

Primary Immunodeficiency UK Update for August 2016

Dear Member,

Welcome to our latest edition of our bulletin. We hope you enjoy reading it. If you missed our newsletter from July then you can download it [here](#).

News

New home for the prion infection surveillance project

The prion surveillance study began in July 2006 and was led by Dr Matthew Helbert, Consultant Immunologist, and Research Nurse Cathy Bangs, working with NHS Trusts throughout the UK in collaboration with the National CJD Research & Surveillance Unit (NCJDRSU) in Edinburgh, and under sponsorship of Central Manchester University Hospitals NHS Foundation Trust. The results to date have now been published in the journal *Vox Sanguinis*. Dr Helbert, lead author on the paper, comments: *'We found that surveillance of 75 immunodeficiency patients exposed to UK-sourced immunoglobulin, including batches derived from donors who went on to develop vCJD, has not detected any clinical cases of vCJD, or of asymptomatic infection in 15 patients who had available tissue samples of sufficient quality for testing. These results have been very reassuring but it is very important that we continue to monitor patients over the long term as we know that prion disease may take many decades to develop after exposure.'* This project is on-going and following the retirement of Dr Helbert in 2015, Dr Anna Molesworth at the National CJD Research & Surveillance Unit, in Edinburgh, will now oversee the recruitment and long-term follow-up of participants over the next several years. She says *'With renewed funding from the Department of Health Policy Research Programme we have been able to appoint a dedicated research nurse to help with outreach to the immunology centres. By working with immunology teams and patients throughout the UK, we hope to understand more about the causes of prion disease, particularly about the long-term risks that may be associated with past treatment with blood products in patients with primary immunodeficiencies.'*

Read more about this project, its results and what it means to patients [here](#).

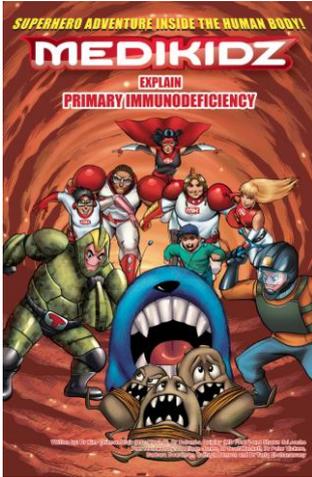
Resources available for members of PID UK



RADAR keys

RADAR keys and PID UK key rings are now available to members of PID UK. The RADAR key enables you to open over 9000 accessible toilets in the UK. If you would like one please email Hannah@piduk.org stating whether you would like one with a normal or a larger head for easy use.

Medikidz explain Primary Immunodeficiency



Thanks to a kind donation from BPL Ltd we now have a small stock of this booklet comic available.

The comic is aimed at 8 to 15 year-olds to help improve the understanding of PID. It uses superheroes to explain what a PID is and how it is treated. Medikidz, the medical education company, launched the book in the autumn of 2014.

If your child would benefit from this comic and you would like a copy please contact Hannah at Hannah@piduk.org.

PLEASE NOTE: We are happy to send out these materials to our members free of charge but would welcome donations to cover their cost, and postage and packaging.

Changed your address?

If you've moved house since registering as a member of PID UK email Hannah@piduk.org with your new address so we can stay up to date.

Questions and Answers

Here are some of the queries PID UK has received recently. Click on the links for the answers.

Q. I was wondering if PID patients in the U.K. get a vaccine for [pneumococcal pneumonia](#) offered by their GPs/specialists or if they have to ask for it?

Q. Why are my doctors' trialing taking me off my [immunoglobulin](#)?

Health news

New health research tool to tell good science from bad

A new online tool, [Understanding Health Research](#), has been developed which helps patients and the public better understand health research in context. The tool guides you through a series of questions to help you review health research that you have come across.

London Tube 'Please offer me a seat' badges for hidden disabilities

People with hidden health conditions are being offered "Please offer me a seat" badges in a bid to help their journey on London transport. Read more [here](#).

Opportunities to get your voice heard

Review of personal independence payments (PIP)

The Department of Work and Pensions (DWP) has put out a call for evidence for feedback on how PIP is working.

Having a rare disease such as a PID can put an extra hurdle in place for people trying to claim benefits such as PIP. If you have claimed PIP in the past, please tell the DWP about your experience [here](#).

Impact of rare disease survey

EURORDIS has launched a survey about the impact of rare disease on daily life. Specifically the survey looks at social care and coordination of care need. The survey takes 15 – 20 mins to complete. Find out more information [here](#).

PID UK out and about

This month, Susan, our Director, attended a NICE Public Health Advisory meeting on Antimicrobial Stewardship.

Donations



Thank you to everyone who made donations to PID UK in the last month.

Special thanks go to the friends of Kathryn Hennessey; Myrtle and Coleen Watterson and their aunt who collected change in a tin and made a donation of almost £150 to PID UK.

Fundraising

Good luck to all our runners!



Paul Ash (left) is once again taking part in the Great North Run (GNR) to raise money for PID UK. Paul has supported us for a couple of years and crossed the finish line of the GNR last year even in the incredible heat so fingers crossed it's cooler this year. You can sponsor Paul [here](#).

Mark Denovan is running in the Scottish Half Marathon in October. You can sponsor him [here](#).

The joint head shave and marathon

This September Sandeep is running the New Forest Marathon to raise money for PID UK and Drew, his best friend, and one of our patient representatives, has promised to shave his head if we can get Sandeep's fundraising total to £1000 (only £300 to go). We would love to see a bald Drew so please help sponsor Sandeep by going to his [Just Giving page](#).

Want to fundraise for PID UK?

Help us to do more to support the PID community by fundraising. We have lots of ideas on our [fundraising page](#). Email [Hannah](#) at PID UK who will support you with any activity you would like to do.

Or get social?

Have a look at the [PID UK Facebook page](#) and visit the [UK PID Patient group](#) for people with PID who are based in the UK and want to talk to and exchange messages with other UK patients.

With best wishes from,

The PID UK Team

