

PRIVACY NOTICE

Last updated on 25 May, 2018

Introduction

Welcome to the European Society for Immunodeficiencies' (hereinafter referred to as ESID or the Society) privacy notice.

ESID respects your privacy and is committed to protecting your personal data. This privacy notice will inform you as to how we look after your personal data when you visit our website (regardless of where you visit it from) or when you interact with any of the online forums, registration forms, sign-up forms, other digital activities carried out through this website ("Activities"). This Privacy Notice also describes your choices regarding the use, access and correction of your personal information and informs you about your privacy rights and how the law protects you.

Important information and who we are

Purpose of this privacy notice

This privacy notice aims to give you information on how ESID collects and processes your personal data through your use of this website, including any data you may provide through this website when you sign up to any of our activities including signing up for our newsletter, applying for membership and requesting funding.

This website is not intended for children 18 years of age or younger and we do not knowingly collect data relating to children.

It is important that you read this privacy notice together with any other privacy notice or fair processing notice we may provide on specific occasions when we are collecting or processing personal data about you so that you are fully aware of how and why we are using your data. This privacy notice supplements the other notices and is not intended to override them.

Controller

The European Society for Immunodeficiencies is the controller and responsible for your personal data (collectively referred to as "ESID", "we", "us" "society" or "our" in this privacy notice).

Changes to the privacy notice and your duty to inform us of changes

It is important that the personal data we hold about you is accurate and current. Please keep us informed if your personal data changes during your relationship with us. You can always log in to our membership area and use the 'My Profile' section to update your details.

Third-party links

This website may include links to third-party websites, plug-ins and applications. Clicking on those links or enabling those connections may allow third parties to collect or share data about you. We do not control these third-party websites and are not responsible for their privacy statements. When you leave our website, we encourage you to read the privacy notice of every website you visit.

The data we collect about you

Personal data, or personal information, means any information about an individual from which that person can be identified. It does not include data where the identity has been removed (anonymous data).

We may collect, use, store and transfer different kinds of personal data about you which we have grouped together as follows:

Identity Data includes first name, maiden name, last name, username, title, date of birth and gender.

Contact Data includes postal address of either you or your institution, email address and telephone numbers.

Financial transaction Data includes details about payments to and from you and other details of services you have purchased from us.

Technical Data includes internet protocol (IP) address, your login data, browser type and version, time zone setting and location, browser plug-in types and versions, operating system and platform and other technology on the devices you use to access this website.

Profile Data includes your username and password (which is stored in an encrypted form), your interests, preferences, feedback and survey responses.

Usage Data includes information about how you use our website and services.

Marketing and Communications Data includes your preferences in receiving marketing from us and our third parties and your communication preferences.

We also collect, use and share **Aggregated Data** such as statistical or demographic data for any purpose. Aggregated Data may be derived from your personal data but is not considered personal data in law as this data does **not** directly or indirectly reveal your identity. For example, we may aggregate your Usage Data to calculate the percentage of users accessing a specific website feature. However, if we combine or connect Aggregated Data with your personal data so that it can directly or indirectly identify you, we treat the combined data as personal data which will be used in accordance with this privacy notice.

We do not collect any **Special Categories of Personal Data** about you (this includes details about your race or ethnicity, religious or philosophical beliefs, sex life, sexual orientation, political opinions, trade union membership, information about your health and genetic and biometric data). Nor do we collect any information about criminal convictions and offences.

Purpose of collection

The personal information we collect from you is used to enable us to provide you with any of the Society services and activities (as described in section 3).

If you fail to provide personal data

Where we need to collect personal data by law, or under the terms of a contract we have with you and you fail to provide that data when requested, we may not be able to perform the contract we have or are trying to enter into with you (for example, to provide you with membership and/or membership discounts. In this case, we may have to cancel your membership, but we will notify you if this is the case at the time.

How is your personal data collected?

We use different methods to collect data from and about you including through:

Direct interactions. You may give us your identity, contact and financial data by filling in forms or by

corresponding with us by post, phone, email or otherwise. This includes personal data you provide when you:

- apply for membership;
- apply for funding (awards, grants, scholarships etc) or participate in elections;
- apply for meeting attendance;
- request marketing to be sent to you;
- enter a competition, promotion or survey; or
- give us some feedback.

Automated technologies or interactions. As you interact with our website, we may automatically collect Technical Data about your equipment, browsing actions and patterns. We collect this personal data by using cookies and other similar technologies. Please see our cookie policy [\[LINK\]](#) for further details. Third parties: We work closely with third parties (including, for example, business partners and sub-contractors in technical, and payment services, advertising networks, analytics providers, academic institutions and search information providers) from whom the Society may receive information about you.

How we use your personal data

ESID may use your personal information in the performance of any contract we enter into with you, to comply with legal obligations, or where the Society has a legitimate interest in using your information to enhance the services we provide. Legitimate purposes include but are not limited to one or all of the following: providing direct marketing and assessing the effectiveness of promotions and advertising; modifying, improving or personalizing our services and communications; detecting fraud; investigating suspicious activity and otherwise keeping our site safe and secure; and conducting data analytics.

In addition, we may use your information in the following ways:

To provide you with information about services that you request from us;

To provide you with information about other opportunities, events and services we offer that are either (i) similar to those you have already purchased or inquired about, or (ii) entirely new products, events and services related to the society;

For internal research purposes to help enhance, evaluate, develop, and create Society websites (including usage statistics, such as "page views" on ESID's websites);

To notify you about changes or updates to our websites or services;

To administer our services and for internal operations, including troubleshooting, data analysis, testing, statistical, and survey purposes;

To allow you to participate in interactive features of our service; and

For any other purpose that we may notify you of from time to time.

