

Privacy Policy

The 'International League Against Epilepsy (ILAE) British Chapter' respects your privacy and is committed to protecting your personal data.

This policy notice is provided in a layered format so you can click through to the specific areas set out below.

It is important that you read the document in full. If you do not agree with the policy please do not use our website or give your data to us.

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1. Important information, who we are and definitions

Purpose of this privacy notice

This privacy notice informs you as to how we collect, process and look after your personal data in the course of interacting with us, whether by visiting this website, becoming an ILAE British Chapter member, signing up to our events, and tells you about your privacy rights and how the law protects you.

This website is not intended for children and we do not knowingly collect data relating to children.

Data Controller

We are the International League Against Epilepsy British Chapter (referred to as ILAE British Chapter, or to 'we' or 'us' or 'our'). We are a registered charity in England and Wales, charity number 228157.

Registered office: Institute of Neurology, Queen Square House, Queen Square, London, WC1N 3BG.
Contact email address members@ilaebritsh.org.uk. Telephone: 0203 627 3609.

In respect of your personal data, we are the data controller. Before you become an ILAE British Chapter you will need to read and agree to this policy notice.

If you have any questions about this privacy policy, including any requests to exercise your legal rights, please contact members@ilaebritsh.org.uk. This is your email contact in respect of all queries relating to your data protection rights and we aim to respond promptly to all such emails.

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

This policy notice was created on the 21st May 2018.

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, which you can do by emailing Hannah Stapley at members@ilaebritsh.org.uk.

Definitions

"Website" or "site" means www.ilaebritsh.org.uk and any website under the ownership or control of ILAE British Chapter from which a link has been created to these terms and conditions.

"User", "you", "your" and "yours" means the person(s), firm, company or organisation accessing the website.

"Material" and "content" means information, data, text, graphics, video, audio, images, links or programming code contained or available on our website.

Third-party links

This website may include links to third-party website and applications. Clicking on those links 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 policy notice of every website you visit.

2. Legislation

The ILAE British Chapter is committed to protecting your personal information and respecting your privacy. We shall ensure we comply with the applicable data protection and privacy legislation ("Applicable Law"), including the Data Protection Act 1998 (the "Act") and the General Data Protection Regulation (Regulation (EU) 2016/679).

3. Data protection principles

We will comply with data protection law. This says that the personal information we hold about you must be:

1. Used lawfully, fairly and in a transparent way.
2. Collected only for valid purposes that we have clearly explained to you and not used in any way that is incompatible with those purposes.
3. Relevant to the purposes we have told you about and limited only to those purposes.
4. Accurate and kept up to date.
5. Kept only as long as necessary for the purposes we have told you about.
6. Kept securely.

4. 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).

ILAE British Chapter is a professional membership organisation for all those who work, or have an interest, in the field of epilepsy. We process personal data relating to our charitable activities, to help our members to meet their charitable objects by influencing the regulatory, policy and research environments, and connect members via educational events to encourage collaboration and share learning. You may be asked for personal data if you want to take advantage of specific services we offer, such as receiving members briefings and email updates, joining email lists and networks or taking part in workshops, conference and courses.

We will use the personal information you provide to administer our relationship with you and deliver the services you have told us you wish to use or to send you information that you have requested.

Information that you supply will be treated in confidence and in accordance with the principles of the GDPR.

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 or similar identifier, title, date of birth and gender

Contact Data Includes home address, work address, email address, telephone

number, billing address

Financial Data Includes bank account details

Transaction Data Includes details about payments to and from you and details of events you attended and associated services we have provided to you.

Technical Data Includes internet protocol (IP) address, browser type and version, time zone setting and location, operating system and platform and other technology on the devices you use to access our website.

Communications Data Includes emails and notes of conversations.

We do not collect any Special Categories of Personal Data (www.ico.org.uk) about you (this includes details about your race or ethnicity, religious or philosophical beliefs).

