IMMUNO
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UK

April Newsletter

Welcome to the first Immunodeficiency UK newsletter!

PID UK became Immunodeficiency UK this month and we now officially support individuals and families affected by both primary and secondary immunodeficiencies in the UK. You may have questions about our new organisation Immunodeficiency UK and how it will differ from PID UK, so we have prepared a Q&A to help.

Click here to read Q & A

You should have also received our new privacy policy. Click here to view the policy.

Meet our team

Dr Susan Walsh has become CEO of Immunodeficiency UK, having led the development of PID UK since its inception in 2013 and now works full time for our new charity.

Jen Rush joined Immunodeficiency UK this month and will look after our fantastic supporters, raise funds for

our work, and manage the Immunodeficiency UK marketing.

Jen is looking forward to meeting our brilliant community of supporters, so please do get in touch at jen.rush@immunodeficiencyuk.org if you have a fundraising idea!

World PI Week

We've just come to the end of World PI Week and we've been taking part in the global campaign, which aims to raise awareness and improve diagnosis and treatment of primary immunodeficiencies. To mark the week, we shared a video featuring stories from individuals and families affected by PIDs.

Throughout the week we also published some of our patient stories and links to useful resources from World PI Week and IPOPI online.
Don't forget to follow us on Facebook, Twitter and Instagram and look out for the hashtag **#WorldPIWeek**.

Can you help support people like Jenna?

"Immunodeficiency UK, has helped me enormously. I came across their website when I was searching for information at the start of the pandemic. I was so excited when I saw that they had published

information about complement deficiency. Finally, I understand what complement deficiency is! Having this information has given me the confidence to ask my GP questions."

Read Jenna's story

With your support we can help even more people like Jenna get the help and information that they need. Please consider making a one-off or regular donation, which will help us to ensure that those affected have the knowledge needed to manage their condition effectively and to ensure that their health needs are understood and addressed by those involved in policy and delivery of healthcare.

Make a donation

Remote consultations - your patient perspective

Since the onset of the COVID-19 pandemic many consultations have moved from face to face to remote consultations by telephone, video link or on-line.

Immunodeficiency UK would like to gather information on the community's perspective of the use of remote consultation with your Immunology Team. The survey should take no more than 10-15 minutes to complete. The information gathered, using your anonymous feedback, will be used to compile a report which we will share with the immunodeficiency community and immunology service providers.

Take part in the survey

We would be so grateful if you take part as it is so important you have a say in how these services are delivered.

Shielding experience through art

On March 16th 2020, Michael, who has XLA, had to shield from the coronavirus pandemic that engulfed Scotland and the rest of the world. During this time, he was living alone, in a first floor flat with no garden space and had to leave his work during this time. Michael stayed inside entirely for 96 days and waited 118 days until he could hold a loved one.

‘19/3’ is the story of that time and the art displayed was created in and inspired by this period. This project deals with isolation, loneliness, paranoia, fear and his attempts and failure to find hope during this time.

See 19/3 the isolation project

Michael on his website says, *‘I think there’s a deep lack of understanding, in the grand scheme of things, on how horrible it is to be simply told; “do not go outside”. I spent days awake, not sleeping, sleeping too much, not eating, eating too much, extremely upset at my circumstances and also wondering if it would have been easier to just not stay inside. To go out and risk it, drive down and hug my mum. It haunted me to know people were having more normality while I stayed inside. To miss out on my work routine and life, all because of a condition I was born into. I didn’t choose for this life or the way the last year has unfolded for me, that is how it simply arrived at my door. It’s something that will stay with me, and I’m happy that rules and restrictions have been reassessed that I’ll never have to lock myself away from the outside like that again.’*

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