

Witness Name: Sammie McFarland

Statement No.: 1

Exhibits: SM/1 – SM/50

Dated: 25 September 2023

UK COVID-19 INQUIRY – MODULE 2

WITNESS STATEMENT OF SAMMIE MCFARLAND ON BEHALF OF LONG COVID KIDS

Introduction

1. My name is Sammie McFarland. I am the Chief Executive Officer and co-founder of Long Covid Kids. Long Covid Kids is a registered charity (Charity Registration 1196170). The charity's registered address Fletcher & Partners, Crown Chambers, Bridge Street, SALISBURY, SP1 2LZ.
2. I make this statement on the basis of my own knowledge or belief. Where something is outside my own knowledge, I will refer to the source. I am happy to give oral evidence to the Inquiry in Module 2 to expand upon the matters set out in this statement or address any other issues arising.
3. In this statement I will detail:
 - I. Who we are and what we do;
 - II. Long Covid in children;
 - III. Long Covid Kids' engagement with and representations made to Government
 - IV. The impact of Government decision making on children with Long Covid
 - V. Case studies of Long Covid children's experiences.
4. I rely on the Long Covid Kids' Rule 9 questionnaire response dated 15 December 2022 and will add to that statement.¹ Since preparing Long Covid Kids' Rule 9 questionnaire response I have identified further documents relevant to the Inquiry's Terms of

¹ INQ000099699

Reference and the scope of Module 2 which I now refer to and exhibit to this statement. I will also, in this statement, set out various reports on the impact of the pandemic and government decision making on children with Long Covid as well as my own view based on my own experiences and those gathered from my contact with people with Long Covid.

5. For most children initial recovery from acute Covid-19 will be swift. For some children, however, that is not the case; 186 children have died from Covid-19 **[SM/1 - INQ000000]**, 38,079 children were hospitalised with Covid-19 **[SM/2 - INQ000000]** and an estimated 69,000 children are living with Long Covid **[SM/3 - INQ000000]**
6. The World Health Organisation (“WHO”) states that in children and young people *“symptoms generally have an impact on everyday functioning such as changes in eating habits, physical activity, behaviour, academic performance, social functions (interactions with friends, peers, family) and developmental milestones.”*²
7. Thousands of children have suffered varying degrees of life changing and long-term harm to health. In a recent study relating to the Omicron wave, 12-16% of infected children and young people met the research definition of Long Covid at 3 and 6 months after infection.³
8. The importance of their voices to this Inquiry cannot be understated. To my mind these children have suffered twice over; from both the direct and indirect impacts of the pandemic. They have felt both the devastating impact of the response to the pandemic - in terms of lockdowns, loss of face-to-face education, interference with education, social contact with peers and all the disadvantages children suffered generally, and then on top of that they have suffered ongoing harm to their health from prolonged and debilitating symptoms of Covid-19.
9. Children, their short-term and their long-term health, should be taken seriously. The experience of children suffering from long-term health impairments and disability caused by Covid-19 should be at the heart of this Inquiry. All parents should be told

² World Health Organisation (2023) ‘A clinical case definition for post COVID-19 condition in children and adolescents by expert consensus’ at page 6.

³ Pereira, Mensah, Nugawela, Xu, Shafran et al (2023) ‘Long COVID in Children and Youth after infection or reinfection with the Omicron Variant : a prospective observational study, The Journal of Paediatrics. Available here: [https://www.jpeds.com/article/S0022-3476\(23\)00311-6/fulltext](https://www.jpeds.com/article/S0022-3476(23)00311-6/fulltext).

about the risks, including the risks arising from re-infection. Whether your child develops Long Covid is a roulette and there should be adequate warnings about this risk.

I. My personal experience

10. I did not ask to be a patient advocate; I have had to become one. The devastating experience of Long Covid on my daughter's health means I have found myself fighting for children who have suffered harm. I have received abuse on social media, been harassed and told that I am making up the daily battles with her health struggles.
11. It is hard to express in words the devastating impact Covid-19 had on my youngest daughter, KM. Before she contracted Covid-19 she was a healthy, extremely active 14-year-old. She trained in ballet, aerial silks (circus aerobics like Cirque de Soleil), and aerial hoops. She was extremely fit and able. Like many children that we support, over a period of weeks, she did not get better and was completely exhausted and exhibiting a myriad of symptoms. As one example, after a short dog walk, she would turn white and sleep for 3 hours. I knew something was wrong, yet it was difficult to obtain a medical appointment for her.
12. However, in June 2020, during a blood draw for myself, a nurse who had never met my daughter before, told me that she was mimicking my symptoms (I also experienced fatigue and multiple other symptoms after the Covid-19 infection although not the same symptoms as my daughter). This was devastating to hear. I felt that I had been a bad mother and had failed to care for my daughter. I complained to the GP Surgery about the comments made by the nurse, and I received a letter of apology dated 25 June 2020 [SM/4 - INQ000000].
13. There was no information provided to us about post-viral conditions let alone Long Covid. I had sought advice from my GP over the telephone, and in person when he came to our garden to take blood. On more than one occasion I was advised to "do more each day to get better". I was so keen to get better and followed the advice despite feeling significantly unwell after activity. I set up a fun and gentle assault course in the garden to motivate us to "do more" and rebuild her stamina just as the GP had advised. KM started the assault course but after less than ten minutes she experienced

agonising pain in her chest, she turned white and clutched her chest. After this collapse, she was unable to get out of bed for eight months unaided, or without immediate deterioration to her health. She was unable to maintain her personal care or complete any of her normal activities and was not attending school. Sometimes she was unable to respond to us. She has suffered many consequences; she cannot participate in fulltime education or usual activities, and the duration of her illness and the ongoing dismissal of her symptoms have impacted her mental health and affected her higher education options. It has been extremely distressing to watch my child who had been previously completely healthy, happy, and dancing around being unable to move and full of self-doubt. It was like watching my child fade away - she is no longer the child she was.

14. Sadly, KM's experience was not isolated – there were in 2020, and remain to this day, several thousands of children who have suffered life changing loss of health due to infection from SARsCOV-2. I have included within my statement case studies of other families who have been affected by Long Covid.

15. Whilst the narrative that Covid-19 is mild in children is widespread, as a parent and person who has borne witness to the devastating harm caused to children in our group, this is difficult to hear as there is no way of knowing which child will next suffer prolonged damage to health from mild Covid-19, and in some cases varying degrees of disability.

