

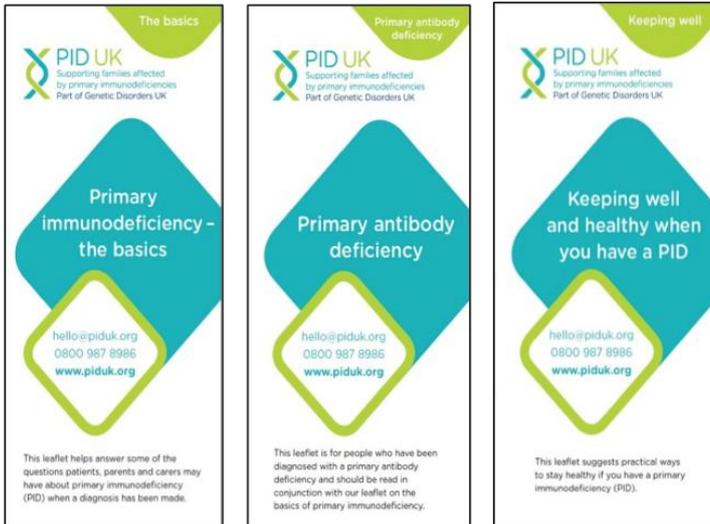
PID UK bulletin for April and May 2016

Dear member,

It has been a busy couple of months for PID UK! We hope you enjoy reading our latest update.

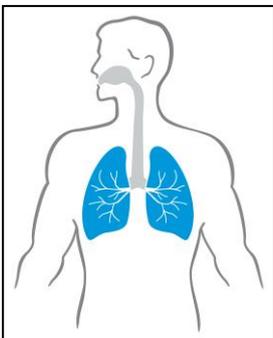
New resources from PID UK

To celebrate World PI Week, PID UK was proud to launch three new leaflets.



These leaflets will be especially useful if you have been diagnosed recently or have difficulty in explaining your condition to other people. They should be available in your clinic soon and can also be downloaded from our website [here](#).

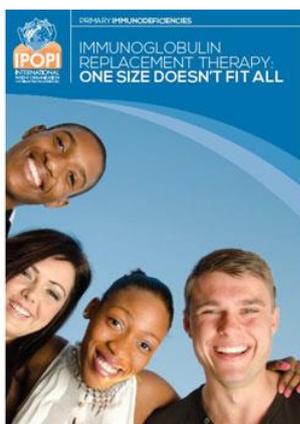
Bronchiectasis and PID



Bronchiectasis is a condition in which damage to the airways causes them to widen and become flabby and scarred. As a known health complication in PID take a look at our [recommended resources](#) on this topic.

Going on holiday?

There are many companies that will provide people with PID with travel insurance so our advice is to shop around. You can find an extensive list of companies [here](#).



Immunoglobulin therapy – one size doesn't fit all!

Take a look at this new IPOPI booklet. It underlines the key principle that immunoglobulin therapy should be chosen on an individual basis, according to a patient's needs and preferences. Available on our website [here](#).

PIDs in the news



Maryland became the 37th state in the USA to put in place a newborn screening programme for severe combined immune deficiency (SCID). Read more at <http://touch.baltimoresun.com/#section/-1/article/p2p-86821867/>

IPOPI launches Burden of Treatment Study with UK Kick-Off

PID UK, IPOPI's National Member Organisation in the UK, was the first to launch the questionnaire in World Primary Immunodeficiency Week. The study aims to quantify and measure the impact of the different immunoglobulin treatments adults take to manage their PID. If you would like to participate in the study contact us at hello@piduk.org. Find out more [here](#).



Health news

Renewed call to tackle antimicrobial resistance

A long-term solution to antibiotic resistance can only be achieved if we act now, an expert has said. The comment comes as NICE launches a new [quality standard](#) that aims to help healthcare professionals and organisations tackle the problem.

PID UK activities

[PID UK responded](#) to the NHS England Clinical Commissioning Policy public consultation on Haematopoietic Stem Cell Transplantation (HSCT): Teenage and young adults (TYA). In collaboration with the CGD Society, PID UK replied that this policy was discriminatory to people with PID aged 25 years and older for whom HSCT, also known as BMT, may be a clinically recommended option. We will keep you posted on developments over the next few months.

Margaret Bennett, our patient representative from Birmingham, attended Biotest Ltd's event to raise awareness of PID among GPs.

PID UK had a stand at the Immunology and Nurses Conference in Lincoln where our materials were in much demand. Susan, our Director, and Margaret attended representing PID UK.

Susan took part in a [World PI Week IPOPI policy event](#) at the European Parliament in Brussels joining members of the European Parliament Mr. Faria, Mr Zorrinho and Mr Piecha, patient representatives from 8 other countries, doctors, stakeholders and industry representatives to commemorate the importance of raising awareness on PID around the world.

In memoriam donations

We would like to give sincere thanks to:

David Moore, Irene, Phil, Yoko and Thomas who made a donation to PID UK in memory of Marie who sadly died last year, just one week before her 1st birthday.

Ken and Beth who made a donation in memory of their son Jonathan who died in 2009 having been diagnosed with Job syndrome.

We are truly humbled and touched that at a time when you were remembering someone dear to you, you also thought of others now living with PID. Thank you.

Fundraising



Thank you to all our donors and fundraisers. Your support means we are able to expand the range of information and help we can give to the PID community. Your contribution means such a lot.

Here's news from our sporty supporters:

Cheryl Gibbs ran the Milton Country Park 5k to raise money for PID UK as her son Lewis has XLA. Well-done Cheryl!

Many thanks to Lauren Daly took part in the Midlands Tough Mudder Event on the 22nd May. She completed this five-mile obstacle course challenge inspired by her sister who was diagnosed with a PID when she was 12 years old. You can add to her sponsorship [here](#).

Catherine Guy ran the Vitality London 10,000 on the 30th May as her boyfriend was diagnosed with CVID and values our website for getting advice. Catherine's friend Lucy also ran with her to show her support. You can help sponsor Catherine and Lucy [here](#) and [here](#). Thank you Catherine and Lucy!

We would like to give thanks to Paddy McMahon and his brother Kev for putting on their running shoes to do the Great Manchester Run on the 22nd May. They ran in memory of their uncle Chris, who was affected by an immune deficiency and who sadly passed away.



Thank you to Joan Hart who requested donations to PID UK instead of 80th birthday presents. Happy Birthday Joan, we are very grateful for your support.

With best wishes,

The PID UK team