PAIGE LACOMBE

Thriving

Ten-year old Paige LaCombe is the picture of positivity, in spite of the scars and myriad health problems caused by a battle with Stevens Johnson syndrome (SJS). “Paige inspires me. I wish I could be as strong as she is,” said her mother, Renee.

Paige was misdiagnosed with epilepsy, and in March 2013 she was prescribed an unusually high dose of a medication to control the condition. The medication caused a severe allergic reaction which was incorrectly diagnosed by her local hospital as pink eye; they sent Paige home with a prescription for antibiotics. This string of regrettable medical errors led to Paige developing Toxic Epidermal Necrolysis (TENS), a more severe variant of SJS, in which the body essentially burns from the inside out.

For four days, Paige’s condition continuing to deteriorate, and her parents did not know what was happening to their daughter. Luckily, a family friend saw pictures of Paige and immediately suspected SJS. Paige was rushed to Shriners Children’s Hospital in Galveston, TX, where she remained for the next two months. During that time, Paige lost more than 80% of her skin. While many who contract TENS do not survive, Paige did. And she is not just surviving; she is thriving.

“SJS almost took me away from my family,” said Paige. “I have never been so scared in my life.”

“Everyone at Paige’s school has been great,” said Renee. “I was worried that she would be picked on, but anytime someone says the wrong thing to her, her friends all surround and protect her.” Renee credits Paige’s BostonSight® PROSE treatment, which she completed with Ryan Dimit, OD, at Alkek Eye Center in Houston, TX, for much of her daughter’s ability to lead a full, happy life. “PROSE treatment saved her. I can’t imagine her life without her PROSE devices. She used to sit in the corner, in the dark, with her eyes closed because she was in so much pain. I never want to see that again.”

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Paige and her family are determined that good things will come out of her situation. “I want nothing more than to help save someone from going through what I went through,” said Paige. To that end they have established SJS Awareness Louisiana. Their third event, “Running to Spread Awareness”, is a 5k and a 1 mile run that will take place in October 2015. They have also been successful in their requests to the Governor of Louisiana, the mayor of Scott, LA, and the city president of Lafayette, LA, to declare August as SJS Awareness Month. But there is more to be done.

“I want more people to be aware of the dangerous side effects that so many medications can have,” said Renee. She believes that both prescribing physicians and dispensing pharmacists have an important role to play in further educating the public about potentially life-threatening side effects of certain medications; and that hospital staff need to have more training on the basic steps to take at the first sign of an allergic reaction.

“SJS has changed so many things about me,” said Paige. “It made me different from others, but it made me stronger, too. I will always keep fighting SJS.”