



**MARTIN CASASOLA**

## Eyes wide open

It seems unimaginable that infected tonsils could lead to so much suffering. But as anyone who develops Stevens Johnson syndrome (SJS) knows, medication toxicity can trigger a serious, overwhelming allergic reaction. In the case of Jose Martin Casasola Chirinos (pictured, second from left, with his parents and sister), a shot of penicillin administered in a Lima, Peru, hospital did just that. It was 2006, and he was six years old. His parents, Jose and Doris Chirinos, could only watch as his symptoms appeared. “Three hours after receiving the shot, Martin had red, swollen spots all over his body,” his mother recalls. “They turned into blisters, and he developed a high fever.”

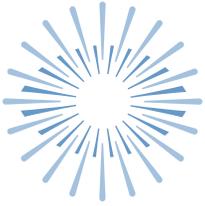


He soon had tachycardia—an abnormally fast heart rate that can lead to cardiac arrest and death—and was transferred to a larger hospital where the diagnosis of SJS was finally made. “The doctor told us his chances of survival were 50 percent,” says Mr. Chirinos. During the following two weeks as his condition stabilized, Martin’s eyelids were closed; the family was told that the inside of both eyelids had been damaged.

Once at home, Martin slowly recovered, but his eyes were so sensitive that he had to wear sunglasses and avoid the outdoors. Some days, his eyes were so red and uncomfortable that he couldn’t go to school. “He wasn’t the same happy boy who liked to run, jump, go to the beach and play football,” says Mrs. Chirinos. “At school, he was the victim of bullying.”

After six years of searching for help for Martin, the family made a fortunate connection on the internet with a patient of Karen G. Carrasquillo, OD, PhD, who told them about Boston Foundation for Sight. “I called BFS and sent them Martin’s medical records,” says Mr. Chirinos. He spoke with Sheila Kelly, LSW, clinical case manager, who started helping the family find a way to bring Martin to BFS for care.

*continued on page 2*



## BOSTON FOUNDATION *for* SIGHT

*Martin Casasola continued*

“Once we were fairly sure that Martin was a potential candidate for PROSE treatment, I contacted the First Hand Foundation, a non-profit organization that provides funding for children with health-related needs,” Ms. Kelly explains. “They agreed to cover the cost of his treatment, and BFS helped with transportation expenses for him and his sister, Sheyla,” Ms. Kelly explains. “We arranged for them to stay at the nearby Sheraton Hotel when they arrived in August 2013. It was during our annual SJS Care Week, so Martin got to meet other kids with SJS.” Each summer, BFS invites patients with SJS to come for a week of care and special activities. The most important person he met was Dr. Carrasquillo, who was concerned about the 13-year-old boy she examined that day. “Martin’s eyes were extremely dry—bone dry—which is why he had extreme light sensitivity and poor vision,” Dr. Carrasquillo explains. “This is what we often see in patients with SJS. When I see eyes like that, my heart goes out to the patient.” She was also concerned about Martin’s demeanor. “He was very sweet, but very introverted and quiet, even though I speak Spanish, and there was no language barrier.”

Once Dr. Carrasquillo applied BostonSight® PROSE devices, his entire behavior changed. “It was like he woke up,” she says. “When patients have severe light sensitivity, they can barely open their

eyes, and they can’t look you in the eye. They spend their lives squinting. Once they can open their eyes, their faces relax. I said ‘Martin, nice to meet you!’” Martin says he was immediately comfortable with Dr. Carrasquillo. “She said she could help me,” he says. “Once I could open my eyes wide, I could see clearer, and I was more hopeful.”

Martin and Sheyla went back to the hotel and used Skype for a conversation with their parents, who were at home in Lima, waiting for news. They immediately saw that the news was good. “Martin’s eyes were open again,” says his father. “He looked so happy.”

“The change in Martin’s life is incredible,” says Sheyla. “Today he’s more sure of himself, and he has more friends. My parents are calmer because my brother is more independent.”

SJS is a chronic disease. Although Martin’s condition is relatively stable, his skin is still very sensitive, and he continues to require medical attention. His family, like so many with a loved one with SJS, hopes to raise awareness in the medical community and beyond that medications can cause such a destructive disease.

Thanks to BFS, they worry far less about Martin’s eyes. “Before he went to BFS, his face was like darkness,” says his father. “Now it’s like heaven.”