

This policy explains how and why we use your personal information. This means you stay informed and allows us to use your data fairly and lawfully.

Behçet's UK is committed to protecting your personal information and being transparent about what information we hold. This policy is designed to give you a clear explanation about how we collect and use the personal information you provide to us and ensure that we are honest and clear about your privacy and personal information at all times.

This policy applies to all the websites we operate, our use of emails and any other methods we use for collecting information. It covers what we collect and why, what we do with your information, what we will not do with your information and what rights you have.

## WHO ARE WE?

Whenever you see the words 'we', 'us', 'our', 'the charity' it refers to Behçet's UK.

At Behçet's UK we are committed to protecting your privacy. The purpose of this statement is to explain how we process your data, whether you are a member, using our helpline service, interested in fundraising, making a donation or just browsing our website.

Behçet's UK is registered charity in England and Wales number 326679.

We are registered with the Information Commissioner's Office (ICO) as a Data Controller for the processing of Personal Data under reference ZA326761.

We are registered with the Fundraising Regulator and follow their best practice code: [Code of Fundraising Practice](#).

We have memberships associated with National Voices, Genetic Alliance (Rare Disease UK), EURORDIS, International Society for Behçet's Disease, NCVO, Small Charities Coalition, and the Helplines Partnership.

## YOUR ACCEPTANCE OF THIS POLICY AND OUR RIGHT TO CHANGE IT

By using our websites, social media pages, services (including helpline, phone, and email) or providing your information to us, we will collect and use your information in the way(s) set out in this policy. If you do not agree with this policy, please do not use our sites, social media pages or services.

We may make changes to this policy from time to time. If we do so, we will post the changes on this page and they will apply from the time we post them. This policy was last updated in February 2021.

## WHAT IS PERSONAL DATA

Personal data is information that can be used to help identify an individual, such as name, address, phone number or email address. Some categories of data are more sensitive and are referred to as special category data, including health information. Non-personal data is data that cannot identify you personally, but can provide us with information to improve our services.

## THE INFORMATION WE COLLECT

We collect information when you interact with us in order to meet the aim of the Charity.

### *We collect three kinds of information*

#### 1. Non-personal information

Such as IP addresses (the location of the computer on the internet), pages accessed and files downloaded. This helps us to understand how many people use our websites, how many people visit on a regular basis and how popular/useful our web pages are. This information doesn't tell us anything about who you are or where you live.

#### 2. Personal information

We will ask you for information in order to provide you with the services requested, for example to send you information or process a donation.

#### 3. Sensitive personal information or special category data

We may ask you for information about your health, for example, if you or a family member are living Behçet's, so that we can provide you with relevant information and support or in order to support your safe participation in an event. We may also collect this information if you make the information public or if you tell us about your experiences relating to Behçet's (for example, if you agree to share your story with us). We only collect this information with your consent.

### *Under 16s*

We are committed to protecting the privacy of the young people that engage with us. If you are under 16 and would like to get involved, please ensure you have consent from a parent or guardian before you provide your personal information to us. We do not send any marketing communications direct to children under 16.

## HOW WE COLLECT YOUR INFORMATION

We'll only collect information about you that we need and does so in the following ways:

### *Information you give to us directly, for example when you:*

- Become a member of Behçet's UK
- Sign up (yourself or others, including your children) to take part in or attend one of our fundraising, support or professional events.
- Apply for Personal Grant Aid.
- Apply for one of our research grants.
- Nominate or receive a nomination for the Behçet's UK Members Award.
- Buy products from us.
- Make a donation or tell us about your fundraising plans.
- Tell us about a gift in your will.
- Request information from us such as an Employer's Guide or Medical Factsheets.
- Contact our Helpline, when you may choose to provide details, including details of a personal nature, in particular about you or someone else's health.
- Choose to share your story with us.
- Take part in surveys, questionnaires or get involved with our campaigns.
- Volunteer with us or apply to work with us.
- Post on our social media pages or participate on our HealthUnlocked Forum.
- When you visit our websites, we collect technical information such as the IP address you use to visit the website, your browser type and version and your browsing history.
- Contact us or become involved with us in any other way not listed above.

### *Information from third parties*

We may also receive information about you from third parties if you have given them permission to share this information and indicated that you wish to support Behçet's UK, for example, if you set up a fundraising page for us with JustGiving, Virgin Money Giving or Facebook, sign up to an independently organised event like the London Marathon or Ultimate Challenge.

