**DMD Pathfinders Data and Privacy Statement**

This privacy policy sets out how DMD Pathfinders uses and protects any information that you give us when you use our services.

DMD Pathfinders is committed to ensuring that your privacy is protected. Should we ask you to provide certain information by which you can be identified, then you can be assured that it will only be used in accordance with this privacy statement.

DMD Pathfinders may change this policy from time to time by updating this page. You should check this page from time to time to ensure that you are happy with any changes. This policy is effective from [date].

**What we collect and why**

We may collect the following information:

* When browsing our website, we may collect your IP address and website usage data to support the future development of our website.
* When you register to be a supporter or member, we will collect your personal data (name, date of birth, contact information including email address, and whether you are an adult with DMD/parent/carer/relative) using Polldaddy, a third party application. We use this information to provide updates about what DMD Pathfinders is doing and to tell you about opportunities for you to get involved and to gather feedback (including direct marketing purposes) in accordance with your preferences regarding how and when you wish this information to be provided.
* When you provide your email address via our website or agree during the member application process to receive our email newsletter, we will input your name and email address into Mailchimp, a third party application, to enable easy distribution of the newsletter. Mailchimp may share this information about our Subscribers with third parties in order to provide and support their Services or to make certain features of their Services available to us.
* When you request advice or advocacy, we may collect your personal data as defined above and record information and opinions about the issues you have asked us to look at. We will use this data to help you achieve the outcome you want.
* When you complete a survey, we will collect your personal data as defined above, as well as a range of other information you provide when answering the survey questions, using Polldaddy, a third party application.. We will use this data in an anonymized way to provide information to commissioners and health professionals to evidence need for specific services and our reach. We will tell you how the information will be used before you complete each survey.
* When you register or attend one of our events, we may collect your personal data as defined above as well as your preferences/interests in engaging with DMD Pathfinders. We will use this information to ensure our events meet your needs and may use the information to contact you to invite you to become a member or sign up to our newsletter.
* We use a third party provider, Hootsuite to manage our social media interactions. If you send us a private or direct message via social media the message will be stored by Hootsuite for three months. It will not be shared with any other organisations.
* If someone makes a complaint to us we make up a file containing the details of the complaint. This normally contains the identity of the complainant and any other individuals involved in the complaint. We will only use the personal information we collect to process the complaint and to check on the level of service we provide. We usually have to disclose the complainant’s identity to whoever the complaint is about. This is inevitable where, for example, the accuracy of a person’s record is in dispute. If a complainant doesn’t want information identifying him or her to be disclosed, we will try to respect that. However, it may not be possible to handle a complaint on an anonymous basis.
* If you apply to work or volunteer for DMD Pathfinders, we will only use the information you supply to us to process your application and to monitor recruitment statistics. Where we want to disclose information to a third party, for example where we want to take up a reference or obtain a ‘disclosure’ from the Criminal Records Bureau we will not do so without informing you beforehand unless the disclosure is required by law. Personal information about unsuccessful candidates will be held for 12 months after the recruitment exercise has been completed, it will then be destroyed or deleted. If you take up up employment or a volunteering role with DMD Pathfinders, we will compile a file relating to your employment/volunteering. The information contained in this file will be kept secure on our Google Drive and will only be used for purposes directly relevant to your employment of volunteering. Once your employment/volunteering with DMD Pathfinders has ended, we will retain the file in accordance with the requirements of our retention schedule and then delete it.

**Security of your data**

We are committed to ensuring that your information is secure. In order to prevent unauthorised access or disclosure,we have put in place suitable physical, electronic and managerial procedures to safeguard and secure the information we collect online.

Personal data on members and supporters is collected via the registration poll hosted by Polldaddy. This data is stored on the Polldaddy servers for 7-14 days while it is transferred to our user database, after which point it is permanently deleted. Data stored on Polldaddy is not encrypted but is subject to Automattic’s Privacy Policy. On completing the survey users are informed of this and if they prefer to submit registration data more securely they can provide this over the phone instead.

