debra
THE BUTTERFLY SKIN CHARITY
*Help stop the pain of EB*

Research funding opportunities

Our ambitious plans for EB research

# DEBRA UK
# Research Round-up

2024

# DEBRA UK

**DEBRA UK was the world's first epidermolysis bullosa patient support organisation, founded in 1978. We are one of the largest UK funders of EB research and have been committed to a remarkable research journey for EB – from gene discovery to cutting-edge trials of therapies to control symptoms and manage complications like cancer.**

## Find out about:

- funding and PPI opportunities
- our current research portfolio
- updates on 2024 research applications
- opportunities to promote your work through DEBRA

> "We fund research in the UK and internationally, working with the world's best scientists and clinicians. Our priority is to improve quality of life for people living with EB as quickly as possible."

**Dr Sagair Hussain**
Director or Research, DEBRA UK

# Funding and PPI opportunities

**Our international call** for project grant, small grant and PhD award applications runs annually from 1 February to 31 March. Proposals addressing symptom control in EBS are particularly encouraged in line with our research strategy towards life-changing treatments and drug repurposing.

We'd like to share our funding opportunities for UK and international researchers:

- DEBRA project grants of up to £200,000 for 2-3 years.
- DEBRA small grant awards of up to £15,000 for 1 year.
- DEBRA non-clinical PhD studentship awards of up to £140,000 for 4 years (previously UK only – now expanded to an international offer).

We strongly encourage PPI in our funding application process. Applicants joined our virtual **Applications Clinic** in February 2024 to involve our EB community members in the direction of their proposals and the wording of their applications.

**"It has been helpful to experience the reviewer side of your grant evaluation process and I hope to put in my own grant next cycle."**

Feedback from a researcher

**We'd like to remind UK researchers of our jointly funded opportunities:**

- MRC/DEBRA jointly funded Clinician Scientist Fellowship awards
- MRC/DEBRA jointly funded Career Development award
- MRC/DEBRA jointly funded Clinical Research Training Fellowship
- Action Medical Research/DEBRA project grants
- Fight for Sight/DEBRA small grants

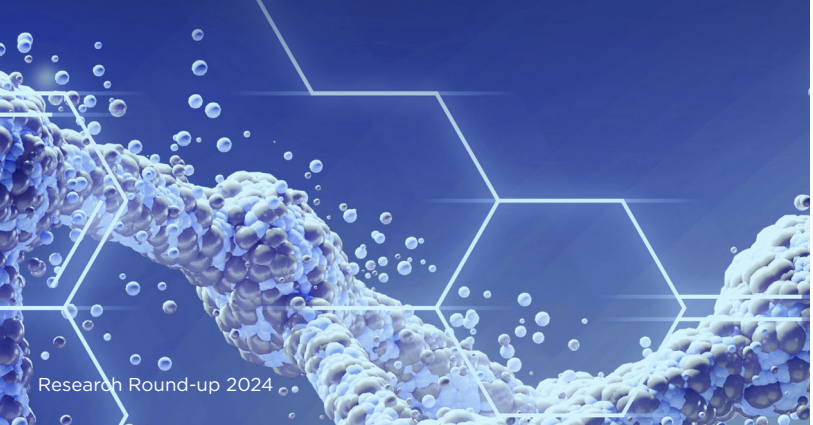
UKRI Medical Research Council

action medical research for children

If you wish to discuss your proposed research area in advance of submission, please contact **Dr Sagair Hussain**, Director of Research.

# Updates on 2024 applications

2024 was a challenging year for the research charity sector with rising costs and increased demand. With more applications and a reduced budget, **we awarded over £700,000 of research funding for project grants, small grants and even more DEBRA UK PhD studentships** as part of our commitment to build a clear career pathway into and through EB research. We have partnered with DEBRA groups in France and Ireland and with independent charities to increase our impact.



Your applications are appreciated and carefully considered by our **Scientific Grants Advisory Panel** and **DEBRA members living with EB**. Applicants have the opportunity to read and respond to comments from our external reviewers as part of the process.

