

# Stevens - Johnson Syndrome (SJS/TEN)

## SJS: WHAT IS IT?



Stevens - Johnson Syndrome (SJS) and Toxic Epidermal Necrolysis Syndrome (TEN) another form of SJS are severe adverse reactions to medication and in some instances mycoplasma pneumonia. Adverse drug reactions (ADR'S) account for approximately 770,000 hospitalizations each year that result in injury or death making it the fourth leading cause of death in the United States.

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

## EDUCATE BEFORE YOU MEDICATE

Almost any medication including over-the-counter drugs, such as Ibuprofen, can cause SJS and TEN. Most commonly implicated drugs are anti-convulsants (such as lamotrigine), antibiotics, (such as sulfa, penicillin, cephalosporin) and anti-inflammatory medications. In some instances it has been caused by viral infections and mycoplasma pneumonia.



## WHO CAN GET SJS OR TENS?

Although SJS afflicts people of all ages many of its victims are children. More female cases have been reported than male, however it does not discriminate against anyone. The SJS Foundation hears from people around the world who suffer from SJS and TENS.

## SJS: KNOW THE SIGNS!

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

## SYMPTOMS

- Rash, blisters or red splotches on skin
  - Persistent fever
  - Blisters in mouth, eyes, ears nose genital area
  - swelling of eyelids, red eyes
  - Conjunctivitis
  - Flu-like symptoms
  - Recent history of having taken a prescription or over the counter medication
- Target lesions are not always seen in SJS/TEN!**



**IF YOU NOTICE TWO OR MORE OF THESE SYMPTOMS, CONTACT A PHYSICIAN IMMEDIATELY!**

*The Stevens - Johnson Syndrome Foundation is a non-profit organization.*

*Your donations are tax deductible and will provide invaluable aid to a worthwhile cause.*

*To make a contribution to the SJS Foundation, please contact us at:*

Stevens - Johnson Syndrome Foundation  
P.O. Box 350333, Westminster, CO 80035  
e-mail: [sjsupport@aol.com](mailto:sjsupport@aol.com) / phone 303 635-1241  
[www.sjsupport.org](http://www.sjsupport.org)

**Risks:** SJS and TENS are life-threatening reactions. 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, hair loss (alopecia) scarring of the esophagus and other mucous membranes, arthritis, and chronic fatigue syndrome. Many patient's pores scar shut, causing them to retain heat. These are just some of the side-effects that have been reported.

## TREATMENT:

First and foremost, affected persons must stop taking the offending drug immediately to prevent complications. Treatment for SJS is good supportive care. Because patients literally burn from the inside out, burn, infectious disease, ophthalmology and dermatology teams are recommended. IV fluids and high calorie formulas are given to promote healing. Antibiotics are given when necessary to prevent secondary infections such as sepsis. Pain medications such as morphine are administered to make the patient as comfortable as possible. Most SJS patients can be managed in medical ICU however, TENS patients should be treated in a burn unit. Amniotic membrane grafts can help prevent permanent blindness if used in the first 3 to 5 days of diagnosis. Immumoglobulin (IVIg) treatment has been beneficial in treating SJS/TEN!



## DRUG REACTIONS: A SERIOUS ISSUE

Drug reactions are one of the top leading causes of death in the United States. Yet, less than one percent are reported to the FDA, because there is no mandatory reporting system in effect for post marketing adverse drug reactions. Similarly, no one has an accurate count of SJS and TENS. Although SJS is listed as a rare disease, it may be more prevalent than previously thought.

## WHO WE ARE:

The SJS Foundation was founded to be a resource to SJS victims and their families. Our mission is to provide support services, and compile and distribute valuable information about SJS regarding treatments and therapies that may prove beneficial to SJS sufferers. We work to promote awareness of the signs of SJS so that a quick diagnosis can be made and the offending agent stopped as soon as possible.

## SJS/TEN SUPPORT:

The SJS Foundation has support group facilitators around the world as well as online support groups. No one should have to go through Stevens - Johnson Syndrome alone.



**STEVENS  
JOHNSON  
SYNDROME  
FOUNDATION**