

## Privacy Policy

Mitrofanoff Support ("we") are committed to protecting and respecting your privacy.

This policy (and any other documents referred to within it) sets out the basis on which any personal information we collect from you, or that you provide to us, will be processed by us. Please read the following carefully to understand our views and practices regarding your personal information and how we will treat it. By visiting [www.mitrofanoffsupport.org.uk](http://www.mitrofanoffsupport.org.uk) you are accepting and consenting to the practices described in this policy.

For the purpose of the General Data Protection Regulation 2018 (GDPR), the data controller is Mitrofanoff Support of registered office Market Chambers, 3-4 Market Place, Wokingham, Berkshire, RG40 1AL.

Our nominated representative for the purpose of GDPR can be contacted at [legal@mitrofanoffsupport.org.uk](mailto:legal@mitrofanoffsupport.org.uk)

We rely on your consent as the legal basis to process your personal information. There are a few exceptions to this which will always be highlighted to you at the point of collection.

### INFORMATION WE COLLECT FROM YOU

#### Information you give to us directly

We may collect and store information about you when you interact with us. This could include, but not be limited to:

- Register to become a member
- Fundraise on our behalf
- Donate to the charity
- Register for our events (e.g Patient Education Days, annual ball)
- Provide information for our journal
- Submit an enquiry
- Make a complaint
- Give us feedback
- Volunteer with us
- Participate in discussions on our social media pages (e.g Facebook)
- Enter into a contract with us
- Respond to a survey we post
- Call our office to ask for information/advice
- Talking to us at events

The personal information collected about you may include your name, address, email address, telephone number, birthday, medical condition and IP address. Any health-related information that you disclose to us is classed as sensitive personal information and we only collect that where necessary. For example, you may talk about your medical issues on the Mitrofanoff Facebook group or email us about your medical situation in order to get some general advice.

#### Information you give us indirectly

When you interact with us on our social media sites we may also obtain some personal information about you depending on the privacy preferences you have set on your platform and the privacy policies applicable to each of those platforms. You are able to change your settings on those platforms. We may also obtain information about

your visit to our site (for example, the pages you visit and how you navigate our site) by using cookies (see below).

With regard to each of your visits to our site and/or social media pages we will automatically collect the following information:

- technical information, including the Internet protocol (IP) address used to connect your computer to the Internet;
- information about your visit, including page response times, download errors, length of visits to certain pages, page interaction information (such as scrolling, clicks, and mouse-overs), your address to send membership information to, and any phone number used to call our office.

## **COOKIES**

Our site uses cookies to distinguish you from other users of our site. This helps us to provide you with a good experience when you browse our Site and also allows us to improve it. For detailed information on the cookies we use and the purposes for which we use them see our Cookie policy on our website.

## **USES MADE OF YOUR INFORMATION**

We use personal information held about you in the following ways:

- Providing you with the information and services that come as part of our membership package, for example, our journal, details of events and access to our closed Facebook community;
- Responding to you if you have contacted us with a query, for example, general medical advice;
- Notifying you about changes to our service;
- Enabling us to organise events that you have consented to attend, for example, our annual ball or a patient education day
- Circulating our governance documents, for example our Chairperson's annual report and our Treasurer's report;
- Administering any one-off or on-going donations you make and claiming Gift Aid;
- Ensuring that content from our site is presented in the most effective manner for you and for your computer;
- Administering our site and for internal operations, such as troubleshooting, data analysis, testing, research, statistical and survey purposes;
- Processing any application for you to volunteer with us;
- Recording and dealing with any complaints or any requests to remove you from our database or any other internal record keeping;
- Protecting your vital interests in the event that we think, in our reasonable opinion, that there is a risk of serious harm to you or someone else;
- Complying with any legal obligations that We are subject to;
- Improving our site to ensure that content is presented in the most effective manner for you and for your computer; and/or
- Ensuring our site is kept safe and secure;

We will only retain and use your personal information for as long as necessary for the purposes for which it was collected, taking into account any guidance provided by the UK Information Commissioner's Office.

