

# DEBRA Membership Policy

## Summary

DEBRA is a Membership organisation; our members are at the core of DEBRA's charitable work.

DEBRA's Membership Scheme plays a key role in helping to involve members in shaping DEBRA's priorities and services and enables engagement and relationship development between members and DEBRA UK in line with DEBRA's Values.

## Document control

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## Definition

The terms 'Membership' and 'Members' wherever employed in this document shall refer only to persons either having EB or having direct experience of EB which means having a close family relative or partner with EB including those who are working as health professionals or researchers specialising in EB and whose names shall from time to time be maintained on the DEBRA register of Members.

Members referred to above are separate and distinct from the legal members of the charity who shall be the Trustees. This non-legal class of membership may be termed 'EB members.'

## Purpose

The DEBRA Board of Trustees determines the rules of Membership and the Membership categories as governed by the Articles of Association of DEBRA. A Register of Members will be kept by the Membership Manager.

This policy will:

- Be clear and transparent on eligibility for membership and the associated responsibilities of DEBRA staff and members.
- Outline what DEBRA will provide to members and how DEBRA will work them in line with DEBRA's Values.

## Objectives

- To develop and maintain a well-managed Membership scheme that attracts people in the UK who are living with all types of EB, their immediate families, unpaid carers and healthcare professionals and researchers specialising in EB.
- To develop relationships and act as a central Membership body that supports and communicates relevant information and benefits to its Membership across the UK, through communication channels such as social media, email and post.
- To enable members to have a voice, and input into DEBRA's priorities, services, and values

## Policy Details

### a. **Membership eligibility:**

Membership is available to UK residents who meet one of the following criteria:

- i. Have an EB diagnosis or awaiting a diagnosis of EB (clinically presenting as EB and being treated by clinicians)
- ii. Immediate family or unpaid carer of someone diagnosed with EB
- iii. Work as a healthcare professional (inc. paid carer) or researcher, specialising in EB or have an interest in EB
- iv. Be a DEBRA trustee or committee member
- v. Be an ex-DEBRA trustee or committee member

### b. **Definitions:**

**UK resident** - your main home is in the UK, and you are registered with a UK NHS medical practitioner.

**Immediate family** – parent, guardian, spouse/partner, child, or sibling.

**Unpaid carer** - An individual who provides practical EB support on a weekly basis or more. This support will be different to what would be required for someone of a similar age, who lives without EB. For example, an unpaid carer may support with EB management, dressing changes, special meal preparation or personal care.

### c. **Where membership eligibility is not met:**

Applicants will be advised of the reason for non-acceptance and where applicable signposted to alternative DEBRA groups such as DEBRA fundraising and supporters, or other organisations and services.

### d. **How to become a member**

- DEBRA membership is free.
- A membership application form must be completed and submitted to the DEBRA membership team for processing.

- The person completing the form on behalf of others in the households does so with their consent.
- Everyone will be allocated a unique membership number and an individual record set up on our database.
- Where a membership has lapsed/been cancelled a new membership form is required.

#### **e. Membership benefits**

Benefits include but are not limited to, the following:

- Access to the Community Support Team\*
- Regular relevant member updates via post, email, and social media
- Use of the DEBRA UK holiday homes\*
- A DEBRA support grant fund\*
- Invitations to our Members' events\*
- A 10% discount in DEBRA charity shops

*\*Individual terms and conditions apply and associated policies.*

#### **f. Communicating with members**

- Communications and updates specific to the EB community is a benefit of DEBRA membership. The only circumstance where we will not send out communications is when a member has requested not to receive them.
- On occasion when post is sent out to members, only one copy will be sent to the household.

#### **g. Membership Data and records**

- The Membership Manager and Company Secretary are responsible for maintaining a register of members.
- **DEBRA's Privacy Policy** sets out how DEBRA uses and protects information you give us. DEBRA will always process your data fairly and lawfully and will only collect data from you for the purposes specified in our Privacy Policy to deliver our services and provide support.

- DEBRA respects Members' privacy and will not pass on details to any third party without appropriate consent. Information that has been archived will only be shared with a relevant professional if we are legally bound to do so.
- Full details of DEBRA's Privacy Policy can be found at [www.debra.org.uk/privacy](http://www.debra.org.uk/privacy).
- Members are responsible for advising DEBRA of changes to their contact details. This will ensure we do not lose contact with a member and membership lapses and is cancelled.
- The online 'change to membership' form should be completed <https://www.debra.org.uk/join-the-debra-membership-scheme/membership-change-of-info-form>. Alternatively, members can notify the membership team by email or telephone.
- DEBRA will archive/remove from the database any individual who no longer wishes to be a member, or for any of the reasons listed in section h.
- Data will be managed in line with DEBRA's Data Retention policy.

#### **h. Cancellation of membership**

Membership will be cancelled in the following circumstances:

- When we are notified that a member has died.
- At the request of a member.
- DEBRA has lost contact with the member and are unable to communicate with them on 2 or more occasions over a 12-month period. Notification that membership will be cancelled will be sent, where possible, to the last known contact's details available (an example would be where mail has been returned twice in 12 months and no contact has been possible by phone or email). Membership will be reinstated on receipt of updated contact details.
- A member no longer resides in the UK.
- DEBRA has a right to cancel membership. This includes, but is not limited to, non-compliance with DEBRA's policies or terms and conditions, or acting in a way that does not reflect DEBRA's Values.
- Membership records will be archived in accordance with DEBRA's Retention Policy.

## Trustee nominations

Members are encouraged to apply to be a committee member or a Trustee of the Charity. Committee membership and Trustee opportunities will be published on the website and promoted as one of the ways that members can get involved with DEBRA

## Diversity monitoring

DEBRA is committed to serving people living and working with EB. By providing us with accurate data via the Membership Application Form, you help us to ensure we provide services fairly to all our members and help form our strategy for reaching out to new members in the future.

DEBRA's Equality, Diversity & Inclusion policy can be viewed here: <https://www.debra.org.uk/equality-diversity-inclusion-policy>

## Compliments and complaints

If a member wishes to raise a concern, make a complaint or submit a compliment about anything relating to Membership or the Membership scheme, they should in the first instance contact the Membership Manager. DEBRA's policy for Concerns, complaints and compliments can be viewed here:

<https://www.debra.org.uk/compliments-and-complaints>

## Reference documents

- DEBRA GDPR policy
- DEBRA Support of Non-UK Citizens Residing in the UK Policy
- DEBRA Community Team Referral policy
- DEBRA Equality and diversity policy
- DEBRA Compliments and Complaints Policy

## Contacting us

Membership Manager

DEBRA

The Capitol Building

Oldbury

Bracknell

Berkshire

RG12 8FZ

Email: [membership@debra.org.uk](mailto:membership@debra.org.uk)

Telephone: 01344 771961 option 1

## Sign-off

Name	Date	Signature
SLT	January 2024	
CPC	January 2024	