

Maternal Pituitary Support Community Interest Company Company Number: 13907290 Registered Address: 7 Bell Yard Street, Holborn, London, WC2A 2JR

Maternal Pituitary Support Privacy Policy Updated 27 May 2022

This Privacy Policy, along with information on our website may be subject to change at any time, without notice.

This Privacy Policy was updated 27 May 2022.

This Privacy Policy applies to Maternal Pituitary Support Community Interest Company ("Maternal Pituitary Support", "we", "us", "our") and you the Member ("Member", "you", "your").

If you do not accept this Privacy Policy, you must cease using our website, membership and community immediately.

By joining and remaining as a Member, the Member confirms that they have read, understood and agree to the Membership Agreement, Terms & Conditions and Privacy Policy.

1. About us

- a. Maternal Pituitary Support promises to respect any personal data you share with us and keep it safe. We will be clear when we collect your data and we will not share your data with a third party.
- b. We only send marketing communications by email if you have explicitly stated that you are happy for us to do so. We may send marketing communications to you by post or telephone as long as you have not opted-out, and we feel there is a legitimate interest in you receiving the communications.
- c. Our marketing communications includes information and latest news regarding our work, information about our membership, our campaigns, events and fundraising activities.
- d. If you want to change your communication preferences at any time please contact us on info@maternalpituitarysupport.org

2. Where do we collect information about you?

- a. When you give information to us directly, you may give us your information when doing some of the following activities.
 - Signing up to our e-newsletter through our website.
 - Using our Contact Us form on our website.



- Through our fundraising activities e.g. signing up to an event, becoming a member, making a donation.
- When joining our campaigns, events, research or awareness activities.
- b. As you use our website, community and membership, you may give us your information when doing the following activities.
 - Like most websites, we use "cookies" to help us make our site and the way you use it – better. Cookies mean that a website will remember you. They are small text files that sites transfer to your computer (or phone or tablet). They make interacting with a website faster and easier – for example by automatically filling your name and address in text fields.
 - In addition, the type of device you are using to access our website or apps and the settings on that device may provide us with information about your device, including what type of device it is, what specific device you have, what operating system you are using, what your device settings are, and why a crash has happened. Your device manufacturer or operating system provider will have more details about what information your device makes available to us.
 - Our website provider is Squarespace. You can see <u>Squarespace's</u> <u>Privacy policy here.</u>
- c. Information available publicly.
 - This may include information found in places such as Companies House and information that has been published in articles/ newspapers.
- d. Social Media.
 - Depending on your settings or the privacy policies for social media and messaging services like Facebook, WhatsApp or Twitter, you might give us permission to access information from those accounts or services.

3. What personal data do we collect?

The type and quantity of information we collect and how we use it depends on why you are providing it. Depending on the specific activity, we may process the following kinds of information.

- a. Personal information including but not limited to the following: name, postal address, phone number, email address, date of birth, financial/payment information.
- b. Sensitive personal information, such as your health condition.
- c. Non-personal information such as IP addresses (the location of the computer on the internet), pages accessed and files downloaded. This



helps us to determine how many people use our website, how many people visit on a regular basis, and how popular our pages are. It allows us to monitor and improve our service.

4. Sensitive personal information

Some of the personal information you may share with us falls under what is deemed as sensitive information, for example, your health condition.

- a. This information is subject to even stricter rules than ordinary personal information and you can be assured that any sensitive information you choose to give will be kept confidential and only used in accordance with this privacy policy.
- b. When requesting sensitive information we will seek your consent.

5. How do we use your information?

We will mainly use your data for the following services.

- a. Provide you with the services, products or information you asked for.
- b. Administer your donation or membership.
- c. Keep a record of your relationship with us and how you prefer to be contacted.
- d. Understand how we can improve our services, products or information.
- e. Send marketing communications to you.

