Dear Prime Minister

My name is K, I am 16 years old, and I got infected with covid March 2020. My symptoms started off mild; a slight cough, heart palpitations and weakness. We reached out to the NHS for advise on the matter, they decided not to help and instead told my mother I was faking being ill for attention, that I was copying my mothers symptoms of covid. My mother had difficulty breathing and weakness, where as my symptoms were to do with my heart and a fever. We were being told kids couldn't get covid, they couldn't of been more wrong.

After 2 weeks I started getting better, for a month I felt more like my previous self (a fit healthy teenager with no underlying health conditions). 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.

This 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 badly bullied at school and online, it felt like the whole world was against me, I had no friends, no one I could talk to.

Over the next year my mental health has still not improved because of the society, doctors are still not helping and I am still ill. I have been diagnosed with 2 ovarian cysts, POTT's, and a heart murmur (with many things still unsolved) we have only got diagnoses because we have pushed so hard for it. The cysts would cause me to loose consciousness often because of the pain, this caused many complications in everyday life.

I have just hit my 2 year mark, yet I am still very unwell, I am still in pain everyday. I am on so many meds (which all 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 of had to get this ill for someone to do something, I deserve a normal happy life. So open the windows, make tests free again. Make a difference.

Stop making everyone ill, stop ignoring us.

Thank you for listening.

Yours sincerely,

K

Rt Hon Boris Johnson MP
Prime Minister
10 Downing Street
LONDON SW1A 2AA

1st April 2022

Dear Prime Minister,

The 20th September 2020 was the day my journey with Long Covid began. It started with a cough which persisted, and the next day my mum took me for a test and two days later it, surprisingly, it came back negative. I then went on to lose my sense of taste and smell and so a week later we went for another test – this time it came back positive and from that point on things progressively got worse.

My first hospital visit was on the 1st October when overnight I developed a full body rash as if it were sunburnt. My lymph nodes on my neck had also become so swollen that it became difficult for me to move my head. Although they weren't supposed to see people with Covid in person, my GP at the time cleared the surgery to see me and immediately sent me to the hospital where I was admitted. One of paediatricians at the time suspected I may have MIS-C, the Kawaski-like disease, but the Registrar overruled him the next day because she said I wouldn't be smiling if I was seriously ill despite developing a fever overnight. I was discharged home after 24 hours with no follow-up plan.

My GP did her best to support me but there were no referral pathways for me specifically related to ongoing Covid illness. By December she had referred me to the community paediatrician who we spoke to on a telephone appointment 2 days after my 16th birthday. When he heard about my ongoing list of symptoms, he decided I needed to be admitted immediately for testing and sent us to our local hospital. Upon arrival, we were told the Doctor we were sent to see did not exist and an A&E doctor would assess me instead. The A&E doctor said to us " unfortunately I am one of those doctors who doesn't believe in Long Covid" but she went to talk to the paediatric team about being admitted for tests. We waited for 4 hours. The only test I had was a chest xray. Then we found out that the paediatric team and the adult team couldn't agree who should admit me because of my age. The A&E doctor told my mum that if I was her daughter, she'd just leave, so we did.

My mum wrote a complaint that night to the hospital and the next day we were sent to that same hospitals' day assessment unit. They were extremely understanding and did lots of blood tests and an ECG but they could not understand why I had been referred to them and did not provide us with any answers.

The lowest point in my Long Covid journey was actually on Christmas Eve 2020 when throughout the day I had developed nerve pain that was so severe I ended up crying to my parents because I couldn't even lie down. After trying to make it through the night, I got up on Christmas Day to find

that I couldn't even walk to the edge of the bed without my chest cramping up. At this point I told my mum I felt as though dying. She drove me to the hospital as I was fading in and out of consciousness and vomiting from the pain. When we got there, we were seen pretty quickly by the nurse and then seen by the A&E Doctor within 20 minutes. The first question the doctor asked me was if I'd been on a ventilator and when I responded no, he went on to imply that Long Covid only affects people who have had severe covid illness and hospitalisation. He then told me that Long Covid doesn't exist in kids as he hadn't seen it with his own eyes, despite figures having been released just days earlier stating that Long Covid did in fact exist in children. After asking about my moods, and me responding that I had been dealing with low moods since I got ill, he told me that this flare up must have all been in my head because of my low moods. He went on to comment – and this is my particular favourite – "depressed? Why are you depressed? If I was 16, I'd be so happy. You should just go home and enjoy Christmas". He didn't give me any tests, or any pain medication, because he stated I was too young for that.

