



Andrea Pett-Joseph with her son Brandon, who has Epidermolysis Bullosa. "I have to campaign for this," she says.

Tender mercies

By **MONICA CORCORAN**

CAUSE: Epidermolysis Bullosa. An estimated 100,000 Americans suffer from this rare genetic skin disorder that causes severe blisters and wounds.

CRUSADERS: Andrea Pett-Joseph, manager at Brillstein-Grey Entertainment, and her husband, Paul Joseph. The couple founded a Los Angeles branch of the EB Medical Research Foundation when their son Brandon was born with EB in 2003.

ANDREA PETT-JOSEPH'S STORY:

"I had a normal pregnancy and the delivery was fine. But it changed in a blink; Brandon was missing all the skin on the tops of his hands and his feet when he was born. He had to be treated like a burn victim — wrapped in bandages from head to toe.

Everything ran through my mind for those first few months: How is he going to go down the slide? How is he going to walk? How will he

shave? He has to be able to dance at prom! We had to train ourselves to hold him properly.

We have to pop his blisters as soon as they form or they will get bigger. That's what causes the scarring. Basically, every part of his body is affected. If he rubs his eye, he tears his cornea. We have to worry about his esophagus, which can blister and close up. No one specializes in EB, so you have to find a dermatologist and an internist who has seen it before. There is no treatment or cure. Now, he's a little over 2½. We keep a super-positive outlook and let his experiences flourish. We won't let this hold him back. When he asks, 'Mom, how come I can't be on the baseball team?', we will explain it to him. But he goes in the pool, so we'll say: 'Hey, Brandon, you'll be on the swim team.'"

CAMPAIGN: On Aug. 14, EBMRF and Courtney Cox-Arquette will host their first annual EBingo Night at the Comedy Store. Tickets start at \$200; call 310-205-5119 for more information. Visit ebkids.org for other ways to get involved.