II. A brief overview of Long Covid Kids

16. Long Covid Kids was established in September 2020 by a group of families whose children became victims of Long Covid. Long Covid Kids supports, represents, and advocates for children and young people living with the ongoing symptoms of Covid-19 known as Long Covid. This includes the families/caregivers and education and health professionals working with them. Long Covid Kids is managed by me, one part-time employee, a small team of volunteers and the Charity's Board. Our volunteers have suffered long-term harm from SARS-CoV-2 infection. Long Covid Kids supports over 11,000 families and has over 29,000 Twitter followers and over 4,000 Instagram followers.

17. Long Covid Kids campaigns to reduce the risk of children becoming infected with Covid-19 by providing information on infection harms and layers of protection available in order that parents and carers can make informed choices and risk assess for the benefit of the children that they care for. We also lobby for adaptations to be made for affected young people in educational establishments.
18. We raised awareness that children were getting sick with Covid-19 and not recovering, raising concerns about the range of symptoms children experience, lack of paediatric clinical case definition, lack of public health messaging and the urgent need for health care support. We also raise awareness about the impact of Long Covid on children including the loss of education caused by children being on long-term sick leave from school and lack of support and awareness in education settings. We also advocate to raise awareness of the impact on parents being unable to work due to the need to look after chronically ill children, the impact on siblings, the need for vaccines for children and called for biomedical research for children.
19. Long Covid Kids was set up by me with the support of Frances Simpson in September 2020. Both Ms Simpson and I contracted Covid-19 in March 2020. Both our children also contracted Covid-19, and thereafter did not recover. In stark contrast to the public health messages we heard, we did not experience short symptoms and our acute illnesses, deemed mild or non-severe, extended to debilitating and long-term damage to health. We connected with other people through social media that suffered ongoing debilitating symptoms. I initially was in contact with about seven families with children who had Covid-19 but seemed not to have recovered and were experiencing extremely distressing ongoing symptoms. I should be clear that the impact and daily impairment from Long Covid can be very significant: it is a serious illness and can cause varying degrees of disability as I have described in my daughter's case above.
20. In order to raise awareness about Long Covid in children, Long Covid Kids made a film in September 2020. The film "Our Unhappily Ever After", released in October 2020, was put on YouTube and shared on social media. **[SM/5 INQ000000]**
21. After sharing the film, around 300 families contacted Long Covid Kids on Facebook. Suddenly we were offering support to families that had been through the same experience as our core group of seven families had. They described it as a "life raft." I

felt validation as other families were experiencing the same lengthy recovery despite Government messaging that children were not affected by Covid-19 infection. This awareness gave me the strength to start campaigning. Each family's experience was equally as distressing as ours; similar, and yet unique. I couldn't leave people struggling and there was no help for my own daughter either.

22. As a group of families, we had not had any support from General Practitioners ("GPs") about post-viral conditions and there was a complete lack of awareness (and therefore treatment). We had all been told or made to feel, that we were neurotic parents. It remains a point of frustration and hurt that we were made to feel like this when it was well-known that some people, including children, contract Long Covid, and enduring post-viral illness is not a new phenomenon. [INQ000146629, INQ000192120]

III. Paediatric Long Covid

23. From the outset of the pandemic, there has been a failure to adequately communicate the risk of infection, death and serious long-term illness and consequences in children. This negatively impacted children and young people who suffered long-term damage to health from Covid-19. We have consistently been concerned about the lack of information published by the government, the Royal College of Paediatrics and Child Health, and by healthcare providers on the risk of Covid-19 on children. Early public health statements suggested that Covid-19 posed only a minimal risk to children, however our members and supporters' children's lived experience was completely contrary to this. It remains extraordinary to me that in the face of growing evidence of long-term sequelae in children, the response was to minimise the experiences of these children.⁴

24. Long Covid Kids participated in stakeholders' meetings with the WHO about the definition of Long Covid for children. We raised concerns about the focus on anxiety as a key symptom when the evidence from FAIRHealth's 2022 exercise shows that in 0–12-year-olds, it was not even in the top five diagnoses.⁵ As parents that have had to

⁴ UK Chief Medical Officer, Statement from the UK Chief Medical Officers on schools and childcare reopening, 23 August 2020

⁵ FAIRHealth (2022) Patients Diagnosed with Post-COVID Conditions – An analysis of Private Healthcare claims using the official ICD-10 Diagnostic Code. Available here:

<https://s3.amazonaws.com/media2.fairhealth.org/whitepaper/asset/Patients%20Diagnosed%20with%20Post-COVID%20Conditions%20-%20A%20FAIR%20Health%20White%20Paper.pdf>.

fight for help for our children and have repeatedly been dismissed as being over anxious or for having mental health problems causing symptoms, this is a concern. Mental health problems certainly arise in unwell children, not least because of their poor experience of health care and their loss of health, of social interaction and of education, as well as the pain and concern they experience from suffering prolonged symptoms whilst everyone else in their peer group moves on.

25. Prevalence of Long Covid in children has become highly debated and contentious, partly because of inconsistencies in age groups reporting data. From our perspective a cautious approach should be taken to support the children suffering from debilitating symptoms. It is a significant health burden which drastically impairs their quality of life, including access to education, family and social functioning. Rather than dismissing children, the voices of children with Long Covid should be listened to so that their experiences can be at the centre of changes and improvements.

IV. Our engagement with government and decision makers

Overview of key engagement with government

26. From an early stage, we sought to engage with the Government, healthcare providers and schools. Harm to children from Covid-19 infection has been consistently overlooked and public messaging about the risks of Long Covid to children has even been dismissive despite the Government being presented with evidence of its devastating effect upon some children. Long Covid Kids has raised concerns about rates of transmission of the disease, infection harms, risks of Long Covid, mitigation measures in schools and asked that Long Covid be taken into account in decision making on non-pharmaceutical interventions (NPI).
27. We were the first to identify the risks of Long Covid in children as we saw our children suffer and fail to recover. Despite turning to the Government and GPs for help, we received no treatment and witnessed our children suffer.
28. One of our members, Ms Simpson joined our group because she was concerned over the fact that her children were sick and did not seem to be recovering. Ms Simpson had connected with other families through adult Long Covid networks and found that there were many families that had children with suspected Long Covid who were not getting

support from the health care system. In order to prove that there was a substantial cohort of children with Long Covid, Ms Simpson conducted a survey on Long Covid in children and young people which was published in the British Medical Journal in October 2020 [SM/6 - INQ000000].

