



UKPIPS Privacy Policy

This policy describes how and why UK Primary Immune-Deficiency Patient Support (UKPIPS) uses your personal information, how we protect your privacy when doing so, and your rights and choices regarding this information. We promise to respect any of your personal information which is under our control and to keep it safe. When we collect your information, we aim to be clear about what we will do with it.

Our use of personal information allows us to keep you informed about the charity and its work and to make better decisions to fulfil the charity's objects of supporting patients with a primary antibody deficiency or other primary immune deficiency, their partners, family and carers.

Who we are

In this Privacy Policy, "UKPIPS", "we" or "our" means:

UKPIPS, a charitable company limited by guarantee and is a registered charity number 1148789 in England and Wales and SCO44636 in Scotland.

How we collect information about you

We collect information in the following ways:

Information you provide to us directly

You may give us your information to sign up for one of our events, make a donation, register as a volunteer or medical advisor, join our patient network, use our information services or otherwise communicate with us.

When you use our website, we collect your personal information using "cookies" and other tracking methods. There are more details on the cookies and tracking methods we use in our Cookie Policy on the UKPIPS website - [cookies explained](#)

Information you provide to us indirectly

Your information may be shared with us by third parties, for example:

- Fundraising sites like Just Giving or Virgin Money Giving
- If you are a researcher and your information is shared with us by the principal investigator or institution
- From business or charitable partners and search/analytics providers on our website

Social Media

Depending on your settings or the privacy policies for social media and messaging services like Facebook, WhatsApp or Twitter, you might give us permission to access information from those services, for example when you publicly tag us in an event photo.

What personal information we collect

We collect, store and use the following kinds of personal information:

- Your name
- Your contact details (including postal address, telephone number, email address and/or social media identity)



- Your date of birth
- Your gender
- Your bank or credit card details where you provide these to make a payment
- If you volunteer for us or apply for a job with us, information necessary for us to process these applications and assess your suitability (which may include things like employment status, previous experience depending on the context)
- Information relating to your health (for example if you are taking part in or attending an event for health and safety purposes, as well as where you share your experiences of PAD and PID with us)
- Where you have left us a legacy, any information regarding next of kin with which you may have provided us to administer this
- Information as to whether you are a taxpayer to enable us to claim Gift Aid

Under the Data Protection laws, certain types of personal information are considered to be more sensitive. This includes information about health, race, religious beliefs, trade union membership, sex life or sexuality, or genetic/biometric information.

We only collect this type of information about our supporters where there is a clear reason for us to do so, for example health information where you have asked us to provide advocacy support.

Wherever we do this, we will make it clear why we are collecting this type of information and what it will be used for.

How we use your information

We will use your personal information to:

- Keep a record of your relationship with us
- Provide you with the information or services you asked for
- Respond to or fulfil any requests, complaints or queries you make to us
- Administer your donation or support your fundraising, including processing Gift Aid
- Manage our events
- Send you correspondence and communicate with you
- Further our charitable objectives
- Administer our website and display content to you in a way that is appropriate to the device you are using (for example if you are viewing content on a mobile device or computer)
- Safeguard our staff and volunteers
- Process your application for a job or volunteering opportunity
- Meet our legal obligations, for instance to perform contracts between you and us, or our obligations to regulators, government and/or law enforcement agencies

Advocacy and Other Information Services

You may provide information about your health when you speak, email or contact our staff and volunteers. They will use this information to answer your questions. Your questions will be recorded for the purposes of your enquiry and for evaluating the services we provide. They will be stored securely and only kept for the purpose for which they were provided. Information you provide will not be used for marketing purposes and will not be passed to anyone else without your express permission.



Social Media

You will be asked to provide your email address when you register on our Facebook page and we may contact you for administrative purposes and changes to our pages. With your consent, we may also use your email address to send you information about our work. We advise users to be careful not to post information which would allow other users to identify them, however some users may choose to do so.

Managing Your Contact Preferences

We would like you to tell us how you want us to communicate with you, in a way that suits you. Our forms have preference questions and we include information on how to opt out of communications from UKPIPS. If you don't want to hear from us, that's OK. You can change your preferences any time. Just let us know when you provide your data, or contact us on 07531 076409 or email admin@ukpips.org.uk, or through the "contact us" form on our website.

