

## MARCH NEWSLETTER



Dear PID UK member,

Welcome to our last newsletter under the banner of Primary Immunodeficiency UK (PID UK). As many of you are now aware PID UK is separating from Genetic Disorders UK (GD UK), its parent charity, on the 1st April and setting up as a independent charity called Immunodeficiency UK.

Thank you for kind messages of congratulations and support for this exciting step forward.

You may have questions about the new organisation Immunodeficiency UK and how it will differ from PID UK. We hope the following questions and answers will help.

### Frequently asked questions



#### Q. Why has PID UK become a new charity?

A. GDUK created PID UK in 2013 with money raised from Jeans for Genes Day to provide support to the primary immunodeficiency community. PID UK has grown to be the leading patient organisation for individuals and families in the UK affected by immunodeficiency conditions. When GDUK was reviewing its future, it was felt this was a good time for PID UK to move forward as an independent charity with its own board of trustees.

#### Q. Why has PID UK changed its name?

A. PID UK stands for Primary Immunodeficiency and the charity recognised a need to also support people with secondary immunodeficiency conditions. After some thought, it was decided that simply Immunodeficiency UK was the more appropriate name. Our Charity Number is 1193166.

#### Q. What is the difference between PID UK and Immunodeficiency UK?

A. Everything that PID UK did before it will continue to do, but for both primary and secondary immunodeficiency patients.

#### Q. Will I notice any difference to the services I receive?

A. No.

#### Q. Has the team changed?

A. Dr Susan Walsh who ran PID UK will be the Chief Executive of Immunodeficiency UK. She is assisted by three trustees – Dr Matthew Buckland (Chair of Trustees and Medical Advisory Panel) and Hannah Bruce (Patient Advisory Panel) and Lisa Gagliani, the former interim CEO of GD UK. Susan will also be supported by Jen Rush who joins part time (10 hours/week) to run marketing, fundraising and provide administrative support.

#### Q. I was a member of PID UK. Am I already a member of Immunodeficiency UK?

A. This cannot happen automatically. In compliance with GDPR we need to ask permission of existing members of PID UK to transfer over the data we hold so they can become a member of Immunodeficiency UK. To give consent for your data to be transferred please email [hello@piduk.org](mailto:hello@piduk.org) by 31 March 2021. If you want to re-join as a member after that date, please email [hello@immunodeficiencyuk.org](mailto:hello@immunodeficiencyuk.org). This will mean that you will be kept informed about our work with regular updates.

#### Q. How do I become a member of Immunodeficiency UK?

A. If you give your permission for the transfer of data, as above, then you will automatically become a member of Immunodeficiency UK. For those wanting to join after the 1st April a new membership registration system will be available from the 1st April.

#### Q. Is the PID UK helpline still running? How do I access it?

A. Yes. Our phone helpline service can be accessed at 0800 987 8986. Email enquiries until the 31st March should be sent to [hello@piduk.org](mailto:hello@piduk.org). From the 1st April please use [hello@immunodeficiencyuk.org](mailto:hello@immunodeficiencyuk.org)

#### Q. Is GDUK still involved in Immunodeficiency UK?

A. No, the trustees of GDUK have handed over Immunodeficiency UK to the new board of trustees; effective 1st April 2021.

#### Q. I have a standing order/direct debit set up with PID UK. What will happen to that?

A. We hope that you will want to keep supporting the work of the new charity Immunodeficiency UK but, of course, you can choose to cancel your standing order/direct debit mandate at any time. The PID UK bank account into which your donation is currently made will remain open during a long transition period until a new Immunodeficiency UK bank account is fully operational and the funds of PID UK have been transferred over to Immunodeficiency UK. We have recently been advised that the process of setting up the new Immunodeficiency UK account will take up to 12 weeks and we will contact you as soon as we have the new bank account details so you can change your payment instructions. We truly value your regular giving as a means of supporting our work for the community.

#### Q. Will the contact details change?

A. You can call us on **0800 987 8986**.  
Email us: [hello@piduk.org](mailto:hello@piduk.org) until the 31st March or [hello@immunodeficiencyuk.org](mailto:hello@immunodeficiencyuk.org) after the 1st April.  
Write to us: PID UK, PO Box 12635, Colchester, CO7 5AN

#### Q. Will the website be different?

A. We are working on a brand-new website for Immunodeficiency UK but until then the existing PID UK website will be re-branded to reflect our new identity on the 1st April. Any PID UK website traffic will be directed to this website address [www.immunodeficiencyuk.org](http://www.immunodeficiencyuk.org) from the 1st April. Our aim is to ensure that all the resources we currently have available remain available to the community. Please bear with us whilst we work through the changes needed.