Data collected from additional Polldaddy surveys will be stored on the Polldaddy servers until the completion of the survey period, after which point they will be transferred to our Google Drive and permanently from the Polldaddy servers. Data stored on Polldaddy is not encrypted but is subject to Automattic’s Privacy Policy. On completing the survey users are informed of this and if they prefer to submit survey data more securely they can provide this over the phone instead.

Email addresses will be stored on Mailchimp servers until an individual requests their data be removed. DMD Pathfinders has a data processing agreement with Mailchimp which complies with UK/EU data protection legislation. Mailchimp has put in place suitable physical, electronic and managerial procedures to safeguard and secure the information it holds.

Personal data is stored by DMD Pathfinders on a spreadsheet on Google Drive. This is available only to DMD Pathfinders staff and volunteers where their roles specifically require access to this data

As part of the G Suite, Google Drive provides a high level of data encryption and its securoity measures comply with ISO 27001 standards on security.

DMD Pathfinders has an data processing agreement with Google which ensures compliance with data protection legislation. Google agrees not to use or share any data we store on Google Drive.

In addition to this privacy policy, DMD Pathfinders has a comprehensive Data Protection Policy which sets out key principles and safeguards for maintaining data protection in line with the data protection act.

**How we use cookies**

A cookie is a small file which asks permission to be placed on your computer's hard drive. Once you agree, the file is added and the cookie helps analyse web traffic or lets you know when you visit a particular site. Cookies allow web applications to respond to you as an individual. The web application can tailor its operations to your needs, likes and dislikes by gathering and remembering information about your preferences.

We use traffic log cookies to identify which pages are being used. This helps us analyse data about web page traffic and improve our website in order to tailor it to customer needs. We only use this information for statistical analysis purposes and then the data is removed from the system.

Overall, cookies help us provide you with a better website, by enabling us to monitor which pages you find useful and which you do not. A cookie in no way gives us access to your computer or any information about you, other than the data you choose to share with us.

You can choose to accept or decline cookies. Most web browsers automatically accept cookies, but you can usually modify your browser setting to decline cookies if you prefer. This may prevent you from taking full advantage of the website.

**Links to other websites**

Our website may contain links to other websites of interest. However, once you have used these links to leave our site, you should note that we do not have any control over that other website. Therefore, we cannot be responsible for the protection and privacy of any information which you provide whilst visiting such sites and such sites are not governed by this privacy statement. You should exercise caution and look at the privacy statement applicable to the website in question.

**Controlling your personal information**

You may choose to restrict the collection or use of your personal information in the following ways:

* whenever you are asked to fill in a form on the website, look for the page that allows you to agree what your data can be used for, including preventing your data being used for direct marketing purposes
* if you have previously agreed to us using your personal information for direct marketing purposes, you may change your mind at any time by writing to or emailing us at [info@dmdpathfinders.org.uk](mailto:info@dmdpathfinders.org.uk)

We will not sell, distribute or lease your personal information to third parties unless we have your permission or are required by law to do so. We may use your personal information to send you promotional information about third parties (e.g. pharmaceutical companies, equipment companies, etc.) which we think you may find interesting if you tell us that you wish this to happen.

You may request details of personal information which we hold about you under the Data Protection Act 1998. A small fee may be payable. If you would like a copy of the information held on you please contact us at [info@dmdpathfinders.org.uk](mailto:info@dmdpathfinders.org.uk)

If you believe that any information we are holding on you is incorrect or incomplete, please write to or email us as soon as possible, at the above address. We will promptly correct any information found to be incorrect.

**Where you can get more information**

You can access information about your rights to data on the information Commissioner’s office website here: <https://ico.org.uk/>

Please contact us for any additional information or if you would like to see our data protection policy and relevant data processing agreements.