We do not use your data for the purpose of data profiling and we will not sell or lease your personal information to third parties unless we are required by law to do so.

We process personal data about members, council members, event delegates, suppliers and exhibitors to our events. The categories of person about whom we process personal data are described in more detail section six.

We store your personal data just for the intended purpose and we collect only the minimum personal data necessary, that it's accurate, and kept for only as long as necessary, after which it is deleted from our database.

5. How your personal data is collected

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

Direct Interactions. You may give us your Identity, Contact, Professional Details and Financial, and Transactional Data by submitting information through the website, our registration platforms or by corresponding with us by post, phone, email or otherwise. This includes personal data you provide when you:

- instruct us to provide services to you;
- create a membership account through the website application form;
- attend an ILAE event;
- subscribe to our membership emails, newsletters or publications;
- request marketing to be sent to you;
- enter a survey; or
- give us some feedback.

Automated technologies or interactions. As you use our website we may automatically collect Technical Data about your equipment, browsing actions and patterns. We collect this personal data by using cookies. We may receive Technical Data about you if you visit other websites employing our cookies. Our use of cookies is explained in section eleven.

Third parties. We may receive personal data about you from various third parties as set out below:

- Technical Data from the following parties: (a) Ink and Dots Limited, whose privacy policy you can obtain by emailing members@ilaebritish.org.uk and (b) analytics providers such as Google based outside the EU.
- Identity and Contact Data from the following parties: (a) Activate Events, whose privacy policy you can see here- www.activateevents.com/privacy-policy-2018, (b) Affinity Events, whose privacy policy you can see here - <http://www.affinityevents.co.uk/privacy-policy>, (c) etouches, whose privacy policy you can see here - www.etches.com/event-software/privacy-policy.
- Contact, Financial and Transaction Data from providers of technical and payment services such as Stripe, which has servers based outside the EU.

6. How we use your personal data

We will only use your personal data when the law allows us to. Most commonly, we use your personal data in the following circumstances:

- Where we need to perform the contract we are about to enter or have entered into with you
- Where it is necessary for our legitimate interests (or those of a third party) and your interests and fundamental rights do not override those interests
- Where we need to comply with a legal or regulatory obligation.

We may also use your personal information in the following situations, which are likely to be rare:

- Where we need to protect your interests (or someone else's interests)
- Where it is needed in the public interest [or for official purposes].

Purposes for which we will use your personal data

We will generally process your personal data for contractual necessity in providing membership services and events. We may also use personal information for additional relevant and related purposes where you might reasonably expect us to do so, where the benefits of doing so are not outweighed by your own interests or fundamental rights or freedoms.

We have set out below a description of all the ways we plan to use your personal data, and which of the legal basis we rely on to do so, in addition to your consent where this is given. We have also identified what our legitimate interests are when appropriate. Note that we may process your personal data for more than one lawful ground depending on the specific purpose for which we are using your data. Please contact us if you need details about the specific legal ground we are relying on to process your personal data.

ILAE British Chapter members

Type of data

- **Identity** - first name, last name and any title you wish us to use
- **Contact** – mobile telephone number, email address, alternative email address, work address, home address
- **Basic professional profile** – job title, current work address, specialist field, CCT date
- **Financial and Transactional** – information as to how the membership subscription has been paid for, payment amount and payment date, bank account details (if postal standing order form is submitted).

We process your personal data for the following purposes:

[Purpose]

[Lawful basis]

- | | |
|---------------------------------------------------------------------------------------------------------------------|-----------------------|
| • Provision of membership services including administration and transactional communications relating to membership | Contractual Necessity |
| • Compliance with ILAE British Chapter Rules and Regulations | Contractual Necessity |
| • Contacting you regarding newsletters, invitations and information about ILAE British Chapter events/meetings. | Legitimate Interests |
| • Contacting you by email to provide related information and information /marketing communications (if any). | Consent |
| • Compliance with legal or regulatory requirements | Regulatory Necessity |

Event delegates

Type of data

- **Identity** - first name, last name and any title you wish us to use
- **Contact** – mobile telephone number, email address, alternative email address
- **Basic professional profile** – job title, current work address, specialist field, years of experience, previous courses attended, preferred course modules
- **Other personal** – dietary requirements or allergies.
- **Financial and Transactional**– invoice details, information as to how the course has been paid for, payment amount and payment date.

