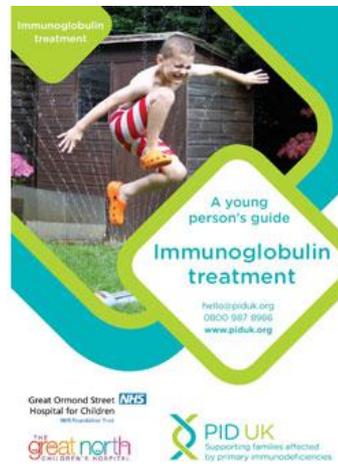
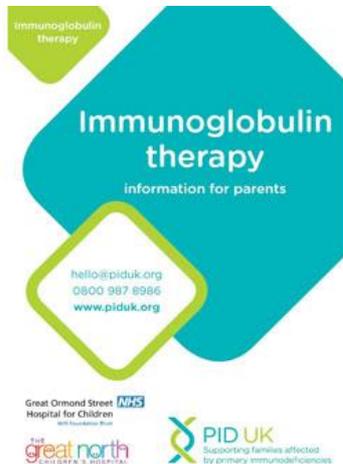


# Primary Immunodeficiency UK update for September and October 2016

Dear PID UK Member,

Welcome to our latest e-bulletin bringing you to date with all our news.

## New from PID UK



Working in collaboration with Great Ormond Street Children's Hospital and the Great North Children's Hospital in Newcastle PID UK has produced [a young person's guide to immunoglobulin treatment](#) and a [booklet for parents of affected children](#), with information on this important therapy. The guides are available on our website and printed copies will be available on request from immunology centres.

## Healthcare news

### Zika virus and immunoglobulin therapy

The European Medicines Agency (EMA) has issued a statement confirming that there is no increased risk of contamination with the Zika virus for patients who take plasma-derived medicines. Following this the International Patient Organisation for Primary Immunodeficiencies (IPOPI) released an updated position statement on this topic. Read more [here](#).

### Newborn screening for SCID

Catalonia has become the first Spanish region to introduce SCID newborn screening and from next year SCID screening will start in New Zealand.

## Research news

### Faulty RASGRP1 gene causes newly discovered human immunodeficiency

A multi-institutional, international team of scientists has discovered the genetic cause and biological mechanisms linked to a new human immunodeficiency. The study, which is published in Nature Immunology, also identifies a potential treatment. Read more [here](#).

## EURODIS survey on the impact of rare diseases on daily life

This survey wants to hear from you on how living with a rare disease has impacted your autonomy and daily life including work and school. It also wants to know more about the level of support you receive, how your care is organised and costs of your care. This project will support European countries in implementing necessary changes in social care systems. The survey takes about 20-25 minutes and can be accessed [here](#). Please help get the PID voice heard by taking part.

## FAQs



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

Q. Is there any contraindication to being on immunoglobulin therapy and having [immunisations](#) using killed vaccines?

Q. I have just started university and have a PID should I have the meningitis and septicaemia [vaccines](#)?

Q. I have a PID, should I be concerned about [mercury dental fillings](#)?

Q. Are [low platelet levels](#) with CVID a common complication? And do I need to do anything about it?

Q. I am giving the [flu jab](#) to a group of students and one of them has XLA, does he need to be segregated from the other students during playtime, lunch etc?

Q. I have a PID and my child has been offered the [nasal flu vaccine](#) at their school. If they have the live vaccine am I at risk?

Q. If I set up my infusion and then have to go out [can I leave my infusion](#) for a couple of hours?

## PID UK activities

It has been a super busy couple of months for PID UK. Susan, Director of PID UK, attended the IPOPI/ESID/INGID biennial conference presenting a poster on PID UK's patient experience survey and took part in the Rare Disease All Party Parliamentary Group meeting on [access to medicines](#) and the National Institute for Health Research event 'Think Research' Rare Diseases Patient Day.

PID UK staff and patient representatives were delighted to take part in four immunology patient events in October. These were held at John Radcliffe Hospital, Oxford; Royal Manchester Children's Hospital, Salford Royal Hospital and the Royal Hospital Belfast.



These provided wonderful opportunities to learn about the issues affecting patients and to share our resources directly with patients and talk about PID UK's work. Read our Michael Ingleston's (patient representative for Northern Ireland), write up of the Northern Ireland event [here](#).

Rae McNairney, a patient representatives for Scotland, attended a Scottish Policy Keynote Seminar on the future of the NHS in Scotland.

Susan, Director of PID UK, was selected as a Patient and Public Voice (PPV) member of NHS England's Immunology and Allergy Clinical Reference Group.

## Fundraising



Thank you to our sporty supporters Sandeep Longia, Paul Ash and Mark Denovan who took part in marathon events to raise money for PID UK.

A huge thank you to Mr Bradley, who took part in a 24 hour running event for PID UK, running an AMAZING 75 miles and raised £150.

Thank you also to Drew Tyne who raised money for us by shaving off his precious locks of hair.



Watch Drew's transformation [here](#).

Huge thanks too to Samantha and Robert Kemp, and customers at Samantha's shop who raised money for PID UK through the sale of books and the auction of a signed cycling shirt by Sir Chris Hoy.



Thank you also to Bill Ingleston who spoke to the ladies of South Antrim Trefoil Guild and passed on the donation he was given to PID UK.

## Social Media

Hannah, a key member of staff for PID UK and one of our patient representatives, has created a facebook group called 'UK PID Adolescent'. This group is for those PID patients aged between 13 and 25 to talk and support each other. You can find the group at <https://www.facebook.com/groups/ukpidadolescents/>



## Congratulations

Congratulations to Katy Mae who won her local communities Amazing Courage Award with over 1,000 votes. She has regular immunoglobulin treatment and been through several different operations so is very deserving in winning this award.

With best wishes from,  
**The PID UK Team**

