

SCOTTISH COVID-19 INQUIRY

OPENING STATEMENT for LONG COVID KIDS in SCOTLAND

1. The children of Scotland should be able to thrive and look forward to a positive future.
2. Long Covid, the long-term illness caused by Covid-19, has blighted that prospect for too many. For too many, Long Covid presents a seeming insurmountable obstacle to an engaged, fulfilling and productive life.
3. The Inquiry has embarked upon its listening project "*Let's be heard*". In an adult world, the voice of children is all too often ignored, disregarded or belittled. I ask all of us in the room to pause and think back. Did we hear the voice of children in decision-making on masking, school mitigations, examinations, or immunisation? Or is our recollection that children were simply told how it was going to be? Now hear what they have to say in the short video "*Our unhappily ever after*": <https://youtu.be/RiIambG8vs0>
4. A recitation of common symptoms - exhaustion, cognitive impairment, chronic pain – fails to convey the true lived reality of this disabling and devastating illness. The Inquiry has been offered and we trust will hear from those with

that lived experience. Of children and young persons housebound, bedbound, and isolated; distraught, humiliated, and suicidal. Of professional scepticism, indifference and inaction in response. Of the struggle to gain recognition, respect and action.

5. Long Covid Kids is a grass-roots organisation formed by individuals who have borne the burden of that lived experience and who have become disillusioned and frustrated by the slow, inadequate and reprehensible response by government - national and local - to the long term illness caused by Covid-19.
6. They are the citizens who continue to suffer from the effects of the disease, who either are, or look after, those who are at greater risk of morbidity upon reinfection with Covid-19. There are over 250 families supported by Long Covid Kids in Scotland with a child suffering from long term symptoms having contracted Covid. There are believed to be around 10 000 children and adolescents suffering from Long Covid in Scotland. They are entitled to answers to many questions, but above all they are entitled to know whether their suffering, their sacrifices and their fate was avoidable?
7. For that purpose, amongst others, this Inquiry must engage in a robust, probing, challenging and unrelenting critical analysis of what those entrusted with their care, in government and in our health service, did and failed to do to recognise and act upon the risks of Long Covid.
8. This Scottish Inquiry proceeds alongside that undertaken by Baroness Hallet. It has chosen to set its own course. One that is different from that taken by the UK Inquiry, though the final destinations may not be too far apart. For reasons that are understandable but not necessarily optimal, this Inquiry has chosen to defer its consideration of decision-making until experiences and recollections

have been recorded. However, when the time comes for analysis the expectation must be that the Inquiry will look at the peculiar nature of the Scottish response: that of the Scottish Government, Scottish local authorities and Scottish Health Boards.

9. The possibility of long-term post-viral illness was well known before the pandemic. The question that has been asked of Baroness Hallett is that if Long Covid was foreseeable why was it not foreseen? In this inquiry I ask, in addition, **why was it not foreseen by our Scottish elected representatives and our Scottish health and education officials, exercising their responsibilities for the care, wellbeing and education of the children, and young people of Scotland?**
10. One of the recurring themes the Inquiry will hear from those with the lived experience of Long Covid is the struggle for recognition of the illness and recognition of the need for specific diagnostics, focused treatment and sympathetic support for those who continue to suffer: a professional scepticism that manifests itself in abject indifference to need.
11. Baroness Hallett has already been referred to the then Prime Minister, Boris Johnson's apparent scrawled response to the Department of Health and Social Care call for recognition and support for people with Long Covid – "BOLLOCKS" - and to his apparent admission in his witness statement to the UK Inquiry that that he did not, at least initially, believe that Long covid truly existed. What we ask is for this Inquiry to ascertain is whether our First Minister, our Scottish Government, our Health Boards and local authorities any better? Did they challenge, did they gainsay, did they follow the science? Or were they indifferent, were they acquiescent, were they supine in challenging such attitudes. Did they recognise the risks, the consequences and the need of individuals; and most importantly did they act? And if they didn't, why not?

Are they guilty of an attitude to long Covid that found its expression in the crude terms referred to?