29. In the first year of the pandemic, Long Covid Kids had to demonstrate that children and young people also suffered from Covid-19 as there was little public information available that children and young people could suffer from debilitating symptoms and from Long Covid. On the Long Covid Kids Facebook page members would support each other to draft letters to hospitals, to GPs, and to Members of Parliament (“MPs”) to gain recognition that Long Covid existed and raise awareness so that other children and young people would be protected from harm with mitigations. Members received responses throughout the first year offering minimal support or minimising the risk of Long Covid in children [SM/7 - INQ000000]. We therefore spent the first year evidencing the impact of Covid-19 infection and Long Covid on children and young people using lived experiences.

30. We used social media to build up awareness of Long Covid, sharing examples of cases, images and quotes from families, and ran surveys and polls in our support group which we would then share the results of to generate conversation about Long Covid in children.

31. I refer to and produce a chronology of the work Long Covid Kids has undertaken between January 2020 and Spring 2022 [SM/8 - INQ000000]. I have identified some of the key events here.

32. On 23 December 2020, I wrote to Chris Loder MP on behalf of Long Covid Kids, sharing our film “Our Unhappily Ever After” and raising other matters including the need to count Long Covid in children and the hospitalisation rates for children with Covid-19 [SM/9 - INQ000000].

33. On 7 January 2021, Long Covid Kids wrote to Layla Moran MP (who led the All Party Parliamentary Group (“APPG”) on Coronavirus) stating that Long Covid Kids represented over 400 children and “*almost all the stories are the same*”, they were all struggling to receive adequate healthcare support. [SM/10 - INQ000000]

34. In the lead up to the first parliamentary debate on Long Covid on 11 January 2021, Long Covid Kids wrote to MPs as part of the Parents United Against Unsafe Schools campaign, raising concerns about infection rates and Long Covid in children and young people. This took the form of a briefing sent to MPs on 11 January 2021 [**SM/11 - INQ000000**]. The briefing stated:

“A 70% more transmissible variant is now in play, and the prevalence of long-term symptoms and life-long disability being incurred by children and young people as the result of coronavirus infection is uncertain. Before attempting to widen the opening of schools, we recommend the government ensure:

- A significantly lower rate of infection within the population*
- The development of safety measures such as class size limits to facilitate social distancing and the reduction of the risk of airborne transmission, based on published and appropriate scientific data*
- That schools are provided with sufficient resources to enact the safety standards set out above”.*

35. From early 2021, members of Long Covid Kids attended the Long Covid Ministerial Roundtables, initially chaired by Lord Bethell of Romford. At these meeting we raised concerns about the minimization of the risk of serious long-term illness in children. Long Covid Kids attended Ministerial Round Tables on Long Covid on 23 February 2021 [**INQ000060080**], 30 March 2021 [**SM/12 - INQ000000**], 16 June 2021 [**INQ000061094**], 21 July 2021 [**INQ000061418**], 23 September 2021 [**INQ000067049**] and 7 December 2021 [**INQ000067606**].

36. On 26 January 2021, Fran Simpson and Charlie Mountford-Hill and myself gave evidence on behalf of Long Covid Kids to the APPG on Coronavirus which was relied upon in its report on Long Covid in March 2022 [**SM/13 - INQ000000**]. I shared my personal experience and raised concerns that the Government had not communicated that children can suffer long term lasting effects and the common symptoms of Long Covid in children. I also said that I wanted the Government to recognise transmission via aerosol transmission to stop people becoming infected and ensure that schools were safe for children.

37. At paragraphs 17 – 23 of the report, the APPG made findings and recommendations relevant to Long Covid in children. Notably the APPG found that the UK Government's Covid-19 Policy applicable to educational settings failed to adequately protect pupils from contracting Covid-19 and therefore resulted in their developing Long Covid. The APPG acknowledged the wide range of symptoms experienced by children; it found that the UK Government had failed to adequately acknowledge the prevalence of Long Covid among children and that the UK had failed to establish specialized care pathways for children living with Long Covid.

Engagement concerning schools – Safety, Ventilation and Mitigation measures

38. The administrative decision-making around advice to schools is an important aspect of our work; much of our work is centred on minimising the risk of Long Covid in children and young people in schools.

39. On 12 April 2021, with Safe Ed for All, Long Covid Kids wrote to then Secretary of State for Health and Social Care, Matt Hancock MP, raising concerns about risks of acquiring Covid-19 and mitigation measures in schools. [SM/14 - INQ000000] The letter requested a meeting and stated:

“Schools – Mitigation Measures Required URGENTLY

- *Improved ventilation and monitoring in all classrooms to reduce the risk of SARS-CoV-2 airborne transmission*
- *Masks (multi-layer) mandated in secondary, encouraged in primary*
- *Social distancing in primary and secondary*
- *Remote learning / rotas to reduce the numbers in school classrooms*
- *Suspension of fines during the pandemic (as per Scotland & Wales)*

Please do whatever you can to help the Department for Education understand that safety improvements are necessary”.

40. On 4 May 2021, Long Covid Kids wrote to the Secretary of State for Education, Gavin Williamson MP, (copied to Education Secretaries for the Devolved Administrations) about mitigation measures in schools. [SM/15 - INQ000000] This was part of a campaign by Parents United. The letter stated:

“It is essential that the UK achieves effective suppression of Covid19, and the safe reopening of schools plays an essential part in this. A further spike in infections following the current lockdown would pose a range of unacceptable risks, including:

- the proliferation of further variants, which threaten our reliance on current vaccines as a pathway out of the Covid crisis*
- compounding the already abhorrent UK death toll, presently standing at around 114,000 increased numbers of Long Covid sufferers, whose condition is poorly understood and may yet prove to cause permanent disability*
- further prolonged lockdowns, harsh restrictions, economic decline, psychological damage, and harm to the education and well-being of children*

The previous full reopening of schools in September contributed significantly to the current wave. Government data indicates that, when schools were fully open, school-aged children were twice as likely as the general population to be the index case within a household, with secondary school-aged students being 7 times more likely to be the index case.”

41. Long Covid Kids did not receive a response to this letter.

42. On 9 July 2021, Long Covid Kids wrote to the then Secretary of State for Health and Social Care, Rt Hon Sajid Javid MP [**SM/16 - INQ000000**], stating that:

“We urge you to consider the lived experience of children with Long Covid, and early evidence from researchers when creating policy. The health devastation of Long Covid on children is already impacting the workforce, creating poverty as parents lose their jobs while caring for children enduring unnecessary chronic health issues.”