We process your personal data for the following purposes:

[Lawful basis]

- | | |
|----------------------------------------------------------------------------------------------------------------|-----------------------|
| • To record you as a participant in an event | Contractual Necessity |
| • Administration and transactional communications relating to events | Contractual Necessity |
| • Compliance with ILAE British Chapter Rules and Regulations (including sharing relevant required information) | Contractual Necessity |
| • Publication in event materials | Consent |
| • Compliance with legal or regulatory requirements | Regulatory Necessity |

Exhibitors/Sponsors

Type of data

- **Identity** - first name, last name and any title you wish us to use
- **Contact** - mobile telephone number, email address, alternative email address, work address
- **Basic professional profile** – job title, current work address, specialist field
- **Financial and Transactional** – invoicing details, information as to how the sponsorship has been paid payment, payment amount and payment date.

We process your personal data for the following purposes:

- | | <i>[Lawful basis]</i> |
|----------------------------------------------------------------------------------------|-----------------------|
| • Administration and transactional communications for exhibitors sponsoring our events | Contractual Necessity |
| • Provision of services relating to our events | Contractual Necessity |
| • Compliance with ILAE British Chapter Rules and Regulations | Contractual Necessity |
| • Contacting you regarding future events | Legitimate Interests |
| • Publication of your name address in event programme [subject to the right to object] | Legitimate Interests |
| • Publication of event sponsorship details on our websites | Legitimate Interests |
| • Compliance with legal or regulatory requirements | Regulatory Necessity |

Suppliers

Type of data

- **Identity** - first name, last name and any title you wish us to use
- **Contact** – mobile telephone number, email address, alternative email address, work address
- **Basic professional profile** – job title, current work address
- **Financial and Transactional** – purchase order and invoicing details

We process your personal data for the following purposes:

- | <i>[Purpose]</i> | <i>[Lawful basis]</i> |
|----------------------------------------------------------------------------------------------------------------|-----------------------|
| • Administration and transactional communications for suppliers assisting with our events or office operations | Contractual Necessity |
| • Provision of services relating to our events | Contractual Necessity |
| • Compliance with ILAE British Chapter Rules and Regulations | Contractual Necessity |
| • Contacting you regarding future services | Legitimate Interests |
| • Compliance with legal or regulatory requirements | Regulatory Necessity |

Website users

Type of data

- **Technical**

We process your personal data for the following purposes:

- | <i>[Purpose]</i> | <i>[Lawful basis]</i> |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------|
| • Administration and protection of our charity and this website (including troubleshooting, data analysis, testing, system maintenance, support, reporting and hosting of data. | Legitimate Interests
Legal Obligation |

Opting out

We strive to provide you with choices regarding certain personal data uses. You can ask us to stop sending your messages about ILAE activities and events at any time by contact us at any time.

7. Disclosures of your personal data

We may have to share your personal data with the parties set out below and in Appendix A for the purposes set out in section six above.

- Professional advisers including lawyers, bankers, auditors and insurers based in the United Kingdom who provide consultancy, banking, legal insurance and accounting services to us
- Event registration management service providers such as etouches and Eventbrite
- Email management service providers such as MailChimp based in the US
- IT and system administration service providers based in the EEA
- IT and system administrations services providers not based in the EEA
- Postal service providers such as Royal Mail
- Third parties to whom we may use to provide services for us. For example, event management companies

Such parties, listed above and in Appendix A, have contracted with us as data processors under the requirements in the GDPR. They are contractually bound to only use personal data for the agreed purpose(s). Relevant persons working for these third parties will have access to your personal data under the terms of the data processor contract, but only to the extent necessary to perform their services for us.

