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## Child Finds “A Light of Hope” Waltham group helps girl, 4, avert blindness

**Waltham News Tribune - March 22 - 24, 2011**

**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.

*To continue reading, please turn to page 6.*

*Reprinted with permission from [Waltham News Tribune](#). Photos by David Gordon.*



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

## Patient Profile - Rami Blum “My Insurance Policy”

It was 1974 and Jaram “Rami” Blum was a young man of 18, serving his mandatory military service in Israel, when his life was abruptly changed by a flying piece of shrapnel. The jagged piece of metal struck Rami in the face, immediately blinding his left eye. Rushed into emergency surgery, Rami would spend the next six months in the hospital and endure a second operation, this one to remove his natural lens. He eventually regained some limited vision, but his life was forever altered. He had to stop playing sports, which was very difficult for the active young man. Studying and reading were much harder and more time consuming, and many daily functions became a struggle.



For the next 36 years, Rami tried both hard and soft contacts in an effort to improve the vision in his left eye, with little success. He lived a full life - moving to the United States, becoming a successful entrepreneur, and raising a family - but still he worried about what would happen to him and his family if anything ever went wrong with his good eye. He saw various doctors over the years but was always told that there was nothing that could be done to help him.

Fortunately, in 2010, his ophthalmologist told Rami about Boston Foundation for Sight, and for the first time in years he dared to hope. Soon afterwards he completed PROSE treatment with Dr. Lynette Johns, and now, for the first time in 35 years, he can see clearly with both eyes!

**“This is my insurance policy. If anything ever happens to my right eye I know I will still be able to see.”**

“This tragic injury happened when he was so young. We are extremely pleased to be able to give Rami back his sight all these years later,” added Dr. Johns.

*Click to read more inspirational [PROSE patient stories](#)*

## Help Us Name Our E-Bulletin!

The Communications team has decided that our monthly e-bulletin is too fabulous not to have an equally great name. **We need your help.** If you have a suggestion for a great name, please send it to Melissa at [webmistress@bostonsight.org](mailto:webmistress@bostonsight.org) by April 20th. Please use the following as guidelines:

- The name should relate to Boston Foundation for Sight, PROSE, or vision in general.
- The name should not be more than 2-3 words or 20 characters/letters.
- The name must be original, and not infringe upon any existing copyrights.

All ideas are welcome and we will announce the winner in our April edition. Thank you!!

## Research and Education News

### **Kellogg Eye Center Postgraduate Spring Conference: *Current Practices and New Approaches to Cornea and Cataract Surgery***

The [83rd Annual Postgraduate Spring Conference](#) will be held May 13 - 14, 2011, at the W.K. Kellogg Eye Center in Ann Arbor, Michigan. This conference is for comprehensive ophthalmologists, cornea specialists and ophthalmologists-in-training.

This year's presenters include PROSE Clinical Fellow Karen S. DeLoss, O.D. Dr. DeLoss' presentation, *Contact Lenses for Dry Eyes: A New Paradigm*, will be presented during the Ocular Surface Disorders session. Kellogg PROSE Clinic cornea specialists H. Kaz Soong, M.D., Alan Sugar, M.D., Shahzad I. Mian, M.D., and Roni M. Shtein, M.D. will present during multiple sessions as well. Click here for more about the [Kellogg Eye Center PROSE Clinic and doctors](#).

The fee is \$595 for physicians and \$200 for physicians in training, retired physicians and allied health professionals. There is no charge for Kellogg employees, but registration is required. For more information, please download their brochure at: <http://cme.med.umich.edu/events/pdf/U029248.pdf>.

## Patient and Community Resources

### **Donations Needed for Patient Lounge**

Boston Foundation for Sight is seeking donations for our patient lounge. We are looking for books, games and DVDs for children and adults. If you have some new or like-new items you would like to donate, please send them to Boston Foundation for Sight, 464 Hillside Avenue, Suite 205, Needham, MA, 02494, to the attention of Melissa Hatch. If you have questions please email Melissa at [webmistress@bostonsight.org](mailto:webmistress@bostonsight.org). Thank you!!