43. In this letter, we raised various concerns that there was no paediatric clinical case definition for Long Covid and so our members reported having difficulties accessing help, requested that the list of acute symptoms be updated, that the government acknowledge children could get Long Covid and requested measures to minimise infection. The measures suggested included the reinstatement of face masks in schools and funding for CO2 monitors and high efficiency particulate air (HEPA) filtration for schools. We received no response to this letter.

44. On 23 September 2021, Long Covid Kids met with Rt Hon Sajid Javid MP who chaired a Ministerial Roundtable on Long Covid [INQ000067049]. Long Covid Kids recorded a blog post on 28 September 2021 which sets out the matters we raised with Sajid Javid. [SM/17 - INQ000000] These were:

- *“The symptom list on the NHS and Government websites needs updating*
- *Masks must be reinstated in schools including primary schools*
- *Statistics: 31% of all cases are currently in ages 5-14 years olds. 80% of hospitalised children are admitted "due to" Covid. 60% of those have no underlying medical condition.*
- *Children are unable to obtain referrals to Long Covid hubs.*
- *Chris Whitty states that it is inevitable that unvaccinated children will catch Covid.*
- *Prevention needs to be a focus. We need mitigation measures in schools to protect NHS resources and the long-term health of children and families.*
- *The average age of children in our Long Covid support group is 10 & this age group has no protection.*
- *There is no cure for Long Covid, prevention must be the focus. We need a child focused public awareness campaign.”*

45. On 2 November 2021, Long Covid Kids published a statement raising concerns about the decision of the JCVI not to recommend vaccinations for children. [SM/18 - INQ000000]

46. On 29 November 2021, Long Covid Kids attended a meeting with Rt Hon Jeremy Hunt MP. Long Covid Kids stated that tens of thousands of children and young people are at risk of developing Long Covid, without us fully understanding the development impact of this and that a key action would be to offer vaccination to children, with the aim of reducing individual risk, as well as that of communities and wider society and educational disruption [INQ000249053].

47. On 21 February 2022, Long Covid Kids issued a joint statement with Long Covid SOS raising concerns about removing all Covid measures [SM/19 - INQ000000]:

“Long Covid has never formed part of policy making decisions during this pandemic, despite repeated requests on our part both in writing and in person to ministers. People with Long Covid need to protect themselves from reinfection, which can seriously

exacerbate symptoms. They and the millions of clinically vulnerable will effectively be forced to shield and become prisoners in their own homes. Since we do not know who will get Long Covid, or how long those living with Long Covid will remain sick, all members of society remain vulnerable.”

48. In March 2022, Long Covid Kids wrote to Layla Moran MP, Damien Hinds MP and Andrew Gwynne MP [**SM/20 - INQ000000**, **SM/21 - INQ000000**, **SM/22 - INQ000000**] requesting their support for the scheduled visit of children and young people with Long Covid to the Prime Minister’s office at 10 Downing Street on 1 April 2022.

49. On 1 April 2022, a group of children and young people with Long Covid delivered Long Covid Kids’ support guide to Downing Street [**SM/23 - INQ000000**]. Each child represented 10,000 young people in this country who have been seriously impacted by the condition, and they had come from every corner of the UK with letters addressed to Boris Johnson MP describing the toll this illness has taken on their lives [**SM/24 - INQ000000**] Extracts from some of these letters have been reproduced below:

49.1. K’s [age 16] letter to Boris Johnson stated *“I got infected with Covid in March 2020. My symptoms started off as mild; a slight cough, heart palpitations and weakness...I started getting better, for a month I felt more like my previous self. This is when Long Covid came in, it hit me like a brick. I was severely weak needing help to eat, drink and go to the loo. I was like this for 8 months. It took a massive hit onto my mental health. I became very depressed, I started self-harming and my anxiety increased to the level of having a panic attack every time I left the house. During this time everyone was telling me I still wasn’t ill. I started getting bullied at school and online it felt like the whole world was against me. I have been diagnosed with 2 ovarian cysts, POTs, and a heart murmur with many things unsolved. We have only got a diagnosis because we pushed hard for it...I am still in pain every day. I am on so many meds (which come with awful side effects). I struggle to eat and drink, I can’t go to school. I am in so much pain mentally and physically. Please help to stop others becoming like me. I shouldn’t have had to get this ill for someone to do something. I deserve a normal happy life. So open the windows and make tests free again. Make a difference. Stop making everyone ill. Stop ignoring us. “*

49.2. A's [age 10] letter to Boris Johnson stated *"I lived[...]with my mum, step-Dad and three cats, Tiny, Storm and Evie. My Dad lives near you in London and he comes to see me every month. I have had Long Covid for 2 years, since I was 7 and it has been absolutely horrible[...] I have a wheelchair now because my legs hurt when I walk and I am too tired to do anything, even fun things. I saw my friends last weekend and that was the first time since before Covid started. I feel like they are not my friends anymore because we are all different now. They don't understand why I've not been at school and they don't understand what Long Covid is like."*

49.3. J's [age 11] Letter to Boris Johnson stated: *"I am 11 years old and I have had Long Covid for nearly 15 months after getting Covid in January 2021. It's been a very difficult journey for me. Having Long Covid means I can't do anything I used to enjoy, like sports, school, walking my dog and even caring for my bunny. I used to go to dance classes, swimming, gymnastics, karate, I used to go on long walks with my family, I was able to hang out with my friends, go to sleepovers and I was also able to do a full day at school; I can't do any of that now and I need a wheelchair as I can't walk long distances. My arm has started to hurt just writing this letter. Now I struggle to do two hours of school. It doesn't feel like school anymore. I haven't done a full week or a full day in months. I used to be so excited about the future, but now I don't know what it will be like. Here are some questions I would like to know the answers to; Why isn't there more research into Long Covid in children like me? Will you try to help me and the thousands of other children with Long Covid to get better? Why won't you or the government make schools safer and decrease the amount of Covid? I am worried about more children getting sick. I have missed a year of school, how will you help me to catch up and how will it affect my future? I can't do school since I had Covid for a second time last summer, because my brain just doesn't work and I can't think or concentrate. It stresses me out and I get frustrated and that makes my Long Covid and PANS symptoms even worse. I can't even write this letter properly because my hands hurt so I had to type and need my Mum to help me a lot because typing this letter has taken me 3 days so far!"*

50. The visit was planned in coordination with staff at Downing Street, so Long Covid Kids had to provide the details of the children and adults attending for security. The children were assured that their individual letters would be received by the Prime Minister's office. The visit to Downing Street required significant effort. I refer to and produce **[SM/25 - INQ000000]** being the letter I sent forwarding the Prime Minister's office the letters.