Depending on your settings or the privacy policies for social media and messaging services, we may access information from those accounts or services.

If you have been named as the Executor on a Will, we may receive your details in order to administer a gift left to us in that Will.

### *Your credit and debit card information*

If you use your credit or debit card to donate to us, or pay for your membership subscription, we will ensure this is done securely. We do not store your credit or debit card details following the completion of your transaction. All card details are securely destroyed once the payment or donation has been processed.

All purchases and donations completed online are handled securely by CAF or PayPal and we do not receive your card details.

## HOW WE USE YOUR DATA

### *We will mainly use the information we collect about you to:*

- Provide you with the services, products or information you asked for, for example, an information pack or fundraising materials.
- Administer your donation or support your fundraising, including submitting your details to HMRC to claim Gift Aid, if applicable.
- Administer your participation in an event, which may include sharing your details with a third party event organiser.
- Keep you up-to-date with the impact of your support and our work (including volunteering and events) and to ask for financial and non-financial support.
- Manage the Behçet's UK Members Award
- Manage our Personal Grant Aid Fund, including assessing suitability and awarding.
- Manage our research grants, including funding availability notifications and the peer review process.
- Support and further our mission, for example if you have shared your story or given us consent to use your photo, we may use this in marketing or promotional materials.
- Process merchandise orders.
- Enable us to monitor the effectiveness of marketing on Facebook and other platforms.
- Carry out any obligations arising from any contracts entered into by you and us.
- Process a job or volunteering application.

### *Keeping a record of your relationship with us*

We record contact we have with you, so we have a clear understanding of our relationship, how you've supported us or have been supported by us in the past. We may also collect and retain your information if you send us feedback about our services, give us a compliment or make a complaint.

### *Understanding how we can improve our services, events, products or information*

We believe it is important to make sure that all of our services are the very best they can be, which is why we evaluate them. Once you've used one of our services, taken part in an event, received information or bought a product, we may get in touch to ask you about your experience. You don't have to take part but it's really valuable to help us improve in the future.

### *Safeguarding*

Safeguarding is everyone's responsibility, and therefore we have a duty, wherever possible, to share any concerns that we have about conversations, emails, posts, messages or comments that indicate you or someone else might be at risk, with the relevant services. This includes reference to abuse or neglect.

Though we will always try to share our concerns with you, we reserve the right to share information with external agencies without checking first; especially if it is thought that by sharing our concerns with you might put others at risk, or increase the risks identified.

### HOW WE MAKE SURE IT IS LEGAL TO PROCESS DATA

The law requires us to set out the lawful grounds on which we collect and process your personal information as described in this policy. Depending on the purposes for which we use your data, one or more of the grounds listed below may be relevant.

#### *Where it is needed to fulfil our contractual obligations*

The data processed to meet contractual responsibilities includes, but is not limited to, data relating to employment records, fulfilling merchandise orders, applying for a grant from us.

#### *Where it is in our legitimate interests to do so*

In certain instances, we collect and use your personal information by relying on the legitimate interest legal basis. In broad terms, our 'legitimate interests' means our interest in being able to run Behçet's UK as a charitable entity effectively in pursuit of our aims and ideals. This includes:

- Sending our quarterly newsletter, by post and email to keep supporters informed of our work and progress towards our goals.
- Sending direct marketing material to supporters by post for fundraising purposes.
- Conducting research to better understand who our supporters are and better target our fundraising activity.
- Conducting research to better understand who is using our Information and Support Services and their impact to improve our service offering.
- Measure and understand how our audiences respond to a variety of marketing and communications activity so we can ensure our activities and services are well targeted, relevant and effective.
- Providing information about Behçet's.
- Processing donations.
- Administering events.
- Staff recruitment and taking applications for volunteers and contacting volunteers about their role.
- However, 'legitimate interests' can also include your interests, such as when you have requested information or certain goods/services from us, and those of third parties.
- To continue processing personal data on an individual who has exercised their right to erasure/to be forgotten. We will need to keep basic data to identify that individual and retain it solely for suppression purposes to prevent further unwanted processing.
- To follow guidance and recommended best practice of government and regulatory bodies.
- For management and audit of our business operations including accounting.
- To carry out monitoring and to keep records of our communications with you and our staff (see below).
- If we rely on the 'legitimate interests' basis to use your personal information, we will only use the information in accordance with the purposes described in this policy.