## Application success rates

**Small grants:** 2023: 100% | 2024: 17%

**Project grants:** 2023: 28% | 2024: 14%

**PhD awards:** 2023: 67% | 2024: 75%

> **“Just to say, it’s impressive how efficiently you’ve managed to run peer review for this round. It’s increasingly rare to get comments quickly and for them be so helpful, so congrats!”**

Feedback from a 2024 applicant for research funding

# Our current research portfolio

**2024 has been a great year for DEBRA research, with PhD funding awarded for training four new EB researchers in England, Scotland, Ireland and Australia.** We have continued to drive drug repurposing for all EB types with **funding for a trial of dupilumab in the US**. We have **expanded our partnership with the NHS to study EB in the UK healthcare system** and **funded a project on gene and cell therapy for blocked airways in EB**. We are proud to have **awarded funding to establish the first EB clinical research centre in Africa** at the Regional Dermatology Training Centre in Tanzania.

**Five research projects, some part-funded and others exclusively funded by DEBRA UK, have come to an end in 2024**. These ranged from short projects on the basics of gene therapy, to investigations of wound healing and skin cancer and a trial of cannabinoid oil.

Our new projects, progress updates and final reports on completed work are **summarised here** and publications resulting from the research we fund are listed on our **Research Impact page**.

Our research direction is informed by the results of our **2023 Insight Study** which involved **over 300 members** of the EB community and over 150 healthcare professionals.

Ayda, has EBS.

# Our current research portfolio

**PhD: fighting RDEB skin cancer**
CRUK Scotland Institute, UK, 2025-2029

**PhD: mRNA therapy for JEB**
Queen's University, Belfast, 2025-2029

**PhD: increasing YAP/TAZ to accelerate wound healing**
QMUL, UK, 2025-2029

**PhD: reducing DEB/JEB eye scarring**
University of Melbourne, Australia, 2025-2029

**PhD: reducing blisters in JEB**
QMUL, UK, 2024-2028

**PhD: nanoneedle wound study in RDEB**
KCL, UK, 2022-2025

**PhD: Improving skin repair in JEB**
QMUL, UK, 2024-2028

**Therapy for airway disease in JEB**
UCL, UK, 2025-2027

**Repurposing dupilumab to treat itch in all EB types**
Northwestern University, USA, 2025-2026

**Cannabinoid treatment for all EB pain and itch**
UMCG, Netherlands, 2018-2023

**Living with EB in the UK**
University of East Anglia, UK, 2024-2026

**Eye drops for all types of EB**
University of Birmingham, UK, 2023-2025

**Screening drugs to target RDEB cancer**
CRUK, UK, 2023-2025

**Permanent gene therapy for DEB**
KCL, UK, 2024-2027

**Sequencing EBS genes**
CEDIGEA, Argentina, 2023-2025

**Treating JEB with laminin protein**
QMUL, UK, 2023-2026

**Improved blister treatment for EBS**
QMUL, UK, 2023-2026

**DEB cancer and mouth wound healing**
QMUL, UK, 2024-2027

**Wellbeing toolkit for all EB parents**
Cardiff University, UK, 2024-2027

**Psoriasis tablets repurposed for EBS**
France, 2024-2026

**Repurposing statins for RDEB skin cancer**
EB House Austria, 2024-2027

**Partnership: RDEB pre-clinical cancer models**
CRUK SI, UK, 2024-2029

**Partnership: Understanding EB patient information held within the NHS**
NHS England, UK, 2024-ongoing

**The first EB clinical research centre in Africa**
RDTC, Tanzania, 2025-2027

**CRISPR/Cas9 to repair RDEB gene**
CIEMAT Spain, 2024-2025

**'Biofilms' delay EB wound healing**
University of Birmingham, UK, 2024-2025

**Simplified genetic testing for all EB types**
KK Women's & Children's Hospital, Singapore, 2024-2026

**Improving delivery of RDEB gene therapy**
CIEMAT, Spain, 2024-2025

**KEB and skin cancer**
University of Edinburgh, UK, 2020-2023

# Opportunities to promote your work through DEBRA

We love to share **blogs from researchers** working on EB and also provide the opportunity to share and promote EB research through our **Research and Health webinar series**. Please email us at **research@debra.org.uk** if you would be interested in participating.

We also welcome potential speakers for our **Members' Weekend event**, which is an opportunity to meet DEBRA members living with EB and share research highlights in a presentation or Q&A session. Please contact **Dr Sagair Hussain** if you would be interested in participating.

*Thank you*

**to all our researchers for the work you do towards increasing understanding of EB and driving us towards potential treatment options.**

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Please forward this newsletter to any colleagues you think may also be interested in applying for our funding. If you have received this email from a colleague, **please leave your details** so we can keep you updated with future funding opportunities.

## Thank you again to everyone involved in research on EB.

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