

JANUARY NEWSLETTER



Dear PID UK member,

Welcome to our first newsletter of 2021. I think we are all agreed that it has been a gloomy start to the year but there is lots of hope that through the UK vaccination programme we will begin to feel an increased sense of security and movement towards a more normal way of life this year.

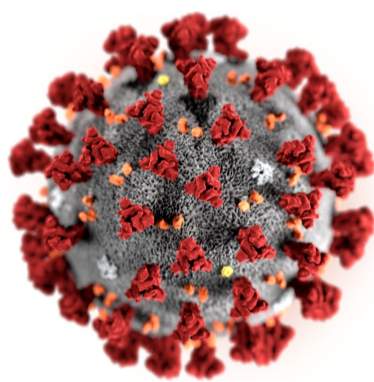
While the COVID-19 vaccination might provide a lower level of protection in people who are immunocompromised compared with the rest of the population, it is still very important that you take up the offer of the vaccination as it is safe and will offer a certain amount of protection against catching COVID-19. How much protection is given by the vaccines to people with primary and secondary immunodeficiency is the subject of the study we highlight below.

It is important that you receive two doses of the vaccine to maximise the protection that vaccination offers you and this is currently being assured with the Government's vaccination programme. The COVID-19 vaccine can protect you from getting seriously ill with COVID-19 although if your immune system isn't functioning optimally this protection will not be complete. As yet, there is currently no evidence that the vaccines can stop you passing on the virus to others even if you make a good immune response. This means that even after you or those around you have been vaccinated, it is very important that you still follow Government guidance, social distancing guidelines and continue to wash your hands regularly.

We hope that the articles in this newsletter help reassure you that your special circumstances and needs in this COVID pandemic are not being forgotten.

Take care and keep safe.

Study starts to look at COVID vaccine responses in patients affected by primary and secondary antibody deficiency.



The UK Primary Immunodeficiency Network (UK PIN) are about to launch a research study to explore how effective COVID vaccinations are for people affected by primary and secondary antibody deficiency (PAD and SAD, respectively). This is a vital piece of research with the COVID vaccination programme now being rolled out nationally as it is not known, at present, what level of protection patients with antibody deficiency will develop after immunisation through antibody or T-cell responses.

The work will be funded by UK Research and Innovation (UKRI) and the aim is to involve over 1000 adults with PAD/SAD over the next six months by recruitment of patients through the collaboration of as many immunology centres as possible.

The research will also help to address some fundamental questions about how COVID is affecting the antibody deficiency community. These include finding out how common asymptomatic and symptomatic COVID infection occurs in this patient group, how often and for how long the virus persists and if COVID infection results in protective antibody or T-cell responses.



Professor Alex Richter (*pictured left*) of the University of Birmingham and Professor Siobhan Burns (*pictured right*) of University College London are co leading this project on behalf of UK PIN. Professor Richter says, 'We are delighted to launch this important project with the help of UKRI funding. It builds on our research indicating that people with antibody deficiency may be at an increased risk of severe COVID-19 infection. At present we don't know if this risk is due to the underlying immunodeficiency or due to other health complications associated with immunodeficiency. The project will help address lots of important questions that will help inform how we care and manage patients in the context of their risk to COVID.'

So how can patients take part? Professor Richter says 'We are seeking to recruit patients with PAD and SAD who have had COVID or who are eligible for COVID vaccination. The study will involve a questionnaire, diary, COVID swabs and blood tests'.

Professor Richter encourages patients to register their interest with their local immunologists and let their team know if they have had or are to be offered the vaccine. Individuals should not delay the vaccine if they are offered it.

Susan, Director of PID UK, says 'We are so pleased that this study is going ahead. Knowledge is power against this devastating virus and we need to learn so much more about COVID's impact on the PAD and SAD communities and how beneficial vaccination is for this patient group. We encourage all patients to ask their immunology teams if they are eligible to take part in this study'.

Danny's story - the COVID pandemic and having the COVID vaccine



"My name is Danny Boxer and I have CVID. I am a hospital doctor, and this influenced my journey. I had had a few chest infections as a teenager/young man and was comprehensively investigated by a chest physician who made the diagnosis in about 1987, in my early 30s.

Immunodeficiencies were not widely recognised then and I was initially looked after at The Royal Brompton (a chest hospital) who started me on replacement therapy a few years later. It was only later that I came under specialist Immunology care.

During the pandemic, I am fortunate to have the companionship of a wonderful wife. We are empty nesters so are fortunate in having adequate space and a garden. The biggest hardship has been being isolated from our family, we have 5 grandchildren, 2 of whom were born during lockdown. Not being able to properly interact with them as well as our elderly parents has been horrible.

I work as a Consultant Radiologist. Due to shielding I have not been able to work on site but during the summer I received suitable IT such that I can now work from home – but greatly miss interactions with patients and colleagues. I have noticed that my general health has been better than usual, shielding does have some advantages.

