



CANDIDATE PACK FOR CHAIR

WELCOME

Dear Applicant,

Thank you for your interest in the role of Chair of Trustees at DEBRA UK

DEBRA is a national charity and patient support organisation for people living with the rare, genetic skin blistering condition, epidermolysis bullosa (EB) also known as 'Butterfly Skin'. Our vision is for a world where no one suffers with EB, and we will not stop until this vision becomes a reality. Established in 1978 by Phyllis Hilton, whose daughter Debra had EB, DEBRA UK is now a national charity supporting 3,000+ members. We employ over 380 staff and 1,200 volunteers who support us across a network of 80 charity shops located throughout England and Scotland.

From the discovery of EB genes to funding the first clinical trial of potential gene therapy, we have played a pivotal role in EB research globally and have been responsible for making significant progress in advancing diagnosis, treatment, and daily management of EB. We are committed to making sure that the estimated 5,000 people living with EB in the UK and their families and carers get the vital and wide-ranging support they need.

Our current Chair retires from office in 2025 and we are now seeking to appoint a new Chair, who will continue and build upon a legacy of providing clear and inclusive leadership of the Board of Trustees and, with the board, hold the Chief Executive to account as we deliver on our five-year strategy, ensuring we stay true to our mission and vision, and maximise our impact. Other duties demanded by this appointment are championing our values, leading by example and, in partnership with the Chief Executive, acting as a public face of the charity.

We are keen to hear from outstanding leaders with a track record of achievement and who can evidence a history of sound judgement, who share our values and who can engage, inspire, and influence at all levels. You will bring a sophisticated understanding of the Chair role, with knowledge of Board development to include performance management, succession planning, and the effective leadership of trustee teams.

If this sounds like you, and you share our commitment to improving the quality of life for people living with EB, we would be very pleased to hear from you.

David Bendor-Samuel
Chair of Nominations & Governance &
Co-Vice Chair of Trustees



ABOUT US

The history of DEBRA dates from 1963 when Phyllis Hilton had a daughter called Debra who was born with Dystrophic EB. In 1978, after realizing treatment was not advancing, Phyllis organised a meeting for parents of children with EB in Manchester and it was this meeting that led to the charity officially being formed as the world's first EB patient support organisation, taking its name from Phyllis' daughter. The DEBRA name was also intended as an abbreviation of Dystrophic Epidermolysis Bullosa Research Association (D.E.B.R.A).

In the 40+ years since, DEBRA has grown in scope with sister organisations located in 40 countries, a worldwide research programme and strong clinical and nursing services. To read more about our history, [please click here](#).

WHAT WE DO

DEBRA UK exists to provide community care and support services to improve quality of life for people living with all types of inherited and acquired EB. We also fund pioneering research to find effective treatments for all types of inherited EB

From the discovery of EB genes to funding the first clinical trial of potential gene therapy, we have played a [pivotal role in EB research](#) globally and have been responsible for making significant progress in advancing diagnosis, treatment, and daily management of EB.

The income we generate from our [fundraising activities](#) and our network of [charity shops](#), enables us to provide care and support to improve the quality of life for people living with EB today and fund pioneering research to find treatments. [Find out more about how we raise and spend money](#).

SPECIALIST HEALTHCARE

We support [specialist healthcare](#) by working with the 4 national EB centres and over 60 EB healthcare professionals including specialist EB nurses to ensure our members are connected with the services they need to improve their quality of life.

COMMUNITY SUPPORT

Through our [Community Support Team](#) we deliver a variety of support services for the EB community including general information about EB, support with any issues impacting everyday life including [benefits and grants](#), advice for employers and schools, housing, emotional support and much more.

RESEARCH TO FIND TREATMENTS

We invest in potentially life-changing research and are currently funding 20 [research projects](#) with the aim of finding treatments to significantly reduce the devastating symptoms and pain of EB whilst we work towards finding cures

Working with



4 national EB centres

Collaborating with



60 EB healthcare professionals



20 EB research projects



3,800+ DEBRA members

CULTURE AND VALUES

Our values provide a set of common beliefs, behaviours and understanding to support and enable us to work collectively to achieve our mission. We will build these values into everything that we do – how we interact with each other, training, recruitment, reward and recognition and wellbeing.

MAKING A DIFFERENCE

We make a positive contribution to the lives of the EB community, our colleagues and the community we live in through the individual work and activities undertaken by each employee and volunteer.

INCLUSIVE

We value diversity and proactively seek to support, engage and nurture every individual within the DEBRA community.

RESPECT

We treat our members, colleagues, volunteers and customer, 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 are motivated 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.

CARE

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 and raising awareness of EB. We care for one another.

COMMITTED

We look for solutions, working together to create positive change. We deliver on our promises through hard work, collaboration and determination.



ROLE DESCRIPTION

Role title: Chair of Trustees

Key relationships: Board of Trustees, Chief Executive

ROLE PURPOSE

The Chair's role is to lead the Board of Trustees, ensuring that it fulfils its responsibilities for good governance and strong performance across DEBRA UK and for the achievement of strategic priorities and plans. The Chair, through the Board, holds the Chief Executive to account for the Charity's mission, vision and impact, and provides clear and inclusive leadership to the Board of Trustees, helping each trustee fulfil their duties and responsibilities. The Chair supports the Chief Executive and ensures that the Board functions well as a unit and works closely with the Senior Leadership Team ('SLT'). They will additionally act as an ambassador and, in partnership with the Chief Executive, assume a role of the public face of the charity.

