



Dystrophic Epidermolysis Bullosa Research Association of America

DEBRA OF AMERICA TO HOST 7TH BIENNIAL PATIENT CARE CONFERENCE FOR PEOPLE WITH EPIDERMOLYSIS BULLOSA AND MEDICAL EXPERTS FROM JULY 30 TO AUGUST 2 IN NASHVILLE, TENNESSEE

Four-Day Conference For People With Rare Genetic Disorder

NEW YORK, NY (April 14, 2014) — [debra of America](http://debra.org) will be hosting the biennial 2014 [debra Patient Care Conference](http://debra.org/PCC2014) (PCC) for children and families affected by Epidermolysis Bullosa (EB), a rare, debilitating, and fatal genetic connective tissue disorder that affects 1 out of every 20,000 live births in the United States. Because their skin is so fragile, they are often known as ‘Butterfly Children.’ The conference runs July 30 to August 2, 2014 at the Gaylord Opryland Resort and Convention Center in Nashville, Tennessee.

The *debra Patient Care Conference* will bring together people with Epidermolysis Bullosa, their families, caregivers, advocates, leading medical experts, sponsors, and exhibitors from across the United States. [debra](http://debra.org) of America’s EB Nurse Educator, Geri Kelly from Cincinnati Children’s Hospital Medical Center, will be available to meet and answer questions. The conference is currently at capacity, which sets a conference record with almost 500 people registered to attend. Sponsors include; Hollister Wound Care (Platinum), Mölnlycke Health Care (Gold), National Rehab (Gold), Scioderm (Silver), Edgepark Medical Supplies (Bronze), and Ferris Mfg. Corp. (Bronze). For sponsorship opportunities, exhibitor booth/signage, and more, visit: debra.org/PCC2014

Epidermolysis Bullosa (EB) is a rare genetic connective tissue disorder in which people do not produce a vital protein which allows their skin to adhere to itself. The most prominent symptom is skin so fragile that even the slightest friction can cause severe blistering and sores inside and outside their bodies. EB afflicts both genders and all racial and ethnic backgrounds equally. That means taking off a shirt or a hug from a loved one is incredibly painful and causes the skin to peel away. There is no cure or treatment for EB; pain management, wound care, and preventative bandaging are the only options.

For many families, the *debra Patient Care Conference* is their only opportunity to hear talks and meet with members of the medical profession who have developed expertise in particular areas of EB care and research. They can also speak with bandage manufacturers and distributors about new wound care products. Attendees will enjoy a variety of activities including, the Kids Room for younger guests, interactive sessions like the Teen Roundtable and EB on Social Media, time to socialize with new and old friends, and the exciting Family Field Trip.

Brett Kopelan, [debra](http://debra.org) of America’s Executive Director and father to Rafi, a six-year-old girl with EB says, *“The record attendance we are having this year clearly demonstrates how important our Patient Care Conference is to the families that live with EB. Not only will the conference provide an opportunity to hear about the tremendous progress researchers are making toward a treatment, but it will also allow for an opportunity to fun. The one hundred plus children attending will be able to socialize and play games in one of our three fully staffed playrooms, while their parents are able to meet face to face with the professional community dedicated to caring for those with EB and finding a cure for what we call, ‘the worst disease you’ve never heard of.’”*

ABOUT DEBRA OF AMERICA

The Dystrophic Epidermolysis Bullosa Research Association of America ([debra](http://debra.org) of America) founded in 1980, is headquartered in New York City, and is the only national nonprofit that supports the research for treatments and a cure, while providing services and programs to those who suffer from Epidermolysis Bullosa (EB). debra.org

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FOR MEDIA COVERAGE

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WHAT IS EB? Epidermolysis Bullosa (EB) is a rare genetic connective tissue disorder in which children do not produce a vital protein which allows their skin to adhere to itself. Because their skin is so fragile, they are often known as ‘Butterfly Children.’ EB afflicts both genders and all racial and ethnic backgrounds equally. The most well-known and prominent manifestation of EB is blistering or tearing of the skin from any friction. That means taking off a shirt or a hug is incredibly painful and causes the skin to peel away. Imagine your child suffering from a disease where more than 70% of their body is covered in open sores and blisters.

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