

A MOTHER'S FIGHT

Courteney Cox shares why she has joined the battle against a rare skin disease.

Over the years I have been involved with many worthwhile charities and always lend my support to causes that are near and dear to me. I began supporting the Epidermolysis Bullosa Medical Research Foundation about six years ago, when my daughter Coco was born. A year before, my manager's nephew Brandon was born with EB, a rare genetic disorder that causes the skin to tear and blister at the slightest touch or trauma and, consequently, requires the skin to be bandaged daily. It can also cause webbing of the toes and fingers and scarring of the esophagus and other body parts. As a new mom, I was drawn to help in any way I could and joined the organization's honorary advisory board.

When I first met Brandon he was only a few months old, and I saw his bandaged body and the scars from recent wounds. I also saw a smiling and playful young boy whose family was overwhelmed

by the enormity of this disease, but were willing to face the challenge. Together we set out to raise support and awareness for EB through a variety of events, including Drag Queen EBingo, a carnival celebration at Santa Monica Pier, a Malibu picnic and a Rock & EBowl event at Pinz. Because it's an orphan disease (so rare it hasn't been "adopted" by the pharmaceutical industry), very little funding is directed towards EB research. At the time of our first event, I was the spokesperson for the skincare line Kinerase, so it made sense to bring them on board and start raising money for research. My husband, David Arquette, and I also joined other celebrity supporters to create holiday cards, and we designed a collection with Satya Jewelry.

Early on, at our first fund-raiser, David and I met a young woman named Christina. She was in a wheelchair, no longer had the use of her fingers and was very soft-spoken due to her esophageal scarring, but she wrote beautiful poetry as an

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outlet for the pain she faced each day. We decided to have her poetry bound in a book and were able to get it to her just days before she passed away.

Even though the symbol for EB is a butterfly (because those who suffer from it have skin as fragile as a butterfly's wings), these children are actually very strong. They face each day with renewed strength and determination to not let the disease define who they are or hinder them from leading normal lives. I've been so touched by those who suffer from this disease and their strength of spirit. ebkids.org



Cox with Luke Langhor at the Old Navy Rock & EBowl event at Pinz