MAIN RESPONSIBILITIES

Strategic leadership of the charity

- Foster a positive culture across the organisation and its members
- Ensure that our Trustees, SLT, staff and volunteers work consistently toward achieving DEBRA's Charitable Objects.
- Provide clear and inclusive strategic leadership to the charity and its Board, ensuring maximum impact for its EB members.
- Ensure that the charity abides by its Scheme of Delegation ('SOD') and that all Trustees are given the support required to allow them to fulfil their responsibilities for the effective governance and oversight of the Charity.
- Lead the Board to fulfil its duties and ensure that in terms of maintaining the sound financial health of the charity; ensure budget-setting processes are followed and that the charity's reserves are monitored.
- Ensure that DEBRA's Charitable Spend is focused on meeting our Charitable Objectives.
- Champion and model our values.

External relationships

- Act as a credible ambassador for the DEBRA UK cause and charity itself.
- Act as spokesperson for the organisation and in partnership with the Chief Executive.
- Represent the charity at various external functions, meetings, and events.
- Promote the charity's interests to potential supporter communities as opportunities arise.
- Develop relationships with the EB community and be approachable

Governance and Board development

- Ensure that governance and oversight arrangements are complete, fully up to date and working in the most effective way for the Charity, and that the charity meets its statutory and regulatory obligations.
- Develop the knowledge and capability of the Board of Trustees as a collegiate team and ensure that succession planning arrangements are in place.
- Encourage positive change where appropriate and address and resolve any conflicts within the Board.
- Lead the board in the task of recruiting and developing trustees.
- Chair meetings of the Board of Trustees effectively and efficiently, bringing impartiality and objectivity to the decision-making process.
- Ensure DEBRA's Trustees are fully engaged and that decisions are taken in the best, long-term interests of the Charity.
- Lead the Board in attaining high performance and ensuring collective ownership.
- Foster and maintain constructive relationships between Trustees and between the Board and SLT.

Relationship with the Chief Executive

- Build and foster strong, effective and a constructive working relationship with the Chief Executive, ensuring their accountability for the achievement of strategic objectives.
- Provide support and constructive challenge to the Chief Executive (and SLT) as required, ensuring regular updates and developing and maintaining a relationship founded on openness and mutual trust and respect.
- Manage the Chief Executive's performance and ensure they have the opportunity for professional development and appropriate external professional support.
- Ensure that the DEBRA colleagues and volunteers' welfare is managed



PERSON SPECIFICATION

PART ONE

KNOWLEDGE AND EXPERIENCE

- Compelling track record of having operated at a senior, strategic leadership level within an organisation of comparable size and complexity.
- Unblemished record of achievement in any sector.
- Knowledge of the specific characteristics of the charity sector, ideally with some insight into effective charity governance and its implementation.
- Strong stakeholder management experience, including bringing on board stakeholder communities which have competing perspectives or priorities.
- Track record of influencing and of promoting causes and organisations.
- Sophisticated understanding of the Chair role, with knowledge of Board development to include performance management, succession planning, and the effective leadership of trustee teams.

PART TWO

SKILLS AND ABILITIES

- Strong strategic leadership skills with the ability to motivate senior staff and volunteers and unite teams behind a common cause.
- Ability to foster and promote a collaborative and inclusive team environment.
- Effective networker and adroit relationship-builder with persuasive communication, influencing and interpersonal skills.
- Able to listen to / actively engage with the Debra Membership.
- An excellent relationship-builder.
- Strong financial management skills, with the ability to interrogate detailed financial information.

PART THREE

LEADERSHIP STYLE AND BEHAVIOURS

- Strategic acumen, with a big picture perspective.
- Ambassadorial style with personal stature and presence.
- High capacity for self-reflection: emotionally intelligent and generates trust and confidence quickly.
- Strong personal commitment to DEBRA's policies.
- Available to commit the time to the role and is willing to travel and attend events out of office hours.
- Demonstrates passion and commitment to the charity and its cause and empathy with the EB community.

TERMS OF APPOINTMENT

REMUNERATION

The appointment is offered on a voluntary basis with expenses incurred on DEBRA UK business reimbursed in full.

TIME COMMITMENT & LOCATION

Board meetings are held quarterly online and at DEBRA's office in Bracknell. A two-day residential meeting is usually scheduled for the Autumn with a strategic focus. The Chair will also be required to spend additional time out with their duties.

DEBRA embraces technology and trustees attend meetings in person (Bracknell head office) or virtually. The Chair can operate as suits the charity and themselves best.

The Chair is an ex officio member of two board committees (Finance, Risk and Audit; Nominations & Governance) and a member of the REMCO.

Additionally, the Chair is expected to have regular meetings with the Chief Executive, the Vice-Chairs of the Board and individual trustees.

The Chair will be expected to represent the Charity at various events and meetings with many different levels of stakeholders.

TERM OF APPOINTMENT

Initial term of four years, renewable for a further two.

HOW TO APPLY

To make an application, please go to <https://starfishsearch.com/jobs/debrauk-chair> and click on the apply now button, with the following prepared:

- your CV (no more than three sides).
- A covering letter that sets out your motivation for the role and describes the specific experience you can bring to the appointment.

We would also be grateful if you would complete the Equality and Diversity monitoring form on the online application process. This form is for monitoring purposes only and is not treated as part of your application.

RECRUITMENT TIMETABLE

Closing date for applications:	Friday 21st March 2025
Preliminary interviews:	First half of April 2025
Final Panel interviews:	Late April / Early May 2025