

DEBRA

Company Secretary Candidate Information Pack 2025



Welcome from the CEO

Dear Candidate,

Thank you for your interest in joining us as Company Secretary at DEBRA.

DEBRA is a national medical research charity and patient support organisation for people living with a group of rare, genetic skin blistering conditions known as epidermolysis bullosa (EB). People with EB have skin as fragile as a butterfly's wings, which is why EB is also commonly 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 over 4,000 members.

We employ over 320 staff and 1,200 volunteers who support us across a network of 80 charity shops located throughout England and Scotland.

The Company Secretary plays a central role in our organisation. As a key advisor to the Board of Trustees, you will provide expert guidance on how our governance should be directed and managed, ensuring that DEBRA meets all legal and regulatory requirements. Your leadership in this area will help safeguard the integrity of our decision-making and ensure we remain accountable to the people we serve.

You will work closely with our Board and Senior Leadership Team, ensuring that our decision-making is robust and aligned with our values, and that we continue to meet the highest standards of accountability as a charity.

This is a unique opportunity to contribute to a cause that truly matters, where your skills will help shape the future of our organisation and improve lives every day. We're excited to meet candidates who share our passion and want to be part of something deeply meaningful.

If you believe you have the skills and attributes for this role, we would be very pleased to hear from you.

Warm regards,

Tony Byrne

Chief Executive Officer, DEBRA





About DEBRA UK

We are the UK's EB patient support organisation with over 4,000 members. Every year, over 1,000 of our members access our support services.

What we do

We are the UK EB charity; a national medical research charity and patient support organisation for anyone in the UK living with an inherited form of EB, their family members, carers, plus healthcare professionals and researchers specialising in [epidermolysis bullosa \(EB\)](#).

We also provide community support services for people living with acquired EB, known as epidermolysis bullosa acquisita (EBA).

Every year, over 600 of our members access support through our [EB Community Support Team](#).

As well as being the EB patient support organisation, we are also one of the largest funders of EB research globally, and we established DEBRA International, which now runs independently in support of a global network of over 50 [DEBRA patient support organisations](#).

In 2024 we invested over £3.4m in [EB research](#), community care and support, and [specialist healthcare](#). We also spent close to £1m to help ensure more people in the UK are aware of EB and of what we do as a charity. With more awareness we hope to secure more support. .

We are incredibly grateful to be able to count on the support of our colleagues and volunteers who help us run [our network of charity shops](#). Along with our other fundraising activities, they provide the revenue that enables us to deliver EB community care and support services for today and conduct vital research into effective EB treatments for all types of EB for tomorrow.

About DEBRA UK

What we do

DEBRA 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 discovering the first EB genes to funding the first clinical trials in gene therapy and drug repurposing, 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 every person living with EB in the UK, their families, and carers get the vital and wide-ranging support they need.

Find out more about how we [raise](#) and [spend](#) money.

EB specialist healthcare and wellbeing

We work in partnership with the NHS and other organisations to ensure that people with EB in the UK get the healthcare and wellbeing support they need.

In 2008 we partnered with the NHS to set up the National Specialised Commissioning Group (NSCG) to oversee the provision of specialist healthcare for people with all types of EB in the UK. Today the NHS provides a world-class EB healthcare service through four specialist EB healthcare centres and the Scottish EB health service. And in 2017 we provided co-funding for the Rare Disease Centre, a first of its kind facility at St. Thomas' Hospital in London which provides specialist healthcare support for adults and children with complex rare genetic diseases, including EB.

Throughout our history we have and continue to invest in initiatives with the objective of improving patient outcomes for people living with EB. From the establishment of specialist podiatry services and the development of an accredited podiatry course to clinical and research fellows, we continue to explore possibilities and partnerships that will benefit our members and the wider EB community today and in the future.

Our journey to patient-centric EB healthcare

As well as establishing much of what is now known about EB through pioneering research and commissioning the first EB [drug repurposing](#) clinical trial, we have also led the way in ensuring people with all types of EB have access to world-leading specialist EB healthcare and community support services.

Find out more about some of the [key milestones on our journey](#) to delivering patient-centric EB healthcare and community support.

