

Member Services 2023-2026 Strategy

DEBRA UK

Changing lives faster together



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Foreword

Epidermolysis bullosa (EB) is an extremely painful skin blistering condition, which causes the skin to blister and tear at the slightest touch. With skin as fragile as a butterfly’s wings, EB is often referred to as ‘butterfly skin’.

EB can affect the hands and feet only or, in the most severe cases, any part of the body, including blistering on the eyes and internal organs. People living with EB live in constant debilitating pain and in severe cases it can be fatal.

In addition, EB is rare, with significantly fewer people affected than for better-known conditions, such as cancer and heart disease. Patients living with EB therefore have fewer “natural supporters”. But they cannot wait for a cure to be found – they need effective control of symptoms, a better quality of life, and tangible support to enable them to take control of their own lives.



We live today in an era of enormous scientific and medical innovation. There are real scientific advances, new technologies, and new treatments. It is a time of real opportunity for improving the lives of people living with EB. Progress to finding novel treatments and pathways to cures is progressing like never before, but no matter how speedy the progress, there are many families throughout the UK that need help today. DEBRA supports people living with EB and their families and funds life-long care for all EB types, and for people of all ages throughout the UK. DEBRA also invests in research into potential treatments and cures for EB.

We need to accelerate the pace and breadth of our service to members. To achieve this, we are committed to increasing our funding and driving programmes of world-class, innovative, and collaborative member care initiatives that will bring measurable improved outcomes for everyone living with EB.

Working with our members we can achieve this ambitious and essential journey to alleviate suffering and help people take control of their lives.

Tony Byrne
CEO, DEBRA UK

The Story of DEBRA UK to date

DEBRA was the world’s first EB patient support organisation, founded in 1978 by Phyllis Hilton whose daughter Debra had Dystrophic EB. When told by medical professionals that nothing could be done for her baby, she set out to find ways to treat Debra’s skin using cotton dressings. We have come a long way since then.

Today, all UK patients have access to state-of-the-art dressings, and DEBRA is international in scope with a network of over 50 DEBRA groups worldwide sharing information and best practice.

Investing in a future free of EB, DEBRA funds:

- specialist healthcare
- life-long community support
- pioneering research
- raising awareness
- international collaboration and best practice.

We work in partnership with the NHS to deliver an enhanced EB healthcare service. We fund pioneering research, working with researchers at the best institutions across the world to improve treatments and to search for a cure. We invest in the development of clinical best practice guidelines – for both clinicians and families.

DEBRA Member Services provides practical, financial, emotional support, and advocacy for people living with EB and their families, connecting patients with the specialist services they need and a support network across the EB community. DEBRA Member Services also provide holiday homes across the UK which offer much needed respite and affordable and safe holidays for the EB community.



Vision, Mission, Ambition and Values







- Our vision** A world where no one suffers with epidermolysis bullosa (EB).
- Our mission** Provide life-long care, while seeking cures, for all those affected/impacted by living with EB.
- Our ambition** DEBRA is the national charity and patient support organisation for people living with or directly affected by EB. We have achieved global recognition as a leading authority on EB, and are the only UK charity specifically aimed at continuously supporting the EB community.

This document summarises our Member Services strategy which is designed to address the issues which matter most to people living with EB.

We will ensure that our members are at the centre of our decision making. Our ambition is to fully understand what our members need and deliver programmes and initiatives to lessen the day-to-day impact of EB and help empower people to effectively manage life living with EB.

To achieve this, we are embarking on a new, member-centred journey from 2023 to 2026, which will be underpinned by this new Member Services strategy.

Our values, and how we live them... In DEBRA, we are....

-  **Making a difference** Through the individual work and activities undertaken by each employee and volunteer we make a positive contribution to the lives of the EB community, our colleagues, and the community we live in.
-  **Inclusive** We value diversity and proactively seek to support, engage, and nurture every individual within the DEBRA community.
-  **Respectful** We treat our members, colleagues, volunteers, and customers, with respect. We value the views and diversity of others and intervene when those around us do not uphold the high standards we expect.
-  **Passionate** We go the extra mile to achieve individual and collective goals. We do our best every day, so that we can move forward in our quest to improve the quality of life of our members and find a cure for EB.
-  **Caring** We prioritise the needs of others, looking to brighten the day of those around us. Doing a great job really matters whether we are supporting members, serving customers, fundraising, or raising awareness of EB. We care for one another.
-  **Committed** Although life has its challenges, we look for solutions, working together to create positive change. We deliver on our promises through hard work, collaboration, and determination.

