

## **Data Protection and Privacy Policy**

### **Contents**

- Purpose of policy
- Responsibility for your data
- Why we collect data
- How we use your data
- What data we collect
- Our legal process for processing personnel data
- Data storage
- Your rights
- Confidentiality and security of your data
- Who we share data with
- History and updates

### **Purpose of policy**

Desmoid Aid UK (“us”, “we”) respects the privacy of every person who visits our website and online publications (“you”) and are committed to ensuring a safe online-experience. This privacy policy outlines the personal data we may collect about you and how we may process it, as well as how our service providers might do the same. This privacy statement also tells you about your rights to control this data.

### **Responsibility for your data**

Desmoid Aid UK is subject to the General Data Protection Regulation and the Data Protection Act 2018. We are registered with the Information Commissioners Office as a Data Controller.

### **Why we collect data:**

We collect, store and process personal data for the following purposes:

- To help us improve our service to you
- Inhouse marketing (opt out option for all users)

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- Research into Desmoid Fibromatosis tumours, only with your consent and with affiliated organisations
- Annual reporting to the Charity Commission; Desmoid Aid UK's annual report and selected pre agreed partners with Desmoid Aid UK
- HMRC

Our primary goal in collecting personal data from you is to give you an enjoyable customised experience whilst allowing us to provide services and features that most likely meet your needs. We do give you the option to access our sites' homepages without subscribing or registering or disclosing your personal data. Please note that we do not intend to collect any personal data from children under thirteen years of age and no child under thirteen should submit any personal data to any of the sites. Should we discover that any such personal data has been delivered to any of the sites, we will remove that information as soon as possible.

#### **How we use data:**

1. Please note that Desmoid Aid UK website might contain links to external sites. This privacy statement does not cover the activities of such third parties. You should consult those third party sites' privacy policies for information on how your data is used by them. Desmoid Aid UK does not sell or pass on personal contact details to any organisation and will not do so in future without asking you for a specific opt-in to that scheme.
2. Some of your personal data may be collected and processed with the intention of providing it to other named organisations, but this will only be done where you have given your consent at the time of accessing such content or signing up for such an event (separately to this privacy statement).

#### **What data we collect**

We collect personal data such as your name, organisation and email address in order to reply to your query.

We collect personal data from donations made over £10,000

#### **Our legal process for processing personal data**

Under the General Data Protection Regulation (GDPR) and the Data Protection Act 2018, organisations are required to have a legal basis for processing personal data. The legal bases we use for processing data are:

Legitimate interests for the purposes of fulfilling our activities and the provision of our services.

Consent when people opt into our mailing lists.

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## **Data storage**

Personal data that you have submitted as part of an enquiry or grant application to us is archived after one calendar year except in exceptional circumstances where an additional enquiry or grant application is made

Your personal data is stored on servers in the European Economic Area (EEA). If we share your personal data with any third-party service provider in the course of providing you with our services, those third parties are required to process your data in accordance with contracts which comply with current European data-protection legislation.

## **Your rights:**

Under the GDPR and the Data Protection Act 2018, you have the following rights:

**Right to be informed.** This Policy provides you with information in relation to how your data is processed. This ensures that we are transparent about what we will do with the information you supply to us.

**Right to object to the processing that is likely to cause you damage or distress.** Where you challenge the accuracy or lawful processing of your information, we will consider this.

**Right to receive an electronic copy of any information you have consented to us holding.** You can ask us to provide you with the personal data about you we hold, securely and in a machine-readable format, so it can be moved, copied or transferred to be used across different services or for you to give to another organisation. This is called a subject access request and we will need to verify your identity before giving such information.

**Rights related to automated decision making.** If there is additional profiling based on the information we hold, then you can object to us making decisions about you based on such processing.

You can make a request at any point by email to the charity. We will respond to a request within one month of receipt. However, where a request is received to erase data, we may not be able to delete all data (for example where data is linked to financial transactions that must be kept for a set period of time under financial regulations).

We use cookies on our website to improve the performance of the site.

## **Confidentiality and security of your personal data**

We are committed to keeping the data you provide us secure and will take reasonable precautions to protect your personal data from loss, misuse or alteration. The transmission of information via the internet is not completely secure. Although we will do our best to protect your personal data, we cannot guarantee the security of your data transmitted to our site; any transmission is at your own risk. Once we have received your information, we will use strict procedures and security features described above to try to prevent unauthorised access.

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Data processors (i.e. those who process your personal data on our behalf, for the purposes listed above), who have access to, and are associated with the processing of your personal data, are obliged to keep the information confidential and not use it for any other purpose than to carry out the services they are performing for us in line with the standards set out in the GDPR.

**Who we share data with:**

We may share personal data with third parties for the purposes of providing services to you, such as associated charities.

Finally, we will share data with the appropriate authorities (e.g., police, law enforcement agencies and other parties) where we have a legal obligation. For example, for the detection and prevention of fraud, or where data is required in relation to a criminal offence.

We do not sell or share data with any other third parties other than those listed above, covered under the trading data clause and where we use a third party to securely process our data on our behalf.

**History and updates**

This privacy policy is subject to occasional revision, and we place any updates on this web page. If we make substantial changes to this privacy policy, we will notify you through the website interface, or, if you have provided your email address, by email. You are always responsible for keeping your email address up to date. Any changes to this privacy policy will be effective immediately and your continued use of our websites after such time shall constitute your acceptance of the amended policy.