



BOSTONSIGHT

PROSE EYE VIEW

BOSTONSIGHT'S MONTHLY E-NEWS. WELCOME TO OUR COMMUNITY OF SIGHT!

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Healthy Eyes, Happy People

2016 is the sixth consecutive year that BostonSight will dedicate time during the summer to the treatment of survivors of Stevens Johnson syndrome (SJS) or toxic epidermal necrolysis (TEN), two closely related diseases of the skin and mucous membranes.

In order to care for as many SJS survivors as we can, we have expanded this patient networking and outreach event from one to two weeks. We are thrilled to be hosting 40 survivors and their loved ones.

Can you help adults and children suffering with SJS? Your gift, of any amount, will help us provide vision-saving medical treatment and support to those most in need.

Those who live through an SJS diagnosis are called “survivors”. Although they survive, most never fully recover, and experience lifelong implications. Initial flu-like symptoms are followed by a rash that covers much of the body; many survivors lose a large quantity of skin and are hospitalized for months. Permanent damage can occur, including to the mouth, nose, genitals, and digestive tract. The pain caused by the ocular damage from SJS has been described as “extreme” and “unimaginable”.

BostonSight’s understanding of the unique struggles experienced by SJS survivors led us to create SJS Care Weeks. SJS is a rare disease, striking only a few people per million in the United States each year. PROSE patients who attend are able to connect with and learn from others with shared experiences and struggles, often for the very first time in their lives.

August is SJS Awareness Month and we put together some important facts to help increase your own SJS awareness. We wanted you to know more about recent research that has been done on SJS.

Finally this month, we introduce you to Jen, a SJS survivor who is feeling much more normal again, thanks to PROSE treatment.

Best wishes,

The PROSE Eye View Editorial Team



FEELING NORMAL AGAIN

Jen Ballard - a patient's story

There are many things about wearing BostonSight PROSE devices that make Jennifer (Jen) Ballard happy. The most unexpected one is how natural they look. "Originally I was devastated to learn that I needed ocular prosthetic devices," remembers Jen. "I just wanted to be normal again."

Jen, who has lupus, developed a potentially deadly MRSA (methicillin-resistant staphylococcus aureus) infection. She was transferred from her local hospital in Maine to Brigham and Women's Hospital in Boston. Although Jen is allergic to penicillin and other related medications, her doctors thought that the danger to her from the staph infection outweighed the risk of giving her nafcillin.

Shortly after starting on the nafcillin therapy, Jen developed Stevens Johnson syndrome (SJS), a sometimes fatal, violent allergic reaction. SJS sufferers most often react to medications, but SJS can also be caused by infections and environmental factors such as radiation; in some cases, the cause is never determined.

As is so often the case with SJS, doctors initially did not know what was wrong with Jen, and so the nafcillin was not immediately discontinued. She spent the next four months in the hospital; most of her stay was spent in the burn unit.



Jen had lost a significant percentage of her skin and suffered with extreme eye pain (SJS affects the mucous membrane tissue that lines many body cavities – including the eyes). "The pain was something that I can't even describe. In retrospect, it doesn't even seem real," Jen remembered. She lived in complete darkness, with her mother on hand to apply eye drops and ointments almost constantly.

Jen suffered with dry eye for the next eight years, never realizing that it was caused by her SJS. She would apply eye drops every 15 minutes, and often woke

in the middle of the night due to the pain. "My eyes ruled my life. I had to be sure that I had enough drops for the whole day every time I left the house, and I was spending SO much money on them." Even with these challenges, Jen was grateful to even be alive.

A ruptured cornea and subsequent cornea transplant that refused to heal properly led to a referral for BostonSight PROSE treatment with Alan Kwok, OD. "PROSE treatment is one of the best things that could have happened to me. Every day I am more comfortable. I can see better, my life is easier, and I have a sense of peace knowing that my eyes are protected."

Jen recently took a step that makes her feel even more "normal". She packed a travel bag with a second set of PROSE accessories and supplies, so that she can just pick up and go for an evening or a weekend. Jen has reclaimed her life and can be spontaneous again – with the help of BostonSight PROSE.



SJS AWARENESS

Awareness is the first step Recent Research on SJS

“Awareness” is defined as: knowledge or perception of a situation or fact. Since August is Stevens Johnson Syndrome Awareness Month, we wanted to share some important facts about the disease with you.

- Stevens Johnson syndrome is one of the most serious adverse reactions to medications. Approximately 5% of people who contract SJS, and 30% of those who develop TEN (toxic epidermal necrolysis, the more severe variant), do not survive.
- Medications that are known to cause SJS include ibuprofen and other NSAIDs; certain antibiotics, including penicillin; anti-inflammatory medications, such as Bextra; medications to treat gout, including allopurinol; and drugs to control seizures such as Dilantin.
- SJS can also be caused by environmental factors such as radiation. Infections can also trigger SJS, including herpes, influenza, hepatitis, and HIV. In some cases, the cause is never known.
- The most common early symptoms of SJS are: flu-like symptoms, including swelling of the eyes; red rash or blisters; persistent fever; and blisters. If you develop symptoms of SJS, it is very important to tell your doctors about all medications, including prescriptions, over the counter drugs, and supplements, that you have taken recently, as it can take up to 1-2 weeks for symptoms to appear.

Recent Research on SJS

A great deal of effort is made by dedicated medical professionals each year to study Stevens Johnson syndrome (SJS) and toxic epidermal necrolysis (TEN). In 2016 alone, more than 100 scientific papers have been published so far, in professional journals, which directly or indirectly deal with SJS. Some examples are listed below; you can view them all by [visiting PubMed](#) and searching for Stevens Johnson syndrome.

- A paper studying a possible [connection between SJS and corneal ectasia](#).
- The [role of an ophthalmologist](#) in SJS management
- A study of the [urogynecologic complications](#) of SJS and TEN
- [Racial disparities](#) in SJS/TEN
- SJS complications [beyond the eyes and skin](#)





COMMUNITY RESOURCES



World Sjogren's Day

July 23 marks the Seventh Annual World Sjogren's Day, commemorating the birthday of Henrik Sjogren, MD (pictured); Dr. Sjogren is credited for having discovered the eponymous disease in 1933. Sjogren's syndrome is a chronic autoimmune system disease that (like Stevens Johnson syndrome), affects the glands in the human body that produce moisture, causing dry eyes and mouth; dry mouth, caused by an inability to produce saliva, can affect oral hygiene and digestion. Other hallmarks include fatigue and chronic pain.

Although there is no known cure for Sjogren's syndrome, BostonSight PROSE treatment can sometimes be an ideal solution for those who suffer with dry eye. Check out this [excellent fact sheet](#) from the Sjogrens Syndrome Foundation to learn more.

Ocular hygiene and fireworks safety at *Connected Visions*

Ocular hygiene is important for everyone, but even more so for those who wear BostonSight PROSE devices. [Visit our blog](#) for an important reminder of the proper steps to take to [prevent infections](#); while you are there, check out our tips to [avoid accidents](#) while watching or using fireworks.



COMMUNITY NEWS

An update on our cosmetic improvements

In February, we let you know about some improvements that were being made to our Needham headquarters to improve BostonSight patient experience. Since then, we have continued to replace flooring and painted the walls; this project is expected to be completed in the fall with the renovation of our exam hallway and front end. We have also replaced much of the furniture in our patient and community waiting areas. The overall effect is a more comfortable, inviting, and visually pleasing atmosphere. We hope you enjoy it!



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