Executive summary

The devastating nature of EB drives our determination to achieve our vision and minimise the suffering that EB brings and empower our members to effectively live with EB.

This strategy is the start of an updated care journey. We want to build on our successes but adapt our services so that they better meet the needs of people living with EB and enhance quality of life. We will develop our engagement with the wider EB community and focus on supporting their needs more proactively and broadly.



Claire Mather
Director of Member Services
DEBRA UK

We will:

- engage with the wider EB community, especially people living with EB (individuals with EB, families, and carers), and with social and healthcare professionals to better understand current needs
- deliver a more proactive service, anticipating needs led by our improved data capture and analysis
- broaden our reach, ensuring we reach people of all ages and EB types, as well as reaching out to people living with EB throughout the whole of the UK
- increase our membership base so we can build long term engagement, allow more people living with EB to benefit from our services, and to inform them of advances in care and research into EB
- work in close collaboration with the DEBRA research team - keeping members informed, sharing opportunities to take part, and prioritising key needs from the combined perspectives of care and research. Taking eye care as an example, we are actively seeking treatments in this field and providing specialist lighting for immediate relief

To achieve this, we need a step change in our approach to member support and how we work with our members, other people living with EB, local and international organisations, as well as government bodies to achieve what we have worked towards for over 40 years.

We will increase our funding and drive a programme of world-class, innovative and collaborative member support initiatives that will bring hope and tangible outcomes for everyone living with EB.



A chronic and debilitating skin condition, EB is not constrained by boundaries. As the patient voice organisation for those living with EB in the UK, we also cannot be constrained by boundaries in our ongoing work to make EB manageable and liveable. Our new members services strategy puts members' concerns and priorities front and centre, with a focus on fully engaging our members to inform our decisions.



Carly Fields
Chair of DEBRA Charitable
Purposes Committee
DEBRA UK

This strategy puts members first, concentrating on tangible outcomes and proactive delivery of services. In direct consultation with those with EB, DEBRA will ensure that funding is focused on members' primary concerns relevant to the day-to-day challenges they face. This strategy also embraces partnerships with other organisations with overlapping interests, including dermatologists, ophthalmologists, podiatrists, and oncologists, in addition to strengthening our relationships with rare disease organisations and other bodies who can support our members with their specialist services. We know that living well with EB can be achieved more effectively by working collaboratively and we welcome anyone to join us in our journey.

Our members

- at the heart of everything we do



There is believed to be at least 5,000 people living with EB in the UK, although the exact number is unknown as in many case the condition goes undiagnosed.

DEBRA’s membership, which comprises people living with EB, partners, relatives, carers plus healthcare professionals and researchers specialising in EB, is over 3500 of which over 1600 are people living with EB.

DEBRA will continue to serve and support our current members, adapting our service delivery to meet their needs. In addition, we will focus on providing support to people living with EB who are currently not DEBRA members.

We want everyone living and working with EB to be a DEBRA member, and therefore able to access relevant, proactive support and community connection, which helps families live better with EB.

As our membership grows, our impact will grow - our advocacy will be more effective, our understanding of the needs of people with EB will deepen, our fundraising and supporter engagement will be even more effective, and our lobbying power will increase. All this in turn will enable us to improve how we support our members.

If our membership is to increase, our members will need to feel valued and see some benefit for themselves. To this end, we want our members to be at the heart of everything we do as a charity - so that DEBRA has a truly mutually supportive relationship with our members.

Our approach

- build, provide & empower

While we have provided great service to our members’ in the past, we cannot rest until we have helped all members of the EB community live as full a life as possible.

Propelled by the need to improve everything what we do, we have identified three broad areas where we need to refocus the direction we have been taking and reflect on what improvements we need to make with, and for, our members.

First, we build - we will grow our membership and engage more fully with the EB community. Next, we will provide - enabling members to gain access to the specialist health and social care they need. And finally, we will empower our members so they will have choice and independence throughout their journey of life living with EB.

We also recognise that the Members Services team cannot be effective without adequate resources, proper training, good communication and strong collaboration with our fellow directorates including Research, Finance and IT, Fundraising, Marketing Communications, and HR. This is captured in a fourth area - teamwork.



