

**FOR IMMEDIATE RELEASE**

**debra of America Celebrates National Epidermolysis Bullosa Awareness Week with 15th Annual Benefit For Children with Painful Genetic Disorder on October 24 at The Museum of Modern Art**

**Honoring Sonya and Mats Wilander, Former #1 and International Tennis Hall of Fame Member**

**Be Part of the Cure For “Epidermolysis Bullosa (EB) – The Worst Disease You’ve Never Heard Of.™”**

**New York, NY (October 1, 2013) — The 15th Annual debra of America Benefit** will be held Thursday, October 24 from 7:30PM to 10:30PM at The Museum of Modern Art in New York City. The benefit will honor Sonya and Mats Wilander in recognition of their years of hard work after their son was born with EB. The Wilanders have been instrumental in helping **debra of America** raise awareness of the disease and funds to support **debra of America’s** mission. The event marks the beginning of National Epidermolysis Bullosa Awareness Week, which was legislated by Congress in 1984 and occurs annually from October 25 through October 31. EB Awareness Week was created to increase awareness of this debilitating disorder, to promote the need for a cure and to spur advocacy initiatives on behalf of those suffering with the emotional, financial, and physical burden of the disease.

The **15th Annual debra of America Benefit** will feature catering from pinch Food Design, open bar, silent and live auctions auctioneered by Alan Kalter (the voice of the *Late Show with David Letterman*), a live DJ, and private viewing of The Museum of Modern Art’s 5th Floor Painting and Sculpture Galleries, which includes Van Gogh’s *The Starry Night*. The evening will recognize the courage of families that adopt EB children, as well as pharmaceutical companies for their recent work in developing therapies for those with EB. Proceeds from the event benefit **debra of America**, the only national nonprofit dedicated to funding research for treatments and a cure, while providing supportive services and programs for those who suffer from the rare and painful genetic disorder, Epidermolysis Bullosa.

Tickets to the benefit range from \$100 to \$2,500, with Individual tickets beginning at \$200 and a Couples ticket at \$375. A ‘Friend of Butterfly Children’ ticket is \$2,500; a ‘Sponsor EB Family to Patient Care Conference’ ticket is \$1,750; and a ‘Sponsor EB Family to MoMA Benefit’ ticket is \$1,000. A ‘Young Ambassador’ ticket (35-and-under) is \$100. The benefit is open to all guests. Purchase tickets or make a donation by visiting: [debra.org/benefits](http://debra.org/benefits), by email: [events@debra.org](mailto:events@debra.org), or by phone: (855) CURE-4-EB.

**SPONSORSHIP**

The **15th Annual debra of America Benefit’s** title sponsor is Mölnlycke Health Care. Additional sponsorship is provided by; Scioderm (Platinum), Fibrocell Science (Silver), National Rehab (Silver), Novella Clinical (Silver), Capstone Partnership (Bronze), Hollister (Bronze), Rosen, Livingston & Cholst LLP (Bronze), and Shire (Bronze).

**ABOUT EPIDERMOLYSIS BULLOSA (EB)**

Epidermolysis Bullosa (EB) is a rare, genetic, connective tissue disorder. There are many genetic and symptomatic variations of EB, but all share the prominent symptom of extremely fragile skin that blisters and tears from minor friction or trauma. Internal organs and bodily systems can also be seriously affected by the disease. EB is always painful, is often pervasive and debilitating, and in some cases lethal before the age of 30. EB affects 1 out of every 20,000 live births and those born with it are often called ‘Butterfly Children’ because, as the analogy goes, their skin is as fragile as the wings of a butterfly. There is no treatment or cure. Daily wound care, pain management, and protective bandaging are the only options available. Learn more at: [debra.org/whatiseb](http://debra.org/whatiseb)

**ABOUT DEBRA OF AMERICA**

The Dystrophic Epidermolysis Bullosa Research Association of America was founded in 1980 and is the only national nonprofit dedicated to funding research for treatments and a cure, while providing supportive services and programs for those who suffer from the rare and painful genetic disorder, “Epidermolysis Bullosa (EB) – The Worst Disease You’ve Never Heard Of.™”

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**FOR PRESS COVERAGE AND IMAGES**

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