51. Unfortunately, neither the Prime Minister nor anyone from his office met the children and they did not receive a response to their handwritten letters; instead, we received a response from DHSC, on behalf of the Prime Minister, dated 1 June 2022 **[SM/26 INQ000000]**. We were therefore deeply shocked and upset by the response received. Instead of recognition of the children's physical experiences, or the work of our charity led by volunteers, we received what appeared to be a standard letter on the impact of Covid-19 on children's mental health.

52. On 28 June 2022, I followed up in writing to the Prime Minister by letter **[SM/27 - INQ000000]** reflecting these views. Long Covid Kids received a response from James Morris MP, on 6 September 2022, in which there is brief acknowledgement of the letters written by Long Covid Kids members **[SM/28 – INQ000000]**.

53. We raised our concerns with all of the relevant decision makers involved in policy on school openings and closures. Almost none of our letters evidencing lived experience were acknowledged or responded to. We are still campaigning for improved ventilation and air quality in schools.

Engagement with decisionmakers in Scotland

54. Long Covid Kids Scotland is a separate charity and were refused Core Participant status in Module 2A. To assist the Inquiry, I have exhibited and set out below a short summary of their advocacy in Scotland **[SM/29 - INQ000000]**:

54.1. Attendance at roundtables on Long Covid with Cabinet Secretary for Health and Social Care and the Clinical Priorities Unit on 22 November 2021 and 21 February 2022

- 54.2. Attendance at Cross-Party Parliamentary Group for Long Covid on 8 September 2021, where we presented to the CPG, and at further meetings on 8 December 2021, 9 March 2022, 8 June 2022, and 26 October 2022
- 54.3. Submitted a Scottish Parliament Long Covid Debate briefing note to Members of the Scottish Parliament (MSPs) on 19 May 2022
- 54.4. Updated the SIGN Long Covid Guidelines Implementation Support Note to support paediatric Primary, Secondary and Allied Healthcare professionals in Scotland from March to July 2022
- 54.5. Attended an in-person meeting on 28 June 2022 at the Scottish Parliament with then Cabinet Secretary for Health & Social Care, Humza Yousaf, with families in Scotland whose children were affected by Long Covid.

55. Through our advocacy in Scotland, Long Covid Kids emphasised that lived experience is essential to understanding the nature of Long Covid, and must be included in policy creation, decision making and the planning and implementation of robust and meaningful support services.

Engagement with the Welsh government

56. There is no separate organisation advocating for the rights of children with Long Covid in Wales, so Long Covid Kids engage in advocacy with the Welsh Government directly. The below is a summary of this advocacy:

- 56.1. On 21 May 2022, Kate Davies, Long Covid Kids lead in Wales, wrote to Jeremy Miles in his capacity as MS for Neath for him to hear the personal story of a child living with Long Covid and issues relating to education in Wales [SM/30 - INQ000000]. On 30 May Jeremy Miles' office replied to arrange a meeting.
- 56.2. On 22 June 2022, Long Covid Kids wrote to the First Minister asking for insight into the Long Covid Expert Group that they had established for a pathway to treat children.
- 56.3. On 10 July 2022 Long Covid Kids received a reply from the Health Secretary's department promising insight into the final pathway once it had been finalised.
- 56.4. On 2 July 2022, Long Covid Kids' representative for Wales, Kate Davies, wrote to the First Minister of Wales about the expert subgroup on Long Covid in children.

- 56.5. On 19 July 2022, Long Covid Kids received a letter from Lois Hullen [**SM/31 - INQ000000**], Women and Children's Health Branch stating that once a final pathway was in place it would be shared with Long Covid Kids.
- 56.6. On 10 October 2022, Long Covid Kids had a discussion with members for the Welsh Government Education department to discuss installing CO2 monitors and adequate ventilation in schools.
- 56.7. On 6 December 2022, Long Covid Kids met with Sian Jones and Sian Garstang of the Welsh Government Education Department where they agreed to distribute Long Covid Kids resources via school newsletters.

Engagement with the Northern Ireland Executive

57. Long Covid Kids has also tried to advocate in the Government of Northern Ireland on behalf of children with Long Covid. Most notably, in April 2022, Long Covid Kids engaged with Gavin Robinson MP [**SM/32 - INQ000000**] to discuss the lack of Long Covid support for under 16s, lack of mitigation measures in schools and lack of testing. This meeting led to Written Questions and letters from Gavin Robinson to DHSC.

Long Covid in Children and Young People Study (CLOCK)

58. Long Covid in Children and Young People Study (the CLOCK Study) is a UCL research project which is the only paediatric study funded by NIHR which aims to determine the symptoms of Long Covid, define Long Covid and determine how many young people suffer from it. The CLOCK Study was a study in relation to Long Covid in children due to the lack of research into this area. Long Covid Kids was invited to participate in monthly meetings after the project's first findings were released. However, from our experiences, we had concerns about how the study was conducted and how it has since been interpreted.
59. We contributed to discussions on patient and public involvement in the study, but we withdrew our support from the study because we were not being meaningfully involved in co-producing the study. Decision making was not shared between researchers and patient groups, and we were not afforded the opportunity to make the material changes that we deemed necessary to ensure that the CLOCK study addressed the real needs of children and young people with Long Covid. Our view was that our involvement had

been purely cosmetic rather than enabling us to represent the Long Covid Kids community.

60. In our experience, the CLoCk study has been problematic because it has been wrongly portrayed as showing Long Covid as a consequence of the pandemic, rather than as a physiological consequence of infection from Covid 19. For example, in the Ministerial Roundtable on 7 December 2021 [INQ000067606] which I attended, it was said that there was an “overlap of symptoms” between the children. It was pointed out at that meeting that people with Long Covid could have physiological biomarkers including organ damage and blood clots and that these are biomarkers for Long Covid, albeit they are not yet identified as such.⁶ However, the CLoCk survey was presented as showing that fatigue and anxiety were the main symptoms of Long Covid in children but that these were also found in children without that diagnosis. Of course, children suffered in the pandemic, however, to extrapolate overlapping symptoms as there was no such thing as Long Covid in children is obviously wrong and not consistent with our personal experiences.⁷ Due to the concerns above likely impacting the conclusions and study, there is an urgent need for further paediatric biomedical research. This is a finding of the CLoCk study as well.