EB community support, membership, and engagement

Our [EB Community Support Team](#) works with the EB community, healthcare, and other professionals to improve quality of life for people living with all types of EB.

The team offers support, advocacy, information, and practical help at every stage of life with EB.

The [membership and engagement team](#) works closely with members to maximise engagement and member involvement opportunities, ensuring the needs of our members are at the heart of our thinking and help guide the services we offer for the entire UK EB community.

Our membership scheme includes opportunities for [discounted holiday home respite breaks](#), [grants](#), and bespoke [events](#) where members from across the UK can come together to share knowledge and experience, make vital connections and friends, and access expert advice and support from our EB Community Support Team.



About DEBRA UK

DEBRA research and support initiatives

DEBRA is the largest UK funder of [EB research](#), and in the top 15 UK-based research funders across all diseases and conditions investing in global research.

Since we were established in 1978, we have invested over £22m and been responsible, through funding pioneering research and working internationally, for establishing much of what is now known about EB.

We are now at a stage of our research journey where we need to accelerate the pace of discovery, to find effective drug treatments for every type of EB. We started this journey in 2023 by commissioning our first [EB drug repurposing clinical trial](#) and hope to commission further clinical trials in 2026 and beyond.

In 2024 we commissioned an EB Priority Setting Partnership (EB PSP) study for EB which followed the [James Lind Alliance \(JLA\)](#) research method. This important study helped us identify the most important unanswered research questions about all types of EB. The results will help us understand what EB research we should be prioritising in the future.

The EB PSP study is the first global study of its type to be commissioned by a rare disease patient support organisation.



Our mission, vision and values

Our mission

Provide life-long care, while seeking cures, for all those affected/impacted by living with EB.

Our vision

A world where no one suffers with epidermolysis bullosa (EB).

Our values



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.



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

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

Our commitment to equality, diversity and inclusion

We recognise that for a community to thrive every member needs to feel valued, listened to, respected, welcome and represented.

At the beginning of 2021 we started our EDI journey by forming an EDI Steering Group with representation from across our organisation. This group took the following steps:

- Developed and published our EDI policy
- Identified and made available on-line EDI training for colleagues and volunteers
- Started monitoring and developed a plan to ensure EDI was integrated within our recruitment strategy
- Created a framework for collecting and reviewing recruitment, colleague, volunteer and membership diversity data
- Created and rolled out an EDI Impact Assessment
- Invested in bespoke EDI training for our Senior Leadership Team and EDI Steering Group

We are committed to creating a culture which is inclusive and respectful, founded on equality, diversity and inclusion. Everything we do to achieve our EDI mission is underpinned by our values. When developing our new values, our members, colleagues, and volunteers endorsed “inclusive” and “respect” as two of the six chosen values, these, and our wider set of values have been integrated into all our people processes and support our EDI journey.

At DEBRA we are deeply committed to inclusive working practices, so during the application process we commit to:

- Offering a guaranteed first stage interview for disabled applicants who meet the minimum criteria for the role.
- Paying for childcare costs if interviews take place in person.
- Covering travel costs to and from in-person interviews.
- Making reasonable adjustments at every stage of the process — for example, arranging a BSL interpreter or accessible interview format as needed.
- Providing recruitment documents in alternative formats, such as accessible Word versions, on request.

If there is anything else you are concerned about or that would support you throughout the recruitment process, please let us know.

About the Company Secretary opportunity

Job title:	Company Secretary
Reports to:	Chief Executive Officer (CEO)
Location:	Head office (Bracknell)
Purpose:	The key purpose of the position is support and provide guidance to the DEBRA Board of Trustees as to how the Charity governance should be directed and managed, to ensure legal and regulatory requirements are met.
Salary range:	£45,000-50,000 dependant on skills and experience.

