[Your full address]

[Your email address and mobile phone]

[Date]

[MP's Name]

[MP's Constituency Office Address]

**Request for support of Downing Street Letter regarding the ongoing crisis of Long Covid.**

Dear [MP’s Name],

My name is [your name] and I am writing to you today as your constituent, to seek your support in addressing the ongoing crisis of Long Covid, which is having a dramatic impact on not only the health of the nation, but also the workforce and the UK economy. The seriousness of this issue has failed to attract the attention it deserves.

 [I am one of the] / [There are] 1.9 million individuals, including 62,000 children, that are suffering from the prolonged, debilitating, and sometimes disabling, effects of this illness (1). I have grave concerns about the lack of investment in research and treatments that we urgently need in order to improve the health outcomes of individuals with this illness.

An alliance of charitable organisations comprising [Long Covid Kids](https://www.longcovidkids.org/), [Long Covid Support](https://www.longcovid.org/), [Long Covid SOS](https://www.longcovidsos.org/) and [Long Covid Physio](https://longcovid.physio/) are working on behalf of those with Long Covid. Together, these groups delivered a letter to No. 10 Downing Street on the 6th December 2023, urging the government to take immediate and comprehensive action to address the challenges posed by Long Covid. The letter is below for your review.

I kindly request that you lend your support to this letter in your capacity as a Member of Parliament. I would like to request your support in the following ways:

1. **Posting about it on social media:** Your voice on platforms such as Twitter/X can reach a wide audience and draw attention to the challenges faced by those with Long Covid.
2. **Writing a letter in support:** A formal letter from you expressing your support to the ongoing crisis of Long Covid, and endorsing the goals of the Downing Street letter would be invaluable. Should you find it beneficial, please feel free to use the template provided below.
3. **Signing the petition:**

<https://you.38degrees.org.uk/petitions/urgent-investment-for-long-covid-call-to-action-for-rishi-sunak>

As my representative in Parliament your support for this letter will amplify its impact and contribute to positive outcomes for the millions impacted by the illness and the knock on effects to their family, friends and wider community.

Your office's assistance in this matter would be greatly appreciated. If you require any additional information or clarification, please do not hesitate to contact me.

I look forward to receiving a response from you soon and appreciate your dedication to serving the interests of our community.

Yours sincerely,

[Your name]

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1. <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/prevalenceofongoingsymptomsfollowingcoronaviruscovid19infectionintheuk/4august2022>

**Call for Urgent Investment in Research and Treatment Trials for Long Covid**

Dear Prime Minister,

We write on behalf of the 1.9 million people in the UK, including 62,000 children (1) and young people, who are living with long-term impairment and disability following a COVID-19 infection. In addition to representing their voices, our concern extends to those previously infected with SARS-CoV-2 who are unaware of the potential life-limiting issues they could face in the future due to the damage inflicted by this virus (2,3).

We, as an alliance of charitable organisations comprising Long Covid Kids, Long Covid Support, Long Covid SOS and Long Covid Physio, share grave concerns about the lack of investment in biomedical research and clinical trials into treatments that could address the complex pathophysiology and improve the health outcomes of individuals whose lives have been seriously affected by this condition.

We commend the government's efforts during the pandemic when more than £50 million of government funds were allocated to fund Long Covid research projects and set up the ONS monitoring of Long Covid prevalence. This research has provided a clearer understanding of the depth, complexity and impact of this condition which is now widely documented (4). However, it is now more than two years since this funding was allocated, and scientists are struggling to access funding to pursue existing or new Long Covid research. Importantly we now need to progress this evidence and expand our understanding of paediatric Long Covid. The development and trialling of potential treatments and condition-specific support services, underpinned by adequate, sustained and equitable funding streams, is now urgent and overdue (4).

To characterise the current impact of Long Covid in the UK, our organisations have contributed to global research which demonstrates that:

* Long Covid symptoms can result in severe limitations that affect people's ability to participate in activities of daily life.
* Individuals report having to significantly alter their lifestyles and sacrifice participating in normal daily activities. This includes being unable to complete work-related activities (economic impact), challenges in engaging with friends and family (social impact) and experiencing stigma (4, a,b,c,d,e).
* The symptoms of Long Covid can last for months and years (5), with a substantial number of patients from March 2020 continuing to suffer significant symptom burden and disability.
* When individuals feel able to return to their usual activities many experience debilitating health consequences in the days and weeks following participation (6).
* Long Covid impacts people of all ages. Children and young people report that COVID-19 and Long Covid have impacted their attendance and attainment in education (5).
	+ These children and young people are part of the next generation of the UK adult workforce. Long Covid has rendered them less able to learn and acquire the knowledge and skills they need to build successful careers and contribute to the country’s social and economic activity.