When we legitimately process your personal information in this way, we also consider and balance any potential impact on you (both positive and negative), and your rights under data protection laws. We will not use your personal information for activities where our interests are overridden by the impact on you, for

example where collection and use of your information would be excessively intrusive (unless, for instance, we are otherwise required or permitted to by law).

#### *To comply with our legal obligations*

We may need to collect, process and disclose personal information to comply with a legal obligation. For example, where we are ordered by a court or regulatory authority or we are legally required to hold donor transaction details for Gift Aid or accounting/tax purposes. We may also use personal information to cross check and prevent known malicious activities on Behçet's UK's websites.

#### *With your consent*

In many instances, we will rely on obtaining your consent to our use of your personal information in a certain way (for example, asking for your consent to use your personal information to send you marketing information by email and to share sensitive personal information with us).

### STORING YOUR DATA

When you give us your details, you agree to us recording your details on our secure database, so we can provide you with the best possible service every time you contact us. We hold your personal information for as long as required to provide you with the information or services you have requested, to administer your relationship with us, to inform our research into Behçet's, to inform our supporters' preferences, to comply with the law or to ensure we do not communicate with people who no longer wish to hear from us.

Behçet's UK holds its data on a secure database and access to this system is limited and there is restricted access to data based on a person's role in the organisation.

Some organisations which provide services to us may transfer data outside the EU. All of our current suppliers adhere to the EU-US Privacy Shield. Find out more: <https://www.privacyshield.gov/welcome>

All paper records are securely locked when no members of staff are present and access is restricted based on a person's role in the organisation.

In line with the principles defined in the Data Protection Act 2018 and the General Data Protection Regulation (GDPR), Behçet's UK will ensure that personal data will be processed in ways that are:

- Lawful, fair and transparent.
- Collected for specific explicit and legitimate purposes.
- Adequate, relevant and limited.
- Accurate and up-to-date.
- Not kept for longer than necessary.
- Secure.

#### *Disclosing and sharing information*

Your details will be kept securely and only shared with trusted suppliers, who have a contract with us, who enable us to deliver our charitable objectives, for example, distribution of our newsletter or if required to by law, i.e. with the police or a regulatory body. At all times we remain legally responsible for your data. We do not sell or share your personal information for other organisations to use.

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

Unless we explain otherwise to you, we'll hold your personal information based on the following criteria:

- for as long as we have reasonable business needs, such as managing our relationship with you and managing our operations;
- for as long as we provide services to you;

- retention periods in line with legal and regulatory requirements or guidance.

## COMMUNICATING WITH YOU

We may send Members and Associate Members of Behçet's UK direct mail or emails, including our quarterly newsletter, which will include updates on our work - the research we're funding, the information and support services we offer. We may also contact you about fundraising, campaigning and events. We do not ask for consent to write, email or call you about these things, because, as a charity, each of these activities is fundamental to how we work, so we have a legitimate interest to contact you. However, you have the option to opt-out of receiving marketing communications by post or phone at any time. Contact our Administration team by writing to us at Behçet's UK, 124 City Road, LONDON, EC1V 2NX, emailing us at [info@behcetsuk.org](mailto:info@behcetsuk.org) or calling us on 0345 130 7328.

You can unsubscribe from receiving emails at any time by clicking on the unsubscribe link in our marketing emails. Our mass email service allows us to track who has opened our emails including newsletter and what links have been clicked on. This allows us to monitor what information is most useful to improve our content and information in future.

If you have indicated you do not wish to be contacted by us, we will retain your details on a 'do not contact' list to help ensure that we do not contact you accidentally. However, we may still need to contact you if you carry on dealing with us, including (but not limited to):

- Processing a donation, you make or any continuing Direct Debit.
- Providing you with information you need in order to participate in an activity, event or campaign for which you have registered.
- Sending you information you've requested or merchandise orders placed.
- Explaining and apologising where we have made a mistake.
- Dealing with future legal claims in connection with a contract we have with you.

### *Marketing communication*

We never sell personal information about our members or supporters to any other organisation.

We never call people who have had no prior contact with the charity to ask for money or who have asked us not to call them. We only contact people who would reasonably expect to be contacted because they have recently supported the charity in some way.

