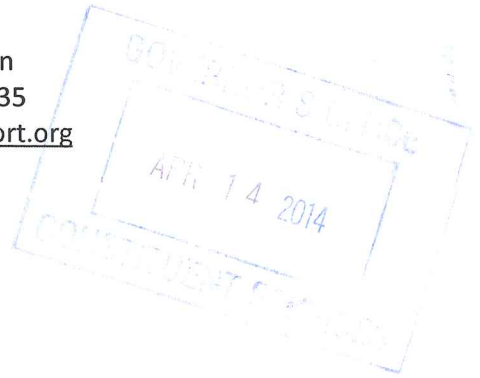


Stevens Johnson Syndrome Foundation  
P.O. Box 350333, Westminster, CO 80035  
Phone: (303) 635-1241, Web: [www.sjsupport.org](http://www.sjsupport.org)



The Honorable Governor Deval Patrick  
Massachusetts State House  
Office of the Governor  
Room 280  
Boston, MA 02133

Dear Governor Patrick:

My name is Tara Stepanian and I am a resident of the state of Massachusetts. I am writing to you on behalf of the Stevens Johnson Syndrome Foundation, a nonprofit organization and a partner organization based in Massachusetts, Boston Foundation for Sight.

Stevens Johnson Syndrome (SJS) and TEN (Toxic Epidermal Necrolysis) - another form of SJS - are severe adverse reactions (ADR's) to medication. I am sure most people are aware that heart disease, cancer and diabetes are the three leading causes of premature death in America today and these conditions are almost 100% avoidable.

According to the New England Journal of Medicine, over 2 million Americans fall ill and are hospitalized every year from taking these recommended drugs. And of the 2 million that are admitted, over 140,000 are never released; they die. That's equivalent to crashing a fully loaded 747 aircraft every day.

SJS is one of the most debilitating ADR's recognized. It was first discovered in 1922 by 2 pediatricians A. M. Stevens and S.C. Johnson after diagnosing a child with severe ocular and oral involvement to a drug reaction.

Almost any medication including over the counter drugs, such as ibuprofen, can cause SJS. Most commonly implicated drugs are anti-convulsants, antibiotics (such as sulfa, penicillin and cephalosporin) and anti-inflammatory medications.

Although SJS affects people of all ages, a large amount of its victims are children. There have been numerous cases reported due to the use of Children's Ibuprofen products. Many of these children have been left blind and several have died. Unsuspecting parents are not warned of the danger from these seemingly safe products readily available to us in our local grocery store. One of the first signs of SJS is a high fever. Parents then administer more of these products desperately trying to reduce their child's fever unknowingly giving them more of offending drug. More female cases of Stevens Johnson Syndrome have been reported than male. However it does not discriminate against anyone. The SJS Foundation hears from people around the world who from SJS and TEN. On average, three cases are reported to the foundation every day.

Recognizing the early symptoms of SJS and prompt medical attention are the most invaluable tools in minimizing of the possible long-term effects SJS may have on its victims.

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Our biggest problem is in public awareness. The pharmaceutical companies and the medical communities are under the impression that incidences of SJS/TEN are rare, but this is not the case. Numerous cases are misdiagnosed as chicken pox, measles, scarlet fever or flu. Many cases are never reported.

We recognize that the use of prescribed and over the counter medications are necessary and beneficial to our wellbeing and help many people, but to because each person's body chemistry is different, what may be beneficial to one may be fatal to another.

The only way to combat this devastating problem is through public awareness. The pharmaceutical companies, FDA, AMA and the media can and should take the responsibility to educate the public and the medical community, the doctors, hospitals and nurses.

SJS and TEN are life threatening. If left untreated they can result in death. Complications can include permanent blindness, dry eye syndrome, photophobia, lung damage, chronic obstructive pulmonary disease (COPD), asthma, permanent loss of nail beds, scarring of the esophagus, and other mucous membranes, arthritis, and chronic fatigsyndrome. Many patients' pores scar shut, causing them to retain heat. These are some of the side effects that have been reported.

The SJS Foundation has been existence since 1995 after Jean Farrell McCawley's daughter, Julie, suffered SJS at 11 months old from Phenobarbital.

On a personal note, I work at a world renowned nonprofit eye healthcare organization in Needham, MA – Boston Foundation for Sight – who is on the front line of the battle. We treat patients suffering with SJS, help them regain their sight so that they may reclaim their lives. In 2010, pediatric survivors of SJS and their families were brought together for the first time for the only event of its kind, SJS Kids Week. Since 2010, it has been held annually at the end of July/beginning of August and is dedicated to the treatment of complex corneal disease and support of pediatric SJS patients and their families. We have had the honor and privilege of working with Jean McCawley to help raise awareness and have treated her daughter in our clinic.