## **WHO DO WE DISCLOSE YOUR INFORMATION TO?**

We will only share your personal information with the following third parties for the following purposes:

- Our Trustees and volunteers to enable us to provide our services to you.
- We may need to share your information with data hosting providers or other service providers who help us to deliver our services, projects and fundraising activities. These providers will only act under our instruction and

are obligated by contract to process your personal information appropriately and in accordance with the consent provided.

- If we are under a duty to disclose or share your personal information in order to comply with any legal obligation or to protect the rights, property, or safety of Mitrofanoff Support, our members or others.
- In the event that we merge with another charity, in which case we will disclose your personal information to the prospective charity.

## **WHERE WE STORE YOUR PERSONAL INFORMATION AND HOW WE PROTECT IT**

We use (and will procure that our third-party service providers use) technical and organisational safeguards to ensure that your personal information is kept securely. We limit access to the personal information you provide to us or that we collect about you and take appropriate measures to ensure that our people are aware that such information is only to be used in accordance with this privacy policy.

Specifically, our third-party service providers are:

- Google Drive: cloud storage provider
- Podio: data collectors
- Mail Chimp: marketing automation platform
- Hootsuite: social media post scheduler software
- Ward Goodman: charity accountants
- Wix: website hoster

## **Transfers of Information**

Where possible we and our third-party partners process your personal information within the European Economic Area (EEA). However, we may on occasion need to use the services of a supplier who has to transfer your personal information outside the EEA. It is possible that protection for personal information in countries outside the EEA is not equivalent to the level of protection within the EEA. That said, we take all reasonable steps to impose suitable safeguards to protect your personal information when processed by such suppliers, for example, entering into certain standard contractual clauses approved by the European Commission. By submitting your personal information to us you agree to such transfers, storing or processing at locations outside the EEA.

## **USE OF INFORMATION FOR MARKETING PURPOSES**

We will not provide your personal information to third parties for marketing purposes. We will only use it to market our charity services to you in line with your membership. You can also exercise your right not to receive our marketing information at any time by contacting us at [info@mitrofanoffsupport.org.uk](mailto:info@mitrofanoffsupport.org.uk).

## **RIGHT OF ACCESS**

You have a right to access your personal information, to object to the processing of your personal information, to rectify, to erase, to restrict and to port your personal information. Any requests or objections should be made in writing by emailing [info@mitrofanoffsupport.org.uk](mailto:info@mitrofanoffsupport.org.uk).

## **THIRD PARTY WEBSITES**

Our Site may, from time to time, contain links to and from the websites of our partner networks, advertisers and other charities. If you follow a link to any of these websites, please note that these websites have their own privacy policies and that we do not accept any responsibility or liability for these policies. Please check these policies before you submit any personal information to these websites.

## **AGE RESTRICTION**

If you are aged 16 or under, please obtain your parent or legal guardian's consent before you disclose any personal information to us.

## **ACCESS TO INFORMATION**

GDPR gives you the right to access information held about you. Your right of access can be exercised in accordance with GDPR. Any access request will be subject to a fee of £10 to meet our costs in providing you with details of the information we hold about you.

## **HOW TO MAKE A COMPLAINT**

If you are unhappy with the way in which your personal information has been processed, you may in the first instance contact us using the contact details above.

If you remain dissatisfied, then you have the right to apply directly to the Information Commissioner for a decision. The Information Commissioner can be contacted at: -

Information Commissioner's Office,  
Wycliffe House,  
Water Lane,  
Wilmslow,  
Cheshire,  
SK9 5AF  
[www.ico.org.uk](http://www.ico.org.uk)

## **CHANGES TO OUR PRIVACY POLICY**

Any changes we make to our privacy policy in the future will be posted on our website and, where appropriate, notified to you by e-mail.

## **CONTACT**

Questions, comments and requests regarding this privacy policy are welcomed and should be addressed to [info@mitrofanoffsupport.org.uk](mailto:info@mitrofanoffsupport.org.uk).