

Your Privacy

PRIVACY POLICY

We are committed to keeping the personal information we hold safe and secure. We do not share your personal information with anyone, unless we have your permission.

This Privacy Policy may change from time to time. Please visit this website section periodically in order to keep up to date with the any changes.

If you have any questions about this policy or our privacy practices you can email us at info@pmrgca.org.uk call us on 0300 999 5090, or write to us at PMRGCAuk, BM PMRGCAuk London WC1N 3XX.

WHO ARE WE?

Polymyalgia Rheumatica & Giant Cell Arteritis UK (PMRGCAuk) is a registered charity established to meet the needs of people with these debilitating conditions, their friends, families and helping professionals.

Our registered charity number is 1128723 and our company number is 6763889.

We are a "data controller" for the purposes of the Data Protection Act 1998 and the EU General Data Protection Regulation 2016/679 (known as the GDPR). This means that we are responsible for, and control the processing of, your personal information.

WHAT DATA DO WE COLLECT, WHY DO WE COLLECT IT AND WHAT IS THE LEGAL BASIS FOR COLLECTING IT?

Membership

When you become a member of the charity (online or by post) we ask for your contact details so we can process your membership application and send you a membership card, as well as our *NewsWire* magazine and other updates if you choose to receive these.

Unless you are a professional member, we ask for additional personal information including your date of birth and whether you have or had PMR and/or GCA. We collect this information to give us an overview of our members - this helps us to tailor our support and information services accordingly.

When you renew your membership each year, we ask these same questions again and change our records if your answers change. If your membership lapses, we take you off the mailing list so you no longer receive anything from us. This ensures we keep our data records up to date and accurate.

When we are processing your membership application or renewal, or need to contact you specifically about your membership, we do so using the legal basis of [legitimate interest](#). When you join as a member or renew membership, we ask if you would like to receive our newsletters and other updates by email and/or post. The legal basis on which we send these is having received your [consent](#).

Health information such as whether you have or had PMR and/or GCA is a special category of data. We collect and process it [in the course of our legitimate activities](#) to provide the best service to our members and - as with all personal data - do not disclose it to anyone outside the charity.

Email mailing list

When you sign up for our email mailing list via our website or at an event or conference, we ask for your email address so we can send you our newsletters and other email updates from the charity. The legal basis on which we send these is having received your [consent](#). We continue to send these updates until you unsubscribe.

Our mailing list is hosted by Salesforce. You can read their privacy policy here: <https://www.salesforce.com/uk/company/privacy/>

Helpline

If you call our helpline, we make a written record of some of the information you give us during the call, such as how long ago you were diagnosed, whether you have PMR or GCA or both and the reason for your call. For monitoring and evaluation purposes we aggregate this information and anonymise it - this means that individual callers can not be identified from the monitoring and evaluation report.

In addition, we ask if you consent to us recording your name on a call record. This means that if you phone the helpline again, the person who answers is able to refer to notes from a previous call and may be better able to help. However, if you do not agree to this, we do not record your name.

Other circumstances

If you provide us with your personal data in other circumstances - for example providing your postal or email address so that we can supply our information pack - we only use this data to fulfil your request. You will not be added to our mailing list unless you explicitly opt in.

MEMBERSHIP PAYMENTS AND DONATIONS

Any financial information you submit to our online membership system is processed exclusively by Stripe. You can read their privacy policy here: <https://stripe.com/gb/privacy>

Any financial information you submit to our online donations page is processed exclusively by Stripe. You can read their privacy policy here: <https://stripe.com/gb/privacy>

Any money raised from fundraising via our Virgin Money Giving page is processed by Virgin Money Giving. You can read their privacy policy here: <https://uk.virginmoneygiving.com/giving/terms/privacy-policy.jsp>

PMRGCAuk does not hold any financial data or have access to it.

STORING DATA

Data is stored securely on our Salesforce database, in Dropbox folders, within Gmail and Mailchimp and in the PMRGCAuk website. Where data is stored on paper (for example our membership forms) these are stored securely by a staff member and shredded when they are no longer needed.

DO WE SHARE YOUR PERSONAL DATA WITH ANYONE ELSE?

PMRGCAuk does not and will never share personal data with anyone else without express consent. The only exception to this would be if we were legally obliged to do so.

HOW CAN I LEAVE YOUR MAILING LIST?

You can leave any time you choose, just let us know by calling 0300 999 5090, sending an email to info@pmrgca.org.uk or writing to BM PMRGCAuk, London WC1N 3XX. Every e-newsletter will also have an unsubscribe option at the end. Under the GDPR we are obliged to act on your request as soon as possible and at least within one month.

WHAT ARE MY RIGHTS?

Under the General Data Protection Regulation (GDPR) anyone whose personal data is stored by PMRGCAuk has a set of rights relating to it. Those rights are as follows:

- The right to be informed
- The right of access
- The right to rectification
- The right to erase
- The right to restrict processing
- The right to data portability
- The right to object
- Rights in relation to automated decision making and profiling.

If you would like to exercise one or more of the rights in relation to the data we hold about you please let us know in writing and we will be happy to help.

For information on what these rights mean please visit the Information Commissioner's Office website: <https://ico.org.uk/for-organisations/guide-to-the-general-data-protection-regulation-gdpr/individual-rights/>

CAN I COMPLAIN ABOUT HOW YOU ARE USING MY PERSONAL DATA?

If you think we are handling your data incorrectly, please contact us in the first instance and we will do everything possible to rectify the situation. If you are not happy with our response you have a right to contact the <https://ico.org.uk/>