6. Membership

- a. If you are a Member of Maternal Pituitary Support you can use our online Membership Community on the platform Guild. When you become a Member we provide you with a user name and password to access Guild. Posts to the Community are public and are likely to contain sensitive information. We advise users to be careful not to post information which would allow them to be identified. You can see Guild's Privacy Policy here.
- b. We may also collect, analyse and retain your information if you send feedback about our services, participate in surveys or make a complaint.
- c. You may also follow Maternal Pituitary Support on social media e.g. Instagram, Facebook, Twitter and Linkedin. Posts to social media sites are public and are likely to contain sensitive information. We advise users to be careful regarding the information they post and to read the privacy policies of these websites.

7. Sharing your story

a. Some people choose to tell us about their experiences with postpartum hypopituitarism to help further our work. You may take on a role as an ambassador, attend patient focused events, share your story in our



- communications, or with the media. This may include sharing sensitive information related to your health and family life in addition to biographical and contact information.
- b. Should you, your family or Health Care Professionals, or places treating you, not want to be identified, we advise caution and to use first names only, or to change names.

8. Supporting us – Fundraising, Membership and Marketing

- a. We only send marketing communications by email if you have explicitly stated that you are happy for us to do so. We may send marketing communications to you by post or telephone as long as you have not opted-out, and we feel there is a legitimate interest in you receiving the communications. Our marketing communications include: latest news regarding our work, information about our membership, our campaigns, events and fundraising activities.
- b. If you want to change your communication preferences or do not want to hear from us, that is fine. Just let us know when you provide your data or contact us on info@maternalpituitarysupport.org
- c. We administer donations, memberships and other payments received online through our website and by cheques in the post. This includes thanking you for donations. We use Stripe to process our online payments. You can see Stripe's Privacy Policy here.
- d. We record all financial transactions on our database called Airtable and create an individual record for you. We do not retain nor store your card or payment details once the payment has been processed. We store all information inline with our Retention Schedule Policy. You can see Airtable's Privacy Policy here.

9. Building profiles of supporters and targeting communications

- a. We use your data stored in our database to manage your communications preferences.
- b. We may analyse your personal information in our database e.g. how many donations you have given, total value of gifts etc., to produce statistics, and to tailor our communications to you.
- c. We may also access public information found in places such as Companies House and information that has been published online and in articles/newspapers.

10. Third parties & marketing

- a. We do not sell nor share personal details to third parties for the purposes of marketing.
- b. If we run an event in partnership with another named organisation your details may need to be shared. We will be clear with you when you register for the event what will happen to your data.



c. If you are participating in one of our fundraising events, with your consent, you may be invited to join a WhatsApp Group with other participants.

11. Website

- a. If you complete a Form on the website, e.g. Contact us, we process these forms and respond to your enquiry.
- b. We use cookies on our website provided by Squarespace. You can see Squarespace's Cookie Policy here.

12. Membership

a. We use Guild as our Membership Forum. Guild uses Cookies. You can see Guild's cookie policy here.

13. Personnel

- a. We process and store details relating to potential, current and previous staff and volunteers, in line with our retention policies. We do not collect more information than we need to fulfil our stated purposes and will not retain it for longer than is necessary.
- b. We ask you for your personal details including name and contact details. We will also ask you about your previous experience, education, referees and for answers to questions relevant to the role you have applied for.
- c. You will also be asked to provide equal opportunities information. This is not mandatory information if you do not provide it, it will not affect your application. Any information you do provide, will be used only to produce and monitor equal opportunities statistics.

14. General

- a. For general enquiries we respond to your e-mails and letters. Your personal details will only be used to provide you with information or services you request.
- b. We may communicate with you through Facebook, LinkedIn, Instagram, Twitter by responding to your messages, likes and follows.

