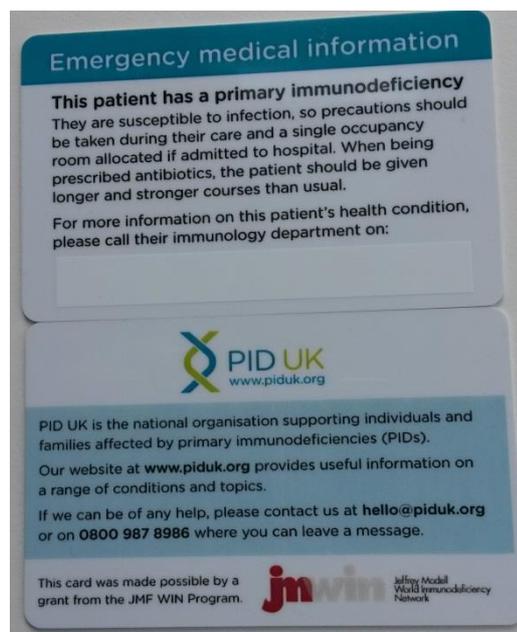


# Primary Immunodeficiency UK update for June 2015

Dear PID UK Member,

We hope the sun is shining where you are and that you are enjoying summer. Here's our latest bulletin covering our work and news about PID from June.

## Launch of new material



We are pleased to announce the launch of our brand new Emergency Card. This card fits into your wallet or purse so you can easily present it to any new medical staff you may see who are not familiar with a PID diagnosis.

The card has space for you to write your immunology clinics number on it for easy reference for both yourself and medical personnel.

## New on the PID UK website

We have updated our frequently asked question sections on [immunoglobulin therapy](#) and use of [antibiotics in the treatment of PIDs](#) to complement the launch of our new booklets on these topics.

## Healthcare advice

Please be careful when barbecuing as the number of cases of food poisoning rises with the appearance of summer. Remember to use different implements for placing food on the barbeque, turning the meat and removing it from the grill.

Take a look at our advice on food safety [here](#).

## Research news

### Potential risk gene for CVID identified

An international study involving major PID centres has identified a potential risk gene in CVID thought to represent a 'missing link' between immunodeficiency and autoimmunity in CVID. Read more about the study's significance [here](#).

## Real life stories

**Tommy** was diagnosed with a PID seven years ago after 54 years of trying to get to the causes of his ill health. His wish is to reduce diagnostic delay so that other people don't have to go through this long journey. Read more [here](#).

**Riley** is just 16 months old and was diagnosed with Hyper IgM Syndrome nine months ago when he became seriously ill whilst abroad. He is now thriving on immunoglobulin therapy. Read [his journey](#) to date as told by his mum Carrie.

If you would like to share your story with others please get in touch [with us](#).

## PID UK activities

**Rae McNairney**, one of our Scottish Patient Representatives, attended the a meeting of the Scottish Parliament's Cross party Group on Rare Diseases on the 10<sup>th</sup> June. You can read Rae's report [here](#).

**Susan Walsh**, Director of PID UK, took part in a NHS Scotland National Plasma Product Expert Advisory Group on the 16<sup>th</sup> June and attended an antimicrobial stewardship Public Health Advisory Committee meeting on the 18<sup>th</sup> June.

## Newsroom

The USA state of Virginia has added SCID to its newborn screening programme. Read more [here](#).

## Corporate sponsorship for PID UK

This month PID UK was delighted to receive a generous donation from the company CSL Behring to help us in our work.

**The Baxalta London (Staines, UK) To Paris Cycling Challenge.** PID UK is proud to be one of the four organisations chosen by Baxalta to receive a proportion of funds raised by their cycling challenge covering 240 miles in 3 days between London and Paris. We wish the team every success with their training for the event on the 30th July. If you would like to sponsor them or want to find out more visit

<http://www.sponsorme.co.uk/bax/bax-london-to-paris-cycling-challenge-july-30th-1st-august-2015.aspx>

## Healthcare news in the news

NHS England published its [response](#) to the recent consultation on principles for investing in specialised services, such as those for required for PID patients. This is in reaction to the 3-month consultation process held earlier this year and which PID UK took part in. The consensus across the 278 consultation responses highlighted the urgent need for improvements in the transparency, timeliness and capacity within NHS England's processes.

NHS England has also published [guidance](#) on how they will manage funding requests for designated specialised treatments that are considered by the referring clinician as potentially clinically critically urgent. This guidance is particularly important for treatments that do not fall currently under existing NHS England commissioning policies.

## Inspired to fundraise for PID UK?

There are so many ways you can help. Here are some ideas: hold a coffee morning; bakes cakes and sell them, have a raffle or car boot sale or hold a sponsored car-washing event. Or if you are sporty we have amazing running, cycling, triathlon and trekking challenges to take part in.

Visit our [fundraising page](#) for more ideas and [contact](#) Hannah with any queries you may have.

Also don't forget our good quality T-shirts and running vests, available via our [webshop](#) - a great way to raise awareness of PID and PID UK.

PID UK would like to give a big THANK YOU to the many fundraisers who have helped us

so far this year. Your support is greatly valued and appreciated.

### **Keeping it social**

Please visit (and don't forget to like) our [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.

### **And finally**

We hope you find our bulletin informative. Please do spread the word about PID UK and get others to support us by becoming a member.

Our next bulletin will be available in the first week of August.

With best wishes from,

**The PID UK Team**