Personal information will not be kept longer than is necessary for the purpose for which it was collected. This means that, unless information must be retained for legal or archival purposes, personal information will be securely destroyed, put beyond use or erased from systems when it is no longer required or, where applicable, following a request from you to destroy or erase your personal information.

Opting out

You can ask us to stop sending you communications at any time by logging into the website and checking or unchecking relevant boxes to adjust your communication preferences or by following the opt-out links on any marketing message sent to you by esid.admin@kenes.com or by esidmem@kenes.com. Please be aware that if you ask to be removed from future communications we will no longer be able to send you messages about your membership, including the reminder to renew your membership.

Cookies

You can set your browser to refuse all or some browser cookies, or to alert you when websites set or access cookies. If you disable or refuse cookies, please note that some parts of this website may become inaccessible or not function properly. For more information about the cookies we use, please see [LINK TO YOUR COOKIE POLICY.]

Change of purpose

We will only use your personal data for the purposes for which we collected it, unless we reasonably consider that we need to use it for another reason and that reason is compatible with the original purpose.

If we need to use your personal data for an unrelated purpose, we will notify you and we will explain the legal basis which allows us to do so.

Please note that we may process your personal data without your knowledge or consent, in compliance with the above rules, where this is required or permitted by law.

Disclosures of your personal data

ESID will not disclose to or share your personal information with any unaffiliated third party except as follows:

- Where necessary in connection with services provided by third parties (i) who provide us with a wide range of office, administrative, information technology, production, payment, or business management services, and (ii) who are required to comply with this policy;
- Where your consent has been provided, with a third party such as an academic institution, school, employer, business or other entity which has provided you with access to a product or service through an integration or access code, information may be shared regarding your engagement with the service or product, results of assessments taken and other information you input into the product or service;
- Where ESID is required to disclose personal information in response to lawful requests by public authorities and government agencies, including to meet national security or law enforcement requirements; to comply with a subpoena or other legal process; when we believe in good faith that disclosure is necessary to protect our rights or to protect the rights, property or safety of our services, users or others; and to investigate fraud

International transfers

We share your personal data within the society. This will involve transferring your data outside the European Economic Area (EEA).

Whenever we transfer your personal data out of the EEA, we ensure a similar degree of protection is afforded to it by ensuring the following safeguards is implemented:

We will only transfer your personal data to countries that have been deemed to provide an adequate level of protection for personal data by the European Commission. For further details, see [European Commission: Adequacy of the protection of personal data in non-EU countries](#).

Data security

We have put in place appropriate security measures to prevent your personal data from being accidentally lost, used or accessed in an unauthorised way, altered or disclosed. Access to your personal data will be restricted to only those who need to know that information and required to perform their job function.

We use third-party vendors and hosting partners to provide the necessary hardware, software, networking, storage, and related technology required to run our Activities. Where practical, we seek to obtain confidentiality agreements that are consistent with this Privacy Notice and that limit others' use or disclosure of your personal information.

Data retention

How long will you use my personal data for?

We will only retain your personal data for as long as necessary to fulfil the purposes we collected it for, including for the purposes of satisfying any legal, accounting, or reporting requirements.

To determine the appropriate retention period for personal data, we consider the amount, nature, and sensitivity of the personal data, the potential risk of harm from unauthorised use or disclosure of your personal data, the purposes for which we process your personal data and whether we can achieve those purposes through other means, and the applicable legal requirements. Your data must be retained for as long as local accounting regulations require and generally for 5 years.

In some circumstances we may anonymise your personal data (so that it can no longer be associated with you) for research or statistical purposes in which case we may use this information indefinitely without further notice to you.

Your legal rights

You have the right to make a written request to be informed whether or not we hold or process any of your personal information (by emailing esid.admin@kenes.com or esidmem@kenes.com). In your written request, you may:

- Request that we provide you with details of your personal information that we process, the purpose for which it is processed, the recipients of such information, the existence of any automated decision making involving your personal information, and what transfer safeguards we have in place;
- Request that we rectify any errors in your personal information;
- Request that we delete your personal information if our continued processing of such information is not justified;
- Request that we transfer your personal information to a third party;
- Object to automated decision-making and profiling based on legitimate interests or the performance of a task in the public interest (in which event the processing will cease except where there are compelling legitimate grounds, such as when the processing is necessary for the performance of a contract between us);
- Object to direct marketing from us; and
- Object to processing for purposes of scientific, historical research and statistics.

Where applicable under your local laws, we will not use your personal information for marketing purposes, nor disclose your information to any third parties, unless we have your prior consent, which we will seek before collecting your personal information.

No fee usually required

You will not have to pay a fee to access your personal data (or to exercise any of the other rights).

What we may need from you

We may need to request specific information from you to help us confirm your identity and ensure your right to access your personal data (or to exercise any of your other rights). This is a security measure to ensure that personal data is not disclosed to any person who has no right to receive it. We may also contact you to ask you for further information in relation to your request to speed up our response.

Time limit to respond

We try to respond to all legitimate requests within one month. Occasionally it may take us longer than a month if your request is particularly complex or you have made a number of requests. In this case, we will notify you and keep you updated.

Changes to this Privacy Notice

Please note that ESID's Privacy Policy is reviewed periodically. The Society reserves the right to modify its Privacy Notice at any time without notice. Any changes to the Privacy Policy will be posted on this page and will become effective on the date of posting. We encourage you to periodically review this page for the latest information on our privacy practices.