

Appendix A – Examples of member involvement activities across DEBRA

Member Services

- Member Services involves the EB community in identifying needs, priorities, satisfaction levels, and activities that directly support people living with EB, for example in prioritising grants, “pathways” project for proactive and self-help support at key life stages, location of new holiday homes, and ways of enabling members to meet and share experiences online and in person.
- Members are involved in the design of Members’ Weekends.
- Healthcare professional members are involved in developing services such as the EB podiatry training course, and online information / publications.

Governance and strategy

- As set out in the DEBRA Articles of Association, at least 50% of DEBRA Trustees are people with direct experience of EB.
- Members are informed of available roles on DEBRA’s committees as well as Board of Trustees.
- The EB Insights study allows members to tell DEBRA where we can improve, what we should be focusing on as a charity to deliver more for the EB community, and what it means to live with EB today. This enables us to devise strategies and plans that address the areas of greatest need.

Research programme and Clinical Practice Guidelines

- DEBRA involves the EB Community in identifying priorities for research funding and for developing clinical practice guidelines.
- All Clinical Practice Guidelines (CPG) Panels are required to include at least one EB patient, as well as clinicians covering a range of expertise in each topic.
- Members are involved in deciding what research we fund at the research grant application stage, with their scores and comments being delivered to board alongside those of other clinical and research experts.
- Members are sign-posted to opportunities to get involved in research external to DEBRA where we are confident about the study and its relevance to our members.
- Members are forming lived experience groups or panels to inform research at the pre-application stage, to influence the design of EB research projects.

- Members submit their testimony of what it means to live with EB in order to influence and strengthen our official submissions to bodies such as NICE, Genetic Alliance and the AMRC.

Fundraising

- Traditionally DEBRA has included members and the EB community in fundraising activities through a variety of volunteering activities such as assisting with campaigns, sharing their stories, attending events, and raising funds should they wish to do so, however it is not an expectation.
- The fundraising team consider the needs and any adjustments required to enable members to be actively included.
- The fundraising team is now considering how to involve members in the design of certain fundraising activities, to see whether they enable more members to be able to take part.

Marketing and communication

- To date DEBRA has valued our members' lived experiences in bringing important information, messages and views to the EB community, and in helping the wider public understand the impact of EB. These stories whether in written words, images or video are actively used across the DEBRA teams and help us understand the needs of the EB community.
- DEBRA supports and empowers the EB community to tell their stories and help others better understand the condition.
- The EB Insights study allows members to tell us directly what they want to see and hear more or less of from DEBRA, and their views shape our plans.
- Members views were sought as part of the brand refresh in 2022.
- As work evolves, we would like to find more opportunities for members to influence what our communications look like - email, our website, campaigns or documents.

People

As part of a new staff on-boarding process, members used to talk to new staff and office volunteers about their lived experience of EB as part of an interactive session, enabling staff and volunteers to better understand how EB affects people differently, and where DEBRA can help.