Global prevalence of Long Covid is estimated at >65 million (1) with 1.9 million of those being from the UK. It has been suggested that this figure could rise to somewhere between 200 (7) and 400 million people globally over the next ten years if we do not act decisively to deliver effective treatments and support services. COVID-19 is mutating and as it freely circulates amongst society it will lead to increased Long Covid cases which we know pose a very real threat to the health, wellbeing and prosperity of our country (8).

We have come together to urge you to act now and provide the essential financial investment required for the necessary and significant improvements needed in understanding and addressing this complex health condition.

Our collective appeal is centred around the urgent need for a clear road map on targeted investment in biomedical and health research. We propose a comprehensive 5-step strategy that includes:

* **Dedicated Research Funding:** Allocate resources specifically earmarked for biomedical and health research into both adult and paediatric Long Covid. By doing so, we can accelerate the pace of discovery by uncovering the intricate pathophysiology of the condition.
* **Collaborative Research Initiatives:** Foster interdisciplinary collaboration between research institutions, healthcare providers, charitable organisations and those with lived experience to create a unified approach with shared expertise, resources, and data, leading to more robust and impactful studies.
* **Treatment Trials:** Fund and expedite clinical trials for potential treatments. By streamlining regulatory processes and providing support for innovative therapies, we can fast-track the development of interventions that improve health outcomes.
* **Public Awareness and Education:** Invest in public awareness campaigns to educate individuals about the potential long-term consequences of COVID-19 and the barriers and stigma they may experience with it. Early awareness can prompt proactive healthcare-seeking behaviour and contribute to more effective management of the condition which in turn will reduce the impact on healthcare services.
* **Service Provision:** Continue funding specialised services to support adults, children, and young people (along with their families) who are suffering from Long Covid. Long Covid, identified as a chronic condition, has demonstrated varied outcomes in paediatric services, with 56% improving one functional severity category while 40% remain broadly the same level of impairment and 0.4% show deterioration (9). At 6 months, the largest UK service has demonstrated that the number of children and young people with over 50% school attendance has more than doubled (10).

Moreover, individuals with Long Covid exhibit the highest healthcare utilisation over a 2-year period, spanning general practice, emergency department, and outpatient care. They also demonstrate the second-highest rates of hospital and critical care admission when compared to both pre-pandemic and pandemic control groups. Long Covid care, estimated at over £3000 per person per year, is nearly four times more than care for the same individuals before the pandemic and nearly three times as much as care in age- and comorbidity-matched individuals before and during the pandemic (11).

Given these substantial healthcare needs and associated costs, patients require ongoing management, monitoring, and support through specialised clinical networks. These networks should be designed to seamlessly integrate research findings into clinical care, ensuring a comprehensive and effective approach to addressing the challenges posed by Long Covid.

We recognise the demands on your time when the UK faces important challenges, but we are committed to informing and supporting the government in developing an effective strategy to address current and future public health emergencies.

As the government takes on board the lessons from the pandemic, as highlighted by the UK Covid Inquiry, we are keen to support future planning and prevention of post-pandemic illnesses and would applaud government efforts in these areas.

Your leadership and commitment will give hope to the people already living with this condition and to their caregivers, friends and families. Demonstrating a proactive response will have a lasting impact on the well-being of our citizens and the overall prosperity of our nation.

Our organisations and the signatories of this letter are willing to provide assistance and expertise to support the success of these endeavours and would be grateful for the opportunity to discuss and help move this urgent initiative forward.

Thank you for your attention to this crucial matter. We look forward to the positive impact that your support can bring to the lives of many.