8. International transfers

Some of our external third parties are based outside the European Economic area (EEA) so their processing of your Personal Data will involve a transfer of data outside the EEA. Whenever we transfer your personal data out of the EEA we ensure a similar degree of protection is afforded to it by ensuring at least one of the following safeguards is implanted.

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-european countries.

Where we use certain service providers based in the US we may transfer data to them if they are part of the Privacy Shield which requires them to provide similar protection of personal data shared between Europe and the US. For further details see European Commission: EU-US Privacy Shield.

9. Data security

ILAE British Chapter takes security seriously. To prevent unauthorised access, maintain data accuracy and ensure the correct use of information, we have in place appropriate physical, electronic and managerial procedures to safeguard and secure the information we collect. In addition, we limit access to your personal data to those employees, agents, contractors and other third parties to have a business need to know. They will only process your personal data on our instructions and they are subjected to a duty of confidentiality.

We do not store any of your finance information such as your bank details.

We will rapidly deal with suspected personal data breach and will notify you and any applicable regulators of the breach where we are legally required to do so.

10. 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 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 purpose for which we process your personal data and whether we can achieve those purposes through other means, and the applicable legal requirements.

By law we must keep basic information about our charitable activities (including Contact, Identity, Financial and Transaction Data) for six years.

If you ask us to cancel your membership we will instantly remove your membership record from our database and your contact details from our mailing list. We will retain your cancellation request, name and email address on file for up to three years. During the three-year period we will not contact you unless it is to remind you to cancel your membership subscription payment (if you have failed to do this).

11. Cookie Policy

What are Cookies?

Cookies are small files of information which save and retrieve information about your visit to a website or application. They reside in your Internet browser to help remember your preference and previous activity. You can find more information about cookies at www.allaboutcookies.org and www.youronlinechoices.eu.

Use of Cookies

ILAE British Chapter's site makes use of cookies to save and retrieve information about visit to our website. Cookies currently used on our site identify you merely as a number.

Cookies can be "First Party", i.e. set by us, or "Third Party" – set by another company to perform the function, for example Google Analytics.

When you visit our website, the following categories of cookies may be set in your browser:

- **Strictly Necessary Cookies.** These allow you to move around the website and use essential features like online billing. These cookies do not gather any information about you that could be used for marketing or remembering where you have been on the internet. We do not require your consent to set these cookies.
- **Performance Cookies.** These cookies collect information so we can analyse how visitors use our site. They do not collect information which identifies visitors personally. They help improve how our website works. A Google Analytics Cookie is used on our site. It allows us to follow the actions of a user during your visit to our site. We use the information to compile reports and to help us improve the site. The cookies collect information in an anonymous form, including the number of visitors to the site, where visitors have come to the site from and the pages they visited.
- **Functionality Cookies.** These allow the website to remember user choices – e.g. region or language and also provide enhanced personal features (e.g. providing a service like completing a membership application form, gaining consent.) They do not collect information which identifies visitors personally. They help improve your user experience and the way our website works. Our site uses WordPress cookies (https://codex.wordpress.org/WordPress_Cookies) and Cookie Consent Cookie.

What if you do not wish to accept cookies?

Cookie information is held on your browser and you can amend your browser settings at any time. However, please be aware that blocking or deleting all cookies will affect the usability of our website. If you do not wish to accept cookies from us then you can set your web browser to reject cookies, although, in that case you may not be able to use certain features on our site. Please consult the documentation for your web browser if you wish to reject cookies; this feature is generally part of the "privacy" options.

