

## Emails sent to the Secretary of State for Health and Social Services

**From:** Sue Dimmock

**Sent:** 29 January 2022 19:36**To:** 'sajid.javid.mp@parliament.uk' <[sajid.javid.mp@parliament.uk](mailto:sajid.javid.mp@parliament.uk)>

**Cc:** 'Margaret Fuller' , 'Lynda Rhodes'

**Subject:** The significant impact of removing Plan B restrictions on people with immune deficiency

Dear Sajid Javid,

I am writing to you as a representative of UKPIPS (UK Primary Immune-deficiency Patient Support) a small charity advocating for people with immune deficiency, across the UK.

Children and adults living with immune deficiency have full or partial impairment of their immune system, meaning they are unable to effectively resolve infections or disease. The term immune deficiency covers over four hundred different conditions and I have the most prevalent of these called Common Variable Immune Deficiency (CVID), a genetic condition, which means I am unable to produce antibodies.

NHS data identifies that in 2019/20, in England and NI, a total of 7,818 people were being treated for immune deficiency with regular antibody (immunoglobulin) replacement therapy (IgRT). This donated immunoglobulin component gives us a limited ability to fight infection. Once it is utilised fighting an infection, we are at risk until the donated component is replaced again, through another IgRT. As our immune systems do not respond like most people's would, we cannot fight 'normal' infections without a combination of our IgRT and antibiotic therapy.

The fear that everyone felt when Covid first hit is the fear our members face every day. In March 2020, no-one had any protection from Covid and general panic set in. UKPIPS members have no (or very limited) ability to fight Covid, or any other infection, and often end up in hospital with serious primary or secondary infections.

Whilst the vaccination programme has offered most members of the public some hope of a normal life, we (despite taking up the three primary doses and the booster) still have limited or no protection against Covid. The same applies if we have been infected with Covid.

We are of course, very grateful to the NHS for the Covid treatments that became available just before Christmas, and for the prioritised PCR testing scheme introduced. However, children under twelve with immune deficiency have no approved treatments and yet are required to attend school normally.

We look to the time when IgRT contains sufficient 'donated' antibodies to give protection. Unfortunately, no-one can tell us when that will be or what that level is since it is likely to be different for each individual. This makes it impossible for us and our clinicians to make *informed* decisions about the level of risk we face undertaking the simplest of activities, particularly anything that involves mixing with other people. Many of our members have been shielding for the past two years and feel there is very little hope for the future without acknowledgement that something must be done to bolster our protections.

I want to ask:

- What is the medium to longer-term plan for people with immune deficiency now that Plan B restrictions are removed?
- If, as reported in the press, Plan B restrictions could continue for people at higher risk of catching Covid, what is specifically being done to enable people with primary immune deficiency to "learn to live with Covid" and lead a normal life again? The removal of restrictions (and masks) only creates

more opportunity for infection, anxiety, and stress in those with immune deficiency. We are told that mask wearing is to protect others more than ourselves, so removing the advice to wear them means that others put us at significantly more risk than previously.

- When will children get access to Covid treatments and what is the process to achieve this?
- When will prophylactic monoclonal antibody products be available for those with immune deficiency and what is the process to achieve this?
- When will our IgRT products have a protective level of anti-Covid antibodies in them?
- When will each person with immune deficiency be offered a routine antibody test to ascertain their level of vulnerability? At present this is often only done if you are enrolled on a research project.
- When will comparative data be available on the efficacy of the new Covid treatments across this cohort?
- Will lateral flow products remain available to us on prescription or through managed access when free access is stopped? As we are advised to test regularly, to ensure we get Covid medication within the treatment window, this seems essential. Testing is also vital for our carers, relatives and social contacts and we would like reassurance that free access will continue for these people also.
- What is being done to support the mental health of people with immune deficiency who continue to be marginalised?

Many of this patient cohort feel very let down throughout this crisis. As things get 'back to normal', it is not clear how members of the UKPIPS community can return to the 'normality' anticipated by the rest of the population, without more information on the antibody levels in our products, access to prophylactic treatments, and knowledge of what our individual risks are and how we can reduce these? I am not referring here to any of the existing control measures, as we are all well practised in using them, from long before Covid. Our immunology teams are doing their best to support us but (aside from post-infection treatments) currently have very little to offer and so we look to the DHSC for guidance.

Yours sincerely,

Sue Dimmock

On behalf of members of UKPIPS

***UK Primary Immune-deficiency Patient Support***

**W:** [www.ukpips.org.uk](http://www.ukpips.org.uk)

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cc: Margaret Fuller and Lynda Rhodes, Trustees,

UKPIPS Medical Advisors, UKPIPS

**Sent:** Monday, 14 February 2022, 16:48:54 GMT

**Subject:** FW: The significant impact of removing Plan B restrictions on people with immune deficiency and the potential impact of removing self-isolation

Dear Sajid Javid and Ms Nadine Dorries,

I attach below, an email sent to Sajid Javid on 29th January 2022 on behalf of members of UKPIPS (UK Primary Immune-deficiency Patients Support). As I have had no confirmation of receipt, nor a holding response to this email, I am resending just in case it has been missed? I am also now copying in Ms Nadine Dorries, my own MP.

The questions raised below have become even more urgent for a response, as the suggestion that the isolation period for those with Covid could potentially be scrapped is incomprehensible for most of our members. As I explained below, most of our members will have mounted no (or a very limited) response to the vaccine and so remain 'at risk' with every contact they make. These people shielded throughout the pandemic and many continue to shield now. Two months ago, they remained at significant risk of Covid complications and were asked to return a priority PCR if they were showing any symptoms of Covid, to receive urgent treatment.

Children at school, adults in the workplace, and anyone trying to live a 'normal' life, will be put at significantly greater risk should this proposal go ahead without further protections for this community. Members feel that they have been "neglected" and "thrown on the rubbish pile", to quote from some of the comments we have received recently.

All the previous points in my last letter still stand but I now add to the list of questions:

- What is the government actively doing to enable people with immune-deficiency to enjoy the same freedoms as everyone else?

Yours sincerely,

Sue Dimmock

On behalf of members of UKPIPS