## World PI Week 2021



Celebrate World PI Week with us from April 22th to 28th.

[World PI Week](#) is a global campaign which aims to raise awareness and improve diagnosis and treatment of primary immunodeficiencies (PI).

Watch this space to find out how you can get involved!

## Government lifts the ban on the use of UK plasma

On the 25th February 2021 the Government issued a [press release](#) lifting the ban on the use of UK plasma for the manufacture of immunoglobulins (IG). PID UK was delighted to hear this news as this development will allow the UK to develop resilience against the worldwide pressures in plasma supply that have so adversely affected patients living with antibody deficiencies over the last few years. As soon as this plasma is fractionated there will be a direct benefit to patients in the security of IG supply.

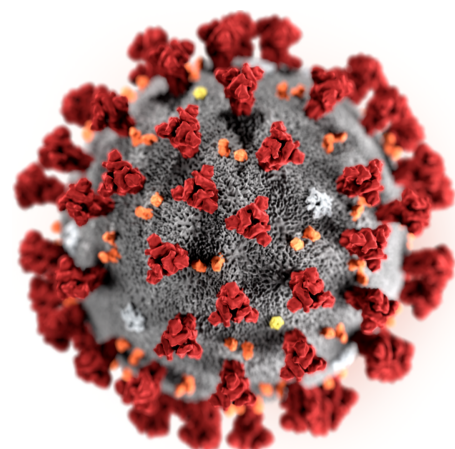
David McIntosh, Chair of the UK Plasma Action Alliance (UKPA), a consortium of stakeholders including PID UK, the professional bodies UK PIN, the Immunology and Allergy Nurses Group and the British Society for Immunology, has been lobbying for this change in Government policy over the last two years. 'The United Kingdom Plasma Action, campaign has been a most satisfying testimony to what can be achieved when like-minded people work selflessly towards a common goal' said David. It's been a privilege to be involved. I can think of no better cause than patient safety and well-being and I'm confident that the UK Government's new plasma policy will help to optimise both.'



## Good news as COVID-19 vaccination programme extended to households of adults with weak immune systems

People living in the same household as adults with weakened immune systems should be offered a Covid vaccine, says the JCVI committee. In the new guidance people with PID fall under the group multiple myeloma or genetic disorders affecting the immune system and people with secondary immunodeficiency under long term conditions leading to immune suppression.

<https://www.bbc.co.uk/news/health-56566892>



## Easing of COVID rules in the four home nations

England, Scotland, Northern Ireland and Wales are taking different routes out of the lockdown restrictions. For an overview of the key dates and rules in your country please take a look at this guide [UK lockdown roadmap dates: When England, Scotland, Wales and NI are easing Covid rules - timeline in full \(inews.co.uk\)](#).

## Key dates for end of shielding for the clinically extremely vulnerable (CEV) and vulnerable community

In England and Wales the shielding period will end on the 31st March.

In Wales guidance for vulnerable groups from the 1st April is available [here](#).

For England in line with the government's [COVID-19 Response - Spring 2021](#) roadmap published last month, those on the shielded patient list can begin to follow the national restrictions alongside the rest of the population, but are still advised to take extra precautions to keep themselves safe from COVID-19. Letters to patients with updated guidance will be sent out. These set out practical steps people can follow to reduce their risk of catching the virus, including continuing to maintain strict social distancing and to keep their overall social contacts at low levels, such as working from home where possible.

Northern Ireland a graduated easing of the advice for the CEV people is planned, to commence on 12 April 2021. See [Coronavirus \(COVID-19\): guidance for 'clinically extremely vulnerable' and 'vulnerable' people | nidirect](#)

In Scotland shielding is due to end on 26 April, when adults will be able to return to work and further education and children will be able to go back to school. See [Coronavirus - support if you've been shielding - mygov.scot](#)



## Update on the presence of SARS-CoV-2 (Covid-19) antibodies in immunoglobulin products

Many of you have been in touch regarding when there will be protection against Covid-19 in immunoglobulin (IG) products as this will give many people in the community some protection against the virus for those who are unable to benefit from the Covid-19 vaccination programme.

