



EB Is Everybody's Business: Finding A Cure For Epidermolysis Bullosa

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Who can resist kissing and cuddling a newborn baby? What person doesn't want to touch those little fingers and toes and sweet baby nose? How do the parents of a child with Epidermolysis Bullosa react when they learn that these acts of love can result in the removal their child's very skin? The answer is this: they band together and fight for a cure, like Michael and Karen Peshkur, the parents of little Grace who is a victim of this rare and horrifying disease.

Grace Peshkur is three years old. She loves Disney. Her imagination lets her soar to places her scarred and blistered body won't allow her to visit. She can sit and watch the neighborhood children playing outside in the summer heat and only dream to join them. It's then she turns to her mother and says, "I don't want these boo-boos anymore."

The disease ravaged over 90% of Grace's small frame. She is much akin to a burn victim; most of her body is one open wound. Her little arms and legs are bandaged, her body needs to be wrapped-up at all times. Blood seeps through them. The seams of clothing are too rough on her sensitive skin. A dressing change is needed twice a day, taking two to three hours and is excruciatingly painful. Like a butterfly's wings, Grace's skin will just flake away at the slightest touch. It's a condition she was born with. The odds were one in a million, yet both of her parents unknowingly carried the gene giving them a one in four chance of bearing a child with EB. There are approximately 12,500 cases of EB in the United States and the life expectancy of an individual suffering this horror is only 20 years. Grace has the most severe form of EB, Recessive Dystrophic, affecting all three layers of her skin as well as her insides.

EB eliminates the glue that holds the layers of skin together. An EB patient's layers of skin separate at the slightest touch. It attacks all tissue, often deteriorating internal organs. Some people must be fed intravenously because their esophagus is deteriorated. Grace's mother, Karen, nodded her head and said, "it is the cruelest disease."

Outside the Peshkur residence on July 11, Congressman Tim Bishop addressed the dire need for national awareness about the disease. He is currently introducing legislation to reserve the last week in October as National Epidermolysis Bullosa Awareness Week.

Many organizations have offered their services to help Grace and other children who suffer from this and various illnesses. The Children's Foundation of Suffolk Inc. has worked with the Peshkurs closely. When Grace's esophagus was closing down the Children's Foundation flew her to Cincinnati to have immediate surgery. The organization donates over \$10,000 a year to children in the most financial need. This year they are holding their annual Pig Roast at the Maritime Museum in West Sayville on September 10 at 6 p.m. to raise money for children like Grace. "People tend to shun them," said Cindy Wilkinson, Board of Directors. "They think that they can get the disease and that is just not true. It is not airborne or contagious." This is what the public needs to know. For additional information about the foundation phone calls can be made to 567-1111.

The Grace Peshkur Foundation is also having an event to help raise awareness of EB. Carol Mazurek, who coined the slogan "EB is Everybody's Business," is Co-Chair of the Butterfly Ball. "Grace is a big part of my heart. She's a fighter," Mazurek said. The 2<sup>nd</sup> Annual Butterfly Ball will take place at the Huntington Town House on October 22<sup>nd</sup> cocktail hour begins at 6:30. For ticket information please contact Helen at 656-6115, or Maureen at 588-0254. Donations can also be sent to The Grace Peshkur Foundation at PO Box 2379, Holtsville, NY, 11742-2379. Please visit [www.OURGRACE.org](http://www.OURGRACE.org) for further information.

The Holtsville Fire Department will also be sponsoring a Barbeque on August 13 from 1-5. For details call 475-5238 extension 68.

Michael Peshkur, Grace's father acknowledged that you can't take the disease "day by day, its hour by hour." Amidst the pitiful cries of pain from Grace's blistered baby lips, and the agony of another day's "dressing", the Peshkurs agree that they "are blessed. We are the luckiest parents in the world. Grace taught us to appreciate the little things in life." And that has made all the difference.