We will not call people who are registered with the Telephone Preference Service (TPS) or companies registered with Corporate TPS, unless those people or companies have consented to be called by us.

We may use the personal data you have provided to us via one platform (such as on our website, via email or on a social media channel) to send you personalised content and messaging on another. Examples of this activity include using our website cookies and social media advertising.

## COOKIES AND OTHER ONLINE TECHNOLOGY

We may use cookies, web beacons, and similar technologies to collect, use and share certain information about your device(s), your use of our websites, app(s) or services.

We don't store personally identifiable information, but we do use the information we gather to help improve the experience of our website. For example, they help us to identify and resolve errors, or to determine the most relevant information and services to show our visitors in the future.

### *Cookies*

See our [Cookie Policy](#)

### *Web Beacons*

We use Mailchimp, which is a web based email service provider, to send out mass emails such as our e-newsletter, important communications and marketing. Emails sent by Mailchimp use email tracking technology to help provide you with the best experience we can.

The technology places an invisible single pixel gif image (also called a web beacon) in emails to detect when they have been opened and when links within emails have been clicked. Web beacons allow us to collect information about when you open the email, your IP address, your browser or email client type and other similar details. We use this data to create reports about who has or hasn't opened emails or clicked links and this information helps us to improve our email content so you receive more useful and relevant information from us.

### *Links to other websites*

Our website contains links to and from the websites of other relevant stakeholders. If you follow a link to any of these websites, please note that these websites have their own privacy policies and that we don't accept any responsibility or liability for these policies. Please check these policies before you submit any personal data to these websites. This privacy policy applies solely to the personal data collected by Behçet's UK.

## KEEPING YOUR INFORMATION UP TO DATE

We really appreciate it if you let us know if your contact details or circumstances change.

Simply let us know by contacting the Administration team:

- by post: Behçet's UK, 124 City Road, LONDON EC1V 2NX
- by email: [info@behcetsuk.org](mailto:info@behcetsuk.org)
- by telephone: 0345 130 7328

## HOW TO CHANGE THE WAY WE CONTACT YOU

Your personal preferences and keeping your data accurate is of utmost importance to us.

If at any stage you do not want to hear from us, want to change your contact preferences or want to update your details, contact Administration team:

- by post: Behçet's UK, 124 City Road, LONDON EC1V 2NX
- by email: [info@behcetsuk.org](mailto:info@behcetsuk.org)
- by telephone: 0345 130 7328

Any marketing email we send you will contain information about how to unsubscribe from email marketing communications.

During any phone, or email conversation you have with us, please feel free to let us know how you prefer to be contacted.

## RIGHT OF SUBJECT ACCESS

Here is a list of the rights that all individuals have under the General Data Protection Regulation (GDPR). They don't apply in all circumstances. If you wish to use any of them, we'll help you as much as possible.

You have a right to:

- access your information. This is called a Subject Access Request. Whether you are requesting information about yourself or on behalf of someone else;
- correct any information that we hold about you;
- erase any of your information that we no longer have a right to hold about you;



- access a machine readable version of your data, although there are some conditions;
- ask us to stop us doing anything with your data unless we must by law or a contract;
- stop any automated decision making. This is where a computer makes a decision about you. It should be noted that we do not do this.

View our [Subject Access Request Procedure](#) to exercise any of these rights.

### IF YOU WANT TO COMPLAIN

Behçet’s UK aims to support our service users to the highest possible standard at all times. To help achieve this, we encourage anyone who is not completely happy with the service they have received in any aspect of our work to let us know immediately, using the complaints procedure which is available on the website or by contacting the Administration team by email at [info@behcetsuk.org](mailto:info@behcetsuk.org) or by calling 0345 130 7328.

If you are unhappy at any time about the way we process and/or use your personal information, please contact The Charity's Data Protection Officer who will investigate your concerns. Please write to them at Behçet’s UK, 124 City Road, London EC1V 2NX, email [dpo@behcetsuk.org](mailto:dpo@behcetsuk.org) or call 0345 130 7328.

We appreciate the opportunity your feedback gives us to learn and improve. Find out more in our [Complaints Procedure](#). If you are unhappy with the way your (or your child's) data are being processed, and we have been unable to satisfactorily resolve your concern, you have the right to complain to the Information Commissioner's Office (ICO): [www.ico.org.uk](http://www.ico.org.uk)

Version	Date	Author
1.3	02 February 2023	Gemma Darlow