Sincerely,

**Sammie McFarland**, Long Covid Kids

**Professor Mark Faghy**, Long Covid Physio, Professor of Clinical Exercise Science, University of Derby

**Ondine Sherwood**, Long Covid SOS

**Jo Dainow**, Long Covid Support

Endorsed by:

**Professor Danny Altmann**, Professor of Immunology, Imperial College London

**Professor Amitava Banerjee**, Professor of Clinical Data Science and Honorary Consultant Cardiologist, University College London

**Professor David Strain**, University of Exeter Medical School

**Dr Terry Segal**, Consultant Paediatrician, Clinical Lead Adolescent Services University College London Hospitals, Co-Lead Pan London Post COVID service

**Dr Carrie MacKenzie**, Consultant Paediatrician, Clinical Lead SYB CYP Post Covid Service

**Dr A T Anbu**, Consultant Paediatrician, Lead for CYP Long Covid and ME/CFS services, Alder Hey Children’s NHS Foundation Trust, Liverpool

**Dr Richard Tozer**, Consultant Paediatrician, Torbay and South Devon Healthcare NHS Trust, Clinical Lead South West Children and Young People Post Covid Service

**Dr Cervantee Wild**, Research Fellow, Oxford University

**Dr Jeremy Rossman**, Senior Lecturer in Virology, University of Kent and Long Covid Kids

**Professor Kate Hunt**, University of Stirling

**Dr Tim Nicholson**, Reader in Neuropsychiatry at King’s College London and Consultant Neuropsychiatrist in the King’s College Hospital Long COVID service

**Dr Rae Duncan**, Consultant Cardiologist and Long Covid Research Clinician, The Newcastle Upon Tyne Hospitals NHS Foundation Trust

**Dr Abbas Khushnood**, Consultant Paediatric Cardiologist and Paediatric Long Covid Research Clinician, The Newcastle Upon Tyne Hospitals NHS Foundation Trust

**Professor Carolyn Chew-Graham OBE,** GP Principal, Professor of General Practice Research, Keele University

**Dr Helen Davies**, Consultant Respiratory Physician, University Hospital of Wales, Cardiff

**Professor David Price**, Chair of Infection & Immunity, Cardiff University School of Medicine and Systems Immunity Research Institute

**Dr Samantha Jones**, Research Fellow, University Hospital of Wales, Cardiff

**Professor Brendan Delaney**, Professor of Medical Informatics and Decision Making, Imperial College London

**Dr Daniel Munblit,** Reader in Paediatrics, King’s College London

**Professor Tim Rhodes**, Professor of Public Health Sociology, London School of Hygiene and Tropical Medicine, UK

**Dr Hannah Baynes**, Consultant General Paediatrician with Adolescent Interest, King’s College Hospital, London and Convenor of the RCPCH Young People’s Health Special Interest Group (YPHSIG)

**Dr Michael Wacks,** Consultant General Paediatrician and South-East London CYP Long COVID Champion, King’s College Hospital, London

1. <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/prevalenceofongoingsymptomsfollowingcoronaviruscovid19infectionintheuk/30march2023>
2. <https://www.nature.com/articles/s41591-022-01689-3>
3. <https://www.nature.com/articles/s41579-022-00846-2>
4. a) <https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0277317>

b) <https://www.tuc.org.uk/sites/default/files/2023-03/LongCovidatWork23.pdf>

b) <https://www.bma.org.uk/media/6056/addressing-the-health-challenge-of-long-covid-final.pdf>

c) [https://www.bma.org.uk/media/7318/bma-long-covid-report040723.pdf](https://www.bma.org.uk/media/7318/bma-long-covid-report040723.pdf?_gl=1*ob1qsf*_up*MQ..*_ga*MTUxNDEwNDI3NC4xNzAxMTgxODg3*_ga_F8G3Q36DDR*MTcwMTE4MTg4Ni4xLjAuMTcwMTE4MTg4Ni4wLjAuMA..)

d) <https://bit.ly/3R7mFdv>

e) <https://www.pslhub.org/learn/coronavirus-covid19/appg-on-coronavirus-long-covid-report-22-march-2022-r6432/>

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2. <https://link.springer.com/article/10.1007/s11136-023-03513-y>
3. <https://www.newscientist.com/article/mg26034670-800-long-covid-what-we-now-know-about-its-causes-and-possible-treatments/>
4. <https://bmcprimcare.biomedcentral.com/articles/10.1186/s12875-023-02196-1>
5. <https://adc.bmj.com/content/108/Suppl_2/A462>
6. Characterisation of patients referred to a paediatric tertiary post-COVID service: a service evaluation (Goddings et al in prep)
7. <https://papers.ssrn.com/sol3/papers.cfm?abstract_id=4598962&fbclid=IwAR01k-8gEMPp9DHqz9aRvdo8msTcj87ldfcDZpurFXRBPOz3Q7MOd_kR-90>