1 Build

1.1 Members at the centre of our decision making

To help ensure member concerns and needs are at the heart of our work and governance, we commit to the following:

- having a Board that comprises more than 50% of members who either have EB themselves or have a close family member or partner that does
- having a cross-organisation member engagement strategy that focuses on retaining, growing, and placing members at the centre of the charity’s operations/strategic decisions
- encouraging member feedback through regular feedback forums, inclusion in committees and working groups
- acting on the feedback we receive from members
- acting on the conclusions and observations emerging from the patient insight study (a study engaging with members and healthcare professionals to better understand EB and the needs of the community)

ACTIONS

In 2023-26 DEBRA will:

1. Ensure the board composition adheres to the 50% EB member rule
2. Craft a quantified response to the patient insight report, with target outputs enumerated
3. Establish engagement forums

1.2 Member retention

To keep our members involved and engaged, we commit to the following:

- map the EB journey for members, so DEBRA can anticipate needs and members are prepared for critical junctures in their life (from birth through to end of life)
- segment our members to ensure we provide appropriate support for people with different types of EB
- “win back” campaign targeting lapsed members
- clarify the member value proposition – communicate the “mutual benefit” for members and for DEBRA
- improve our member-focused space online

ACTIONS

In 2023-26 DEBRA will:

4. Ensure that most of our member support work will be proactive, rather than reactive, and prioritise delivering personalised care pathways
5. Craft an updated member value proposition that will enthuse our existing members and attract new ones

1 Build

1.3 Growing membership

To grow and diversify our membership, we commit to the following:

- arrange, attend, or host specialist clinics, events, and meetings
- design targeted recruitment pushes
- build partnerships with organisations with specialist skills and resources that could benefit members
- launch accreditation schemes and courses
- demonstrate the benefits of being a member of DEBRA and of the wider EB community

ACTIONS

In 2023-26 DEBRA will:

6. Following the outputs of a commissioned patient insight report, use its findings to design and implement a strategy to recruit new members
7. Special attention will be given to identifying how DEBRA can support those living with less severe EB, but who could benefit from DEBRA at certain life moments



2 Provide

2.1 Quality community support & service delivery

To ensure we work to the best possible standards, and report on our progress, we commit to the following:

- craft an operational framework that will ensure the Community Support Team focuses on the critical issues affecting our members. See Figure 1
- establish engagement measures and reports; review all recent feedback mechanisms to establish our benchmarks; shared communication calendars and plans
- prepare and empower our members for key stages as their lives change, supporting them as required:

Birth

EB may be unexpected, no/little knowledge, urgent help, uncertainty, fulltime/long term carer, impact on family life and work.

Specialist care, equipment, benefits, dressing delivery, liaison between professionals/family, someone to turn to.

Education

Mainstream school/access to support, equipment/adaptations, peer group isolation, lack of knowledge by staff.

Information, plan well in advance, school visit-teach staff and pupils, equipment, and grants.

Transition from paediatric to adult services

Uncertainty, fear/lack of familiarity, reduced service, pros/cons of independence for child/parent, welfare changes, carers to enable independence, social isolation.

Facilitate change of service, CST constant, grants for driving/travel, benefit support, housing.

Employment

Daily unpredictability of EB, time for dressings, odour, distraction of pain, employer reluctance to support/lack of knowledge, sick leave, return to work after being carer, ability to work.

Information, benefit/earning advice, budget management, workplace visit, hobbies/focus.

Family life

Uncertainty, relationships, childcare, EB takes priority, limited funds/finance management, stress.

Respite in holiday homes, info, sexual health, clinical practice guidelines, grants, budgeting skills, events/gatherings, genetic counselling.

End of life and bereavement

Living with a terminal condition, grief/loss, change in benefits/ housing, funeral, loss of carer role.

Information, coordinated care and support, multi-agency working, someone to talk to, funeral planning, grants, benefit/housing advice.

Life-long care

Supporting families after the death of a loved one signposting help and advice.

Supporting the family members to become advocates of DEBRA - helping them help others.

Keeping them up to date on progress on treatments and potential cures.

ACTIONS

In 2023-26 DEBRA will:

8. Report annually on progress against plan on “how we’ll know we made a difference” – see Figure 1

9. Update our approach to the key stages of life, ensuring that the member data now available to our staff will enable a more proactive service

10. Set out how DEBRA could not just serve those members with severe EB, but also serve people living with less severe EB. These people need help, but as their needs are less urgent than others, there is a reticence about coming forward. DEBRA is there for everybody
11. Ensure a focus on providing a service for the lifetime of our members – and not just when in they are children and young adults

12. Assess the need for mental health support for our members, and where appropriate allocate resources to this area

13. Build on our efforts to invest in podiatry services – raise awareness, training, and access to services

14. Evaluate the impact that recent major events have had on our members (for example, long COVID and the cost-of-living increases) and reorientate our resources as required

Figure 1

Member Services

WHAT we'll do and WHY

Empower

Enable choice and independence throughout the journey of life living with EB.