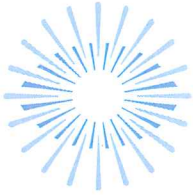
Information on the Boston Foundation for Sight and how we provide much needed help to SJS patients can be found on [www.bostonsight.org](http://www.bostonsight.org).

I am writing to ask you as Governor to issue a proclamation declaring the month of August 2014 "Stevens Johnson Syndrome Awareness Month".

Respectfully yours,



Tara Stepanian  
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## BOSTON FOUNDATION *for* SIGHT

**SIIMA KATABAZI**

### Determined to find help

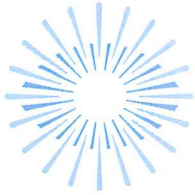
“Yes, we can help.” Siima Katabazi was waiting for those four words, which appeared in an email from Boston Foundation for Sight (BFS) that she received in September 2012. After suffering from Stevens-Johnson syndrome (SJS) for more than a year, she was determined to find treatment for the painful condition, which was robbing her of vision.

As is often true with SJS, her immune system had reacted strongly to medication—in her case, for malaria, which is endemic in Uganda. “In February 2011, I went to see an ophthalmologist, and he prescribed eye drops that made my eyes worse,” she recalls. “I had almost reached the point of surrendering when I started going to the Internet. I searched until I came up with Boston Foundation for Sight and saw that they had helped other people with SJS.”

Ms. Katabazi, who is 38, lives in Kampala with her husband and two daughters and works as a certified public accountant, began making plans to come to BFS. After ensuring that she had the funds for travel, lodging and treatment, she arranged for the long trip, which she made alone—legally blind and wearing a patch on her left eye. She found her way to the Sheraton Hotel in Needham and, the next morning, was seen by Anna Cressey, OD (pictured, on left, with Siima).

*continued on page 2*





## BOSTON FOUNDATION *for* SIGHT

*Siima Katabazi continued*

“Dr. Cressey examined my eyes and told me that they were not as bad as they could have been,” Ms. Katabazi recalls. “She said to me: ‘I believe you will be okay.’ I was so happy to hear that from a professional person.”

The next step was to insert trial PROSE devices. “It was a struggle to get the devices in place because Siima’s left eye was almost closed, and she was in a lot of pain,” says Dr. Cressey. “Once they were in, her eyes opened up.”

For Ms. Katabazi, that first session made all her efforts to come to BFS worthwhile. “I could see things around the room and, in ten minutes, I had no more pain,” she says. “My soul was so happy.”

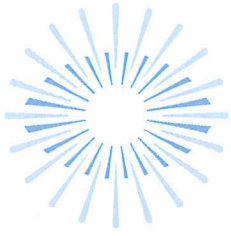
She was soon wearing PROSE devices with her own prescription. “My vision kept improving so that I didn’t need to wear glasses,” she says. “I called my family, and my children were so happy. They couldn’t wait to see me.” She is grateful to her father, who funded the cost of her treatment and travel, and her entire family for their support from the beginning.

The initial offer of help from BFS went well beyond the specialized treatment that returned Ms. Katabazi to her productive life, including her full-time accounting position. BFS staff provided paperwork that paved the way for her to obtain a travel visa. “They wrote to the consulate in Kampala,” she notes. “When I got there, the visa was waiting for me.”

After she arrived in Boston, a blizzard hit. “It was the first time I saw snow in my life,” says Ms. Katabazi, who was wearing open-toed shoes before BFS staff bought her a pair of boots. Before she flew home, Sheila Kelly, BFS clinical case manager, drove her to area pharmacies to stock up on the correct lens solutions, which are not easily accessible in Uganda. Because at home she cooks outdoors over an open fire, BFS staff helped her buy protective glasses that fully cover her eyes.

“The beauty of BFS is that we can really give patients back a big part of their lives,” says Dr. Cressey. “That’s why we’re here. It’s all about the patient.”

Ms. Katabazi experienced just that. “At BFS, they helped me, they coached me, and I am so grateful to them. It was the best care that one would love to receive.”



**EILEEN SHARE**

## Getting through it with your life

Six years after surviving SJS, Eileen Share found BFS and got her sight back. Able to read for the first time in years, she joined a local book group. Soon after she caught the volunteering bug and got involved with a youth literacy organization in downtown Chicago. “I finally felt good enough that I could give something back,” she said.

