

Introducing UKPIPS

United Kingdom Primary Immune-deficiency Patient Support (**UKPIPS**) is an organisation for people living with Primary Antibody Deficiency (PAD) and other Primary Immune Deficiencies (PID)

Is UKPIPS part of another organisation?

No. **UKPIPS** is a stand-alone organisation.

How did UKPIPS come about?

In January 2012, the former **PiA** (Primary Immunodeficiency Association) announced its closure. As Primary Antibody Deficiency is a condition that affects so many with a Primary Immune Deficiency, PAD patients had no support group representation and so **UKPIPS** was born.

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.

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 a PAD or PID. We know that living with a Primary Immune Deficiency affects every area of life, from education and employment, to personal relationships and finances. We aim to enable those in our focus to cope with these issues by providing Advice, Advocacy and Information. We represent their needs of living with a PAD or PID to relevant statutory bodies and encourage them to recognise the unique needs of those of us 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 their needs for continued and appropriate funding at all levels of the NHS.

We aim to raise the profile of PAD and PID 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 a PAD or PID face problems in schools, the workplace and even when admitted to hospital (other than by their own specialist clinics) 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 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 signing up to receive our newsletters. There's a link to the newsletter on the website and you can register there, or you can contact the UKPIPS office by email or phone - please see information below.

Is there a fee to belong?

No. There's no charge to become part of what we call the "**UKPIPS Community**" and all those in the Community are known by their names, rather than the generic term of 'member.' But we depend on donations to continue our work, so we are grateful for any financial help you can give.

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. As a very young organisation, we are formalising our structure to include volunteers who want to give of their time in our support. The best way forward is to look at your skills and think about how you might like apply them for **UKPIPS**. If you'd then tell us something about yourself and how you could use your experience for the benefit of **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 **01386 421228** or **07531 076 409**.

There are also links on the website where you can sign up for **FaceBook** and **Twitter**.

So remember, whether you're someone with PAD or PID, 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 info@ukpips.org.uk

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