We strive to ensure that our members have access to holistic up to date information and advocacy relating to health and social needs to enable choice and independence.

Provide

Access to specialist health and social care/ support

EB is a rare condition requiring specialist care and support to ensure members’ quality of life is maximised.

Build

Grow and engage the EB community

Understanding the needs and enabling networking of our members living and working with EB ensures appropriate support and care is available.

HOW we'll do it AND BY WHEN

5 year

- Members feel better connected, able to influence charitable activity, aware of support available, (annual survey - needs, opportunities, satisfaction, (aim 20% increase 5% YoY) - Member Voice feedback initiatives)
- Increased proactive/reduced reactive calls for support at key stages of life (CST data monthly reports, aim 5% reduction crisis calls YoY)
- Increased downloads of information from DEBRA website and meeting/event attendance (monthly report - increase 5% YoY)
- Clarity of membership and increased number/be representative of members living with all types of EB (monthly report, cross reference data. Increase EBS membership and HCPs 5% YoY)
- Increase in support, training grants awarded and holiday home occupancy (monthly reports and surveys. 5% increase YoY)
- Increased satisfaction in health and social support (annual survey, QoL)
- Increase in partnership work (6 monthly reporting - contracts in place, networks developed)

2 Provide

2.2 Delivering support that make an impact

To ensure members have the practical support they need, we commit to the following:

- provide support grants that specifically address issues related to EB:
 - items that improve health and comfort: (e.g., cooling/drying fans, silk bedding, new-born baby clothes without seams)
 - items that indirectly help living with EB (e.g., washing machine, tumble dryer, carpet)
 - assistance to attend/stay at specialist EB centres: (e.g., hotel accommodation, travel, TV package)
 - other needs, including bereavement support and funeral costs
 - respite holiday homes
- while we are best placed to understand the needs of people living with EB, we also recognise that other organisations are uniquely positioned to deliver certain services that DEBRA cannot do nearly as well. We will partner with other organisations who have the expertise to best provide a solution for members' particular needs (e.g. appropriate wheelchairs/Wish foundations)
- we recognise that members benefit greatly from contact with each other. Member events should not only provide information and/or entertainment, but also facilitate informal conversations between people feeling isolated with a rare disease, or even parents stressed in how best to care for a child with EB. Finding someone in a similar situation can have a dramatic effect on people's mental health

ACTIONS

In 2023-26 DEBRA will:

- 15. Identify and liaise with a number of organisations whose expertise could potentially make a material difference to the lives of our members.
- 16. Sign memorandums of understanding with organisations that can deliver quality solutions for our members.
- 17. Review what the considerations for selecting owned or rented respite homes.
- 18. Review our member events – nationally and locally – and identify what members most want and benefit from.

3 Empower

By increasing the number of people with EB who are DEBRA members and ensuring that they are provided with the specialist medical and social care they need, we will get one step closer to our vision of a world where no one suffers with EB.

Our vision is to empower people living with EB. We will do our utmost to ensure they have the maximum number of options available to them in their life journey – from birth, through childhood and into their adult years. At every critical life stage, they will have the information, awareness of opportunities and greater autonomy, whilst DEBRA will stand shoulder to shoulder with them as each challenge and each opportunity presents itself.

ACTIONS

In 2023-26 DEBRA will:

- 19. Review existing information to ensure resources are accessible and reflect the needs of all members
- 20. Develop a range of EB-specific health and social care information, including key life stages/pathways to enable DEBRA to be as proactive as possible, ensuring members make the right decision for them in good time
- 21. Improve awareness of support and satisfaction of information
- 22. Implement a longitudinal study of the experiences of people with EB, starting with an insight study, to measure levels of control experienced by our members



4 Teamwork

4.1 Investing in the Member Services team

To ensure DEBRA builds and supports an effective directorate team (see Figure 2), we commit to invest in our staff, ensuring they are supported in their efforts to provide the best possible help for our members.