As a doctor I have been following the progress of the vaccine internationally. I had my vaccine in the first week in January, through my hospital.

I was a bit nervous about going to a hospital. As it was the first day of vaccination for the site, I was queuing longer than I would have liked to be around other healthcare workers, but it was ok in the end. I believe the extremely vulnerable are now being fast tracked through the site.

The vaccination itself was fine, just like flu. I had painful arm starting at night for 24 hrs which got better with paracetamol.

Since the vaccine, life has been OK. I have been working, getting some exercise. Missing family and friends, I'm not a great fan of Zoom socials! I am really disappointed that my wife has not been offered the vaccine and I do feel our "bubbles" should be a priority.

If someone is waiting for the vaccine, follow the advice and don't be too proud to ask for help. Take your vitamin D and get obsessive about hand washing!

Thank you so much for sharing your experience and the picture of your gorgeous grand-children Danny!

What's getting you through lockdown?

We are working with a group of students are helping us to put together some tips and advice for ways to get through lockdown. We would really appreciate your input. What has been getting you through lockdown? Yoga, crafting, your pet? Please email emma.bracegirdle@geneticdisordersuk.org with your ideas.

COVID update

UCLH doses first patient in the world in COVID-19 antibody trial



As you may remember we mentioned AstraZeneca's antibody treatment AZD7442 in November's newsletter (see [PID UK- COVID-19 research update: 'Monoclonal Antibody Therapy for Covid-19'](#)). This long-acting antibody combination treatment acts to neutralise the COVID virus and University College London Hospitals (UCLH) is carrying out two trials called STROMCHASER and PROVENT, to explore the effectiveness of the treatment against preventing and fighting COVID-19 infection.

What is important for the immune deficiency community is the start of the PROVENT arm ([PROVENT Study | COVID-19 Clinical Research Study Information \(c19proventstudy.com\)](#)) of the trial which is looking at use of AZD7442 in people who may not respond to vaccination or are at increased risk of COVID-19 infection due to factors such as age and existing conditions. The treatment offers what is known as 'passive immunity' with the antibody treatment being injected directly into the body to give protection, unlike vaccines which 'train' the immune system itself to produce antibodies.

Researchers will assess whether the treatment reduces the risk of developing Covid-19 and/or reduces the severity of infection compared to placebo. Read more at [UCLH doses first patient in the world in Covid-19 antibody trial | UCLH Biomedical Research Centre \(nih.ac.uk\)](#).

A large-scale trial of nebulised interferon beta has started. Early findings suggested the treatment may reduce the chance of a COVID-19 patient in hospital developing severe disease - such as requiring ventilation - by almost 80%. <https://www.bbc.com/news/health-55639096>

Two drugs called tocilizumab and sarilumab prove effective in reducing death rate from COVID. The drugs are anti-inflammatory and can cut deaths by a quarter in patients who are sickest with COVID. As well as saving more lives, the treatments speed up patients' recovery and reduce the length of time that critically-ill patients need to spend in intensive care by about a week.

Dr Matthew Buckland, Chair of our Medical Panel says, 'In general PID patients are likely to benefit from this therapy, but those already on immunosuppressive treatments or biological therapies would need liaison with their immunology unit to determine if this was the correct choice for them.'

<https://www.bbc.com/news/health-55574662>



A third COVID vaccine has been approved. The Moderna vaccine, made by the US company Moderna, is a messenger RNA vaccine like the Pfizer one, which is already being offered on the NHS.

The UK has ordered an extra 10 million doses of this vaccine, but supplies are not expected to arrive until spring. It requires temperatures of around -20C for shipping - similar to that of a normal freezer. <https://www.bbc.com/news/health-55586410>

Public Health England (PHE) study shows that past COVID-19 infection provides some immunity but people may still carry and transmit virus. Between 18 June and 24 November, scientists detected 44 potential reinfections (2 'probable' and 42 'possible' reinfections) out of 6,614 participants who had tested positive for antibodies. This represents an 83% rate of protection from reinfection. The protection against reinfection lasts for about 5 months. BUT early evidence from the next stage of the study suggests that some of these individuals carry high levels of virus and could continue to transmit the virus to others. It is therefore crucial that everyone continues to follow the rules and stays at home, even if they have previously had COVID-19, to prevent spreading the virus to others.

[Past COVID-19 infection provides some immunity but people may still carry and transmit virus - GOV.UK \(www.gov.uk\)](#)

COVID: 'Convalescent plasma no benefit to hospital patients'. Trials show that this potential treatment for COVID using blood plasma does not reduce deaths among hospital patients.

