

NATIONAL EPIDERMOLYSIS BULLOSA (EB) AWARENESS WEEK RUNS OCTOBER 25 – OCTOBER 31

First Legislated By Ronald Reagan And The United States Congress In 1984

New York, NY (October 25, 2012) — [DeBRA of America, Inc.](http://debra.org) will celebrate *National Epidermolysis Bullosa (EB) Awareness Week* from October 25 through October 31, 2012. This is a time to increase awareness of Epidermolysis Bullosa (EB), “the worst disease you’ve never heard of” – while promoting the need for a cure and to spur advocacy on behalf of families suffering with the emotional, financial and physical burden of the disease. First legislated by Ronald Reagan and the United States Congress in 1984, it is now recognized annually as the last week in October.

EB is a rare, debilitating and fatal genetic condition that affects 1 out of every 50,000 live births. The most prominent symptom patients with EB live with is skin so fragile that even the slightest friction can cause severe blistering and sores; both inside and outside their bodies. Caused by a mutation on a gene, EB has a long list of manifestations and secondary complications that require multiple interventions from a range of medical specialists. Every racial and ethnic group, as well as both genders, are affected equally by EB. There is no cure. Pain management, wound care and preventative bandaging are the only treatment options. DeBRA of America is the only national not-for-profit that supports the research for treatments and a cure, while providing services and programs to those who suffer from, Epidermolysis Bullosa (EB).

Support DeBRA of America and the organization’s mission: to improve the quality of life for all EB patients, their families and their caregivers, while encouraging research to find a cure and treatments for EB. This year for *National Epidermolysis Bullosa (EB) Awareness Week*, please show your support by donating to DeBRA of America and being part of the cure. Donate at debra.org/donate

DeBRA of America encourages friends, family and loved ones of EB patients to promote *National Epidermolysis Bullosa (EB) Awareness Week* by doing one or more of the activities listed on debra.org/national-epidermolysis-bullosa-awareness-week

From July 30 through August 1, DeBRA of America held the 6th biennial Patient Care Conference (PCC) for the children and families affected by Epidermolysis Bullosa (EB) at the Gaylord Palms Resort and Convention Center in Orlando, Florida. The conference brought together 80 EB families, 40 leading medical expert speakers, sponsors and exhibitors from around the world – making it the largest PCC in history.

On October 1, DeBRA of America held the *14th Annual Mats Wilander Tennis & Golf Benefit* presented by Mölnlycke Health Care at Quaker Ridge Golf Club in Scarsdale, New York. In 1998, the Wilanders partnered with DeBRA to create this annual fundraising benefit after their son Erik was born with EB Simplex. Guests spent the morning playing tennis with former #1 player in the world, Mats Wilander, while foursomes hit the links for an afternoon of golf. Attendees of the evening fundraiser enjoyed a cocktail reception and dinner, an awards ceremony for the 2012 Honorees (Courtney Roth & Philip Reilly, M.D., J.D.) and a silent/live auction led by Alan Kalter, the voice of Late Show with David Letterman. The evening concluded with DeBRA’s Executive Director, Brett Kopelan presenting a check for \$200,000 to Dr. Jakub Tolar, M.D., Ph.D. (University of Minnesota) for his ongoing work in developing therapies for Epidermolysis Bullosa (EB).

About DeBRA of America, Inc.

The Dystrophic Epidermolysis Bullosa Research Association of America, Inc. (DeBRA) was founded over 30 years ago and is the only national not-for-profit that supports the research for treatments and a cure, while providing services and programs to those who suffer from, Epidermolysis Bullosa (EB). www.debra.org

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