15. Who has access to your information?

- a. We may allow our staff and volunteers to use your information for the purposes for which you have provided it to us (such as delivering mailings).
- b. We will never sell, swap or rent your information to third party organisations, and we do not share your personal information with third parties for their benefit.
- c. There are certain circumstances where we may be required to disclose your personal information by law, or court order, or in appropriate



circumstances, with law enforcement agencies when we believe it is necessary to protect our rights, property or safety and that of our staff, volunteers and supporters.

16. Information collected by third parties

a. Your information may be shared with us by third party organisations, for example fundraising sites like Virgin Money Giving and JustGiving. They will do so pursuant to their own policies on data protection and privacy. It is a good idea to check their privacy policy when you provide your information to understand fully how they will process your data.

17. How we keep your information safe

We place a great importance on the security of all personally identifiable information associated with our supporters, service users, volunteers and staff.

- a. We have security measures in place to attempt to protect against the loss, misuse and alteration of personal data under our control. We comply with the Payment Card Industry Security Standard and the Government-backed Cyber Essentials Scheme.
- b. We use secure server software including secure sockets layer (SSL) to encrypt financial and personal information you input before it is sent to us. While we cannot ensure or guarantee that loss, misuse or alteration of data will not occur while it is under our control, we use our best efforts to try to prevent this.
- c. Information is stored by us on computers located in the UK. Our emails are Cloud based and this data is saved on servers located in the UK. We may transfer the information to other reputable third party organisations as explained above. We may also store information in paper files.
- d. We undertake regular reviews of who has access to information that we hold to ensure that your information is only accessible by appropriately trained staff, volunteers and third party organisations who have been contracted by us to process data. Our approach to personal information involves restricting access to sensitive personal information e.g. health information, to only those departments that need this data in order to carry out their functions.
- e. Unfortunately, the transmission of data across the internet is not completely secure and whilst we do our best to try to protect the security of your information we cannot ensure or guarantee that loss, misuse or alteration of data will not occur whilst data is being transferred.
- f. Where you, or we, have provided a password enabling you to access Guild, it is your responsibility to keep this password confidential. Please don't share your password with anyone.



18. Retention periods

- a. We will keep your information only for as long as we need it to provide you with the goods, services or information you have required, to administer your relationship with us, including your communication preferences. Different types of information have different retention periods e.g. financial information must be kept for six years.
- b. When we no longer need information we will always dispose of it securely, using specialist companies if necessary to do this work for us.

19. Keeping your information up-to-date

- a. We really appreciate it if you let us know if your contact details change.
- b. We may also periodically use publicly available sources to keep your records up to date; for example, the Post Office's National Change of Address database.

20. Your data rights

- a. You can change your communication preferences and also withdraw your consent at any time. You also have the right for inaccurate personal data to be rectified, or completed if it is incomplete, and you can ask us to limit or stop processing your data and erase your data.
- b. Contact us by email to info@maternalpituitarysupport.org
- c. You have the right to access your personal data and supplementary information. If you want to access your information, send a description of the information you want to see and proof of your identity by post to Maternal Pituitary Support, 7 Bell Yard Street, Holborn, London WC2A 2JR. We do not accept these requests by email so we can ensure that we only provide personal data to the right person.
- d. If you have any questions or complaints please send these to info@maternalpituitarysupport.org and for further information about your data rights please see the Information Commissioner's guidance here.
- e. Should your complaint regarding handling of your personal data by Maternal Pituitary Support not be resolved to your satisfaction, you can make a formal complaint to the Information Commissioner's Office.

21. Changes to our Privacy Policy

a. We keep our privacy notice under regular review and we will place any updates on our website.

22. How to contact us

Please contact us if you have any questions about our Privacy Policy or personal data we hold about you.





- a. Our email address is info@maternalpituitarysupport.org
- b. Our postal address is Maternal Pituitary Support, 7 Bell Yard Street, Holborn, London WC2A 2JR, United Kingdom

By joining and remaining as a Member, the Member confirms that they have read, understood and agree to the Membership Agreement, Privacy Policy and Terms & Conditions.