Media Contacts: Tara Stepanian
Boston Foundation for Sight
781-726-7337 x 112 (office)
tstepanian@bostonsight.org

Information: www.bostonsight.org

PEDIATRIC PATIENTS FROM AROUND THE WORLD COME TO NEEDHAM, MA FOR FIRST EVER SJS KID'S WEEK

A WEEKLONG EVENT – JULY 25 – JULY 31, 2010

NEEDHAM, MA (July 25, 2010) – On July 25, 2010, the Boston Foundation for Sight (BFS) will welcome children suffering with Stevens Johnson syndrome (SJS) and their families to participate in our first-ever pediatric outreach event – SJS Kid's Week. Coming from as near as the greater Boston area and as far away as Canada and Africa, 15 families will join together for a week dedicated to the treatment and emotional support of pediatric SJS patients and their families and to raise awareness of this rare but devastating and potentially fatal disease.

Stevens Johnson syndrome and a more severe variant of the disease, toxic epidermal necrolysis syndrome (TENS), are intense immune sensitivity reactions to infections or medications that primarily affect the skin and mucus membranes, including the eyes. For as many as 5% of those with SJS and 40% of those with TENS, the disease is fatal. SJS usually begins with non-specific symptoms such coughing, aching, headaches, burning eyes, and feverishness. They may be followed by a red rash across the face and trunk, which often spreads to other parts of the body. The rash can form into blisters covering the skin and mucus membranes, including the eyes and inside of the mouth. According to the Mayo Clinic, in mild cases, this may cause irritation and dry eyes; in severe cases, it can lead to extensive tissue damage and scarring that can result in blindness.

The disease can also permanently damage the inside of the eyelids, causing the margins to become rough and develop abnormal fine lashes that rub against the cornea. The cornea is most sensitive tissue of the body and the pain and light sensitivity can be intense. It can be further aggravated by the dryness that results from damaged tear and oil glands that are critical to maintaining the ecosystem of the ocular surface.

From an ophthalmic perspective "this is one of the most difficult diseases to manage," said Mark Mannis, M.D., professor and chair, Department of Ophthalmology & Vision Science, University of California Davis Eye Center, Sacramento, Calif. "As a result of the acute phase, critical components of the ocular surface have been severely damaged". "If pediatric patients can survive the acute phase, they are often normal kids again in every way except in regard to the eyes," says BFS treatment partner Dr. Kimberly C. Sippel, M.D., assistant attending ophthalmologist, New York-Presbyterian Hospital, New York, and assistant professor of ophthalmology, Weill-Cornell Medical College, New York. In the visual rehabilitation stage, "the key is to mimic in some way the normal functions of the ocular surface." (ASCRS Eyeworld)

Due to the rareness of SJS, pediatric patients often feel isolated and alone. Parents become advocates for their children, and out of that advocacy come parent-created support networks. The Stevens Johnson

Syndrome Foundation is one such organization, started by Jean McCawley in the late 1990's when her daughter, Julie, was diagnosed with SJS at age 10 months.

Dr. Lynette Johns, O.D., who treats Julie, now 16, and many of BFS' other pediatric SJS patients, was moved by the isolation experienced by these children and their families and envisioned a special week of treatment, care and fellowship. Patients and their families will stay together in two homes rented at the nearby Walker Center in Auburndale. The week will be filled with fun activities, facilitated conversations and group dinners with a goal of creating a strong and vibrant community around these incredibly brave children.

Since 1994 the Boston Foundation for Sight has worked with SJS/TENS patients with complex corneal disease to provide them with a long term treatment solution: prosthetic replacement of the ocular surface ecosystem (PROSE). PROSE is a pioneering treatment model to restore vision, support healing, reduce symptoms and improve quality of life for patients suffering with complex corneal disease. PROSE rehabilitation uses FDA-approved custom designed and fabricated prosthetic devices to replace or augment the impaired ocular surface ecosystem function. For many of the thousands of patients with conditions like Stevens-Johnson syndrome and TENS, PROSE can be the ideal, and sometimes only, treatment capable of restoring vision and dramatically reducing pain and light sensitivity.

Donations are being accepted in support of SJS Kid's Week. To donate, please visit www.bostonsight.org or call 781-726-7337.

About the Boston Foundation for Sight:

The Boston Foundation for Sight (BFS) is an internationally renowned not-for-profit eye healthcare organization dedicated to restoring vision and improving quality of life for our patients and their families. We strive to transform the understanding, treatment and care of complex corneal disease within the global medical community and the public at large. Since our founding in 1994, we have been innovative leaders in research and treatment of corneal conditions.

Our 12,000 square foot facility in Needham, MA, includes a state-of-the-art manufacturing lab, a medical institute staffed with seven doctors and a dozen technicians/trainers, a Clinical Research Center and a new Patient and Community Support Center. We enjoy educational partnerships with the renowned Massachusetts Eye and Ear Infirmary and the New England College of Optometry; each year Cornea Fellows and Optometry Residents come to BFS to be educated in the latest in treatment of corneal disease, and they join our medical staff in cutting-edge clinical research on the next generation of tools in the fight against these insidious diseases of the ocular surface system.

For more information, please go to www.bostonsight.org.

###