



UKPIPS Fact Sheet No. 021

Introducing UKPIPS

What is UKPIPS?

United Kingdom Primary Immune-deficiency Patient Support (**UKPIPS**) is a charitable organisation for people living with immune deficiency, their carers and families. We aim to ensure that anyone with a PID or PAD, their carers and family have somewhere to turn to for advice and support.

Who runs UKPIPS?

UKPIPS is run by a group of volunteers who are all affected by PAD or PID in some way. Either because they have a PAD or PID themselves, or their partner, spouse, parent, child or other family member has PAD or PID. It started in January 2012 because patients had no support group representation.

What do you mean by support?

We aim to support those in our community by enabling them to live their lives as fully as possible, despite having an immune deficiency.

We know that living with an immune deficiency affects every area of life, from education and employment, to personal relationships and finances. We aim to enable you to cope with these issues by providing Advice, Advocacy and Information. We represent people living with an immune deficiency to relevant statutory bodies and encourage them to recognise the unique needs of living with these conditions.

In this time of change within the NHS, we aim to support the specialist clinics who provide our care by presenting our needs for continued and appropriate funding at all levels of the NHS.

We aim to raise the profile of immune deficiency within the general UK population - and specifically within the NHS to lessen the time from the onset of disease until diagnosis and treatment.

We are aware that many with an immune deficiency face problems in schools, the workplace and even when admitted to hospital because people do not understand our needs. We plan to bring about change in these areas through education and publicity.

Is UKPIPS a registered charity?

Yes. We became a Company limited by Guarantee in May 2012 and a registered charity for England and Wales in September 2012. We also gained charitable status in Scotland in February 2014. We have three volunteer Trustees who have agreed to take responsibility under UK law for the running of **UKPIPS**.



How can I become a part of UKPIPS?

You can become a part of the **UKPIPS** community by contacting us via telephone, email, Facebook or Twitter, details are below.

Is there a fee to belong?

No. There's no charge to become part of the "**UKPIPS Community**". But we do depend on donations, so if you can help in this way it would be most welcome. Our website donation page can be found here: <https://ukpips.org.uk/donate/>

Can I become a UKPIPS volunteer?

Absolutely! We're hoping that people in our Community throughout the UK will want to become volunteers for us! Please check our website for volunteering opportunities, or email the office with any experience you have that would be of benefit to UKPIPS and especially its wider patient community. We'd be delighted to hear from you.

How can I contact you if I need help with a problem?

You can message us through our website www.ukpips.org.uk or email us at info@ukpips.org.uk or ring us on **07531 076409**.

There are also links on the website (<https://ukpips.org.uk/>) where you can sign up for **Facebook** and **Twitter**.

So remember, whether you're someone with an immune deficiency, a family member or a Carer, then **please** get in touch - because first and foremost, we're a **Patient Organisation** and we're here for **YOU!**

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For details of information sources, contact <https://ukpips.org.uk/contact-us/>

UK Primary Immune-deficiency Patient Support

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UKPIPS is a Company Limited by Guarantee Number **7957558**