



# Stevens Johnson Syndrome Foundation

Newsletter  
September, 2006

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## SJS Awareness Benefit Concert

Special thank you to Anne Farrell for organizing the SJS Awareness Benefit Concert. Anne is a junior at Colorado State University majoring in journalism. Over the years Anne has volunteered countless hours to the Foundation. The concert was held on August 18th to raise awareness of Stevens Johnson Syndrome. Allergic drug reactions are the 4th leading cause of death in United States and the month of August is Steven Johnson Syndrome awareness month officially proclaimed by Colorado Governor Bill Owens.

Two local Colorado groups of performers donated their time for this event, Brandon Henderson and Nate Moore and the Tracks. Henderson, a California native, writes and records his soulful acoustic music and released his third album in 2005. Nate Moore and the Tracks, of Westminster, Colorado is an up and coming band who just released their debut album, Sand and Cigarettes, earlier this month.

The concert was hosted at Every Day Joes Coffee House, a non-for-profit shop committed to making the Fort Collins community a better place to live. Several SJS survivors and their families attended. It was a great night. All ticket sale proceeds benefited the Steven Johnson Syndrome Foundation.

To view a slide show of the event please visit

[http://www.sjsupport.org/Images/2006/benefit\\_event/index.php](http://www.sjsupport.org/Images/2006/benefit_event/index.php)

More information about the performers can be found on the following websites:

- Nate Moore and the Tracks: <http://www.myspace.com/natemoorethetracks>
- Brandon Henderson: <http://www.brandonhenderson.com/Main.html>

### New Memorial page

#### You are not forgotten!

The Stevens Johnson Syndrome Foundation hears from people from around the world every day of the year. Unfortunately, we also hear from families that have lost their loved one to SJS and TEN. Recently we have seen an increase in deaths. Several were young children. Our thoughts and prayers are with all of these families. We have added a new page to our website entitled SJS Memorial Page. This page is dedicated to all those that have lost their courageous battle with SJS and TEN.

To view the detail:

### SJS Awareness Proclamation's

We are pleased to announce that 14 states have joined us this year in naming **August Stevens Johnson Syndrome Awareness month**. Our deepest appreciation goes out to the following ladies for their help:

- Sherry Callejo of Hawaii - proclamation pending
- Mary Beth Dunn of Alabama, requested in memory & celebration of Heather Rose Kiss.
- Lisa Kendig of Tennessee
- Joyce McCauslin of Pennsylvania

Proclamations were received from the following

[http://www.sjsupport.org/htmldata/sjs\\_memorial\\_page.html](http://www.sjsupport.org/htmldata/sjs_memorial_page.html)

## Stevens Johnson Syndrome Awareness Presentation

By, Jean McCawley

On August 9th it was my honor to visit the Colorado Springs Utility Company. I was invited by Penny Kagey to give a presentation on Stevens Johnson Syndrome for their monthly safety meeting.

Penny knows all to well about SJS and TEN. In 2000 she lost her beloved mother, Kathleen Willis, to Toxic Epidermal Necrolysis. It has since been her goal to educate others into the warning signs of SJS and TEN.

Penny fought back her tears as she described to her co-workers the agony her mother experienced. She and her sister Patsy continually spread the word about SJS hoping to spare another family from the horror of Stevens Johnson Syndrome.

The presentation included the viewing the Diana Cignoni's, 20 minute documentary, "Surviving SJS" and concluded with a question and answer period. The next day I received an email from Penny. The water department director was so impressed he was having the SJS Fact Sheet copied and distributed throughout the water department to over 1800 employees as part of their August Safety meeting newsletter. We are very thankful to Penny and the Colorado Springs Utilities for giving us this opportunity.

## The FDA

Takes a step in the right direction

According to an August 9th report by Reuters news agency, the U.S. Food and Drug administration recently rejected Cephalon Inc. experimental attention deficit disorder drug Sparlon, after a case of Stevens Johnson Syndrome was reported during the clinical trials. An advisory panel to the FDA recommended the drug not be approved due to safety concerns.

states:

- Alabama
- Colorado
- Connecticut
- Kentucky
- Louisiana
- Massachusetts
- Michigan
- Nevada
- New Jersey
- New Hampshire
- Pennsylvania (- A Resolution from the House of Representatives)
- Tennessee
- Wisconsin
- West Virginia

To view proclamations please click on the following link: [<http://www.sjsupport.org/proclamation.shtml>]

## Great sunglasses for SJS patients!



WindRams comes with 3 interchangeable RamFlow lenses. Made of impact resistant poly-carbonate, these lenses are premium optical quality, distortion free and offer the wearer 100% UV protection. They block wind which can cause more discomfort for patients that suffer from dry eye syndrome.

Visit their website at: <http://windrams.com>

## SJS Foundation Reminders!

- Please help us track SJS and TEN cases by completing our SJS Survey Form. We now have 825 completed surveys.
- SJS Awareness products are available on our CafePress SJS Shop. We have recently added a new section with memorial tributes.
- Please use Goodsearch.com when searching the Internet. By designating the Stevens Johnson Syndrome Foundation as your favorite charity, the SJS Foundation will receive a penny for every search. Those pennies add up.

[www.goodsearch.com](http://www.goodsearch.com)

**Buy for Charity!** ([www.buyforcharity.com](http://www.buyforcharity.com))

When shopping this holiday season why not

It is good to see the FDA taking notice of SJS. However labeling of over the counter ibuprofen products has yet to be changed. Recently the Stevens Johnson Syndrome Foundation received new reports of deaths to these products. Both were 5 year old girls. According to the SJS Survey forms we have had 50 cases of SJS and TEN related to these products. We will continue to work towards a labeling change to include Stevens Johnson Syndrome.

If you or a family member has experienced Stevens Johnson Syndrome and you have not reported your case to the FDA, we are asking that you please complete the FDA online reporting form at:  
[www.fda.gov/medwatch/report/consumer/consumer.htm](http://www.fda.gov/medwatch/report/consumer/consumer.htm)

shop online from over 350 stores like Barnes & Noble, Gap, Office Max, 1-800-Flowers, REI, Orbitz, and more at BuyForCharity.com! Up to 35% of each purchase will benefit us if you select the Stevens Johnson Syndrome Foundation as your cause of choice. So anytime you buy online, whether you are looking for Airline Tickets, Flowers, Clothes, Music, or anything else... BuyForCharity.

You can also save money on your own purchases by using their great [Coupons & Specials](#). Don't forgot to click above and enter "Stevens Johnson Syndrome Foundation" as a keyword on the search function, then start saving money on your purchases and help us raise funds in the process.

## How you can help SJS Foundation?

**Now** you can donate your vehicle to help the SJS Foundation Through Vehicles for charity, the SJS Foundation will receive a check once the car is repaired and sold at auction. Your donation through vehicles for charity is tax deductible. [ [Click here](#) ] for more information on how you can help.

If the information contained in our website was helpful to you, please be aware that it has been made available for public access strictly through volunteer effort and funding. The **Stevens Johnson Syndrome Foundation** is a 501(c)(3) non-profit organization dedicated to promoting public awareness to adverse drug reactions as well as to provide immediate information regarding treatment of those suffering from this devastating affliction. Please help us keep this website running. Your tax-deductible donations will help us to continue this good work.

[ [Click here](#) ] to make your generous contribution to **SJS** Foundation...!!

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