

# Child Finds “A Light of Hope”

## Waltham group helps girl, 4, avert blindness

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By Ignacio Laguarda

Eduardo Orges and Cindia Romero were both resigned to the fact that their daughter Damila would someday be completely blind.

Damila contracted Stevens-Johnson syndrome, an intense immune sensitivity reaction to medications, when she was 2 years old, and her body was quickly covered in rashes and blisters. Her skin was peeling off and she was in intensive care for two months.

The condition severely affected her eyes, scarring her eyelids and damaging her tear glands. She developed photophobia, an aversion to sunlight and well-lit places, and could not produce tears.

Hope seemed all but lost until the day Orges and Romero got a call from their family pediatrician, Dr. Jorge Shusman, telling them about a center in the Boston area that works with children like Damila and creates prosthetic devices that allow them to live normal lives and prevent blindness.

“There was a light of hope,” said Orges.

The family began raising funds to travel from their home in Uruguay and visit the Boston Foundation for Sight in Needham so Damila could receive the treatment. They held fundraisers and festivals to gather the money necessary for the flight.

Damila is 4 now, the family is finally in Needham, and Damila is undergoing almost daily treatment at the center.

“Everything is going well,” said Orges, from the center last Friday.

The Orges family arrived in Boston on March 11 and has been staying with a family in Belmont.

Alba Alvarez-Cote, the treasurer for the Greater Boston Hispanic Lions Club, based in Waltham, received



Damila Orges, 4, sits with her parents, Cindia Romero and Eduardo Orges, during a visit to the Boston Foundation for Sight in Needham on Monday morning, March 21, 2011. Orges, who is from Uruguay, would go blind without a special prosthetic the foundation produces.  
- Staff photo by David Gordon



Dr. Karen Carrasquillo, left, with the Boston Foundation for Sight, helps Cindia Romero put a special lens in the eyes of her daughter, 4-year-old Damila Orges, on Monday morning, March 21, 2011. Orges, who suffers from a rare syndrome that prevents her from creating tears, would go blind without the procedure. - Photo by David Gordon

notification that the family was on their way to Boston only two days before they arrived.

“Once you get emails like this that someone is coming from Latin America, we get on it right away,” she said. “We try to help them as much as we can.”

The Orges family received help from a chapter of the Lions Club in Maldonado, Uruguay, as well as the local Rotary Club in their neighborhood.

Alvarez-Cote immediately sprung to action, trying to find host families and raising money for them. She has been helping the family since they arrived.

“It’s a real tight brotherhood type of club,” she said. “It’s an instant kinship.”

She has helped raise about \$300 in checks for the family, and has received gift cards and other items as well. The America’s Food Basket Supermarket also donated some groceries to them.

Further, the Boston Foundation for Sight offered to provide the treatment for Damila at no cost.

The last few days at the center, Orges and Romero have been working with Dr. Karen Carrasquillo to learn how to insert a prosthetic device, known as PROSE, into Damila’s eyes.

The device, which looks like a contact lens at first glance and is the size of a nickel, is actually vaulted in the middle section, leaving an open space in front of the cornea that is filled with a saline solution when applied to the eye. The device rests on the white parts of the eye, and does not touch the sensitive cornea. The saline solution that stays trapped inside the device continuously washes artificial tears over the ocular surface.

The PROSE device was developed at the Boston Foundation for Sight and is made onsite.

Damila’s parents have struggled to apply the device to Damila’s eyes, which is normal in these types of circumstances, said Carrasquillo. She said the patient must insert the device while looking down at the ground because the saline fluid needs to remain in the vaulted portion of the device.

Training a 4-year-old patient with intense light sensitivity and eye discomfort to allow someone to insert the device is a serious challenge, she said.

“It’s very difficult, emotionally, for them,” said Carrasquillo. “They aren’t prepared. Many of them get anxiety because of the trauma they’ve experienced.”

Nonetheless, she said Damila has handled herself better than most. “Damila has been incredible,” said Carrasquillo. “She is a girl who has gone through some very difficult things, but she sits down, without crying, and lets her mom open her eyelid.”

The tricky part comes next. As Romero tries to place the device on Damila's eye, her natural reflexes cause her head to move back. "We're trying to work with her to dominate her reflexes," said Carrasquillo.

The parents have yet to successfully insert the device, but Carrasquillo said they're getting better and should be able to do it without help soon.

Carrasquillo has been able to insert the device over Damila's eyes, and the results so far have been promising.

"When she doesn't have the lens in, her body sags more and she covers her eyes," said Romero. "When she has them on, you can tell that she changes."

Her vision has improved from 20/200 to 20/80 with the prosthetic device.

"That is very significant because that translates to better independence in her mobility," said Carrasquillo. "That's the difference between always being glued to her mother and father and being able to walk around freely."

For now, Damila and her parents will stay in the area for a few more days, as her treatment wraps up.

The family is staying with Nando and Paula Michelin in Belmont, where Romero said they feel like "they're part of the family."

Nando, who was born in Uruguay, was contacted by the Rotary Club in Uruguay about housing the Orges family.

Paula, from Brazil, said they jumped at the opportunity.

"Like thousands of people in this country as immigrants without family, we need to have people from the same background around, that share the same tastes and stories," she said. "It's nice to have them around."

She drives the family to the clinic and has been happy how her 6-year-old son has gotten along with Damila.

"I hope more people can get the help," she said. "We all can do something. There's always something we can do to help others in need. It could be us in the future."

Romero and Orges, both of very few words, said they would like to thank those who have helped them along the way, including the Uruguayan people who helped them raise the money to come to Boston, and in particular to all of the doctors who have helped them, including Carrasquillo, and the Rotary and Lions Clubs that pitched in.

"Thank you so much for everything," said Romero.

Anyone interested in helping the Orges family with donations can contact the Greater Boston Hispanic Lions Club at 781-209-5500.



Dr. Karen Carrasquillo, left, with the Boston Foundation for Sight, helps Damila Orges, 4, and her parents, Cindia Romero and Eduardo Orges, get used to a new lens during a visit on Monday morning, March 21, 2011. Orges, who is from Uruguay, would go blind without the device.  
- Photo by David Gordon