

## FEBRUARY NEWSLETTER



### Struggling to support your children through the pandemic?



To help a free on-line course is available from Public Health England to help parents and carers, teachers, health and social workers, charity and community volunteers better deal with the effect COVID has had on the mental wellbeing of children and young people. Those completing the training will be equipped to better identify children in distress and provide support to help them feel safe, connected and able to take steps to help themselves during the pandemic or other crisis situations. It takes about 3 hours to complete (split into 3 sessions that the learner can complete at their own pace). No previous qualifications are required. Check it out at [PHE launches new Psychological First Aid training - GOV.UK \(www.gov.uk\)](https://www.gov.uk/government/news/psychological-first-aid-training) and enrol on the course at [CYP Psychological First Aid online course - FutureLearn](https://www.futurelearn.com/courses/psychological-first-aid)

### Frequently asked questions



As the vaccination programme is rolled out here are some of the queries we have responded to in the last month. We hope our answers are helpful to the community.

#### Q. I have selective IgA deficiency (IgAD). Will the COVID vaccines work for me?

A. The currently available vaccines produce a protective IgG response against COVID19, so IgAD should not affect protection. As yet we do not know if vaccine induced IgA responses provide additional protection in COVID but we hope that data will follow from the COV-AD study (see 'Study starts to look at COVID vaccine responses in patients affected by primary and secondary antibody deficiency' [PID UK- COVID-19 research update](https://www.piduk.org/news/2021/01/20/covid-19-research-update)) which measures responses to IgG/A/M in patients with immune deficiency of all types receiving vaccination. We do know that males with the primary immunodeficiency XLA, who never make any IgA or IgM, and who are on lifelong IgG replacement only, are very well served by IgG protection only, suggesting that IgA is redundant in the immune system for most people.

#### Q. Can I do what I want after I have been vaccinated?

A. It is essential that everyone continues to stay at home whether they have had the vaccine or not. We do not know how much protection people with certain types of immunodeficiency will have so it is absolutely essential that you continue to follow any shielding guidance you have been given. [PID UK - Lockdown and shielding advice](https://www.piduk.org/news/2021/01/20/lockdown-and-shielding-advice). It's tough but really important. Continue to follow social distancing guidance; wear a face covering and remember hands, face, space and cut down on your interactions with other people.

#### Q. What do I need to bring with me to the vaccination centre?

A. If you are taking medication, please bring a list of these with you to the vaccination centre. Do not bring the medicines themselves. If you are taking a blood thinner called 'warfarin' you will also be going for regular blood tests to monitor the thickness of your blood using a test called INR. The INR test result is a number (for example 2.5). Please make sure you know your latest INR reading and when that was last checked. If you don't know this, you can get it from your GP surgery.

#### Q. I am on a weekly immunoglobulin and wondered if there is an optimum day to have the vaccine if that can be agreed with my GP.

A. Ideally, your infusion and vaccinated should be separated by 48 hours so that it is possible to distinguish between any side effects.

#### Q. Are there any side effects to having the COVID vaccination?

A. Like all medicines, vaccines can cause side effects. Most of these are mild and short-term, lasting no longer than a week, and not everyone gets them. These may include: a sore arm where the needle went in; feeling tired; a headache; feeling achy; feeling or being sick.

You can take painkillers, such as paracetamol, if you need to. If you have a high temperature you may have coronavirus or another infection. If your symptoms get worse or you are worried, call 111.

Read about the coronavirus vaccines at <https://www.nhs.uk/conditions/coronavirus-covid-19/coronavirus-vaccination/coronavirus-vaccine/>

You can report side effects at [Yellow Card Scheme - MHRA](https://www.mhra.gov.uk/yellow-card)

### Rare Disease Day 2021



Rare Disease Day is taking place on 28th February 2021. The day is aimed at raising awareness amongst the general public and decision-makers about rare diseases and their impact on patients' lives.

You can join the campaign this year by sharing materials on social media, telling your story about how you are affected by a rare disease or by making a donation (<http://www.piduk.org/donate>) to support the work of PID UK.

For more details about how you can get involved, please visit <https://www.rarediseaseday.org/>

### Omer's Story

"My advice to any other parents who have a child diagnosed with a PID is to ask as many questions as you can, no matter how silly they might seem. Be positive; live your life to the full as much as possible and keep well."

Read Omer's Story [here](#).



### How to work with your GP

Your GP is a vital part of your health care team and it is important to foster a good relationship with members of your GP practice. This [website article](#) offers advice about how to achieve and maintain this good relationship.

You can download a guide for GPs [here](#). It helps explain your condition to your GP and discusses the key aspects of care.



### Can you help?

As we are getting into 2021, PID UK are busy planning our activities and work for the year ahead. Our aim is always to help ensure that those affected by an immunodeficiency have the knowledge needed to manage their condition effectively. We work hard to ensure that your health needs are understood and addressed by those involved in policy and delivery of healthcare.

To be able to do this, we need your help. We rely on donations from our supporters made directly or through fundraising. If you can, please make a gift or fundraise for PID UK, so that we can still be there for the community.

You can donate via our website [here](#). If you would like to fundraise for us, download your supporter pack [here](#).

### Our newsletter survey results

*'I only became properly aware of PID UK in 2019 even though I was diagnosed 17 or more years ago. The newsletter has been really helpful, reassuring and informative particularly during COVID when GP's and Hospitals were trying to make sense of the GOV's rules etc and clear communication was not available.'*

Thank you so much to everyone who took part in giving feedback on our newsletter last year. We have now analysed the results and here are the main findings:

- 85% of respondents found the newsletter informative or extremely informative.
- 92% of respondents valued updates on the latest medical treatments and advances on PID.
- 64% of respondents valued the sharing of stories & experiences from those living with PID.
- 63% of respondents indicated the newsletter made them feel part of a community.

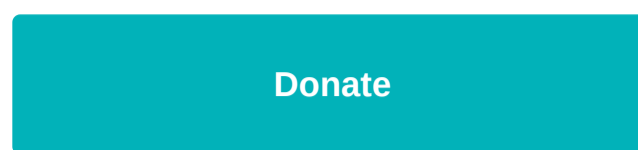
- 61% of respondents valued being informed about PID UK's activities and how PID UK raises awareness of PID.
- 91% of respondents were happy to receive newsletters by email.
- 75% of respondents preferred monthly rather than quarterly newsletters.

We are especially grateful for all your suggestions for newsletter content and we will be taking many of these ideas forward in 2021. You can find the full survey report at [PIDUK - PID UK newsletter survey 2020](#). THANK YOU!

A big thank you to Biotest who are generously offering sponsorship of our newsletter in 2021.

### Take care and best wishes

Susan and Emma  
The PID UK Team



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