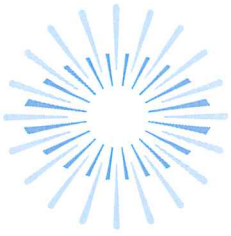
Reflecting on the experience, Eileen shared, “Before getting SJS I was just very involved in my life and volunteering was not on the top of my list. When you have a traumatic experience, you barely get through it with your life. I got through it with the support of family and friends. Some people disappeared and some stepped up and came out of the woodwork. They took the time to help me with no expectations in return. It changed me. I realized that there are a host of people out there that I could help.”

When the UIC PROSE clinic opened in Chicago in 2010, Eileen transferred her care to the doctors at Illinois Eye and Ear but continued to keep up with BFS through the e-bulletin. In March when she saw the call for SJS Kids Week volunteers, she jumped. Since getting sick a decade earlier, “I hadn’t been involved with any SJS patients. I guess I had gotten myself removed from feeling like a patient — I had reinvented my life. Now I was ready to give something back.”

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**“IF YOU CAN SURVIVE SJS,**  
you can survive anything.”



## BOSTON FOUNDATION *for* SIGHT

*Eileen Share continued*

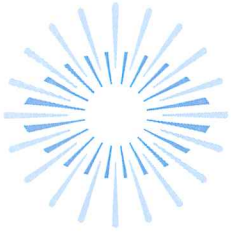
Eileen did not have any expectations before getting on the plane to Boston. She was picked up at the airport and joined by Bailey and her mom Julie, who had flown in from Texas. “From the minute I got in the car there was this instant connection; talking about what it was like when we were sick, realizing that we had been on a journey that was really similar. That was a barrier breaker for me. She got it, she knew I got it. Our age difference or how long ago it happened did not matter.”

Upon arriving on campus, “I felt so welcomed and appreciated! Everyone around me was convinced that I could be useful. I immediately felt like I was part of the community.” From doing dishes in the Yeo House kitchen and playing games on the lawn, to sharing her story in support groups and spending time mentoring young adult girls, Eileen jumped in to help make the week memorable in many ways. “Honestly, I felt like I got a lot more out of the week than I gave. It was amazing,” she said.

When asked about her experience as a mentor, Eileen reflected: “I think I helped them to see that their lives are different, but they are not over. The healing process is long; physically it is enormous, mentally it is enormous. But over time the list of what you can do gets bigger than the list of what you can't do.”

Reflecting on her life post-SJS, Eileen said, “My life is better because of it — fuller, richer, with more dimensions. So many new doors have opened because I have an awareness I might not have had. I wish it didn't happen, but all of these wonderful things have come out of it, including the chance to meet these incredible kids and families. I would not be the ‘me’ I am today — and I like this me just fine. I wouldn't change a thing.”





**JERIANN PEABODY**

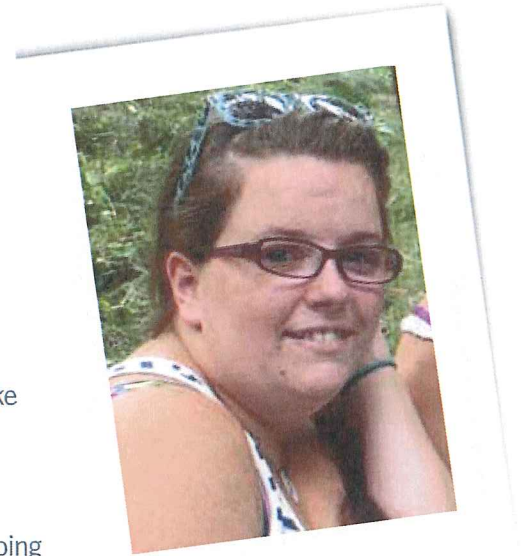
## A hero among us

When Stevens Johnson syndrome hit 22 year-old Jeriann Peabody in October 2011, it hit her hard. By the time she left the hospital, her eyes were severely light sensitive and she was in constant pain, making returning to work and college impossible. And she was one of the lucky ones.

Less than eight weeks later she had an appointment with Dr. James Chodos, a cornea specialist at Mass Eye and Ear, who referred Jeriann to see Dr. Lynette Johns. But like many survivors, while her pain subsided and her vision improved with PROSE, she struggled with other long term effects of SJS. So she turned her attention to finding out everything she could about the disease and what it was doing to her body.

