

### **Privacy Policy**

At PBC Ireland, we are committed to protecting your privacy and personal information.

**What we collect**: We may collect your name, contact details, and relevant health information when you sign up for events, newsletters, or support services.

**How we use it**: We use this information only to communicate with you, provide support, improve our services, and keep you informed about PBC Ireland activities.

**Who we share it with**: We do not share your personal information with third parties, unless legally required or with your explicit consent.

Your rights: You have the right to access, update, or request deletion of your data at any time.

**How we keep it safe**: We store your data securely and take all reasonable steps to protect it from misuse or unauthorised access.

If you have any questions or want to exercise your data rights, please contact us at info@PBCireland.org.

# **GDPR Privacy Policy**

PBC Ireland respects your privacy and is fully committed to complying with the General Data Protection Regulation (GDPR).

### What personal data we may collect

- Name and contact details
- Health-related information (only with your consent)
- Communication preferences

If we collect information in addition to the above, it will be made clear on the website.

#### Why we collect it

- Communicate with you about PBC Ireland news, events, and services
- Provide support and information related to Primary Biliary Cholangitis
- Improve our outreach and advocacy efforts

#### How we protect your data

- Your data is stored securely and only accessible to authorised volunteers or staff
- We never sell or share your data without your consent
- We keep your information only as long as necessary for our purposes or as required by law

Your rights under GDPR

1 Date: 22<sup>nd</sup> May 2025



You have the right to:

- Access the personal data we hold about you
- Request correction or deletion of your data
- Withdraw your consent at any time
- File a complaint with the Data Protection Commission (Ireland) if you believe your data rights have been violated

To update your information or make a request, please contact us at <a href="mailto:info@PBCireland.org">info@PBCireland.org</a>.

# **Complaints and Grievances Policy**

PBC Ireland is committed to a safe and respectful environment. If you have a concern about behaviour, confidentiality, or how we operate, please let us know.

You can raise a complaint by emailing <u>info@PBCireland.org</u> or speaking to a committee member. All concerns are treated confidentially and handled with fairness and care.

We aim to resolve issues promptly and respectfully.

## **Partnership and Collaboration Policy**

PBC Ireland values partnerships that support our mission to improve the lives of people affected by Primary Biliary Cholangitis.

We seek collaborations that align with our values of respect, transparency, and patient-centred care.

- Partners should share our commitment to ethical conduct, confidentiality, and inclusivity.
- All partnerships must clearly define roles, responsibilities, and expectations upfront.
- We maintain full independence in our advocacy and decision-making.
- Any use of PBC Ireland's name, logo, or materials requires prior approval.

We welcome partnerships that help us raise awareness, provide resources, and enhance support for the PBC community.

2 Date: 22<sup>nd</sup> May 2025