Duties of the role:

- Acting as a strategic partner to the Board of Trustees
- Advising the board on corporate governance, compliance, finance, and strategy
- Working with the Chair to facilitate efficient meetings (Producing agendas, taking minutes, conveying decisions, handling meeting correspondence and so on)
- Use of digital governance tools/tech to streamline administrative tasks
- Preparing agendas and papers for Board meetings & committees as well as any extraordinary meetings convened and follow up on action points
- Take minutes, draft resolutions, and lodge required forms and annual returns with Companies House, the UK's registrar of companies
- Maintain statutory books, including registers of directors
- Providing legal, financial and/or strategic advice during and outside of meetings
- Training Trustees and members of the senior leadership team on corporate governance matters
- Organise induction and training support for Trustees

About the Company Secretary opportunity

Duties of the role (continued):

- Keeping up to date with any regulatory or statutory changes and policies that might affect the organisation
- Ensuring that policies related to Governance are up to date and are approved
- Providing support to the Board of Trustees and Committees on specific projects
- Implementing processes or systems to help ensure good management of the organisation or compliance with legislation
- Collating information and preparing reports in relation to governance matters as required
- Identifying and monitoring risks to business performance
- Monitor changes in relevant legislation and the regulatory environment and take appropriate action
- Liaise with external regulators and advisers, such as lawyers and auditors as required

Other:

- To understand, comply with and promote DEBRA's safeguarding policy and procedures. It is the responsibility of all employees to make the working environment safe and secure for all.
- DEBRA has an Equality and Diversity Policy, and it is the responsibility of all colleagues to comply with this.



About the Company Secretary opportunity

Person specification:

Technical competency (qualifications and training)

- Educated to honours degree level or equivalent work experience
- Chartered Company Secretary with ICSA qualification
- Be a full member of a professional body or willing to work towards membership. You will be able to provide evidence of continuous professional and personal development

Experience

- Experience of supporting a complex organisation in a governance, legal or finance capacity
- Demonstrable experience in developing and implementing policy in the context of the governance
- Demonstrable experience of roles and responsibilities in the job description
- Knowledge of UK third sector

Skills and Attributes

- Strong administrative skill and an aptitude for using IT software
- Commercial awareness
- Meticulous attention to detail
- Influencing skills
- Excellent organisation and time management
- The ability to take the initiative
- A flexible and practical approach to work
- Experience of organisations going through significant positive change
- Excellent written, numeracy, verbal and networking skills
- Line management experience
- Gravitas and leadership presence, and excellent presentation skills
- The ability to work with the wider functions, sharing duties and representing other colleagues from time to time

Safeguarding

- Be able to display an awareness, understanding and commitment to the protection and safeguarding of young people and vulnerable adults
- This post requires a continuous Basic Disclosure from the Disclosure and Barring Service

How to Apply

The recruitment process is being undertaken by Inclusive Boards on behalf of DEBRA. If you wish to apply for this position, please supply the following by **11.59pm on 07/12/2025**:

- A detailed CV, setting out your career history, with responsibilities and achievements.
- A cover letter (maximum two sides of A4) highlighting your suitability for the role for which you're applying and how you meet the person specification. Please note that the cover letter is an important part of your application and will be assessed.
- Details of two professional referees together with a brief statement of their relationship to you and over what period of time they have known you. Referees will not be contacted without your prior consent.

If you have further questions after reading this pack, please email DEBRA@inclusiveboards.co.uk or call 0207 267 8369.

Please visit www.inclusiveboards.co.uk/opportunities to apply online or send your CV and cover letter to DEBRA@inclusiveboards.co.uk.



INCLUSIVE BOARDS

About Us

Inclusive Boards is the UK's leading board diversity practice. We have worked alongside over 300 organisations to provide support with Board recruitment, development and governance reviews. We strive to be at the forefront of equity and diversity, and believe that everyone should be represented at Board level. Additionally, we also provide bespoke training sessions on a variety of subjects including personal branding, inclusive recruitment practices and board structures and governance as well as delivering leadership development programmes for underrepresented leaders across a range of sectors.

Contact us today

Improve diversity on your Board, please don't hesitate to contact us via hello@inclusiveboards.co.uk.

To join a Board, sign up to become a candidate via our website and be notified of the latest opportunities as and when they become available.



www.inclusiveboards.co.uk



[@InclusiveBoards](https://twitter.com/InclusiveBoards)



<https://linkedin.com/company/inclusive-boards>