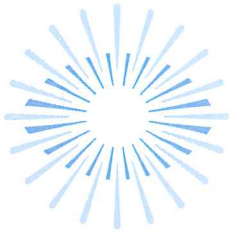
Her research soon brought her to the SJS Foundation website and a support group on Facebook, both run by Jean McCawley. Jeriann quickly became active in the virtual SJS community, asking questions of other survivors and sharing her own experiences. She also connected with SJS Kids Support, a community started by 20 year-old Julie, Jean's daughter and a longtime BFS patient. The fact that Julie "had made a website and videos to help other kids with SJS was amazing. She and Jean are the ones that made me think about helping out others and that I had something that I could give back. They inspired me," said Jeriann

*continued on page 2*



### “IT'S NOT JUST ABOUT THE MONEY.

It is about raising awareness. If people knew more about SJS they would be more understanding about what it is like to go through it. They might also get help sooner.”



## BOSTON FOUNDATION *for* SIGHT

*Jeriann Peabody continued*

Jeriann's friends, with her through every step of her ordeal and recovery, also wanted to help. So when they saw a post on BFS's Facebook page asking for support for the SJS Kids Week Travel Fund, they knew they had found their cause: "I got financial assistance from BFS for PROSE treatment and I wanted to do something for other patients because they were helping me so much."

Homemade poster in hand, they asked a friend down the street if they could stand in front of her store for a few weekends. "Some people didn't get it — some were even rude. But some were very interested and wanted to learn about my experience. One person had a daughter who had SJS too. It turned out well — we were able to increase awareness in our own community and raise \$440 for the Travel Fund!"

In late July, Jeriann, her best friend Rose and her sister Amy (pictured) arrived for SJS Kids Week. Over the next seven

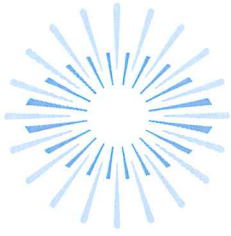
days they shared their hopes and fears in therapeutic groups, went on field trips, and stayed up late into the night talking and laughing with new friends.

"I have to say that it was the best week I have ever had. These girls are amazing and true fighters and I learned so much! I loved meeting all the people who have been through SJS — not just the kids but the families as well. I am so thankful to all the friends, family and supporters that I have met on and even before this journey. I couldn't have made it this far without any of them."

Jeriann and her friends, determined to give back, in turn helped make the journey possible for others as well.

Thank you Jeriann — you are a true hero among us.





**IAN GONZALEZ**

## Facing uncertainty

In December 2007, Ian, son of Maria Teresa and Javier Gonzalez, was admitted to Children's Hospital in Mexico City suffering with Stevens Johnson syndrome (SJS), a rare life-threatening allergic reaction. Severe cases have been described as "burning the body from the inside out" and ocular complications can include inflammation, chronic pain, tissue damage and scarring that can result in blindness.

Ian's best hope for survival lay in his transfer to the Shriners Hospital for Children Burn Center in Texas. Almost Christmas, the wrenching decision was made for Javier to stay home with younger son, Andre, while Maria traveled to Texas with Ian.

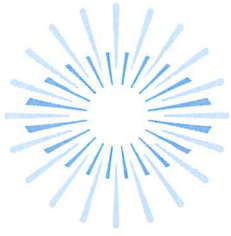
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“**THE MOST INTIMIDATING PART** of a child's first visit is the uncertainty. Even though we faced a language barrier, once Ian was wearing his devices his contagious smile and complete confidence won over. I was so proud to witness his experience and I am blessed to share in his care.”

— **Dr. Lynette Johns**





## BOSTON FOUNDATION *for* SIGHT

*Ian Gonzalez continued*

Ian's recovery was a long and difficult journey that included bouts with pneumonia and sepsis. Miraculously he held on, finally improving enough to go home. But life wasn't the same. Ian's eyes were extremely painful and light-sensitive. He had to wear sunglasses and a hat indoors, and his teacher had to keep the classroom shades down. All Ian wanted was to "be a normal kid" again.

In 2009 Maria learned about BFS through an online SJS community. A group effort lined up insurance coverage and financial support to travel to Needham for PROSE treatment. Today, Ian is a vibrant boy who loves soccer, the beach, horses and laughing. Maria and Javier finally have their son back.

Recently Maria and Ian returned to BFS for SJS Kids Week. Maria: "It was an honor to meet other parents and SJS survivors. It was one of those magical moments that Ian will always treasure in his heart, and so will I."

