

Primary Immunodeficiency UK update for September 2015

Dear PID UK Member,

We hope this finds you well and enjoying the amazing colours of autumn. Here's our update for September.

Tips for keeping well and avoiding infection

It's well known that people with PID can get more infections during autumn and winter so help protect yourself by following the advice below.

Hand washing

Good, regular hand washing can help reduce and protect you against the spread of diarrhoea and respiratory illness so check out the 'when and how' to wash your hands at <http://www.cdc.gov/handwashing/when-how-handwashing.html>

Don't forget you need to scrub your hands with soap for at least 20 seconds (that's the time to sing the Happy Birthday song twice through) to do a good job.

Avoid food poisoning

The BBC has produced this excellent resource covering safety aspects on cooking, storing and reheating food. Visit

<http://www.bbc.co.uk/guides/zq6c82p#ztfw2p3>

Also visit our webpage on [keeping well when you have a PID](#) webpage giving practical ways to stay healthy when you have a PID.

PID UK out and about

This month, Susan, our Director, attended a UK Genetic Testing Network Clinical and Scientific Advisory Group Meeting and the 2nd Biotest Immunology Forum 'Immunology from Research to Practice' and took part in a NHS Scotland National Plasma Products Advisory Panel meeting.

With Susan, Andrew and Stacey from [our patient representative panel](#) attended the Cambridge Patient Meeting at Addenbrookes Hospital, where PID UK had a stand displaying our patient resources.

Live in East Anglia?

We are looking to establish an East Anglia support group and are looking for volunteers to assist our current East Anglia patient representative, Andrew Thomas. If you are interested in helping, then get in touch with Andrew at easternpiduk@gmail.com.

Real life stories

Paul has shared [his story](#) about living life with CVID. If you would like to share your story with others please get in touch [with us](#).

Questions and answers

Here are some of the queries PID UK has been sent recently or been asked at patient events.

- How good is alcohol gel at killing microbes?
- I have a PID and have started having trouble with my bowels with pain and lots of watery diarrhoea for the last two weeks. I have no appetite; I'm losing weight and feel drained. What advice can you give?
- What blood tests are needed to establish if someone has an IgA deficiency?
- I have a PID and am travelling to India to the city of Mumbai. Do I need to take malaria tablets?
- We have a history of heart problems and PID in our family. I wondered if there was any link between heart problems and having a PID?

Click [here](#) for the answers.

Health and research news

Antibiotics

The National Institute for Health and Care Excellence (NICE) has published a [draft guideline to help change behaviour so as to reduce antimicrobial resistance](#). It includes steps to help make people aware of the importance of using antibiotics correctly and the dangers associated with their overuse and misuse. It also includes measures to prevent and control infection that can stop people needing antibiotics or spreading infection to others. The consultation is open until the 20th October.

Research study in the USA indicates very early onset inflammatory bowel disease (VEO-IBD) may be a form of primary immunodeficiency.

VEO-IBD, diagnosed under the age of five years old is often more severe than IBD that develops later in childhood and in adults and can be more difficult to treat. The study found rare and novel variants in genes that regulate B-cells and T-cells with important roles in PID. These findings, using genome-wide association studies, have great statistical power and can guide us in a given direction for the study of disease mechanisms, but require confirmation with functional studies to tell us how variants in those genes are causing disease. Read more about the research [here](#).

Fundraising update

A huge thank you to Ritchie Hunt King and Team Titchfield for cycling the fifty miles around the Isle of Wight. They have raised nearly £600! There's still time to donate to them at <https://www.justgiving.com/Ritchie-Hunt-king1>

A big thank you also to Paul Ash who ran the Great North Run raising over £100. You can still donate to him at <https://www.justgiving.com/Paul-Ash7>

Help us help people affected by PID

We have big ambitions to help the PID community but we need more funds. Fancy holding a coffee morning, a raffle, making cakes and selling them to raise money for PID UK then [contact](#) Hannah for any help you might need. Also take a look at our [fundraising page](#) for more ideas and read our [fundraisers' stories](#).

Donations and webshop

There are several ways you can make a donation to PID UK – online, by post, by text. Read more [here](#). Also consider buying one of [our T-shirts](#) too – a great

way to raise awareness of PID and support our fundraising.

Get social?

Our [PID UK facebook page](#) will keep you up to date with news about PID and healthcare. Also visit the [UK PID Patient](#) group to connect to other UK patients or their newly set up [UK PID Carers](#) group for parents, siblings, spouses and other carers of PID patients.

And finally

Please help spread the word about PID UK and let us know if there are any particular topics you would like us to report on or cover on our website.

Our next bulletin will be available in the first week of November. Keep well and take care.

With best wishes from,

The PID UK Team