61. As there are no blood tests for Long Covid it is dependent on children articulating symptoms which is difficult and can be hard due to their young age. Amongst our members, children, and young people with Long Covid have been found to have myocarditis, muscle aches, fatigue, loss of taste or smell, shortness of breath, nausea, vomiting, diarrhoea, mood changes, rashes, loss of appetite, fevers, coughs, headaches, stomach aches and nasal congestion [SM/33-INQ000000]. Their experiences are real and are not simply a reaction to the pandemic but a consequence of their Covid-19 infections.⁸

⁶ Lai Y-J, Liu S-H, Manachevakul S, Lee T-A, Kuo C-T and Bello D (2023) Biomarkers in long COVID-19: A systematic review. *Front. Med.* 10:1085988.

⁷ SARS-CoV-2 can cause disseminated infections that result in multi-system tissue damage, dysregulated inflammation, and cellular metabolic disruptions. The tissue damage and inflammation has been shown to impair microvascular circulation, resulting in hypoxia, which coupled with virally-induced metabolic reprogramming, increases cellular anaerobic respiration. Both acute and PASC patients show systemic dysregulation of multiple markers of the acid-base balance. Based on these data, we hypothesize that the shift to anaerobic respiration causes an acid-base disruption that can affect every organ system and underpins the symptoms of PASC

⁸ Buonsenso, D.; Camporesi, A.; Morello, R.; De Rose, C.; Fracasso, M.; Chieffo, D.P.R.; Valentini, P. Social Stigma in Children with Long COVID. *Children* 2023, 10, 1518

V. The impact of government decision making on those with Long Covid

Overall Impact

62. The only way to avoid Long Covid is to avoid being infected with Covid-19. There was growing evidence from early summer 2020 that people suffering from infection of Covid-19 were not recovering.

63. Given the known risk of Long Covid, Long Covid Kids is concerned about the impact of specific decisions which led to the high prevalence of Covid-19 throughout 2020 (for example Eat Out to Help Out). Decisions that promoted the spread of infection of Covid 19 inevitably led to more children and young families being infected with Long Covid and increased the incidence of Long Covid. Long Covid Kids is concerned that the known risk of Long Covid in children and young people was not adequately factored into decision making around the spread of Covid 19. Specifically, Long Covid Kids is concerned that the Government's decision making set out in the 2021 Spring Roadmap and in its vaccine strategy, all contributed to leaving schools without adequate safeguards for children, exposing them to avoidable harm.

64. As people with Long Covid, we have been subject to abuse on social media telling us that the daily suffering we experience is not happening. It is very difficult to imagine any other circumstances where a child suffering such life changing consequences of a virus would be disbelieved. The harm done to those children by social media led narratives, the dismissal by healthcare professionals and the oversight by government decisions makers cannot be underestimated and it simply should not happen. To this day, my daughter and other children harmed by Covid experience stigma and bullying due to their disease because of the early narrative that became entrenched.⁹ Children's experiences should be listened to and factored into government decision making.

Impact of inadequate non-pharmaceutical measures in educational settings

65. Policy decisions concerning the use of non-pharmaceutical measures in educational settings have a direct impact on transmission, and therefore, on Long Covid. By failing to take the appropriate action when it was needed, children were and are being left to

⁹ Buonsenso, D.; Camporesi, A.; Morello, R.; De Rose, C.; Fracasso, M.; Chieffo, D.P.R.; Valentini, P. Social Stigma in Children with Long COVID. *Children* 2023, 10, 1518

face the dire consequences of becoming infected in settings where they are meant to be safe.

66. As set out above, we have advocated for the UK Government to ensure a sensible, safe and sustainable approach to education during the pandemic. We were concerned that schools would be reopened without appropriate safety measures in place and wrote to the UK Government in January 2021 as part of Parents United about our concerns.

67. In Spring 2021, schools returned and thereafter the few mitigations that were in place to protect children, were removed. We believe this was in no small part due to undue influence from certain pressure groups. Children and younger people were a major factor in the transmission of the Delta variant in Autumn 2021, as well as the first and ensuing Omicron waves since BA.1 replaced Delta in November and December 2021. This is because classes generally spend protracted time periods mingling at close quarters in poorly ventilated spaces, particularly in colder weather, plus asymptomatic infections and mild illness are more common at these ages, leading, unwittingly, to the overall spread of infection.

68. There are concerns that the high levels of infections among children, particularly in Jan/Feb 2021 and Jan/Feb 2022 resulted in hospital admissions for children with Covid-19, increased incidence of Long Covid, PIMS-TS cases and child deaths [**SM/11 – INQ000000**].

69. The Government has done little to improve air quality in schools or provide HEPA filters, yet still saw fit to remove the mandatory use of masks and to halt random testing for Covid-19. Indeed, it was shown by random testing, that prevalence tracks with school openings and closures [**SM/34 - INQ000000**]. Moreover, households with children were more likely to experience infections than those without, during waves [**SM/35 - INQ000000**]. Government policy has finally started to recognise the need to focus upon clean air, although little support has been provided to implement this.

70. On 11 September 2023, part of the results from the Bradford trial on impact of air cleaning technologies in schools was published in a report prepared for Child of the North and the All-Party Parliamentary Group [**SM/36 - INQ000000**]. Schools in

Bradford participated in a study that provided direct evidence of significant reductions in Covid-19 illness absences when schools were fitted with air cleaning technologies. The report states: “*by combining health records with school absences, the study found that schools that had these relatively low-cost air cleaning technologies fitted showed significantly lower absence rates*”. Long Covid Kids have consistently advocated for these results to be published over the past two years through social media.

Inadequate Public Health Warnings to Parents

There was no public awareness campaign for Covid-19 in children, including sharing information about the symptoms in children of Covid-19 and Paediatric Inflammatory Multisystem Syndrome (PIMS); Long Covid in children. Long Covid Kids believe that as a consequence, testing of children was not prioritised and the symptoms of Covid-19 in children were missed.¹⁰

71. The Government’s guidance on the list of symptoms for Covid-19 did not adequately reflect children’s experience and was not updated in line with developing evidence. This also resulted in the symptoms of Covid-19 and Long Covid in children being missed. Long Covid Kids published graphics in August 2021 that challenged the failures of Government guidance for children and listed the symptoms children experience that were not mentioned in Government guidance. **[SM/37 - INQ000000]**

72. Long Covid Kids are concerned that during the pandemic the Government advisors underestimated the effect of Covid-19 on children, ignored incidences of and the effect of Long Covid on children and did not consider risk of transmission from schools. **[SM/38 - INQ000000]**. We are concerned that may have led to inadequate consideration for mitigation measures in schools and inadequate information to parents and members of the public.