- DEBRA fully funds:
 - community support – with 10 managers who support over 500 people each year and circa 130 members a month
 - membership & projects – with 7 staff informing and working directly with our 3,500+ members
- DEBRA also part funds, through its NHS partnership, EB specialist nursing and dieticians

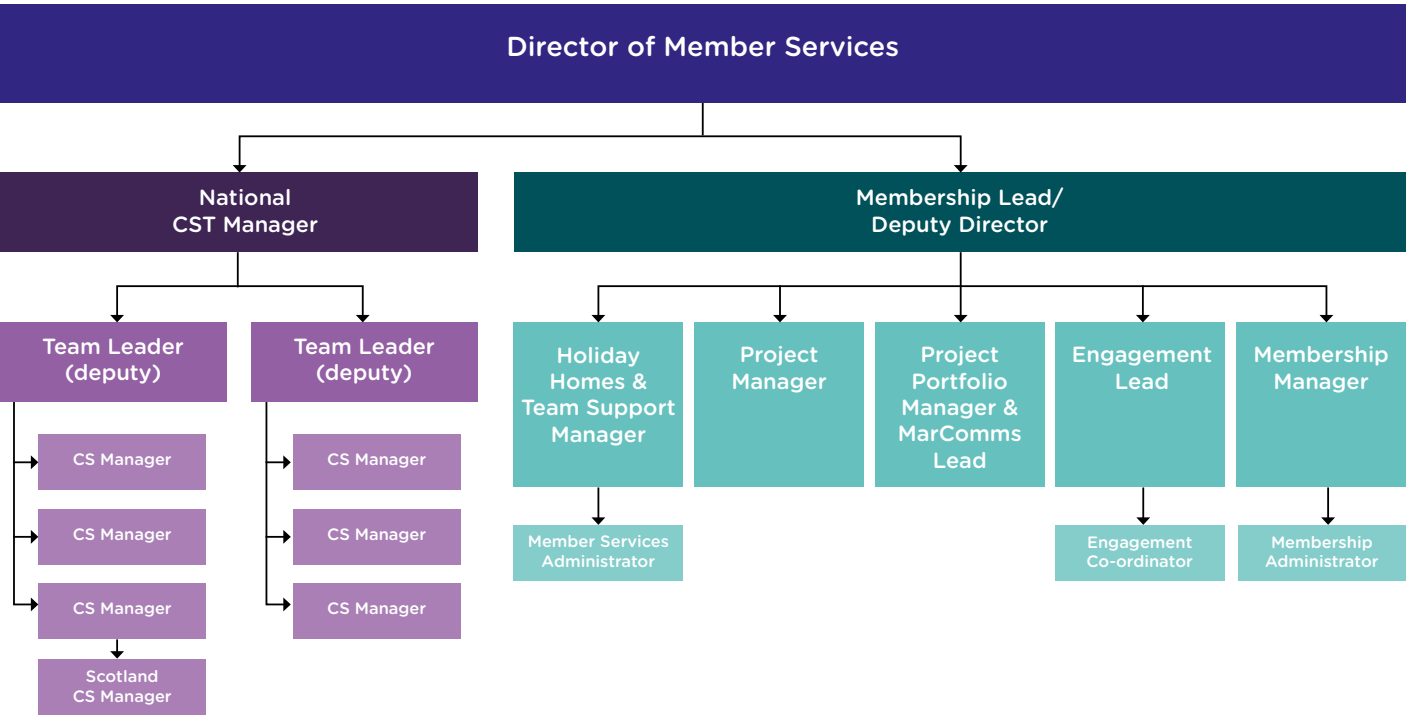
ACTIONS

In 2023-26 DEBRA will:

- 23. Support our staff according to best HR practices
- 24. Develop knowledge and skills in areas of expertise that our members will need most (e.g. benefit advice / bereavement support / mental health and event planning)

2023 Member Services Directorate

Figure 2



4 Teamwork

4.2 Leveraging the resources of the other DEBRA UK directorates

DEBRA is a large charity, with a significant number of staff employed and major income from its retail operations, complemented by a successful fundraising operation. To ensure that DEBRA's impact is greater than the sum of its parts, the directorates of Member Services, Research, Retail and Fundraising, supported by Finance & IT HR, and Marketing & Communications must leverage the outputs and resources of each other. We work collaboratively with each other in DEBRA to optimise additional support for our members.

By working strategically with the DEBRA Fundraising Team we will secure additional funding that will enable DEBRA to provide the following:

- additional holiday homes
- additional engagement/ membership team members
- dedicated dietician and nutrition resources
- more regional and local member events and more funds for support grants

DEBRA has a significant number of retail outlets. With our Retail Team, we will use our facilities to become hubs for our members – sometimes as places to meet, other times, as information sources. We will also ensure our retail staff are enthused and informed about how their work makes an enormous difference to the lives of people living with EB.

