the chance to ask about what covid has done to them. It makes me feel angry and invisible and like I don't matter."*

**Kitty McFarland, age 18:**

*"Long Covid Kids and Long Covid Kids Scotland are the only charities supporting kids with Long Covid. The fact that they have been turned down after everything they have done for us is astonishing. No-one else is going to be able to speak with lived experience from our perspective which is the whole point of the Inquiry isn't it? No-one else is going to be able to relay what we have gone through, no-one else has listened."*

**S, age 14**

*"Long Covid was preventable, Long Covid ruined my life, Long Covid stole my childhood."*

**Sammie McFarland of Long Covid Kids and Helen Goss of Long Covid Kids Scotland said:**

*"We are profoundly disappointed by our provisional exclusion from the Children and Young People module of the UK Covid Inquiry, especially after being emailed directly by the Inquiry about applying. Our distress is compounded by the recognition of Long Covid Kids in Scotland as a Core Participant in the Education and Impact on Children and Young People module, highlighting the disparity in acknowledgment of our important contribution."*

*Children and young people with Long Covid have been consistently ignored, dismissed, and forgotten since the pandemic began. Excluding their voices sends a troubling message that their experiences are not valued by the Inquiry, echoing the UK government's disregard throughout this crisis."*

*The devastating learning loss due to debilitating post-viral illness should be addressed in a module focused on children and education. Our exclusion is a disservice to all children with Long Covid whose lives have substantially impacted; their voices deserve to be heard."*

*It is crucial for the Inquiry to make recommendations that will better safeguard children in future public health crises. We believe this is impossible until the Inquiry demonstrates an understanding of the impact of Long Covid on children and families."*

*We have supported the Inquiry in good faith and are disappointed that our legal team will not have the opportunity to raise important questions on behalf of children injured by COVID."*

**Jane Ryan solicitor said:** *"The approach of the Inquiry demonstrates that it does not understand and cannot possibly ask the right questions on behalf of children and young people with Long Covid. Up till now the Inquiry has consistently sought my clients' input into matters relating to children and young people recognising their unique experience and role. I am puzzled that at this final and vital stage for children and young people with Long Covid the Inquiry has chosen to close the process to them, shut the door and deny them the special rights core participants have. If this decision stands it is shameful. I urge the Inquiry to listen to the concerns of parents, children and young people with Long Covid and grant their application."*

**Background**

The charities have engaged with the Inquiry since 2022 including:

- Providing witness statements
- Meeting with the Inquiry team

- Providing support and attending Every Story Matters events
- Sharing the Inquiry's work with members and supporters
- Participating in impact films
- Being members of the Children and Young People's forum
- Being core participants in the Scottish Covid Inquiry, Module 2 and Module 3 of the UK Inquiry.

On 21 May 2024 the Inquiry emailed Long Covid Kids directly about applying for Module 8. On 17 June 2024 they submitted their application.

On 9 July 2024 the Inquiry found that the charities had met the legal test of having “*significant interest*” in the matters being investigated and therefore could be delegated core participants but in her discretion the Chair, Lady Hallett, declined to do so saying that she was confident that the Inquiry would be able to explore the Government's understanding of the risk that children might acquire Long Covid without their being core participants.

The latest ONS statistics (released on 25 April 2024, relating to a period from November 2023 to March 2024) show that there are currently an estimated 55,801 children in England and Scotland (defined as 3 to 17 years old by ONS) who have Long Covid and have had symptoms persisting for at least 12 weeks.<sup>2</sup>

“*Long Covid in Children and Young People (CYP) Education Experiences and Attendance Survey*” was submitted evidence to Department of Education's Inquiry into School Attendance (2023)<sup>3</sup>. The survey found that a child with Long Covid will lose an average of 20.6 learning hours per week. 40.2% of respondents thought that the school lacked an understanding of the impact that Long Covid has had on their child or young person's education. 81% of CYP did not require support with their learning before COVID-19, since covid 59% need support most or all of the time.

### **Further information**

Long Covid Kids and Long Covid Kids Scotland's original application with supporting evidence is available [here](#). A renewed application will be filed with the Inquiry next week.

For further information please contact: Anthony Burr, [anthony@burrmedia.co.uk](mailto:anthony@burrmedia.co.uk) / +44 7766 459469, [smcfarland@longcovidkids.org](mailto:smcfarland@longcovidkids.org) or [hgoss@longcovidkids.org](mailto:hgoss@longcovidkids.org)

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<sup>2</sup><https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/datasets/selfreportedcoronaviruscovid19infectionsandassociatedsymptomsenglandandscotland>

<sup>3</sup> <https://www.longcovidkids.org/post/how-does-long-covid-impact-attendance-and-educational-experiences>