73. Vaccination lessens the risk of Long Covid in adults and children. However, messaging around juvenile vaccine programmes has, in our view, been poor and has led to vaccine hesitancy. Messaging that focused on how Covid-19 did not pose a threat to children discouraged parents from choosing to vaccinate their child. The conversation focused

¹⁰ APPG report found that children experience a wide range of Long Covid Symptoms and that these symptoms can differ from those displayed in adults. Paragraph 21 of the report **[SM/13-INQ000000]**

on the unknown risk of harm to children from a new vaccine rather than the known risk of harm from Covid-19. Vaccines were advertised for adults for a long time before being advertised for children, which created a separation in the perceived need for children to be vaccinated. We believe that this created space for anti-vaccine campaigns to grow and has contributed to a decline in vaccine uptake generally. [SM/39 - INQ000000]

74. Unhelpful comparisons being made between children and adults meant that the risk to children was considered to be low, because the risk of acute severe Covid-19 was lower relative to adults. However, it would have been more accurate to consider the risk from Covid-19 to children in comparison to other diseases which we vaccinate children against (e.g., Mumps, measles, varicella and rubella) [SM/38 INQ0000]. This metric would have potentially led to a different evaluation of risk and had an impact on public health measures taken.

75. In summary, the concerns raised included our concerns about the high level of infection rate in children, the lack of public information messaging about Long Covid, the obstacles our members and supporters reported in accessing appropriate treatment pathways for their very ill children, mitigation measures in schools and other such issues.

Inadequate data and surveillance

76. Children are commonly asymptomatic or atypical and therefore unrecorded in government data and to the best of our knowledge, Paediatric Inflammatory Multi system syndrome (PIMS-TS8) data has never been publicly available in the UK or centrally recorded (PHE/UKHSA may hold the most complete set of it).

77. We are aware of two separate methods of data collection, one through the orange card system filled out by paediatricians and the other through PICA net which records PICU admissions. Data informs decisions made in health and education and without accurate information on prevalence, the Government cannot assess the significance of an issue. In our view, the limitations outlined above resulted in inadequate consideration as regards to mitigation measures in schools and inadequate information to parents and members of the public.

78. I note that there has also been variance when assessing the prevalence of Long Covid in children. Prevalence estimates for Long Covid specifically in children and young people vary from 1%-70%.¹¹¹² As there was no consensus on what should be included in these studies, these estimates produced vary because each study uses a different method which sometimes led to inaccurate reporting. In addition, there was a significant delay in the research and recognition of Long Covid in children. Long Covid Kids have been working on rectifying this issue so that studies are more consistent and comparable to each other.

79. I co-authored an article [SM/40 - INQ000000] in response to an analysis of Zoe application (app) data by Erika Molteni and colleagues assessed the symptom profile and duration in children with a confirmed positive SARS-CoV-2 test which evidences this issue. In this article, we stated:

“The study provides important information about symptomology but probably underestimates the true prevalence of Long Covid in children. According to the Methods section, the study appears to only assess children with a defined illness duration (onset and recovery). Recovery was defined as a return to asymptomatic condition or the cessation of symptom logging. As such, this would exclude all children with on-going disease and classify children that stop recording as recovered, even if they might still be experiencing symptoms. The authors tested their assumption that cessation of recording indicated recovery by removing those patients from their calculation and found no significant difference in Long Covid prevalence or average symptom duration. However, if patients that ceased recording continued to experience symptoms, these longer duration symptoms would not be identified by the study and their effect would not be accounted for in the existing assumption test.”

80. When put together, the unavailability of data due to underreporting and the uneven approach to looking at prevalence of Long Covid in children, have had an impact on the public’s ability to learn about the risk of Long Covid in children and the decisions made by decision makers who relied on this data.

¹¹ Pellegrino R, Chiappini E, Licari A, Galli L, Marseglia GL. Prevalence and clinical presentation of long COVID in children: a systematic review. Eur J Pediatr. 2022 Dec;181(12):3995-4009

¹² Zimmermann P, Pittet LF, Curtis N. How Common is Long COVID in Children and Adolescents? Pediatr Infect Dis J. 2021 Dec 1;40(12):e482-e487

Impact on educational experiences and attendance

81. Long Covid has had a demonstrable impact on children of compulsory school age.

This issue is highlighted by the Department for Education's latest statistics on pupil attendance:

“Both overall absence and persistent absence rates have been driven by illness during the 2022/23 academic year”¹³ and “illness absence (which includes positive Covid cases) remained higher than pre-pandemic levels, at 3.7% during Spring term compared with around 2.5% pre-pandemic.”¹⁴

82. Children and young people have a right to education regardless of their health status and it is a matter of considerable concern to us that children and young people with adverse health preventing their participation in education have been, and are continuing to be, ignored and inadequately supported. We anticipate that this will be addressed in further detail in a dedicated module for children and young people and we are willing to provide further evidence in that Module.

83. Preliminary evidence from Long Covid Kids' Long Covid in Children and Young People (CYP) Education Experiences and Attendance Survey [**SM/41 – INQ000000**] shows 69.2% of respondents report that their education status has been affected in some way by infection from Covid-19. Changes in education status include a significant reduction in hours, leaving education entirely and the implementation of a new provision of hybrid or home learning by the Local Authority. The survey also shows that a child with Long Covid will lose an average of 20.6 learning hours per week and when scaled up to the total respondents of this survey it is 171,882 lost learning hours per year. When expressed relative to confirmed Long Covid diagnoses nationally for children and young people with symptoms for more than 12 months this equates to 1,091,800 lost learning hours per academic year. 10.4% of respondents are currently temporarily away from school/college ill and 9.5% are currently too unwell to be in education.

¹³ Department for Education (4 July 2023) 'Pupil attendance in schools'. Available here: <https://explore-education-statistics.service.gov.uk/find-statistics/pupil-attendance-in-schools/2023-week-24>.

