

Primary Immunodeficiency UK update for February 2016

Dear PID UK Member,

A warm welcome to our latest bulletin filled with news about our latest resources and activities.

Patient Experience Survey

This week, with support from the company CSL Behring, we have launched a patient experience survey to help us understand your experience of the care you receive. The aim is to help improve the quality of care for everyone living with PID in the UK.

The survey has questions relating to diagnosis, management, homecare treatment, long-term support and the financial implications of having a PID. It should take no more than 30 minutes to complete.

For each completed survey CSL Behring will make a donation of £20, at your choice, to either PID UK or your centre of care. Please do consider taking part. Your answers will be anonymous and treated in confidence. You can access the survey [here](#)

Health Matters



PID UK has just launched its latest booklet 'Looking after your lungs' giving useful advice on how to keep your lungs healthy.

Download the booklet from [our website](#) or get in [touch with us](#) to request a copy.

New on PID UK website

Patient stories

Jonathan, aged 35 years old, was diagnosed with CVID two years ago after a long history of ill health. He shares his story and experience of coping with immunoglobulin infusions on our website [here](#)

Genomics

Medical genomics research will play a crucial part in our understanding of PID. Find out what this research aims to do and how you could be involved by taking a look at this [frequently asked questions section](#), which has been kindly produced and shared with us by Dr Aarn Huissoon, Consultant Immunologist at Birmingham's Heartland's Hospital.

Read how genomics is already helping unravel the mechanisms leading to the development of disease and how this is leading to better-targeted treatment for some groups of patients on our website.

- [Contribution of genetics to the understanding of CVID](#)



PID UK welcomes the new Chair of the Patient Representative Panel (PRP)

We're delighted to announce that Andrew Thomas has been elected as Chair of PID UK's PRP. He will be the spokesperson for the PRP and work with our medical panel to ensure the patient voice is heard.

Quote from Andrew

You can read about Andrew [here](#).

PID UK activities

Highlighting PID on rare disease day

Members of our patient representative panel have been super busy this month representing PID UK at Rare Disease Day meetings and events. Carolyn Grundy, one of our patient representatives for Wales attended the Rare Disease Implementation Group meeting in Cardiff,

PID UK at Rare Disease Day events

Michael Ingleston, our PRP representative for Northern Ireland, had a stand for PID UK at the NIRDP International Rare Disease Day Reception at Stormont.

Fiona Watt and Rae McNairney, our Scottish representatives, were at the Scottish Parliament event and presented a poster on PID UK to Members of the Scottish Parliament

Susan, Director of PID UK, attended the Rare Disease Day event in the Senned National Assembly of Wales with Claire Dyer, PRP member from Wales and Carolyn Grundy, PRP member from Wales, took part in the Rare Disease Implementation Group meeting. Susan also attended the Rare Disease Day event at the House of Commons in London.

Rare Disease UK video

Drew Tyne, one of our PRP members, has CVID and was featured in a video produced by Rare Disease UK. 'Drew talks about having CVID'. You can watch his video [here](#).

Other PID UK activities

Rae McNairney attended the Genetic Alliance Scotland event 'National Conversations initiative – Healthier Scotland – What matters to you' event on the 8th February. [Read her write up here.](#)

PID UK responded to the following NHS England policy consultations: 'Use of Rituximab for cytopenia complicating primary immunodeficiency' and 'Plasma-derived C1-esterase inhibitor for prophylactic treatment of hereditary angioedema (HAE) types I and II'.

Fundraising for PID UK

In May Catherine Guy is running the London 10,000 to raise money for PIDUK. You can sponsor her

here <https://www.justgiving.com/fundraising/Catherine-Guy1>

In September Sandeep Longia is running the New Forest marathon for PID UK as one of his best friends is a patient representative for us. Show your support and sponsor him here https://www.justgiving.com/Sandeep-Longia?utm_source=Facebook

We have lots of fundraising ideas on our website for you to look at and will support you throughout your fundraising journey. To speak to us about fundraising email events@piduk.org.

Facebook and forums

Get the latest news on our activities and find patient support on these useful links. PID UK's [twitter](#) and [PID UK Facebook page](#) keep you up to date with health news and all our activities - please don't forget to like us.

UK PID Patient forum – The UK PID Patient Facebook forum is run by two patient representatives of PID UK and gives patients and carers a chance to vent, talk and support each other. With posts ranging from applying for PIP to infusing whilst not feeling great, this group allows other patients to offer support to those struggling. <https://www.facebook.com/groups/ukpidpatients/>

Wishing you all a lovely Easter Holiday.

With best wishes from,

The PID UK Team