Stevens Johnson Syndrome: BostonSight® PROSE Treatment Can Help

“I AM ABLE TO WORK full time and raise two kids because I have my life back.”

— SJS patient
SJS AND THE EYE

Every year approximately 33,000 people worldwide are stricken with Stevens Johnson syndrome (SJS), including 1,500 in the United States. SJS and a more severe variant of the disease, toxic epidermal necrolysis syndrome (TENS), are intense immune reactions to medication or infection. SJS and TENS cause severe blistering of the skin and mucous membranes, including the eyes. For as many as 5% of those with SJS and 40% of those with TENS, the syndrome is fatal.

SJS can permanently damage the inside of the eyelids, causing the lid edges to become rough and develop abnormal fine lashes that rub against the cornea. SJS also damages tear, mucous and oil glands that are critical to maintaining a healthy ocular surface. SJS can lead to extreme pain and light sensitivity, and scarring resulting in blindness.

Currently there is no cure for the damage to the eyes caused by SJS — but there is help.

BOSTONSIGHT PROSE TREATMENT

Hundreds of patients with Stevens Johnson syndrome have had their visual function restored and quality of life transformed with PROSE (prosthetic replacement of the ocular surface ecosystem) treatment. During BostonSight PROSE treatment, doctors custom design FDA approved prosthetic devices to replace or support damaged ocular functions; improving vision and reducing pain and light sensitivity. BostonSight PROSE treatment is available at a growing number of top-ranked academic medical centers and clinics across the United States.

The prosthetic devices used in PROSE are transparent domes, about the size of a nickel, made of gas permeable plastic that allows oxygen to reach the ocular surface.

PROSE devices fit under the eyelids and rest on the sclera (the relatively insensitive white tissue of the eye), vaulting the damaged cornea and creating a new smooth optical surface that protects the eye from the environment and blink trauma. The removable prosthetic devices are filled with saline at the time of application, creating a reservoir of fluid that continuously bathes the eye in oxygenated artificial tears.

“I AM A BETTER MOM, wife and teacher because of what you do. Thank you from the bottom of my heart.”

— SJS patient
BENEFITS

BostonSight PROSE treatment can:
- Reestablish a healthy and stable ocular surface environment that supports healing and reduces symptoms
- Improve blurry vision by masking surface corneal irregularities and transmitting a sharp image to the back of the eye
- Prevent further damage by protecting the cornea against the environment and eyelids

SYMPTOMS AND TREATMENT SUCCESS

In 2010, BostonSight conducted an online survey of more than 1,000 people with corneal disease.

SYMPTOMS

For the 156 respondents diagnosed with SJS/TENS, including 37 PROSE patients:
- 79% had moderate or severe light sensitivity
- 76% had eye pain or discomfort
- 69% had difficulty reading regular print newspapers, magazines or websites
- 68% had difficulty driving at night
- 68% had difficulty with work or hobbies that require seeing up close

TREATMENT SUCCESS

When asked about success with a variety of treatments:
- 3% had significant success with oral antibiotics, fish oil or flax seed oil
- 10% with topical immunosuppression (Restasis / cyclosporine)
- 12% with topical antibiotics
- 13% with topical steroids
- 18% with artificial tears, lubricant gel or lubricant ointment

90% had significant success with BostonSight PROSE treatment

“I WENT FROM BEING AN active working mom to being totally incapacitated. PROSE gave me my life back after 17 years of pain, FDA studies, and no success in treating any of my symptoms.”

— SJS patient
BOSTONSIGHT NETWORK

BostonSight PROSE treatment is available through a growing network of top-ranked academic medical centers and clinics across the U.S. Each provider site is independently operated, managing their own scheduling and insurance and providing ongoing care.

BostonSight PROSE treatment teams include cornea specialist ophthalmologists, and optometrists who have completed a BostonSight PROSE Clinical Fellowship. Clinical Fellows use a proprietary DTF® CAD/CAM system to design each device precisely to the patient’s unique eye shape. All devices are manufactured at BostonSight’s state-of-the-art lab.

BostonSight PROSE doctors work with patients, their support systems, and other medical providers to understand each patient’s specific needs and reach treatment goals together.

ABOUT BOSTONSIGHT

BostonSight, located in Needham, MA, is a world renowned nonprofit eye healthcare organization. It’s mission is to improve the quality of life for patients and their families by transforming the understanding, treatment and care of complex corneal disease.

Since 1992, BostonSight has restored sight to thousands of patients from around the world.

To learn more please visit www.bostonsight.org.

SCHEDULE A CONSULTATION

For more information or to set up a consultation, visit www.bostonsight.org/consult.

INSURANCE COVERAGE

Many major insurance carriers cover PROSE treatment and services. Financial assistance may be available for those who qualify. Check with your local BostonSight Network Clinic.

FOR PHYSICIAN REFERRALS

To refer a patient for treatment at BostonSight, Needham, MA, visit www.bostonsight.org/referrals.

To refer a patient to another BostonSight Network Clinic, visit www.bostonsight.org/referrals-providers.
BOSTONSIGHT NETWORK

ALKEK EYE CENTER
Baylor College of Medicine, Houston, TX

BASCOM PALMER EYE INSTITUTE
University of Miami, Plantation, FL

BOSTONSIGHT
Needham, MA

BROOKE ARMY MEDICAL CENTER
San Antonio, TX

FLAUM EYE INSTITUTE
University of Rochester, Rochester, NY

ILLINOIS EYE AND EAR INFIRMARY
University of Illinois College of Medicine, Chicago, IL

KELLOGG EYE CENTER
University of Michigan, Ann Arbor, MI

MASSACHUSETTS EYE AND EAR
Boston, MA

NORTHWELL HEALTH
Great Neck, NY

UNIVERSITY OF CALIFORNIA
San Francisco, CA

USC ROSKI EYE INSTITUTE
University of Southern California, Los Angeles, CA

WEILL CORNELL EYE ASSOCIATES
Weill Cornell Medical College, New York, NY

WILMER EYE INSTITUTE
at Johns Hopkins, Baltimore, MD

The BostonSight Network is always expanding.
Visit www.bostonsight.org/providers.

COMMUNITY RESOURCES

PROSE Eye View e-bulletin
WWW.BOSTONSIGHT.ORG/EBULLETIN

Financial, travel and lodging resources
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Patient support organizations
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