

Primary Immunodeficiency UK update for January 2016

Dear PID UK Member,

Hopefully you and your local area have not been too affected by the impact of Storm Gertrude and Henry. The good news is that spring is nearly here.

Welcome to our latest bulletin. We hope you enjoy reading it and find it informative.

Health Matters

Zika virus

There has been a lot of press coverage regards Zika virus. Patients with immune deficiency are often concerned when a new infection is described. It is important to remember that this infection is transmitted by a mosquito bite (like malaria or yellow fever) and so patients in the UK would only need to think about this virus if [travelling to an affected area](#), when they should then heed the [Public Health England advice](#) for travellers, especially pregnant women.

PID UK will post information about any special risks of Zika to individuals with primary immunodeficiency as soon as we learn of it, although we have seen nothing so far to suggest any unusual dangers to anyone except to the developing baby.

Here are some more useful links:

<http://www.nhs.uk/news/2016/01January/Pages/Zika-virus-your-questions-answered.aspx>

<http://travelhealthpro.org.uk/zika-virus-update-and-advice-for-travellers-including-pregnant-women/>

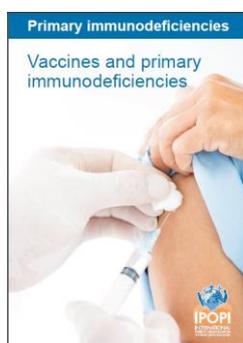
<http://www.fitfortravel.nhs.uk/home.aspx>

Sepsis

The tragic consequences of sepsis have also hit the headlines over the last week so we have posted useful information on what to look for and what to do if sepsis is suspected. Visit

<http://www.piduk.org/whatarepids/management/sepsis>

Now available on the PID UK website



[IPOPI booklet on Vaccines and PID](#)

Community news

XLA Art Exhibition in Edinburgh. Local artist Michael Wight, has XLA, and is show casing events that shaped his world of living with his condition in rich, striking, abstract art. His exhibition is taking place at [Edinburgh Palette Art Studio](#) and runs until the 7th February. Read more about his

work in the [Edinburgh Evening News](#).

Live in Northern Ireland?

We are looking for volunteers to assist our Northern Ireland patient representative, Michael Ingleston. If you are interested in helping please get in touch with Michael at piduk.nipatientrep@gmail.com

Rare Disease Day 2016

There's only 27 days to Rare Disease Day on the 29th February. This is a chance for people affected by PID to join forces and raise awareness amongst the general public and decision-makers about rare diseases and their impact on patients' lives. Find out how you get involved [here](#). Free tickets are still available for the Rare Disease events below. To register click on the links:

- [Welsh Assembly \(The Senedd\)](#) on Tuesday 23rd February between 6pm and 8pm.
- [Scottish Parliament](#) on Tuesday 1st March between 6pm and 8pm.
- [Stormont Parliament Buildings](#) on Monday 29th February from 5pm to 6.45pm.

Questions and Answers

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

Q. There have been cases of swine flu and bird flu reported in Scotland. [Please can you let me know if the annual flu vaccine covers these types of flu?](#)

Q. I've heard that vitamin D is important for the immune system. [Should I be taking vitamin D supplements?](#)

PID UK activities

Susan, Director of PID UK, attended meetings of the British Society for Immunology CIAS Executive Committee and Rare Disease UK Patient Empowerment Group and the Patient Advocates for Newborn Screening Conference.

Andrew Thomas, a member of our patient representative panel, gave an invited talk to staff at BPL Ltd on the 22nd January about his experiences of living with PID.

PID UK took part in a National Voices survey seeking views on how people can have a stronger voice in research and innovation in the Government's Accelerated Access Review process, which aims to speed up patient access to new drugs, devices and diagnostics.

Fundraising for PID UK

A huge thank you to Janine and Mike Williams who raised money as part of their 40th wedding anniversary celebrations resulting in a massive £470 pounds being raised in the process.

Take a look at [our webshop](#) for our T shirts and running vests – they are a great way to raise awareness of PID and raise funds for PID UK.

Get social

Our [twitter](#) and [PID UK Facebook page](#) will keep you up to date on a daily basis. Please don't forget to like us.

And finally

Our next e-bulletin covering news for February will be available the first week of March.

With best wishes from,

The PID UK Team