I am now 18 months on. I have been formally diagnosed with Long Covid. My GP is very caring, and reviews me regularly, but can offer no treatment or support other than a sympathetic ear. I have been seen by the Long Covid clinic, but they only offer rehabilitation which doesn't address the source of my symptoms. My parents have spent hundreds of pounds on private medical appointments to try and help. Although my school have been fully supportive and helped as best they can, the grades achieved at GCSE were lower than predicted because I missed over 6 months of school . I am studying 3 A-level subjects but was meant to be doing more, as I had always been a high achiever, but I'm on a supported special educational needs plan now because of the chronic symptoms I suffer including slower cognitive processing and memory lapses. I'm still suffering regularly with fatigue, chronic headaches, nausea, nerve pain, rashes, chest cramps, tinnitus, brain fog, memory loss and joint pain.

What I want you as our Prime Minister and the wider Government to know is that Long Covid in kids is real. Responding insensitively to children and parent's concerns has a negative impact mentally and physically on children's well-being. We need to be listened to, and we need there to be priority given to addressing the root cause of our illness so that the identification of effective treatment can be prioritised. How many other young lives have to be thwarted before someone will stand up for us?

Thank you for listening.

Yours sincerely,

L

Prime Minister,
10, Downing Street,
London
SW1A 2AA

Dear Prime Minister,

My name is V and I want to tell you about my covid experience.

I contacted covid when my CEV brother brought it home from school over 8 months ago. Since then my life has changed. I wasn't too bad when I got covid, it was manageable and just felt like a really bad cold, so it was quite a shock when I got diagnosed with long covid. I was sad because my brother tested positive on my 12th birthday and I had to cancel all birthday plans.

Before covid I was a busy, active 11 year old doing an after school activity most days and extra Mandarin lessons in school on Thursdays and Fridays as part of my schools Mandarin Excellence Programme. I was learning to play the cello, a member of a lifeguarding club and a Guide. I was in school every day of the week and going in even if I wasn't feeling 100%. I really enjoyed school and my favourite lessons were History, Geography and English Before I got covid I managed to get my bronze open-water and beach lifeguarding medals. I also loved baking from scratch, cooking and hanging out with my friends almost every Friday.

I never fully recovered from Covid, I was always ill afterwards, I had a tummy bug straight afterwards, chest pain and constantly felt like I had a cold. I had about 3 days where I felt well. On about the 15th October, I was told by my doctor that I had long covid. I felt really sad because I had to stop swimming and had to put my life on hold. At this news, I just wanted to be well.

Now that I have long covid, I can only do 1 after school activity every couple of weeks, completely stopped going to my lifeguarding club for the moment because the practical part was too much, my doctor told me to stop swimming and rest. The theory part was too much because I couldn't concentrate and the room was too noisy and too bright. I'm not in school, I haven't been since the 12th October 2021. I see my friends about once a month, this takes a lot out of me and afterwards I feel bad, ill, sometimes I feel like I will never wake up if I go to sleep the pain, coughing and tiredness is so bad. I am doing Mandarin lessons once a week via zoom outside of school to try and keep up, my mum has to pay for it, I get very little support from my school. I have had to pick my options this term, I can't do all 10 GCSE's so have chosen 3 rather than 4 options, but know that even 3 is too much. I haven't even been able to pick the ones I really wanted to do, I wanted to do Drama and Hospitality and Catering, but I cannot physically and mentally cope with those. I am worried about how I will cope with

my GCSE's as I am still so unwell. I can only bake once every other month with the support of my mum, and even then it's out of a box rather than weighing the ingredients myself. And it wears me out for days.

Some of my main symptoms are: feeling tried all the time no matter how much sleep I get, pain all over which gets unbearable in a blink of an eye, a cough that won't go away and makes my throat and chest hurt a lot, brain fog and struggling to think, ankle swelling, reactions to certain foods, light and noise sensitivity, heart racing, strange vision and randomly feeling hot and cold.

I don't like that the covid regulations are being lifted because it's too soon and makes the risk of people with long covid getting covid again higher. I am exempt from wearing a mask at the moment due to it being to hard to breathe. I don't like that I can't wear a mask because I have always been cautious with covid as I am the only one in my household that isn't CEV. I'm scared to go out in case someone does have it and I catch it again.

I don't like feeling like this because I feel like I'm missing out and my life is on hold. I'm missing my clubs, my friends and mandarin trips. I just want to be well and never want anyone else to go through this.

Yours sincerely,

V

Hand delivered to
No. 10 Downing Street
Westminster
London

Dear Boris Johnson,

I'm J. 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 hope you can help.

