

Forgotten Patients, Overlooked Diseases

Terms and Conditions of Membership

These Terms and Conditions (“Terms”) apply to all members of Forgotten Patients, Overlooked Diseases (“FPOD”, “we”, “us”, “our”).

By applying for or renewing membership of FPOD, you agree to these Terms.

1. About Forgotten Patients, Overlooked Diseases

Forgotten Patients, Overlooked Diseases is a UK registered charity (Charity No. 1202442).

Our purpose is to support patients affected by overlooked and complex conditions through education, discussion, advocacy, research, learning, and the development of resources.

2. Membership

Membership of FPOD is available to individuals who pay the annual membership fee.

Members may:

- Vote on key charity decisions, where members are entitled to vote under FPOD’s governing document
- Stand for election or appointment as a trustee, subject to eligibility, FPOD’s governing document, and applicable charity law
- Participate in FPOD projects, events, meetings, and working groups
- Receive updates, opportunities, resources, and communications from FPOD
- Help raise awareness of overlooked and complex conditions and support FPOD’s charitable aims

Membership does not give a member authority to enter into commitments, make representations, or act on behalf of FPOD unless expressly authorised to do so.

3. Membership Term, Fees and Renewal

- Membership runs for 12 months from the date payment is received.
- The annual membership fee is £10.
- Renewal reminders may be issued before the end of the membership period.
- Membership will normally need to be renewed annually for membership rights to continue.
- Membership fees are used to support FPOD’s charitable activities, including events, publications, educational and learning initiatives, research, advocacy, and the development of resources.
- Membership fees are non-refundable except at the discretion of the trustees.

FPOD reserves the right to review and amend the membership fee. Members will be informed of any change before it applies to their next membership period.

4. Member Responsibilities and Conduct

Members are expected to:

- Act respectfully towards other members, patients, volunteers, trustees, speakers, partners, and others engaging with FPOD
- Support FPOD's charitable aims and values
- Engage constructively and appropriately in FPOD discussions, meetings, events, and activities
- Respect the privacy and confidentiality of others
- Not misuse FPOD platforms, materials, resources, events, or communications
- Not engage in behaviour that is harmful, abusive, discriminatory, misleading, defamatory, or otherwise inconsistent with FPOD's charitable aims
- Not claim to represent or speak on behalf of FPOD unless authorised to do so

FPOD reserves the right to suspend or terminate membership where a member's conduct is considered inconsistent with these Terms, FPOD's charitable aims, or the best interests of the charity.

5. Ending or Suspending Membership

Members may end their membership at any time by contacting FPOD.

FPOD may suspend or terminate membership where:

- These Terms are breached
- Membership fees remain unpaid
- A member engages in conduct considered harmful to FPOD, its members, beneficiaries, volunteers, trustees, reputation, or activities
- Continued membership is considered by the trustees not to be in the best interests of the charity

Where appropriate, FPOD will seek to inform the member of the reason for suspension or termination.

Ending membership does not normally entitle the member to a refund of any membership fee already paid.

6. Privacy and Data Protection

6.1 Our Commitment to Privacy

FPOD is committed to protecting personal data and ensuring that it is processed fairly, lawfully, and transparently.

6.2 Data Controller

For the purposes of the Data Protection Act 2018 and UK General Data Protection Regulation (UK GDPR), FPOD is the data controller responsible for the personal information it processes.

6.3 Personal Data We May Collect

We may collect and process information including:

- Name
- Contact details, such as email address, telephone number, and postal address
- Organisation or professional role, where provided
- Membership status and membership dates
- Records of communications with FPOD
- Records or confirmation of membership payments
- Information voluntarily provided when participating in FPOD activities, events, or projects

FPOD does not store members' payment card details where payments are processed through a third-party payment provider.

6.4 How We Use Personal Data

We may use personal data to:

- Process and administer membership
- Manage membership renewals and payments
- Provide information, services, resources, and membership benefits
- Communicate about FPOD events, activities, projects, opportunities, and organisational matters
- Manage participation in FPOD meetings, events, projects, and working groups
- Meet our legal, regulatory, financial, safeguarding, and governance obligations
- Support the effective administration and operation of the charity

6.5 Legal Basis for Processing

Depending on the circumstances, FPOD may process personal data on the basis of:

- Performance of a contract, including administering membership
- Consent
- FPOD's legitimate interests as a charitable organisation
- Compliance with legal obligations

6.6 Data Sharing

FPOD does not sell or trade members' personal data.

Personal data may be shared with third parties where:

- You have given consent

- We are legally required to disclose the information
- It is necessary to administer FPOD's activities or services and appropriate data protection safeguards are in place
- We use trusted service providers to support functions such as payments, communications, website services, event management, or administration

6.7 Data Retention

Personal data will be retained only for as long as reasonably necessary for the purposes for which it was collected and to meet applicable legal, regulatory, financial, and governance requirements.

6.8 Your Data Protection Rights

Depending on the circumstances, you may have the right to:

- Request access to the personal data FPOD holds about you
- Request correction of inaccurate or incomplete information
- Request deletion of your personal data where applicable
- Withdraw consent where processing is based on consent
- Object to or request restriction of certain processing
- Request transfer of your personal data where applicable

You may also unsubscribe from optional FPOD communications at any time.

7. Communications

As part of your membership, FPOD may contact you with information necessary to administer your membership, including renewal information, organisational updates, and information relating to membership activities.

FPOD may also send information about events, projects, resources, opportunities, fundraising, newsletters, and other activities where permitted by applicable data protection and electronic communications laws.

Where applicable, you can manage your communication preferences or unsubscribe from optional communications at any time.

8. FPOD Information and Medical Disclaimer

FPOD provides information, educational resources, discussions, events, and other materials in good faith and for general information and educational purposes.

FPOD does not provide individual medical advice, diagnosis, or treatment.

Information provided through FPOD's website, events, publications, meetings, communications, or other activities should not be regarded as a substitute for advice from an appropriately qualified healthcare professional.

Members and other users should seek appropriate professional medical advice regarding individual health concerns or decisions.

9. Limitation of Liability

To the extent permitted by law, FPOD accepts no responsibility or liability for loss, damage, or adverse consequences arising from reliance on information or materials provided through FPOD's activities, resources, events, website, or communications.

Nothing in these Terms excludes or limits any liability that cannot lawfully be excluded or limited.

10. Intellectual Property and Use of FPOD Materials

Unless otherwise stated, materials produced by FPOD remain the intellectual property of FPOD or the relevant copyright owner.

Members may access and share publicly available FPOD resources for appropriate personal, educational, and non-commercial purposes, provided that FPOD and any relevant authors or copyright owners are appropriately acknowledged.

FPOD materials must not be altered, misrepresented, commercially exploited, or used in a manner that could damage FPOD's reputation without prior permission.

11. Changes to These Terms

FPOD may update these Terms from time to time to reflect changes to its membership arrangements, activities, legal obligations, or organisational requirements.

Members will be informed of significant changes where appropriate, and the most recent version of these Terms will be made available on the FPOD website.

Continued membership following an update will be subject to the latest version of these Terms.

12. Governing Law

These Terms are governed by the laws of England and Wales.

Any dispute relating to these Terms will be subject to the jurisdiction of the courts of England and Wales, unless applicable law requires otherwise.

13. Contact Us

If you have any questions about these Terms, your membership, or how your personal data is handled, please contact:

Forgotten Patients, Overlooked Diseases

Registered Charity No. 1202442

Email: Steven.walker@forgottenpatients.org