



5 West 36th Street, Suite 404
New York, NY 10018

***YOU CAN HELP DEBRA MOVE CLOSER TO REALIZING JONNY KENNEDY'S DREAM...
BRINGING AN END TO THE DEVASTATING DISEASE EPIDERMOLYSIS BULLOSA.***



Dear Friend:

You were moved by the late Jonny Kennedy's story in the film "The Boy Whose Skin Fell Off", which aired on TLC. We appreciate the support and interest you have shown in Jonny's story and in helping the thousands of children and adults in the United States who suffer daily from the pain caused by Epidermolysis Bullosa (EB).

Today, I'd like to tell you a little bit about another "Jonny" - four-year-old John Hudson. He is a bright eyed boy in New York City who has the same severe form of EB as Jonny Kennedy - Recessive Dystrophic EB or RDEB. John Hudson spends three hours every day getting his wounds cleaned and his arms, hands, legs, feet and torso bandaged to protect his fragile skin from further injury and infection. Despite this exhausting and painful routine, John Hudson still finds enough energy to play and charm everyone with his mischievous grin.

Chastity is an adult with RDEB who had so many scars in her throat just from eating her daily meals she could barely swallow anymore. She recently had delicate surgery to reopen her throat. For the first time in her life she can manage to swallow pills essential to her care and comfort. While the surgery was a success, Chastity will always be vulnerable to new scars and may need future surgeries.

At DebRA, we are funding research that is bringing hope to John Hudson and Chastity. This research is helping us move closer to a cure for this devastating disease. But, until there is a cure, DebRA must help ease the day-to-day suffering of EB for patients and their families.

DebRA provides families with free access to an experienced Nurse Educator, free bandages and other medical supplies, a Family Crisis Fund for select non-reimbursed medical costs, and a trained volunteer to help new parents learn how to care for their child.

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The demand for these programs and services is high because there are few EB medical experts and bandages may cost a family \$5000 per month that insurance does not cover. Patients and families have nowhere else to turn for help. Right now, DebRA needs your help to meet these needs and to provide hope for a cure through research.

Sincerely,

A handwritten signature in black ink, appearing to read "Suzanne Cohen". The signature is fluid and cursive, with a long horizontal flourish extending to the right.

Suzanne Cohen

P.S. Today, you can help DebRA provide crucial services to people with EB by filling out and returning the enclosed donation envelope with your contribution.

HR 3768 Katrina Emergency Tax Relief Act of 2005 (Katrina I) suspends limitations on individual and corporate tax deductions for cash contributions to charitable organizations made between August 28 and December 31, 2005. You should check with your tax advisor to determine if the provisions of this act may be beneficial to you for your year end charitable donations.