12. Your rights as a data subject

You have the right to make a complaint at any time to the Information Commissioner's Office (ICO), the UK supervisory authority for data protection issues (www.ico.org.uk). We would, however, appreciate the chance to deal with your concerns about data protection before you approach the ICO so please contact us in the first instance.

You also have the right in certain circumstances to:

- Request access to your personal data (commonly known as a "data subject access request"). This enables you to receive a copy of the personal data we hold about you and to check that we are lawfully processing it.
- Request correction of the personal data that we hold about you. This enables you to have any incomplete or inaccurate data we hold about you corrected, though we may need to verify the accuracy of the new data you provide to us.
- Request erasure of your personal data. This enables you to ask us to delete or remove personal data where there is no good reason for us continuing to process it. You also have the right to ask us to delete or remove your personal data where you have successfully exercised your right to object to processing (see below), where we may have processed your information unlawfully or where we are required to erase your personal data to comply with local law. Note, however, that we may not always be able to comply with your request of erasure for specific legal reasons which will be notified to you, if applicable, at the time of your request.
- Object to processing of your personal data where we are relying on a legitimate interest (or those of a third party) and there is something about your situation which makes you want to object to processing on this ground as you feel it impacts on your fundamental rights and freedoms. You also have the right to object where we are processing your personal data for direct marketing purposes. In some cases, we may demonstrate that we have compelling legitimate grounds to process your information which override your rights and freedoms.
- Request restriction of processing of your personal data. This enables you to ask us to suspend the processing of your personal data in the following scenarios: (a) if you want us to establish the data's accuracy; (b) where our use of the data is unlawful but you do not want us to erase it; (c) where you need us to hold the data even if we no longer require it as you need it to establish, exercise or defend legal claims; or (d) you have objected to our use of your data but we need to verify whether we have overriding legitimate grounds to use it.
- Request the transfer of your personal data to you or to a third party. We will provide to you, or a third party you have chosen, your personal data in a structured, commonly used, machine-readable format. Note that this right only applies to automated information which you initially provided consent for us to use or where we used the information to perform a contract with you.

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 several requests. In this case, we will notify you and keep you updated.

Appendix A

Information on Data Processors used by ILAE British Chapter

Activate Events

ILAE British Chapter uses Activate Events as one of the charities' event management providers. Activate have provided detailed and satisfactory responses to our GDPR Data Processor enquiries and we are confident that they are GDPR compliant. For further details please see Activate Events privacy policy (www.activateevents.com/privacy-policy-2018).

Affinity Events

ILAE British Chapter uses Affinity Events as one of the charities' event management providers. Affinity have provided detailed and satisfactory responses to our GDPR Data Processor enquiries and we are confident that they are GDPR compliant. For further details please see Affinity Events privacy policy (<http://www.affinityevents.co.uk/privacy-policy>).

eBrain

eBrain is an online e-learning platform. ILAE British Chapter members can access the platform free of charge. The ILAE British Chapter only shares Personal Data (name and email address) with eBrain at your request and after specific consent has been obtained. ILAE British Chapter members can be assured that the data is not used for any purposes other than creating an ebrain account and is held securely in accordance with eBrain data policy (www.cdn.website-editor.net/5e6fbe0d546d4802ab620183fbc966dc/files/uploaded/privacy.pdf).

etouches

ILAE British Chapter uses etouches as an online events registration and event management provider. By registering your information with etouches you acknowledge that the information you provide will

be transferred to etouches for processing. etouches will only process your Personal Data to help administer that event on behalf of the ILAE British Chapter.

etouches merely provides the "tools" for Organisers; eTouches does not decide what Personal Data to request on registration forms, nor is it responsible for the continued accuracy of any Personal Data provided. For further details please see etouches' privacy policy (www.etches.com/event-software/privacy-policy).

Eventbrite

The ILAE British Chapter uses Eventbrite as one of our events registration service providers. By registering your information with Eventbrite you acknowledge that the information you provide will be transferred to Eventbrite for processing. Eventbrite will only process your Personal Data to help administer that event on behalf of The ILAE British Chapter.