Legal basis for processing

Data Protection laws mean that each use we make of personal information must have a legal basis. UKPIPS has identified the following legal bases for processing your data;

- Consent – We ask you if we can use your information in a certain way, and you agree to this (for example to tell you about our work, or to send you our newsletters). Where we use your information for a purpose based on consent, you have the right to withdraw consent for any future use of your information for this purpose at any time.
- Performance of a contract – We have a basis to use your personal information where we are entering into a contract with you or performing our obligations under that contract. For example if you are applying to work or volunteer with us.
- Legitimate interests – We have a basis to use your personal information if it is reasonably necessary for us to do so and provided that what the information is used for is fair and does not unduly impact your rights.

This may include:

Use of personal information when we are monitoring use of our website or apps for technical reasons

Use of personal information to administer, review and keep an internal record of the people we work with, including supporters, volunteers and researchers

Where you have signed up with us on a charity place for a third party event, sharing personal information with the third party event organiser so they can administer the event

How we keep your information safe

We have in place technical controls to ensure that electronic information is as safe as possible, including encryption, firewall and passwords, and that our website is protected. We have organisational procedures that ensure that your information is only available to UKPIPS staff and volunteers who need to process that information and that it is held securely.

How long we keep your information for

We keep information for as long as we need for the purposes for which it was collected. Our processes control how long we keep your information, and these are determined by legal and operational considerations. For instance, we are required to keep some personal information for tax or health and safety purposes, and we keep a record of your requests for support whilst we



are working with you, or for keeping you informed of events, our activities, etc.

If you request that we stop sending you marketing or fundraising information, we will keep a record of your contact details and appropriate information to enable us to comply with your request not to be contacted by us.

Sharing your information with other organisations

We will never sell or rent your information to third parties for marketing purposes. However, we may be required to disclose your information to third parties in connection with other purposes set out in this policy. These third parties may include:

- Suppliers who print our newsletters and information leaflets, or who process donations
- Analytics and search engine providers
- IT service providers

Where we are under a legal or regulatory duty to do so, we may disclose your details to the police, regulatory bodies, and/or where we consider this necessary, to protect the rights, property or safety of UKPIPS, its staff, visitors, users or others.

We reserve the right to disclose your personal information to third parties if substantially our assets are acquired by a third party, personal information held by us may be one of the transferred assets. In that case we will inform you before it happens.

Keeping your information up to date

We do our best to keep our records up to date and will periodically contact you to ask for confirmation of that the personal information we hold is correct. We will update our records as and when you inform us of any change.

Your rights

Under UK law, you have rights over your personal information that we hold. You have the right to:

- request a copy of the information we hold about you and details of what we do with that information (known as a **subject access request**)
- update or amend the information we hold about you if it is wrong
- change your communication preferences at any time
- withdraw your consent to use of your personal information where we are relying on consent as the legal ground for processing it
- ask us to remove your personal information from our records
- ask us to restrict the processing of your personal information
- obtain a portable copy of certain personal information where this is processed automatically
- object to the processing of your information for marketing purposes
- raise a concern or complaint about the way in which your information is being used, and
- ask us to explain any automated processing we carry out and the impact of this on you



To make a request for your personal information held by UKPIPS, or to exercise any of these rights, please write an email to: Data Protection Champion, UKPIPS, email: info@ukpips.org.uk
You will need to describe the information that you wish to see.

If we are not sure who you are, we may ask for reasonable proof of your identity before providing you with information or carrying out any of the above actions.

Complaints

If you are unhappy with any aspect of how we are using your personal information, we'd like to hear about it. We appreciate the opportunity to learn and improve from your feedback. We also welcome information on what we do well. Please send your complaint to the Data Protection Champion, address below, who will acknowledge your complaint and ensure that it is handled in line with the UKPIPS Complaints Policy.

You also have the right to lodge a complaint about any use of your personal information with the Information Commissioners Office, www.ico.gov.uk.

Changes to this Policy

We may change this policy from time to time. If we make any significant changes in the way we treat your personal information we will make this clear on the UKPIPS website or by contacting you directly.

Contact us

If you have any questions, comments or suggestions please let us know by contacting our Data Protection Champion at info@ukpips.org.uk, or by phone on 07531 076409.

This policy is effective from 20th June 2018