Here we update you on published papers concerning the presence of anti-COVID-19 in immunoglobulin products.

At first it was unclear whether circulating antibodies to other corona viruses in immunoglobulin (IG) products would be effective against Covid-19. This was an important consideration for people with immune deficiencies as their health depends on treatment with IG preparations that need to contain neutralising antibodies against pathogens in the environment.

A report in *The Journal of Infectious Diseases*, published in December 2020, states that initially 54 intravenous immunoglobulin (IVIg) preparations from plasma collected in Europe and the USA were tested and, although they contained antibodies to corona viruses, none were specific to the new SARS-CoV-2 (Covid-19) virus and cross-neutralisation did not occur. This meant they did not offer any protection against Covid-19.

This paper reported that a study is in progress to follow the development of SARS-CoV-2 antibodies in plasma donations and subsequently in immunoglobulin products. (There is a delay of several months between the collection of plasma and the release of immunoglobulin products.) The paper concluded that in the USA approximately 7.2 million people could have been infected with Covid-19, including 40% who were asymptomatic; that is, 2.2% of the population. 'Based on these facts, the detection of SARS-CoV-2 antibodies in IVIG [intravenous immunoglobulin] lots produced from US plasma, the major source for fractionation, is expected within the next few months.'

Scientists employed by Grifols, a manufacturer of IVIG and other plasma products, wrote to the medical journal [The Lancet](#) in February 2021 with even more promising information.

They stated that more than 1,000 donors contribute to a plasma pool. In May 2020, Grifols established a programme for continuous monitoring of the fractionation plasma pools collected in Spain, Germany, Czech Republic, Slovakia and the USA, to track the incorporation of anti-SARS-CoV-2 antibodies into these pools, and consequently into the resulting batches of IVIG.

The first pools testing positive for anti-SARS-CoV-2 antibodies collected in Spain and the USA were detected from July to early September 2020. From mid-September to November 2020 most pools in both countries were positive with increased titres. The first plasma pool to test positive in Central Europe was in mid-November 2020.

Specific anti-SARS-CoV-2 antibodies were first detected in IVIG products manufactured from plasma collected in the USA in September 2020, with increased titres observed in October 2020. Consequently, anti-SARS-CoV-2 antibodies are being increasingly integrated into therapeutic IVIG products and presumably into intramuscular and subcutaneous IG products. These products, as well as plasma pools, will continue to be monitored for the presence of anti-SARS-CoV-2 antibodies.

### Production of anti-SARS-CoV-2 hyperimmune globulin from convalescent plasma.

There has been some concern among people who rely on IG products that SARS-CoV-2 antibodies are being diverted from plasma pools into products to treat seriously ill Covid-19 patients, thus depleting the antibody levels in immunoglobulin products.

This does not seem to be the case.

[A paper](#) published on the server BioRxiv in November 2020 by Grifols scientists described the process of collecting and processing convalescent plasma to produce a highly purified immunoglobulin G product.<sup>3</sup> This was concentrated to produce a ten-fold increase in SARS-CoV-2 antibody levels from convalescent plasma to the final product and is intended to treat patients with active infections.

As the same company reported encouraging levels of SARS-CoV-2 in standard immunoglobulin products, there does not appear to be any conflict in the production of these differing products. The donated plasma was sourced from individuals who declared a previous Covid-19 infection rather than usual donors whose plasma was pooled in the normal way.

The use of convalescent plasma in the UK has now been discontinued as there was no observed benefit and more effective treatments, including recombinant antibody cocktails, are now available.

PID UK continues to press the IG suppliers for updates and when we have responses you will be the first to know.



## Saying goodbye to Emma

We are sad to announce that Emma Bracegirdle, our fundraising and marketing lead, is stepping down from her work with PID UK to pursue her own business initiative creating digital content for charities.

Susan, our Director says 'Emma stepped into the role when the COVID pandemic broke and hit the ground running in her work for PID UK. She has done an amazing job in helping PID UK support the community through the crisis. Emma gave PID UK a fresh look by her ability to develop engaging digital material for our social media pages, developing patient stories through film and increasing our income streams. I will miss her both as a valued colleague and as a friend. I cannot thank her enough for her work and wish her every success for the future'.

Happy Easter to you and your loved ones.

Susan and Emma

The PID UK Team

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