Eventbrite merely provides the "tools" for Organisers; Eventbrite does not decide what Personal Data to request on registration forms, nor is it responsible for the continued accuracy of any Personal Data provided. For further details please see Eventbrite's privacy policy (www.eventbrite.co.uk/support/articles/en_US/Troubleshooting/eventbrite-privacy-policy?lg=en_GB).

GoDaddy

ILAE British Chapter uses GoDaddy to host the ILAE British website. GoDaddy have been specifically chosen by us as an appropriate provider and we have concluded that the privacy and security arrangements are appropriate. The server is held in the US. Under data protection law we must ensure appropriate safeguards where data is transferred outside the EU. The safeguard here is the EU-US Privacy Shield.

For more information visit this site- <https://www.privacyshield.gov/welcome>. Also, it is important that you read GoDaddy's privacy policy (<https://uk.godaddy.com/Agreements/Privacy.aspx>).

Ink and Dots Limited

ILAE British Chapter uses Ink and Dots Limited to maintain and update the ILAE British Chapter website. Ink and Dots have provided detailed and satisfactory responses to our GDPR Data Processor enquiries and we are confident that they are GDPR compliant. For further details and to obtain a copy of Ink and Dots privacy policy email members@ilaebritish.org.uk.

International League Against Epilepsy (ILAE).

A requirement of being a chapter of the ILAE the ILAE British Chapter must share the Personal Data (name and email address) of its members. The ILAE is fully compliant with GDPR. For further details see the ILAE's privacy policy (<https://www.ilae.org/privacy-and-security/privacy-policy>).

Mailchimp

ILAE British Chapter uses MailChimp as an email marketing service provider. MailChimp has been specifically chosen by us as an appropriate provider and we have concluded that the privacy and security arrangements are appropriate. The server is held in the US. Under data protection law we must ensure appropriate safeguards where data is transferred outside the EU. The safeguard here is the EU-US Privacy Shield.

For more information visit this site- <https://www.privacyshield.gov/welcome>. Also, it is important that you read MailChimp's privacy policy (<https://mailchimp.com/legal/privacy>).

Microsoft 365

We use Microsoft 365 to send and receive emails. We also use it as a cloud storage service provider. Microsoft 365 has been specifically chosen by us as an appropriate provider and we have concluded that the privacy and security arrangements are appropriate. The server is held in the US. Under data protection law we must ensure appropriate safeguards where data is transferred outside the EU. The safeguard here is the EU-US Privacy Shield.

For more information visit this site- <https://www.privacyshield.gov/welcome>. Also, it is important that you read Microsoft 365's privacy policy (<https://www.microsoft.com/en-us/trustcenter/privacy/gdpr>).

Stripe

We work with Stripe to help process credit card transactions and other payment methods when you register for an ILAE British Chapter event. This payment processors will store certain personal information about you. Please refer to their privacy policies to learn more about how they use your personal information (www.stripe.com/gb/privacy and www.stripe.com/privacy-shield-policy). The ILAE British Chapter does not store your credit card account number or banking details.

SurveyMonkey

The ILAE British Chapter uses SurveyMonkey as a survey application service provider to collect information from those who voluntarily fill out our surveys on its platforms. SurveyMonkey has been specifically chosen by us as an appropriate provider and we have concluded that the privacy and security arrangements are appropriate. The server is held in the US. Under data protection law we must ensure appropriate safeguards where data is transferred outside the EU. The safeguard here is the EU-US Privacy Shield.

For more information visit this site- <https://www.privacyshield.gov/welcome>. Also, it is important that you read SurveyMonkey's privacy policy (<https://www.surveymonkey.co.uk/mp/legal/privacy-policy>).

The personal information of survey participants will be transferred to ILAE British Chapter and is subject to the ILAE British Chapter privacy policy.