Yours Sincerely,

J

23rd April 2022

Dear Boris Johnson

My name is E, I am 9 years old and in early September 2021 I tested positive for covid. I caught covid in the second week of being back at school, I must've picked it up from someone in my class, who was showing no covid symptoms, but there were a lot of "colds" going around. After three days my body was in extreme pain and I was unable to move. I lost the ability to use my left leg and my back, shoulders, neck and leg gave me so much uncontrollable pain. I was also very tired and suffered other covid related symptoms.

Sadly after my isolation period was up, I was no better, my parents couldn't control my pain with over the counter pain relief, and the pain I was in was getting worse and I couldn't describe it. My parents had to carry me to the bathroom, had to dress me, wash me and care for me as if I were a toddler or baby. I lost all of my independence and confidence. I couldn't get downstairs and stayed in bed most of the time to try to keep comfortable, sometimes my parents would have to feed me too.

I ended up in hospital but the Doctors could do nothing for me and told me it was just covid and I would get over it. I didn't and I went back into A&E several times, before I was admitted for 13 nights in November. This brilliant Doctor at our local hospital, helped me more than I had been helped before and he made sure my pain was decreased and tested and scanned me for very serious conditions.

When I came out of hospital I was referred to the Paediatric long covid hub, physiotherapy services and the chronic fatigue team too. All of the NHS services are so over full because thousands of children are being really badly effected by Long covid. This means that I have only just started seeing these services, and physiotherapy I only see once a month as they are so busy. It is vital that you give more money to services like this that are helping children with Long Covid so they can expand and help more children like me.

After being in hospital I decided that I wanted to support the NHS and raise awareness of Long covid in children. I have been relearning to walk again since September and now use a walker to get about (before covid I was healthy and fit and had no underlying health issues). I have been walking laps of my garden since 1st December 2021 to raise money for the NHS charities together, and so far have raised over £7000. This is something which is very important to me and I hope will raise the awareness of how covid is effecting children.

In January I started back at school for the first time since September, I started doing a short session a few times a week and am now building this up to 2.5hours-3hours a day. This is because I am suffering with chronic fatigue, constant pain but also brain fog (alongside other covid related issues) which makes concentration very difficult. Since being back at school, I have noticed a large number of children being affected by covid, luckily most of them have not suffered with long covid, but 1 in 7 children will go on to get Long Covid. It is important that schools are safe, with clean air and good ventilation. It is also very important that Primary school children get the vaccine as soon as possible, so we can be protected against covid and long covid.

Although you think taking down covid restrictions is a good idea, I would disagree. Wearing masks protects you and others and is not a hard thing to do. Isolation is important as it stops the spread of covid and means less people will get infected, meaning less work for the NHS. Which would mean more support and money for people with Long covid.

I am still suffering with a weakness in my left leg, constant pain in my leg, back, shoulders and neck, brain fog, chronic fatigue, stiff fingers, gastric issues, hearing problems and sight problems, Long covid has changed my life but I choose to stay positive and keep fighting.

My hopes for the future is that I will get stronger and go back to school full time and do all of the hobbies I love to do. I hope that this letter may have influenced your mind just a tiny bit and that you think again that children can just bounce back from covid.

Yours Sincerely

E

Hand delivered to
No. 10 Downing Street
Westminster
London

Dear Boris,

My name is A and I am 9 years old. I&S I&S

I have had Long Covid for 2 years, since I was 7, and it has been absolutely horrible. The doctors don't know how to help me and some of them don't even believe I am sick. That makes me feel really angry and I don't like to be treated like I am making it up. I can't get to my appointments sometimes because I feel too ill, but they won't come to my house even though Mum asked them to. So I don't really have any help from doctors or physiotherapy or CAMHS or anyone yet. Some of them tell me to just go back to school and then I'll get better. Well, I tried that lots of times and it made me much much worse, so...

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.

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!

I don't know why the Government hasn't helped us yet and that makes me pretty angry and quite depressed. Why don't people think Long Covid is that bad? I know how bad it is but everyone is ignoring it and pretending it's not here. I think as the Prime Minister you can fix this? Maybe you could speak to Nicola Sturgeon and come up with a plan to help us? We need help.

I really hope that you and the Government can help us and do something about this because I really need everyone to understand why I am sick and how I feel every single day. Especially the doctors. I really need you to make things better, please? Not just for me and my Mum, but for all the of the kids who have Long Covid because we're all sick but no one cares.

I hope that you read my letter and I hope that you can do something to help us.

Thank you,

A