

People

Parents' Race to Fund Cure for Teen Son's Painful Skin Disease: 'Time Is the One Thing None of Us Can Get Back'

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When Andrea Pett-Joseph gave birth to her son Brandon in December 2003, she knew something was wrong when the doctors rushed the newborn away without letting her see him.

"I didn't even know I'd had a boy at first," the Los Angeles, California, talent manager tells PEOPLE. "They took him immediately to the NICU because they noticed skin was missing from his body. From his calf down, on both legs, it was just raw and red. It made absolutely no sense."

Then the head of the NICU approached the new mom and her husband, Paul Joseph, with devastating news.

"He said, 'We're not sure what your son has,'" the 51-year-old talent manager recalls, "'but we think it's this'—and he literally pulled out a text book and flipped to a picture. He'd never seen it before."

A biopsy confirmed the doctor's suspicions — Brandon had [Epidermolysis bullosa](#) (EB), a rare and incurable genetic condition that causes painful blisters on the skin and internal organs from even minor friction. The result is disfiguring scars and, often, early death from skin cancer.



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“I remember crying a lot. Then the emotional stuff takes over and you’re looking towards the future and wondering how your child is going to face it,” Pett-Joseph says. “What will he be able to enjoy in life?”

But the new parents’ minds were soon consumed by even more pressing questions as the hospital tried to prepare them to take Brandon home. Doctors told the Josephs they would need to wrap their baby in bandages, pop his blisters with needles and bathe him in bleach to fight infections.



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“It was daunting,” Joseph, a private wealth manager, recalls. “But once you get through the why, how and what ifs, you realize you have a child to take care of.”

Searching for resources on how to care for a child with EB, the couple soon learned “there were more questions than answers,” Joseph says.

Then they discovered doctors in the dermatology department at [The Stanford University School of Medicine](#) were making progress studying EB thanks in large part to support from the [Epidermolysis Bullosa Medical Research Foundation](#), which was founded by the parents of two children with EB.

The Josephs reached out to the EBMRF’s founder, Lynn Fescher, and offered to “bring a spotlight” to her efforts, Pett-Joseph says.

“We have this ability and we have this voice,” Joseph adds. “We can’t squander that.”

“She was very gracious in letting us work with her,” Joseph says of the woman who lost two children to the disease. “She started from ground zero and really did an enormous amount. She had paid a price.”

The couple launched a Los Angeles chapter of the EBMRF in 2005, and took over day-to-day operations of the foundation later that year when Fescher was “ready to pass the baton,” Pett-Joseph says.

Since then, with events ranging from movie premieres to their annual Rock4EB! concert ([Brad Pitt](#), [Courteney Cox](#), [Kaley Cuoco](#) and [Sting](#) attended [this year's benefit](#)), they've raised more than \$5 million for research.



KEVIN WINTER/GETTY IMAGES FOR EBMRF

“The Josephs make the trains run,” says Dr. Jakub Tolar, Director of the [University of Minnesota’s Stem Cell Institute](#), whose research on treating and eventually curing EB with a [blood and marrow transplant](#) is one of several promising projects the EBMRF helps fund. “I see them as my guides and my partners.”

“This is a tragic disorder, there’s no question about it,” Dr. Tolar continues. “But they have this ability to find something hopeful in it.”

Despite all of the progress the EBMRF has made, 13-year-old Brandon's life with EB continues to be far from easy. Brandon's legs and feet are always in bandages and he eats only soft foods to help avoid blisters and scarring in his mouth and esophagus.

"His pain level day-to-day is pretty high," Pett-Joseph says. "Sometimes taking off a T-shirt is painful, brushing his teeth hurts. There's no way around it. EB is a very debilitating, disfiguring disease."

Still, the family does everything they can to find the moments of joy in days characterized by pain.

"It's a heavy weight to carry around so we do everything we can to help him not feel so burdened," Pett-Joseph says.

In between playing the drums and basketball with friends, Brandon is preparing for his Bar Mitzvah this May. His parents continue to do all that they can to ensure they'll be able to share future milestones with their son.

"We're hopeful that what we're doing is more than a step in the right direction," Pett-Joseph says. "And we're hopeful that Brandon is going to get married and have kids and live a beautiful life."