

## giving

**M**any of them can't tumble on a trampoline in the backyard or run barefoot on the beach. These kids often can't play sports with their friends, and some even have difficulty eating solid foods or holding hands with their best friend. Children born with the genetic skin disorder Epidermolysis Bullosa (EB) move through life constantly treating or recovering from wounds and blisters that appear on their fragile skin from the slightest of life's tactile incidents. It's for this that they are called the butterfly children—their skin is as delicate as this beautiful insect's wings.

Eight-year-old Christian is one such kid. A second grader at Sacred Heart Preparatory in Atherton, he spends hours each day treating his skin and has to make sure his friends understand that he can't play rough at school or during his swimming lessons. "He's very courageous about it all," says mom Carmen Sofia Schroeder.

"We've always had the mentality that you just have to keep moving forward. But, it can be pretty intense. I've become Christian's nurse, and the care is 24/7."

Though rare—some estimates show that 100,000 in the U.S. suffer from EB—its complications, from wound infection to internal organ damage and malnutrition, have claimed the lives of many. And hope is often hard to come by for these mentally sharp children and their families—there's currently no cure for the genetic disorder. So like many EB parents, part of living courageously for Christian's family means joining the fight to find a cure.

Schroeder works locally to fundraise and support the EB Medical Research Foundation (EBMRF), supporting doctors looking for a cure. Its founder, Lynn Anderson, was a pioneer in the fight for butterfly children when she created the foundation in 1991 after losing both of her young children to EB. Her children's doctor, Eugene Bauer, had assembled a team of EB researchers at Stanford at the time and desperately needed funding for their work. "He compiled the best research team in the nation," says Anderson, whose fundraising efforts have supported Dr. Bauer's skin graft and gene therapy research for 17 years. "We feel positive that Stanford is coming close to a cure," she adds.

Three years ago, Schroeder and friend Sarah Lucas started a party planning business, SarahSofia, as a means to help the EBMRF and its mission. "We started the business with a main goal being to raise money to find a cure for EB," Schroeder says. "They're so close to completing successful skin grafts. A lot of lives could be saved by this and a lot of pain could be avoided."

By offering to help with the planning for fundraising events, SarahSofia has encouraged local businesses to join in helping out. Menlo Park's Head Over Heels and Pink Tangerine are two businesses that have jumped at the opportunity to host benefit trunk shows or fundraising sales raising thousands for the EBMRF as a result. "By combining our efforts with those of the community," says Lucas of their work, "a greater sense of awareness is reached and a true sense of caring and concern is generated."

Such awareness and caring brings hope, which is the sustenance Schroeder's and Anderson's families have thrived on. "With such wonderful research going on at Stanford, it is truly a time of hope for EB families," Anderson says. "For a long time we lived without it, and it's been a long hard road." [www.ebkids.org](http://www.ebkids.org) ■



Carmen Sofia Schroeder,  
Christian Schroeder, and Sarah Lucas

## The *Butterfly* Children

In honor of EB Awareness Month this October, Gentry spoke with a few women who are fighting to find a cure for children living with this genetic disorder.

### How You Can Help

- Contact SarahSofia event planning to discuss having your local business host a fundraiser for the butterfly children. Visit [www.sarahsofia.com](http://www.sarahsofia.com).
- Find out more about EB online at the EBMRF's website, and share what you learned with friends and family in support of EB Awareness Month.
- Visit with butterfly children who are at Stanford Hospital, or adopt a local EB family to help support them through the upcoming holidays. Call Carmen at 650.926.9404 for information.

—LINDSAY SCHAUER