From:
 Admin

 To:
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 Subject:
 Fwd: Long Covid Kids

 Date:
 12 December 2022 11:21:35



Please note that many of our team members live with Long Covid and may be unable to respond to your message promptly as they work flexibly around their conditions.

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------ Forwarded message ------From: Admin <<u>info@longcovidkids.org</u>> Date: Mon, Dec 21, 2020 at 10:52 PM Subject: Long Covid Kids To: <<u>chris.loder.mp@parliament.uk</u>>

Dear Mr Loder

I live in Dorchester and am the founder of Long Covid Kids .

My daughter and I got Covid in March and have been living with Long Covid ever since. Our personal Covid story can be read <u>HERE</u>.

Long Covid kids represent over 300 children all of whom have disabling symptoms and are struggling to access medical support. We only formed in October and our numbers grow daily.

The adult Long Covid support group established in early summer and represents 32,000 people.

Our group grows daily as parents find us, desperately seeking support.

We require your help, as despite our best efforts our voice is small.

Our children desperately need representation. They seem to have been forgotten in this pandemic.

Please see our short awareness film that we released on Utube, it is just under 3 mins long.

https://www.youtube.com/watch?v=RiIambG8vs0&t=29s

Many of our children became ill in March /April and are still ill with disabling symptoms 9mths later.

Most of our children had 'mild' symptoms when they were infected.

Some children got better for a while after an initial 2-3 weeks of illness and then deteriorated around 5-6 weeks.

Some children were seriously ill immediately.

Long Covid symptoms can come and go in clusters and waves.

Every day can be different.

Parents in our group face a number of ongoing challenges;

1) There are currently no 'return to education plans' to support children with Long Covid.

The expectation from schools, and actually the GP's, is that children should return to school after their isolation period, or as soon as they feel well.

Our children have not felt well since contacting COVID-19.

This puts parents in a difficult position, as they are faced with the heart breaking choice of sending their sick child back to school or receiving fines and ongoing threats of unsupportive intervention whilst worrying about reinfection and the deterioration of their child's long term health.

Long Covid does not have a code that schools can use in their registers. This poses a problem for attendance figures and perpetuates the problem further.

In addition parents are managing their own Long Covid recoveries, which has resulted in some parents losing their jobs while caring for their sick children and experiencing financial hardship.

As you can appreciate, the combination is overwhelming, and daily phone calls / emails from schools and threats of fines further exacerbate their situation and ability to recover.

As a group we are very much pro education, however while our children are too weak to stand/walk/sit up unaided/focus/ concentrate/eat/sleep, our priority is their survival, recovery and long term health.

2) Long Covid is not accepted at local level by the medical community despite being recognised in the British Medical Journal since October, please see here to see how Long Covid has evolved.

https://www.longcovidkids.org/what-is-long-covid

Children are often incorrectly diagnosed or sent away with out diagnosis multiple times.

Parents report medical gaslighting which they site as a barrier to ongoing medical support, and children rarely receive the specialist medical services they desperately need.

The new NHS Long Covid clinics do not plan to offer pediatric services so we do not anticipate this situation changing imminently.

3) Our ongoing concerns over the safety of our children in schools were further strengthened by recent studies highlighting the importance for ventilation, as well as space. Neither of these are being implemented effectively in schools, and both require urgent attention.

Returning to school in January poses significant risk to the long term health of an entire generation.

Please see here for a number of studies that evidence why.

https://www.longcovidkids.org/copy-of-resources

From the scientific evidence we believe all schools should undergo a standardised mandatory risk assessment devised by an expert led task force to include ventilation specialists.

Until then, Schools should remain closed to the majority of pupils, and only welcome 'vulnerable' and key worker children back in.

This strategy would significantly reduce numbers of pupils on site and enable essential COVID-19 protocols to take place for this smaller cohort.

The remaining cohort could be educated through blended learning, combining online, with

part time education, again keeping numbers on site low.

The long lasting effects of COVID-19 are not understood.

Our children are being exposed to a virus without understanding and have developed chronic health conditions.

As parents we see;

- 1. Boys with testicle pain, growing breast buds, experiencing hormonal surges.
- 2. Girls with ovary pain, older girls losing their periods, younger girls racing through puberty at 7/8 years of age when there was no previous sign.
- 3. Children with seizures, pain and mobility issues, inc the inability to walk..
- 4. Children with cognitive impairment, neurological issues, visual disturbances, hearing loss and speech impairment.
- 5. Children with heart pain, head pain, stomach pain, rashes, bumps and sores.
- 6. Children unable to eat, with dangerously low body weights requiring tube feeding.
- 7. Organ damage.

Please see our symptoms gallery for further infomation <u>https://www.longcovidkids.org/long-covid-kids-symptom-gallery</u>

On the 7th January Long Covid will be debated in the Commons chamber, we need you to be our voice and to represent our children.

Please could you kindly consider attending the debate and raising our concerns, and thoughts?

Thank you for considering our request.

I would appreciate the opportunity to discuss our concerns further and look forward to hearing from you.

Yours sincerely

Sammie Mcfarland Founder Long Covid Kids



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