### **Camp David for Pediatric Burn Survivors**

The [Texas Burn Survivor Society](#) offers services to burn survivors and their families, including Stevens Johnson syndrome patients and their siblings, and the children of burn patients at Brooke Army Medical Center PROSE Clinic. Programs include Camp David, a FREE one week summer camp held in Kerrville, TX, one hour north of San Antonio, at the Lion's Camp for Children. Camp David will run this year from July 17-23, 2011. They also offer a bi-annual Teen Retreat and provide financial assistance to patients and their families who are being treated at burn centers in Texas. Applications for the 2011 session of Camp David will be available starting in April. For more information please visit their website at <http://www.texasburnsurvivors.org/>.



## BFS Staffing Update



The BFS team recently said goodbye to staff member James Shortway. James had been with us since 2009 in the roles of Clinic Coordinator and Lab Technician.

We thank him for his dedicated service to the Boston Foundation for Sight community and wish him all the very best in his future endeavors.

We will miss you!

## PROSE Partner News

### Newest PROSE Clinic Opens Mid - April in Chennai, India

We are very pleased to announce that our newest [PROSE clinic at Sankara Nethralaya](#) will begin scheduling patients April 1, 2011. Sankara Nethralaya is a non-profit eye hospital located in Chennai, India. PROSE Clinical Fellow Dr. Rajeswari Mahadevan recently returned to India and will head up the new clinic. For more information please visit our website at <http://www.bostonsight.org/sankara>.



### Please welcome our newest PROSE Clinical Fellow - Optometrist Nasim Shayegan!



Nasim Shayegan, our newest PROSE Clinical Fellow, is an optometrist at Noor Eye Hospital in Tehran, Iran. She also maintains a private optometric practice in Tehran. She received her Bachelor's degree in Optometry from Beheshti University in Tehran in May 2000 and then completed an Optometry Program at City University in London, England in January 2004. After completing her PROSE Clinical Fellowship, Optometrist Shayegan will return to Iran to head up the new PROSE Clinic at Noor Eye Hospital.

# Treatment Option (Dis) Satisfaction

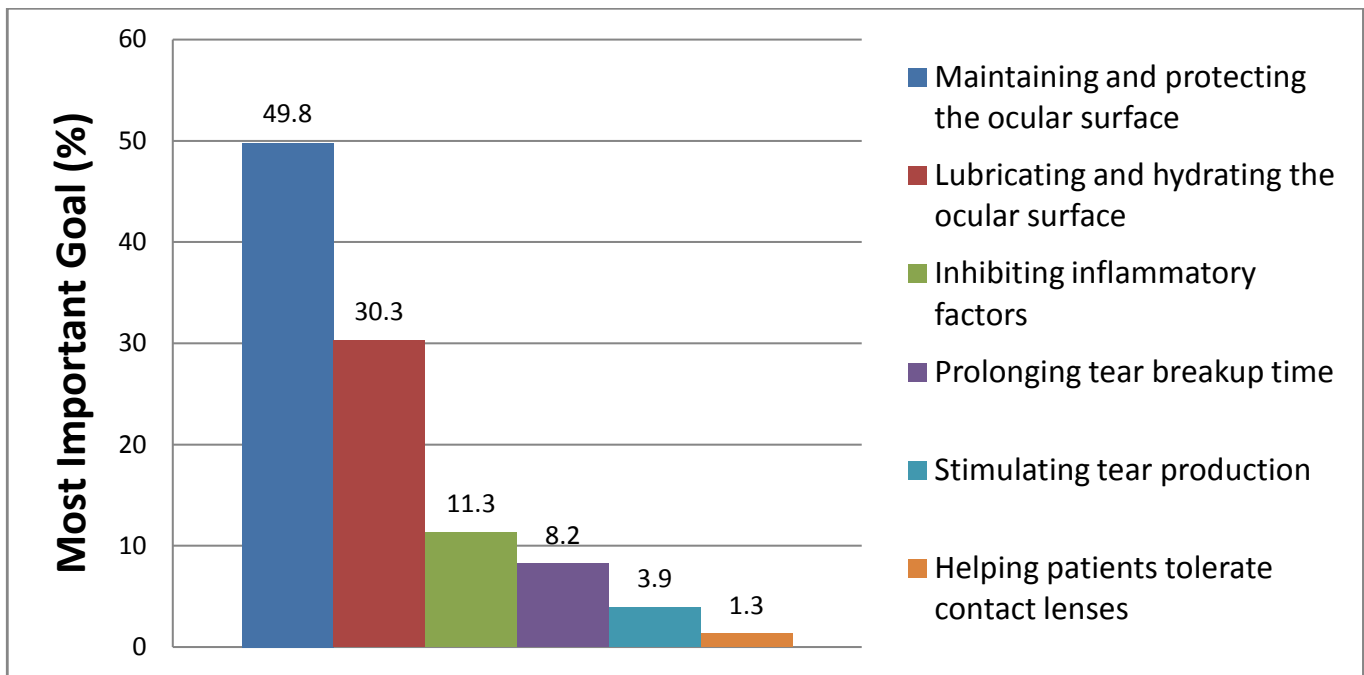
From the BFS Connected Visions Blog - <http://www.bostonsight.org/blog>