[Covid: 'Convalescent plasma no benefit to hospital patients' - BBC News](#)



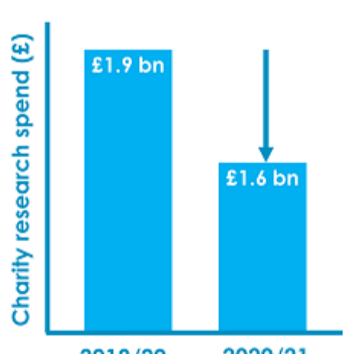
Dr Matthew Buckland sets these disappointing results in context. He says, 'This study has shown that in an unselected cohort of patients with COVID-19 that plasma does not affect outcome. That is not a surprise to those of us following the care of patients during the pandemic. In patients with normal immunity there has been limited benefit from the anti-viral Remdesivir unless given very early in infection. The findings to date have suggested that for most patients the over stimulation of the immune system after infection is more of a problem than the control of the virus, which is why plasma was unlikely to have a benefit in people with healthy immune systems, but it does explain why Dexamethasone, the steroid, has shown such a big benefit.

The position is clearly different for the immune compromised, which is why the trial of the antibody cocktail (see the article above) to prevent COVID has been set up and there may also be some benefit from convalescent plasma use still in PID and SID patients who get COVID.'

#ResearchAtRisk

COVID-19 has put charity-funded #ResearchAtRisk. We need your help calling on the Prime Minister to help protect it.

Our friends at AMRC have created a brilliant platform to help. Anyone wanting to write to the Prime Minister will just have to click on a link, fill in your email address and send a ready-drafted email today. <https://supportmedicalresearch.e-activist.com/page/73363/action/1>



Due to COVID-19 charities expect to **cut £310 million from their research funding** over the next year



This will lead to the **loss of a generation of researchers** and **set back life-saving progress decades**



You can help by emailing the Prime Minister to ask him to provide financial support. Visit <https://bit.ly/2JMUq57>

FAQ's

Q. When will there be COVID-19 neutralising antibodies in our immunoglobulin (IG) therapy to give immunodeficiency patients some protection against COVID?

A. The time from plasma donation to the final 'on the shelf' product is six to nine months so it is likely that we will start to see rising COVID antibody levels present in donated plasma this year. PID UK has been informed by immunoglobulin providers that in the first 3 quarters of 2020, infection rates in the general population were too low to lead to noteworthy anti-COVID-19 antibody levels and as vaccination will only become available to larger parts of population in first half-year of 2021 it is likely to expect to see rising levels within the second half of 2021. The immunoglobulin suppliers have told PID UK that they are continuously monitoring their IG products for COVID-19 neutralising antibodies and some companies will be publishing the results soon. PID UK will keep you updated.



Q. I have an immune deficiency and plan to have children in the future and wondered if the COVID vaccine trials have looked to see if it would affect fertility?

A. There have been no trials in pregnancy or breastfeeding and there is no fertility data. Please see the links for more information.

<https://www.gov.uk/government/publications/covid-19-vaccination-women-of-childbearing-age-currently-pregnant-planning-a-pregnancy-or-breastfeeding/covid-19-vaccination-a-guide-for-women-of-childbearing-age-pregnant-planning-a-pregnancy-or-breastfeeding>
<https://www.rcog.org.uk/en/news/updated-advice-on-covid-19-vaccination-in-pregnancy-and-women-who-are-breastfeeding/>

Q. Which of the COVID vaccines is best for people with PID?

A. Both the Pfizer/BioNTech and Oxford-AstraZeneca coronavirus vaccine in clinical trials, have been found to be safe and offer good protection. However, we do not yet know how effective these vaccines might be for people with primary immunodeficiency. Please see read our statement above on vaccines for people affected by PID and news of a research project that will help understand what protection is given.

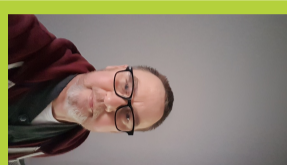
Q. Do I have a choice about what COVID vaccine I'll receive?

A. The vaccine you will be offered will be dependent largely on the supplies available from the manufacturers and the logistics of the roll out of the COVID vaccine programme. Please do have a look at our FAQs on the topic of vaccinations at [PID UK - COVID-19 vaccines and PID](#).

World PI Week

World PI Week is taking place on 22-29 April. This is a global movement to raise awareness of PID.

Our friends at Interel Group are putting together a campaign video and they are looking for people affected by PID to share their story. All you need to do is answer some questions and record them on your phone or laptop. If you are interested in being part of this important campaign, please email emma.bracegirdle@geneticdisordersuk.org



Simon's Story

"My advice for anyone starting their journey would be to ask questions and become knowledgeable about your condition. The more you know about it, the better you will understand your journey."

Simon has XLA(X-linked agammaglobulinemia). You can read his story from diagnosis, to treatment and his experience of having a lung transplant [here](#).

Please don't hesitate to get in touch with us at hello@piduk.org if you think we can help in any way.

**Best wishes,
Susan and Emma**

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