The DEBRA Member Services and DEBRA Research directorates are closely aligned, with the research strategy now clearly focused on patient outcomes. Research priorities will be informed by the observations and recommendation of the Member Services Team, and members themselves.

ACTIONS

In 2023-26 DEBRA will:

- 25. Work effectively with the Fundraising Team to secure funding for additional holiday homes, two more support managers and a dietician as well as more support grants
- 26. Create five new DEBRA member hubs from our retail outlets
- 27. Ensure that the voice of members, coupled with insights from the Member Services team, are effectively communicated to the Research team, especially when Research sets its priorities
- 28. In parallel, Member Services will assist its fellow directorates in their strategy by, for example:
 - giving content to the fundraising team
 - supplying data for advocacy initiatives

Summary of actions

1. Ensure the board composition adheres to the 50% EB member rule
2. Craft a quantified response to the patient Insight report, with target outputs enumerated
3. Establish engagement forums
4. Ensure that most of our member support work will be proactive, rather than reactive, and prioritise delivering personalised care pathways
5. Craft an updated member value proposition that will enthuse our existing members and attract new ones
6. Following the outputs of the patient Insight report, use its findings to design and implement a strategy to recruit new members
7. Special attention will be given to identifying how DEBRA can support those living with less severe EB, but who could benefit from DEBRA at certain life moments
8. Report annually on progress against plan on “how we’ll know we made a difference” – see Figure 1
9. Update our approach to the key stages of life, ensuring that the member data now available to our staff will enable a more proactive service
10. Set out how DEBRA could not just serve those members with severe EB, but also serve people living with less severe EB. These people need help, but as their needs are less urgent than others, there is a reticence about coming forward. DEBRA is there for everybody
11. Ensure a focus on providing a service for the lifetime of our members – and not just when in they are children and young adults
12. Assess the need for mental health support for our members, and where appropriate allocate resources to this area
13. Build on our efforts to invest in podiatry services – raise awareness, training, and access to services
14. Evaluate the impact that recent major events have had on our members (for example, long COVID and the cost-of-living increases) and reorientate our resources as required
15. Identify and liaise with a number of organisations whose expertise could potentially make a material difference to the lives of our members
16. Sign memorandums of understanding with organisations that can deliver quality solutions for our members
17. Review what the considerations for selecting owned or rented respite homes
18. Review our member events – nationally and locally – and identify what members most want and benefit from
19. Review existing information to ensure resources are accessible and reflect the needs of all members
20. Develop a range of EB-specific health and social care information, including key life stages/pathways to enable DEBRA to be as proactive as possible, ensuring members make the right decision for them in good time

List of definitions

Members

Legal Members of DEBRA UK are members of the Board of Trustees with a voting right

members

DEBRA UK members are people living or working with EB

EB community

People living or working with EB

CST

DEBRA funded community support team, provide information, advocacy and support to people living with EB in the UK

Membership team

DEBRA funded team of staff supporting members, including the management of the holiday homes, member events, publications, and engagement

Member Services

The directorate umbrella for all activities undertaken by DEBRA UK to support the EB community members

CPC

The Charitable Purposes Committee is a DEBRA UK Board committee that oversees Research and Member Services charitable activities

21. Improve awareness of support and satisfaction of information
22. Implement a longitudinal study of the experiences of people with EB, starting with an insight study, to measure levels of control experienced by our members
23. Support our staff according to best HR practices
24. Develop knowledge and skills in areas of expertise that our members will need most (e.g. benefit advice / bereavement support / mental health and even event planning)
25. Work effectively with the Fundraising Team to secure funding for additional holiday homes, two more support managers and a dietician as well as more support grants
26. Create five new DEBRA member hubs from our retail outlets
27. Ensure that the voice of members, coupled with insights from the Member Services team, are effectively communicated to the Research team, especially when Research sets its priorities
28. In parallel, Member Services will assist our fellow directorates in their strategy by:
 - giving content to the Fundraising Team
 - supplying data for advocacy initiatives, etc





DEBRA funds pioneering research, specialist healthcare, international best practice and life-long care and support to the EB community. We make a difference today with the aim of a better future for those suffering from the condition.

Together we will #StopThePain.

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DEBRA Royal Patron - HRH The Duchess of Edinburgh, GCVO

DEBRA President - Simon Weston CBE

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ASSOCIATION OF MEDICAL RESEARCH CHARITIES



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