¹⁴ Department for Education (13 July 2023) 'Pupil attendance in schools'. Available here: <https://explore-education-statistics.service.gov.uk/find-statistics/pupil-attendance-in-schools>.

84. 75.3% of respondents reported that their attendance has been greatly impacted by and 54.9% say that their progress with learning has been greatly impacted. 40.2% of respondents from the survey mentioned above thought that the school lacked an understanding of the impact that Long Covid has had on their child or young person's education and a further 25.9% have experienced pressure from schools to send their child or young person to school when they have been unwell.

85. As evidenced above, children and young people living with Long Covid face enormous disruption to education. From an early stage, Long Covid Kids has sought to engage with the Government, health providers and schools. Harm to children from Covid-19 infection has been consistently overlooked and missing from reports and articles that consider education and attendance. Rather than dismissing children, the voices of children with Long Covid should have been listened to so that their experiences can be at the centre of changes and improvements.

VI. Experience of our Members – Children's testimony

86. Whilst some children and young people may recover from Covid-19 with no apparent immediate harm, for some children and young people this is sadly not true. They suffer prolonged illness from Covid-19. Most of the families we support have children who have been severely unwell for 12 months or more and unable to attend full time school. In most cases we do not see children recovering and 'getting better', instead we see our members having to learn to manage symptoms and mitigate the harm they suffer. Many children have been disabled even though they only suffered a 'mild' infection of Covid 19, to the extent that they must now use wheelchairs full or part time.

87. In our short film "Our Unhappily Ever After", Long Covid Kids included testimonies from children who had contracted Covid-19 and had not recovered, suffering serious debilitating illness. Some of the testimonies in this video include:

87.1. *"If felt like a long time ago we were well and could do some of the fun things we like to do we're still at home and we are still unwell. A lot of us are in bed a lot of the time, it can be boring, annoying, frustrating and tiring and we miss our friends"*

87.2. *“We miss feeling well”*

87.3. *“We want to feel better again”*

88.I exhibit to this statement anonymised case studies from Long Covid Kids members suffering with Long Covid [SM/33 - INQ000000]. These case studies explain the impact that Long Covid has had on their children’s personal lives, education, and health, as well as the wider impact on their family. Additionally, the case studies address the effectiveness of public messaging about Long Covid and the difficulties obtaining diagnosis and treatment. Below are extracts from the exhibited case studies which describe the impact of Long Covid on children:

88.1. H, 15 years old, initial infection April 2020, reinfected July 2021, diagnosed with Long Covid December 2021 - *“H still, nearly 2 years later endures daily pain and cannot walk properly. She has no real “life” as such, and always feels unwell. Certainly not a life that any normal 15yr old should be able to enjoy ... Daily she struggles. Daily she is in pain. Daily she picks herself up and keeps trying to be positive -despite this horrendous illness.”*

88.2. E, 16 years old, initial infection September 2021, diagnosed with Long Covid November 2021 - *“Apart from well managed allergies and undiagnosed hypermobility, she had no known underlying condition before Covid. She has been completely bedbound for 14 months and seriously unwell for 23 months. She developed a 36-degree reactive scoliosis and intense pain in her right hip at exactly the same time as Covid Pneumonia was diagnosed.”* When asked about the response from healthcare professionals: *“It was glaringly obvious to E and to us that this was a multisystemic response to Covid. Even with a Long Covid diagnosis, many professionals seemed intent on viewing her presentation through the restricted lens of individual organs, or indeed assuming a psychological causation - despite overwhelming evidence to the contrary.”*

88.3. E, 15 years old, initial infection September 2020, diagnosed with Long Covid October 2020 - *“Unable to attend school, isolated from society, fearful of being reinfected, lost opportunities lost friendships unable to carry out my hobbies like horse riding or helping at the stables”*

88.4. C, 17 years old, initial infection October 2020, diagnosed with Long Covid in May 2021 - *“professionals looking to blame it on his Mental Health played it all down”*

88.5. T, 19 years old, initial infection August 2021, diagnosed with Long Covid September 2021 - *“I missed one year of school after completing year 12. I returned to school a year later but couldn’t manage 3 A levels so dropped 2 subjects. I now have one A level and would like to go to University but I am unable to at the moment because my Long Covid illness is hampering my ability to obtain the necessary qualifications to be accepted on a university course.”* On what public messaging they saw about Long Covid: *“None before I was ill and I don’t remember seeing anything since”*

88.6. S, 13 years old, initial infection September 2021, diagnosed with Long Covid March 2022 - *“He lost all his friends. The occasional visit he received only showed how much they have all moved on while he is left behind, unable to do so. The one hour of chit chatting would completely wipe him out and caused him post exertional malaise. Those have now stopped. His siblings, tutors and occasionally family friends are the only people he interacts with.”*

89. In addition to the individual experiences shared above, I produce [SM/42 - INQ000000] showcasing further lived experience shared by families, children and young people shared on our website to raise awareness. Some examples include:

89.1. J, age 10, living with Long Covid since November 2021: *“No one at school or in health believed me until I ended up in crisis in hospital with a feeding tube. All the doctors asked about was how I see myself in the mirror”. J “was very active and loved to roller skate with her family. Now she needs a wheelchair and can’t walk or attend school. Our whole family are suffering along with her. It’s not fun for anyone.” J “just wants to be back to normal, she is on a lot of medication to help with constant pain, nausea, brain fog and fatigue”.*

89.2. C, age 11, living with Long Covid since September 2021: *“I used to be really active, not it’s hard to get up in the morning”. C “used to be so full of life, always outside, always on the go, played numerous sports. Following Covid, missed*

about a year of school. She now managed school (most of the time) but our weekends are now taken up with her resting to enable her to attend school during the week. Days out are few and far between due to the crashes afterwards. An 11-year-old should not be 'living' this way"

89.3. C, age 8, living with Long Covid since November 2021: *"Long Covid has made me feel annoyed, less energetic, sad and I don't enjoy as much as I used to"* says C, *"On big days out I now have to use my wheelchair because otherwise I get too tired, and I would have an energy crash"*. C *"used to run, jump, skip along on days out, now uses a wheelchair to enable her to manage / pace days out so that she can still experience fun with her family and friends"* says her mum.

Statement of Truth

I believe that the facts stated in this witness statement are true. I understand that proceedings may be brought against anyone who makes, or causes to be made, a false statement in a document verified by a statement of truth without an honest belief of its truth.

Signed:

Personal Data

Dated: 25th September 2023