12. And so as we embark upon evidential hearings I pose - not a comprehensive list – but some questions, in the light of the lived experience of many who question the adequacy of preparation and response to the pandemic.
13. Standing the delayed recognition of Long Covid and the struggle for recognition, was **any** planning undertaken by the Scottish Government, Scottish local authorities or NHS Scotland with particular regard to the effect of a pandemic on the health (and to be considered later, the education) of the children of Scotland? If so, did it include consideration of the effects of long-term illness for children? If not, why not?
14. Did the Scottish Government and others distinctly and proportionately weigh the effect of the pandemic on children and young persons in formulating its initial public health response to the pandemic? Again, if not, why not?
15. Did the Scottish Government and others review, appraise, or re-appraise and revise, its response in the light of the lived experience of Long Covid in children and in the light of the emerging evidence of harm in research? If not, why not?
16. Did decision makers in the Scottish Government and NHS Scotland adequately warn the public of the risk of developing Long Covid and take the disease into account in public health communications? If not, why not?
17. If they did, to what extent was that in response to patient advocacy rather than action initiated from a following of the science? Concerns as to long term consequences of Covid 19 were appearing in social media in March 2020.

Public Health England's first published advice came in September 2020. Where was the distinctly Scottish approach? Those who have struggled against professional indifference and scepticism to highlight the issue of long Covid in children deserve, at the very least, an answer to these questions.

18. For too many their experience has been of little or no accessible designated paediatric diagnostic testing, treatment or support for children and young persons' suffering Long Covid. Did NHS Scotland and individual Health Boards recognise and respond to the distinct needs of children and young persons with Long Covid as knowledge expanded. If not, why not?
19. Bearing in mind that that the risk of Long Covid remains for all of us – including the potentially crippling employment and economic consequences of personal disability and that which might flow from having to care for a child with Long Covid - did the Scottish Government and NHS Scotland ensure that in the light of what was known by the end of 2022, that Long Covid will be the subject of appropriate data collection and modelling, to enhance our knowledge of the disease and the methods of treatment of long terms sequelae? Our children, on whom the burden of responding to a future pandemic will fall, deserve assurance that the learning need has been acknowledged and acted upon. Scottish children with Long Covid - those who continue to suffer - deserve to have some accountability if it has not.
20. Beyond information gathering, did the Scottish Government and NHS Scotland ensure that in the light of what was known by the end of 2022, that NHS Scotland was adequately informed, funded and resourced to provide the specialist help and support that this cohort of sufferers continues to need? If not, why not?

21. As we embark upon the work of the Inquiry, I exhort the Chair to never lose sight of a specific goal.
22. This inquiry must conclude with pellucidly clear findings of fact as to how children and young persons' interests and rights as regards long-term illness were considered, weighed and acted upon - if at all – both in pre-pandemic planning; and, then, in response to the pandemic.
23. It will only be with an understanding of
 - what was considered **and** what was ignored,
 - what was weighed **and** what was discounted, and
 - what was done **and** what was **not** done,that lessons can begin to be learnt for the future.
24. There therefore needs to be **rigour**: rigour in ensuring the Inquiry gives careful and discrete attention to this cohort of affected persons. We look forward to the Inquiry producing background research directed to Long Covid in Children and Young Persons in like manner as it has already produced background research papers.
25. There needs to be **understanding**: understanding of the practical consequences of long-term Covid related illness and the steps taken to avoid and mitigate the same. There needs to be understanding that Long Covid is an ongoing and escalating threat to Scotland's public health, is debilitating, life-altering and can be life-threatening.
26. There needs to be **accountability**: accountability for failures, oversights and indifference.

27. The stated aim of the inquiry – and your Lordship’s point of reference at all times - is to establish the facts of the strategic response to pandemic in Scotland and to ensure that lessons are learned from that response.

28. Only on hard facts, will the Inquiry be in a position to ensure that those who have failed the children and young people of Scotland will learn lessons for the future. We should be able to look at the report of the inquiry and fairly conclude whether their suffering was avoidable.

29. Although the Inquiry is constrained by its terms of reference to consider matters other than planning over only the period 2020 to 2022, it is in the area of Long Covid that it is likely to have its greatest immediate impact. Long Covid is still prevalent. Children are still contracting it and with every infection a number will suffer the extreme effects of that awful and debilitating condition. The Inquiry has the ability not only to reduce the impact of future pandemics, but also impact Scottish children now and in the immediate future. We need to ask ourselves, whose child, grandchild, nephew or niece might this Inquiry save from the inequities of this devastating illness?