

DEBRA OF AMERICA HOLDS 6th BIENNIAL PATIENT CARE CONFERENCE FOR EPIDERMOLYSIS BULLOSA PATIENTS AND MEDICAL EXPERTS FROM JULY 30 TO AUGUST 1 IN ORLANDO, FLORIDA

Three Day Conference For Rare Genetic Disorder Includes Family Field Trip To Downtown Disney's Planet Hollywood And Cirque du Soleil's La Nouba

New York, NY (July 26, 2012) — [DeBRA of America, Inc.](#) will be holding the biennial [DeBRA Patient Care Conference](#) (PCC) for the children and families affected by Epidermolysis Bullosa (EB) from July 30 through August 1 at the Gaylord Palms Resort and Convention Center in Orlando/Kissimmee, Florida. EB is a rare, debilitating and fatal genetic condition that affects 1 out of every 50,000 live births.

The [DeBRA](#) PCC will bring together EB patients, their families, 40 leading medical experts, sponsors and exhibitors from all over the world. This year is the PCC's largest in history, with almost 400 people in attendance. Sponsors include; *Mölnlycke Health Care*, *Hollister Wound Care*, *National Rehab*, *Coloplast* and *Edgepark Medical Supplies*. [DeBRA's](#) Nurse Educator, Geri Kelly from Cincinnati Children's Hospital Medical Center, will be on hand to assist and answer questions.

The most prominent symptom patients with EB live with is skin so fragile that even the slightest friction can cause severe blistering and sores; 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 or treatment. Pain management, wound care and preventative bandaging are the only treatment options. [DeBRA](#) of America is the only national not-for-profit that supports research for a cure or treatments for, while providing services and programs to those who suffer from EB - *the worst disease you never heard of*.

The children with EB will enjoy many fun filled activities over the three day conference, including three separate Kids Rooms with arts and crafts, books, movies and video games, as well as a Teen Roundtable & Ice Cream Social. The Gaylord Palms Resort and Convention Center has also arranged a private meet and greet with popular DreamWorks Animation characters. On August 1, marking the last night of the PCC, [DeBRA](#) will bring the EB children and their families on the Family Field Trip to Downtown Disney for dinner at Planet Hollywood and to see Cirque du Soleil's La Nouba.

Brett Kopelan, [DeBRA's](#) Executive Director and father to Rafi, a five-year-old EB girl, says "we are looking forward to seeing all the EB families at the PCC this year. I am confident that everyone will learn a tremendous amount from the esteemed group of speakers, but more importantly it's my sincere hope that everyone goes home after the PCC having had a great time - because the kids deserve it."

About [DeBRA](#) of America, Inc.

The Dystrophic Epidermolysis Bullosa Research Association of America, Inc. ([DeBRA](#)) founded over 30 years ago is headquartered in New York City, 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). [DeBRA's](#) [14th Annual Mats Wilander Tennis & Golf Benefit](#) will be October 1 at Quaker Ridge Golf Club in Scarsdale, NY. www.debra.org.

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