

a little about yourself and how you would like to use your skills and your experience for the benefit of **UKPIPS** and its wider community.

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

You can message us on our website, or you can ring us on **07531 076 409**.

You can also contact us with your ideas and thoughts about **UKPIPS** - and remember, whether you're someone with PAD or PID, a concerned family member or a Carer, we'll always be pleased to hear from you.



UKPIPS
32 Avon Street
Evesham
Worcestershire
WR11 4LQ

UKPIPS is a Registered Charity in England & Wales, Number 1148789 - and a Company Limited by Guarantee, Number 07957558



UK
Primary Immune-deficiency
Patient Support

The
'NEW'
kid
on the
block!

UKPIPS is a Registered Charity in England & Wales, Number 1148789 - and a Company Limited by Guarantee, Number 07957558

What is UKPIPS?

It means 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 totally new stand-alone organisation.

How did UKPIPS come about?

In January 2012, the PiA announced its closure. A student at Nottingham Trent University, who is living with a PAD, immediately started an on-line forum for PAD's and PID's.

From this, a steering group started and within six weeks, had constituted itself into an organisation seeking to help and support all people in the UK who are affected by PAD or other PID.

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 because their partner, spouse, parent, child or other family member has PAD or PID.

What do you mean by support?

We aim to support our members 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 our members to cope with these issues by providing Advice, Information and Advocacy. We will represent the needs of our members to relevant statutory bodies and encourage them to recognise the unique needs of those of us living with a PAD or PID.

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, in order to lessen the time from onset of disease until diagnosis and treatment.

We are aware that many of our members 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. Our legal structure also allows us to apply for charitable status in Scotland. We have three Trustees who have agreed to take responsibility under UK law for the running of **UKPIPS**.

How can I become a member of UKPIPS?

You can become a member by signing up to receive our newsletters. If you have an internet connection, you'll find our website at www.ukpips.org.uk

You'll find a link to the newsletter and you can register there. If you can't use or don't like the internet, you can fill in and complete the application form that's part of this leaflet.

Is there a membership fee?

No. Membership of **UKPIPS** is free.

Can I become a UKPIPS volunteer?

We are hoping our members all over the UK will want to become volunteers for us!

As a very young organisation, we have no formal structure currently in place for working with volunteers but it has by no means been overlooked! The Trustees are working on this very issue and will let everyone know when we are able to invite you to work with us. In the meantime, please email or write to us, telling us