Primary Immunodeficiency UK update

Dear PID UK member,

Welcome to our first bumper newsletter of 2017! We hope you enjoy catching up on what we have been doing, and hearing about the latest research news and what our supporters are doing to help PID UK.

Report on PID patient experience of Primary Immunodeficiency Disorders services launched

PID UK is proud to announce the publication of a report of the findings from the patient's experience survey held during the spring of 2016. The survey results highlight the importance of early diagnosis and providing access to different treatment options and modes of administration to ensure individual patient needs are best met. The findings will be used to guide PID UK’s work to improve the quality of care for everyone living with PID.

The results have been shared with immunology doctors and nurses through three webinar sessions.

You can download the results of the survey and its recommendations in the executive report here.

Thank you to everyone who took part.

Looking ahead to Rare Disease Day on the 28th February

This year’s theme is research and provides a chance to tell researchers and clinicians how important research is to people and families affected by PID. So we’d love to hear from you with your messages on why research matters and what it means to you so we can share them with the research community. Please send them to hello@piduk.org.

It’s also an opportunity to recognise the crucial role that patients play in research, so please do get in touch to tell us your experience of being involved in any aspect of research.

PID UK activities

It was a busy time for PID UK in the lead up to 2017. Susan, our Director, and Rae McNairney, one of our patient representatives for Scotland, attended the NHS Scotland Immunoglobulin Database Adverse Events/Outcomes workshop on the 11th November. Rae also attended the Genetic Alliance UK briefing session on Rare Diseases in Scotland at the Scottish parliament on the 29th November.

Susan represented PID UK at the UK Primary Immunodeficiency Network (UK PIN) stakeholder meeting on the 16th November. UK PIN gave an update on the Quality in Primary Immunodeficiency Services scheme.
hosted by the Royal College of Physicians. Eleven immunology centres are currently accredited with a further 16 working towards accreditation and it is expected that these services will achieve the quality standard within two years of registering. Susan also attended the NHS England Immunology and Allergy Clinical Reference Group meeting on the 29th November.

Andrew Thomas, chair of PID UK’s patient representative panel, gave an invited talk to NHS commissioners, doctors, nurses and pharmacists at the National Immunoglobulin Database Meeting on the 9th December. In his extremely well received presentation ‘Immunoglobulin therapy – a World Health Organisation listed essential medicine for people with PID’ Andrew talked about his personal experience of living with his PID, how important immunoglobulin treatment is to him and PID patients and community concerns regarding the management of immunoglobulin products, including the need for an essential safety net of plurality of different suppliers and products. He also drew attention to the results from the PID UK patient experience survey relating to patient choice, delivery of immunoglobulin consumables, and the extra financial burden that having a PID can bring. You can access Andrew’s talk here.

PID news

Birmingham wins ESID 2020 bid

Many congratulations to Dr Aarn Huissoon and his team who submitted the winning bid to host the European Society for Immunodeficiencies (ESID) conference in 2020 in Birmingham. In spite of stiff competition from Brussels and Geneva, the UK bid won by a large margin. The Congress will take place at Birmingham’s International Congress Centre from the 14th to 17th October 2020 and will welcome over 2,500 delegates during the four days. The congress will integrate international immunology nursing and patient groups’ (INGID and IPOPI) meetings, making it a truly comprehensive and inclusive immunodeficiency event.

Dr. Aarn Huissoon, Consultant Immunologist based at Birmingham Heartlands Hospital, led the bid on behalf of the Local UK Organising Committee. He said: “The UK has a long history of immunology innovation and Birmingham has played a large part in this, so I am proud to bring ESID 2020 to our wonderful city.”

Immunology matters

Scientists discover trigger that changes whether CD4 immune cells 'help' or 'kill'. Helper T cells, also called CD4 T cells, play a crucial role in coordinating all the different cells in our complex immune systems. Their most well known task is helping B cells make the antibodies needed to protect us from infection. But occasionally they act as ‘killer’ cells, tracking down and killing B cells that are hiding a fugitive such as a virus. In this study researchers were able to show in mouse models that CD4 T cells became helper or killer depending on the type of virus they have to fight.

B cells use mechanical forces to pull antigens from other cell surfaces. Scientists have discovered that immune cells called B cells use mechanical forces to physically pull antigens such as viruses or toxins from the surfaces of other cells. The research might eventually lead us to the design and engineering of vaccines with physical properties tailored to help the production of desired antibodies.

You can access these research findings here.
Genomics and personalised medicine

Baffled by the science and what it means for patients? Then take a look at these excellent films produced by the NHS.

This animation explains how researchers go about identifying 'mistakes' in DNA to arrive at diagnoses for rare disease patients.

This short film gives an update on the 100,000 Genome project and how it will help patients.

And find out how doctors at the University Hospital Southampton NHS Foundation Trust have applied genetic technology to diagnose a rare immune deficiency in a ten-year-old boy, Mathew Knight, who has had infections all his life. Professor Saul Faust, Professor of Paediatric Immunology & Infectious Diseases at the University of Southampton, said: “Mathew’s case is incredible. To go from a sample to molecular genetic diagnosis in three weeks was sci-fi-like dreaming even just a year ago”.

FAQs

Here are some of the questions we have been asked over the last month. Click on the links to find our answers.

1. My young child has just been diagnosed with IgA deficiency. What resources can you offer?
2. I am flying abroad and want to know if I should put my immunoglobulin in the hold of the plane?
3. My son has lower than normal IgA and IgG levels. Should I supplement his diet with vitamins?
4. Can having CVID cause bladder problems?

Donations

A big thank you to all who have made donations to PID UK recently and those who nominated PID UK as their company’s charity. Your generosity is amazing!

Fundraising

Thank you to all our wonderful fundraisers.

Thomas Taylor celebrated his birthday in December by cutting off his much loved locks of hair and donating it to the Little Princess Trust so it could be used to make wigs for children affected by cancer, whilst raising nearly £850 for PID UK. THANK YOU Thomas for helping two great causes. You can still donate to Thomas’ page here.

Our 2017 fundraisers

Huge thanks to Mel who is staying sober until the end of March to raise money for PID UK as her step dad has CVID. She has raised an incredible £950 so far. You can sponsor Mel’s attempt to give up alcohol here.

John Scales is raising money for PID UK by running the Brighton Marathon in April as his wife has CVID. Please help him reach his fundraising total here. Thank you John! We wish you good luck with the training.
Leanne Preedy is fundraising for PID UK throughout 2017 and wants to show her daughter that she can conquer the world. Read their story and donate to Leanne’s fundraising here. Thank you so much Leanne for supporting PID UK.

Support the Four Non Blondes in their cycling challenge

Herbie and Lily Taylor are two truly inspiring children living life to the full with PID. In their honour friends and teachers are cycling from London to Amsterdam on the 12th May to raise awareness of PID and money for PID UK. Thank you 4 Non Blondes! Read more about Herbie’s and Lily’s story and how you can support the fundraising team here.

Get social
Hannah, one of our patient representatives, has created three facebook groups to help PID patients to come together and talk. These are

UK PID Patients for anyone affected by a PID themselves or for those who care for someone affected

UK PID Carers specifically for people who care for someone with a PID

UK PID Adolescents for people aged 13-25 to talk to their peers without parents being involved.

Please do take a look at these important sources of support for the PID community.

With best wishes from,

The PID UK Team