

Primary Immunodeficiency UK update for August 2015

Dear PID UK Member,

Here's our latest bulletin covering PID related news.

Health

Don't forget about your flu jab

With the flu season on its way, having a flu jab is a good idea if you have a PID. Although it may not offer full protection it is a useful precaution against developing flu complications such as chest infections and may help shorten how long you are ill for.

If you live or care with someone who has a weakened immune system, then you are entitled to a FREE flu jab at your doctor's surgery. Or you can choose to pay for the vaccine at shops, including Boots and Sainsbury's.

Take a look at our frequently asked questions section on immunisation [here](#).

New on the PID UK website

You can now access and download all the resources we have for patients, carers and medical professionals on [this new webpage](#).

The resources include advice leaflets on going on holiday, insurance matters, employment rights, condition specific information booklets on CVID, XLA, Selective IgA deficiency, Hyper IgE syndromes, Wiskott Aldrich Syndrome and IgG subclass deficiencies and on the use of antibiotics in PID and immunoglobulin therapy. You can also access IPOPI booklets on a range of topics.

Look out for our new series of leaflets and booklets coming soon!

News about PID UK

PID UK welcomes Stacey Garrity as a new patient representative for the Manchester area. Stacey is mum to her son Zander who has X-linked Agammaglobulinemia (XLA). Read more about Stacey and why she wants to help PID UK [here](#).

Questions and answers

Here are some of the questions PID UK has received recently. Simply click on the links for the answers.

- [Can PID patients donate their organs?](#)
- I have just heard my 6-monthly check up appointment with my immunology team has been cancelled and I will have to wait another couple of months. I have some health concerns. [What should I do?](#)
- My daughter has a PID and is due to have the human papilloma virus (HPV) vaccine. [Is there any problem with her having this immunisation?](#)

PID news

[Driving drug discovery for PID](#)

The Jeffrey Modell Foundation (JMF) and Pfizer's Centers for Therapeutic Innovation (CTI) have announced a [collaborative agreement](#) to carry out research in the field of immunological diseases. CTI and JMF will identify and co-fund translational research projects with leading academic medical centers within the CTI network. The aim is to identify and validate a potential drug candidate for an immunological disease that can be moved into further clinical testing.

Patient involvement

Research respondents needed: A research company wants to interview any patients or unpaid carers of patients who live anywhere in the UK who have been on IV infusions for at least 12 months. They are offering £50 for a 30-minute telephone/webcam interview (the company will provide you with a webcam if required). Please contact Vicky Ogun at Vicky.Ogun@research-house.co.uk if you would like to part and don't forget to mention PID UK as we also get a small donation.

Improving clinical trial participants' experiences: this [survey](#) endorsed by the National Institute of Health Research, NHS Glasgow and Clyde and EUPATI-UK takes about 15 minutes to complete and responses are confidential. The questionnaire may be completed on a patient's behalf by a carer/representative.

National Services Scotland (NSS) wants the views of patients in Scotland on how to improve the accessibility of healthcare in Scotland. They are holding an event in Stirling on Friday, the 18th September. You can download the flyer [here](#).

Please help our sporty supporters reach their fundraising targets

Paul Ash has CVID and is running the Great North Run on Sunday the 13th September to raise money for PID UK. You can read why he's doing it [here](#) and make a donation at his JustGiving page <https://www.justgiving.com/Paul-Ash7>.

Ritchie Hunt King and friends known as the 'Team Titchfield' are cycling 50 miles around the very hilly Isle of Wight on the 20th September to raise money for us. You can help sponsor them at <https://www.justgiving.com/Ritchie-Hunt-king1>

Inspired to help?

Visit our [fundraising page](#) for less energetic ideas to help PID UK and [contact](#) Hannah for any help or advice you might need.

Donations

Thank you to everyone who has fundraised and made donations to PID UK recently. We were particularly delighted and very grateful for the generous donations we received to cover the cost of posting out our emergency cards.

And finally

Please don't forget to help spread the word about PID UK. Our next bulletin will be available in the first week of October.

With many thanks for your support.

Best wishes from,

The PID UK Team

Like us at: www.facebook.com/primaryimmuneuk

Follow us at: www.twitter.com/primaryimmuneuk

199A Victoria Street, London SW1E 5NE