



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

04 April 2019

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

EB is a potentially fatal skin condition that causes constant pain due to unstoppable internal and external blistering. It makes skin as fragile as a butterfly's wing and young sufferers are known worldwide as the "butterfly children". The condition is currently incurable and there are at least 5,000 people living with EB in the UK and over half a million worldwide.

The race is on to try and find a cure for the condition so severe that sufferers lead a life of pain - often unable to even use a pen or lift a cup without fear of blistering.

DEBRA UK, the national charity supporting people suffering from EB, is organising the Congress and hope that the medical and pharmaceutical industry will take advantage of the opportunity by taking up the many sponsorship packages on offer. The Congress (EB 2020) is supported by an Alliance of more than 20 rare disease and dermatology organisations worldwide.

Ben Merrett, CEO of DEBRA UK, says: "For the first time, we are bringing together global knowledge in EB research, clinical management, and the EB Community to shine a spotlight on EB and to find new ways of improving the lives of those living with the condition. We would like to invite anyone who might be interested in attending or sponsoring to visit our website."

For more information on EB 2020 including the programme, sponsorship opportunities, and details on how to attend, please visit www.ebworldcongress.org. For further updates, please follow @EBWorldCongress and use #EB2020 or #EBWorldCongress to engage with us on Facebook, Twitter, Instagram, and LinkedIn.

ENDS

Contact:

THE GLOBAL EB ALLIANCE SUPPORTING THE CONGRESS



Notes to editors

REGISTRATION. Now open at 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 practitioner in order that pooling state-of-the-art knowledge across varied stakeholders will 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): DEBRA 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

twitter.com/charitydebra

www.facebook.com/DEBRACHarity

www.debra.org.uk

FACTS ABOUT EB

- 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