



Dystrophic Epidermolysis Bullosa Research Association of America

FOR IMMEDIATE RELEASE

-- 2015 NATIONAL EPIDERMOLYSIS BULLOSA AWARENESS WEEK --
-- OCTOBER 25 THROUGH OCTOBER 31, 2015 --

Be Part Of The Cure For Rare Disease, Epidermolysis Bullosa (EB) – “The Worst Disease You’ve Never Heard Of.”

NEW YORK, NY (October 14, 2015) — **National Epidermolysis Bullosa Awareness Week** will run from Sunday, October 25 through Saturday, October 31, 2015. First legislated by Ronald Reagan and the United States Congress in 1984, **National Epidermolysis Bullosa Awareness Week** is now recognized annually as the last week of October. Epidermolysis Bullosa (EB) is a painful, often fatal, and always debilitating rare genetic disease with no cure or treatment that affects 1 out of every 20,000 births in the United States. Those born with EB are often known as “Butterfly Children” for their extremely fragile skin.

During this week, debra of America works with advocates throughout the United States to increase awareness for EB, to promote the need for a cure, and to spur advocacy on behalf of families suffering with the emotional, financial, and physical burdens of the disease. debra of America Supporter Led Events are organized throughout the country during this week with proceeds directly supporting people living with EB. For more information, visit: debra.org/ebweek.

DEBRA OF AMERICA EVENTS IN THE UNITED STATES

- **A Regional EB Family Day** – Sponsored by McKesson Patient Care Solutions; October 24; Pittsburgh, PA; debra.org/ebfamilyday
- **Virtual dash4debra** – A virtual run/walk at any time and in any location; October 25-31; Nationwide; debra.org/dash4debra
- **Faces of EB: A Photography Exhibition** – Co-Sponsored by Duggal Visual Solutions; October 27; New York, NY; debra.org/facesofeb
- **Wheels Healing Wounds Car Show** – A car show hosted by EB advocate Robert Cline; October 17; Lexington, NC
- **McKesson at Medtrade: Spin the Wheel for EB** – Sponsored by McKesson Medical-Surgical; October 26-29; Atlanta, GA
- **EB Family Day at CHLA** – Sponsored by Children’s Hospital Los Angeles; October 25; Los Angeles, CA

For more information about these events, please visit: debra.org/events, call: 212-868-1573 x101, or email: events@debra.org.

SOCIAL MEDIA

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ABOUT DEBRA OF AMERICA

The Dystrophic Epidermolysis Bullosa Research Association of America (debra of America), founded in 1980, is headquartered in New York City and is the only U.S. nonprofit providing all-inclusive support to the EB Community, through funding research for a cure and by providing free Programs and Services for those with Epidermolysis Bullosa (EB). For more information, visit: debra.org.

WHAT IS EB?

Epidermolysis Bullosa (EB) is a rare genetic connective tissue disorder in which individuals do not produce a protein that allows their skin to adhere to itself. The most well-known and prominent manifestation of EB is blistering or tearing of the skin from friction. The skin fragility is often compared with the wings of a butterfly, so those born with EB are often known as “Butterfly Children.” There is no cure or treatment for EB. Imagine your child suffering from a disease where more than 70% of their body is covered in open sores and blisters. EB afflicts both genders and all racial and ethnic backgrounds. Amazing strides have been made in research and scientists are getting closer to finding a cure. For more information on EB, visit: debra.org/eb.

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FOR MEDIA COVERAGE

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