Given the negative impact on [quality of life](#) that complex corneal disease can have, finding the right treatment that offers the most relief is essential. Sadly, few people are finding satisfaction.

In BFS' [2010 Patient Survey](#), over 1,000 people living with corneal disease shared their satisfaction with different treatments. We learned that the majority are experiencing little to no success with a majority of the options available! And, when one treatment does not prove to be effective, people tend to move on to something new.

Would you be surprised to learn that ophthalmologists think there should be different– and better– treatment options available too? In a [survey of 245 ophthalmologists](#) (including more than 50 cornea specialists) treating patients with moderate to severe dry eye disease, 94% agreed there was a need for more treatment options! Only 5% thought what was available was extremely or very effective for severe dry eye, and most were recommending four or more treatment approaches to their patients over the course of a year.

Perhaps not surprisingly, ophthalmologists identified “maintaining & protecting” and “lubricating & hydrating” the ocular surface as the top two goals of dry eye treatment.



The three key characteristics of successful therapies they identified were: 1. “Ability to provide continuous relief”; 2. “Patient acceptance” and 3. “Ability to use long term”.

Finally, when asked about the most important criterion for success, they ranked “relief of symptoms/patient satisfaction,” “prevention of damage to the cornea,” and “improved vision” at the top.

## ***Treatment Option (Dis) Satisfaction - Continued from Page 5***

At the risk of tooting our own horn, there is a shining star among the available treatments: [PROSE](#). To remind our readers, the primary long-term [benefits of PROSE](#) treatment is that it:

1. Re-establishes a healthy and stable ocular surface environment that provides constant lubrication/hydration, supports healing and reduces symptoms; 2. Improves blurry vision by masking surface corneal irregularities and transmitting a sharp image to the back of the eye; and 3. Prevents damage by protecting and shielding the cornea and conjunctiva against the environment and eyelids.

PROSE can boast that 80% of patients surveyed reported experiencing significant success. Our published clinical research, which includes assessments with the National Eye Institute's Visual Function Questionnaire (VFQ-25), a widely-used and accepted patient-centered measure of improved visual function and quality of life, reports similarly high levels of success.

When you combine our high level of success with the fact that PROSE meets ALL of the top standards of care for dry eye treatment identified by ophthalmologists across the country, you would think that many more patients with severe dry eye would be sent for a PROSE consult ... but that's fodder for a later discussion.

What do you and your eye doctor think about your treatment options?

## **Tech Tips Corner - Buying Supplies**

**Question:** Where can I buy the various solutions and accessories I need for my PROSE prosthetic devices?

**Answer:** We have created a comprehensive chart that lists all of the solutions and products that you need to properly care for your PROSE prosthetic devices. Please visit our website to see the buying guide chart as well as handy lists sorted by product and retailer - [PROSE Solution and Accessory Buying Guide](#).

**Question:** Is H<sub>2</sub>O<sub>2</sub> (brown bottle hydrogen peroxide) approved for use with PROSE devices and if so, how do I use it?

**Answer:** Visit the [Patient FAQ](#) section of our website to see the answer!

**Question:** Is there a less expensive alternative to Unisol 4?

**Answer:** Visit the [Patient FAQ](#) section of our website to see the answer!

For a complete guide on the use and care of your PROSE prosthetic devices, please visit our website: [PROSE Treatment Guide: Prosthetic Device Use and Care Guide](#).

Q&A provided by Robert Ruscansky, BFS Senior Technician



## ***Child Finds “A Light of Hope” - Continued from Page 1***

“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 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.



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

## *Child Finds “A Light of Hope” - Continued from Page 7*

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.”



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

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.

### ***Child Finds “A Light of Hope” - Continued from Page 8***

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.

***To download a printable version of this article please click here: [Child Finds “A Light of Hope”](#)***

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