

## **THE BRITISH TRUST FOR THE MYELIN PROJECT**

### **PERSONAL DATA PRIVACY POLICY**

#### **History of the Project and who we are**

1. As required under the General Data Protection Regulations 2016, (which we shall refer to as the “Regulations”), the Myelin Project (which we shall refer to as “MP” or “we”, “us, or “our”) has undertaken an assessment of its responsibilities under law. We are a controller of your personal data under the Regulations and responsible for your personal data. The purpose of this policy is to explain why and how we collect and use your personal data. We will first explain the purposes of MP and a short history of its existence. It is important that you read this privacy policy together with any other privacy policy or fair processing policy 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.
2. The purposes of MP as defined by its current Deed of Trust are the relief of sickness and the promotion of medical research on therapies concerning myelin diseases. MP was formed for this purpose in February 1990.
3. In the recent period of five years MP has received a number of substantial legacies and also regular financial contributions which have enabled it to be in receipt of funds for the purposes of MP and in particular for medical research. [EY1]
4. Who we collect Personal Data from and how do we collect it

We collect and process personal data about individuals who have either made enquiries of MP as to its current activities or sought advice for particular problems or alternatively contacted us regarding making prospective gifts, denotations or legacies for MP’s purposes. We process data where this as it necessary for our legitimate interest (to assist our supporters and to manage our finances) or where we are required by law to do so (for example keeping data for tax purposes).

As you interact with our website, we will automatically collect technical data about your equipment, browsing actions and patterns. We collect this personal data by using cookies and other similar technologies. We process data where this is necessary for our legitimate interest (to keep our website updated and relevant).

We will receive personal data about you from various third parties, namely technical information from analytics providers such as Google and financial information from providers of payment services such as your bank. We process this for the reasons given above.

5. The Information that is Stored

We collect the name, title, address, telephone numbers and any other information voluntarily provided including details of any donations made or promised in the future (such as bank account and payment card details). 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.

6. If you fail to provide Personal Data

Where we need to collect personal data and you fail to provide that data when requested, we may not be able to answer your enquiries or take your donation.

7. Who we disclose your Personal Data to

We may share your personal data with service providers who provide IT and system administration services, professional advisers including lawyers, bankers, auditors and insurers and with HM Revenue & Customs, regulators and other authorities for the reasons already given. We require all third parties to respect the security of your personal data and to treat it in accordance with the law. We do not allow our third-party service providers to use your personal data for their own purposes and only

permit them to process your personal data for specified purposes and in accordance with our instructions.

### **Current Policies and Principles relating to MP with particular reference to Data Protection**

8. There are no current plans to change the current policy but should MP wish to reinstate the principle of making contact with interested persons then it would only do so on the basis that those persons had previously consented to being contacted after being informed of the intended purpose.
  
9. We will comply with data protection law and ensure that any personal information held in the future will be:-
  - (i) Used lawfully, fairly and in a transparent way
  - (ii) Collected only for valid purposes that we have clearly explained to the person concerned and not used in any way that was incompatible with that purpose,
  - (iii) Relevant to purposes disclosed and limited only to those purposes,
  - (iv) Accurate and kept up to date,
  - (v) Kept only as long as necessary for the purposes we have explained and usually not in excess of five years from the time it was first received without obtaining consent to hold it any longer than that (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, regulatory, tax, accounting or other requirements),
  - (vi) Kept securely (we will take reasonable steps to do this). 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. We have put in place procedures to deal with any suspected personal data breach and will notify you and any applicable regulator of a breach where we are legally required to do so.

## 10. Your legal rights

Please be aware that, under certain circumstances, you have the following rights:

- 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.
- 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 particular 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.
- 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. (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.

- Withdraw consent at any time where we are relying on consent to process your personal data. However, this will not affect the lawfulness of any processing carried out before you withdraw your consent.

11. 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.

### **Questions and Complaints**

12. Anyone that is unhappy with the way we are managing personal data can complain to the Information Commissioners Office at Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire, K9 5AF. Tel: 0303 123 1113 or 01625 545 745. We would, however, appreciate the chance to deal with your concerns before you approach the ICO so please contact us in the first instance.
13. For current information regarding the Project the interested persons are referred to The Myelin Project <https://www.myelin.org/> . If you have any other questions please contact our Secretary at 173 Wollaton Road, Ferndown, Dorset, BH22 8QS. The Project is associated with similar Trusts with similar objects existing in other companies including the U.S.A. from time to time but no personal information is provided to or shared with any such Trusts. [We do not transfer your personal data outside the European Economic Area (EEA).]

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