



**DECEMBER 2019**

**THE FIRST WORLD CONGRESS ON EPIDERMOLYSIS BULLOSA  
(THE BUTTERFLY CHILDREN) TO BE HELD IN LONDON JANUARY 2020**

The world's leading experts in epidermolysis bullosa (EB) research and clinical management will come together for the first time in London from 19 to 23 January 2020 to share state-of-the-art knowledge on this devastating disease and debate the direction for future research.

EB is a family of rare genetic skin conditions that causes constant pain due to unstoppable internal and external blistering. The potentially fatal conditions cause the skin to become as fragile as a butterfly's wing and young sufferers are known as the "butterfly children". At present the conditions are incurable and impact the lives of 5,000 people in the UK and over half a million worldwide.

Sufferers are often in pain from the time they are born, greatly impairing them in their day to day lives. Parents and nurses devote hours to providing specialist care to help reduce blistering. In many cases, the blistering is so severe that parents are unable to hug or comfort their children.

The race is on to try and find cures and treatments for the "worst disease you have never heard of". EB affects one in twenty thousand new-born babies, the same frequency as Cystic Fibrosis and ALS, but has far less global awareness and therefore funding for research.

There are currently no cures for EB, but thanks to advances in research and growing global awareness of one of the most devastating diseases, scientists are optimistic about finding a cure. The congress will demonstrate and debate these findings, ultimately advance the agenda for finding a medical breakthrough.

The congress will be attended by more than 600 delegates across nearly 200 organisations from 50 countries sharing expertise for this ground-breaking event and come together to develop a road map for potential cures.

Members of the EB Community will be in attendance, offering insights into their daily lives and sharing their experiences managing EB. One such member of the EB Community, Myra Ali, has established a career in journalism and public speaking, demonstrating those with the potentially fatal conditions are not defined by it. Myra has also taken on the role of media ambassador for DEBRA UK, sharing the



life changing impact of specialist EB healthcare for herself and others. Myra will be using her experience as a journalist to conduct interviews with delegates throughout the event.

DEBRA UK, the national charity supporting people suffering from EB, is organising the congress (supported by Congress Partner Cure EB and its Sponsors) and will use this gathering of world leading medical and pharmaceutical industry experts to support international collaboration, and raise awareness of the condition among the general public.

Caroline Collins, Director of Congress, says: *“For the first time, we have gathered together the world’s experts on EB to share their knowledge and to set the agenda for the future of research. We are all gathering with the same common goal, to find cures and treatments and to improve the lives of all those living with EB. We hope the Congress will inspire, educate and raise awareness of this little known but devastating group of conditions.”*

Ben Merrett, CEO of DEBRA UK, says: *“It’s a ground-breaking moment for the whole EB Community. We look forward to hearing from the world’s leading medical experts who are the driving forces for advances in research and clinical management. It is imperative that we invest more into researching these debilitating conditions and find cures that will benefit the more than half a million people worldwide suffering from EB.”*

**ENDS**

**Contact:**

**THE GLOBAL EB ALLIANCE SUPPORTING THE CONGRESS**





## **Notes to editors**

**PROGRAMME.** Now available at [www.ebworldcongress.org](http://www.ebworldcongress.org)

**THE CONGRESS CHAIRS.** Joint chairs are:

Professor Jemima Mellerio of St John's Institute of Dermatology, Guy's & St. Thomas' NHS Foundation Trust, London

Professor Jouni Uitto of the department of Dermatology and Cutaneous Biology, Thomas Jefferson University, Philadelphia

**CONGRESS OBJECTIVES.** To bring together the world's top EB researchers and practitioners in order to pool state-of-the-art knowledge across varied stakeholders to not only give guidance to the professionals involved in EB, but also help in the development of strategies for the research, regulatory, funding, and healthcare communities.

**ABOUT DEBRA UK.** DEBRA ([www.debra.org.uk](http://www.debra.org.uk)): DEBRA UK is the only national charity supporting people suffering from Epidermolysis Bullosa (EB)

*DEBRA UK is a registered charity in England and Wales (1084958) and Scotland (SC039654). Company limited by guarantee registered in England and Wales (4118259).*

#FightEB

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[www.facebook.com/DEBRACHarity](https://www.facebook.com/DEBRACHarity)

[www.instagram.com/charitydebra](https://www.instagram.com/charitydebra)

[www.debra.org.uk](http://www.debra.org.uk)

### **FACTS ABOUT EB**

- Epidermolysis Bullosa (EB) is a potentially fatal skin condition that causes constant pain due to unstoppable internal and external blistering
- EB is sometimes known as butterfly skin because the skin of sufferers is as fragile as a butterfly's wing
- In its most severe forms, EB is fatal
- Even in its mildest forms EB causes lifelong disability and pain
- Extreme disfigurement is often visible but internal tissue damage can be hidden
- EB can affect the whole body and psychological challenges are inevitable
- Excessive blistering creates scar tissue that can cause fingers and toes to fuse together, and can lead to an aggressive form of skin cancer
- There are an estimated 5,000 people suffering from EB in the UK and half a million worldwide
- EB is currently incurable