



## **Batten Disease Family Association CIO Privacy Policy**

### **Privacy notice**

This privacy policy explains how we use any personal information we collect about you when you contact us by phone, email, letter, attend any of our events or when you use our website.

**We take your privacy seriously and are committed to protecting your personal information. We aim to be clear and open about our data and security practices.**

Where we ask you to provide us with any information by which you can be identified, you can be assured that it will only be used in accordance with this privacy statement and in line with the General Data Protection Regulation (GDPR) 2018.

### **What information do we collect about you?**

We collect information about you when you fill in an online form to:

- Apply for membership
- To place orders for free or paid products or services
- Sign up for email updates
- Contact us
- Complete surveys or provide feedback.

This information may include:

- Name, role and organisation
- Contact details including email address
- Demographic information such as postcode and interests

We collect material such as any correspondence you have with us.

We also collect information on your website usage through cookies (see below), if your browser accepts them. The website features tracking software – this means that if you have filled an online form or have previously clicked a link in one of our emails, we may link our website usage information (eg pages visited, IP address, browser & device used) to other information we hold about you, such as your name and organisation.

When you contact us by email, letter or on the phone, we may also record this information on our contacts database system to help us process your request efficiently.

## **How do we use your information?**

We collect information about you to ensure that we can provide support and assistance, your involvement with the Association or process your order or fulfil any contract we have with you.

We use information collected from your website visits to improve the experience we provide to our online users. For example, information like the browser and device you are using helps us to maintain a usable and accessible website for all our audiences.

We may also use your information to help us develop products and services that you need and where we have a lawful basis and permission to contact you, we may use it to send you relevant and timely information about the help and support that we offer.

## **Where do we store your information?**

### **Online forms**

Our website and contact database management system are all hosted on secure servers based in the UK.

### **Security and encryption**

We take great care to ensure that our website operates at the highest security levels and that our suppliers are committed to best practice in digital security. All personal information and financial data is encrypted in transmission. However, the security of data transmission via the internet can never be 100% guaranteed, and data transmission is at your own risk.

### **Cookies**

#### **What are cookies and how do we use them?**

The use of cookies is common practice on modern websites. A cookie is a small text file which is placed on your computer's storage by a website. When you visit our website, your browser checks to see if it has any cookies for it and sends the information in those cookies back to the site in order to tailor and improve your experience.

We also use third-party cookies to track how our websites are used, as well as to carry out our advertising and marketing activities.

#### **Third-party cookies**

When you visit our website, we allow a number of third parties including Google and others to set cookies on your device to help us better understand who our users are and how they use our websites. This information enables us to:

- measure our site's effectiveness
- improve our content and user experience
- make our website more useful and relevant to your interests

- promote our services and resources more usefully online
- make adverts you see online more relevant to you
- limit the number of times you see our promotional advertising.

For example, we use Google Analytics cookies to collect anonymous usage and visitor behaviour information – this includes:

- IP address
- operating system
- browser type
- pages visited
- links you click on
- services you purchase.

Google Advertising cookies help us understand the demographics and interests of our users so we can better meet their needs.

### **Email cookies**

Our emails and website may contain cookies to tell us whether emails are opened and verify any clicks through to links within an email. We use this information to help us understand how an email campaign has performed, what types of emails and content our users find interesting, and what actions our users took, so we can improve our email campaigns in the future and make our emails more relevant to you.

### **Can I refuse cookies?**

Yes, you can use your browser settings to disable cookies. Different browsers offer different levels of control – for example you may be able to accept certain cookies and reject others, such as third party cookies.

If you refuse cookies please be aware our website may not work smoothly for you and there will be certain parts that won't function correctly.

You can delete the cookies stored on your computer at any time.

### **More information**

For further information about cookies, including how to manage your cookie settings, you can visit [www.aboutcookies.org](http://www.aboutcookies.org) or [www.allaboutcookies.org](http://www.allaboutcookies.org).

### **Email marketing**

If you have purchased a product or service from BDFFA or have opted-in to hear about BDFFA's products and services, we will send you information which may interest you. You have a right to stop us from contacting you for marketing purposes at any time. All our marketing emails contain unsubscribe links. You can also contact [admin@bdfauk.org.uk](mailto:admin@bdfauk.org.uk) at any time to request a change to your marketing preferences.

### **How long do we keep your information?**

We do not keep your information for longer than necessary. We keep financial information for seven years due to legal requirements and we delete all other personal information from our contact database management system if we have had no contact with you for three years.

### **Access to your information**

You have the right to request a copy of the information that we hold about you. If you would like a copy of some or all of your personal information, you can:

- email [admin@bdfa-uk.org.uk](mailto:admin@bdfa-uk.org.uk)
- write to BDF, PO Box 379, Shipley, BD18 9GE

We will not charge you for this service unless the request is 'manifestly unfounded or excessive or repetitive'.

### **Keeping your information up to date**

We want to make sure that any personal information we hold about you is accurate and up to date. Please email [admin@bdfa-uk.org.uk](mailto:admin@bdfa-uk.org.uk) to correct or remove information you think is inaccurate.

### **Sharing your information with other organisations**

BDF will not sell your information to any third party. We may share your information with third parties where we have legal duty to do so or to provide you with a service you have requested. For example, we use secure third party partners to process financial transactions. We have contracts in place with all third party suppliers to ensure they are obligated to treat our customers' personal data in compliance with the General Data Protection Regulation 2018.

If BDF is acquired by a third party, personal data held by BDF will be one of the transferred assets.

### **Other websites**

Our website contains links to other websites not run by BDF. This privacy policy only applies to the BDF website so when you link to other websites you should read their own privacy policies.

### **Changes to our privacy policy**

We keep our privacy policy under regular review and we will place any updates on this web page. This privacy policy was last updated on 14<sup>th</sup> July 2023.

### **Your rights**

Data protection regulations give you clear rights over how your data is used by us. You can find out more detail about your rights by visiting the Information Commissioner's Office website's section on [individual rights](#).



You also have the right to report concerns or complain about our handling of your data to the Information Commissioner's Office. Details of how to do this can be found on its [website](#).

#### **Who we are and how to contact us**

BDFA is registered in England and Scotland as a charitable membership association.

If you have any questions about our privacy policy or information we hold about you, you can:

- Email [admin@bdfa-uk.org.uk](mailto:admin@bdfa-uk.org.uk)
- Write to BDFA, PO Box 379, Shipley, BD18 9GE
- This privacy policy was last updated on 14th July 2023.