



# Stevens Johnson Syndrome Foundation

Newsletter  
December, 2006

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## Happy & Healthy Holiday's

Wishing you and your family a happy, healthy and safe holiday season from all of us at SJS Foundation!

Please take a moment to visit our website, [www.sjsupport.org](http://www.sjsupport.org). Categories have been added for easier navigation. Special thanks to, Jean McCawley and Amit Khatri!

### Montel Williams help's Spread SJS Awareness!

By, Jean McCawley

To view a slide show of the event please: [\[click here\]](#)

Over the past 11 years the Stevens Johnson Syndrome Foundation has strived to promote SJS awareness. We've printed fact sheets, brochures, issued press releases and interviewed with local news agencies in attempts to spread the word. We've worked at local fairs handing out fact sheets only to find them thrown in trash cans and littering fields. We've been turned down for proclamations for SJS Awareness month, ignored off by government agencies and foundations for funding into research, all due to the "rare word"!

Most physicians are taught they will never see an SJS case in their entire medical career. Thousands of SJS victims go misdiagnosed suffering horrific side effects due to untimely treatment. Many lose their battle due to the lack of knowledge of health care providers and public awareness. The SJS prayer list continues to grow as more people fall victim to this nightmare.

This past August we received a phone call from a producer of the Montel Williams Show. She was researching on the internet and came across the

### Freeware for blind & visually-impaired

Very helpful site for SJS Patients that suffer eye damage!

At [ScreenReader.net](http://ScreenReader.net) we have freeware for blindness and visual impairment special needs throughout the world. It is free only to individual blind people for their personal use at home.

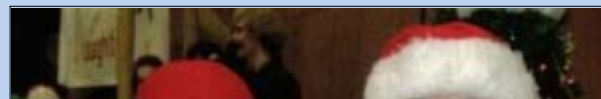
Download the Thunder ScreenReader talking software and your modern XP or Vista computer will be immediately usable by someone who can't see to read the screen.

### Special Offer for SJS Patients from Windrams!

Get the dark glasses you've always wanted with the wind protection you need. [\[Click here\]](#) for detail information on Windrams.

### MY LIFE AFTER TEN

By, Marlene Kerber



Stevens Johnson Syndrome Foundation. She asked me to tell her about Stevens Johnson Syndrome and after a few minutes invited Julie and I to travel to New York to appear on the Montel Show. At first I thought it was a joke. I couldn't believe that it was really happening. Several weeks past and we didn't hear anymore. I assumed it wasn't going to happen at all. Then the call came asking what airport we would be traveling from. I don't know why or how they found us. I believe that our prayers for awareness were about to be answered.

On October 18th Julie and I flew to New York. We arrived very late that night and were met by a very nice young lady from Montel's show. She checked us in to our hotel and told us we would go to the studio for taping at 1:00pm the next day. It was very exciting and Julie was thrilled to get a chance to meet so many nice people.

Montel was wonderful with Julie. He was very compassionate. Before she was brought on the stage he asked me if the lights would be too bright for her. I had to be honest, yes they would be. They were spotlights and Julie can't even tolerate our living room lights. Montel did something so amazing for a TV host to do. He asked his producers to turn the lights down and even had them turn the spotlights off. He did it just so that Julie would be comfortable.

Montel explained to the audience that SJS can happen to anyone. He also told them how there wasn't enough research into Stevens Johnson Syndrome. He then told Julie you just educated a country. He gave us the opportunity to get national coverage and awareness into SJS. After the show aired we received numerous phone calls and emails from across the country, including one from a family who's child was reacting to an over the counter medication. I believe with all my heart that Montel helped to save lives by airing this story about SJS.

On November 20th a film crew came out and filmed a follow up story. Montel doesn't forget about something if he thinks it is a worthwhile cause. Hopefully more people will be able to find out about Stevens Johnson Syndrome before it finds someone they love.

Thank you Montel and your wonderful staff for



All my life, I always looked at my cup as literally empty. I do have a great life, not perfect, not pain free, and not without baggage of just plain old living experiences, life throws our way.

I have had so many things go wrong with my life. But this holiday season is a time to be thankful. This sounds so cliché, however when I have done the worst suffering in my life when I got TEN, it truly gave me one of the best life's that I would have never dreamed that could happen.

There was nothing about this condition that was going to be positive for me. However I made the change and the choice all of us have the power to do, if we choose to make the best of a bad situation.

Five years later, loss of a family, of not being able to work any more, and having to endure the aftermath of TEN, I am so thankful that I did survive. I have met and made some of this most remarkable friends from the SJS support group's as well as great Doctors™s and specialists who do have the compassion for this condition, and some who have even cried with me. I look at that as having to be able to be behind the scenes of medicine and to see the world of technology as a gift.

Not to mention there are some people, who go thru life without a friend. I never have, but there are some who do.! That to me is sad, without one friend can you imagine where we all would be?

It was other SJS survivors and their families, who emotionally held me up when I lost my best friend, my Dad and who have become a different family to me.

And actually on Thanksgiving it was the last time that I had the dinner with my Dad, and the last time, I had seen him, and I am so grateful, to have spent, one more Thanksgiving, to the best Dad

helping promote SJS awareness!

### Tips from SJS Patients

Hello,

I just wanted to share this in case other SJS patients could benefit from it. My eye doctor put me on large doses of Flax seed oil capsules each day. It is supposed to help keep eyes more lubricated, and aid in tear production, and help decrease inflammation. I take 3,600 mg.(or 3 capsules 1,200 mg each) 2-3 times per day (am/noon if needed PM). I notice a big difference! Especially if I don't take it for a day or two. My doctor. said it's all omega-3 oils (like in fish), and also good for your heart, skin, other stuff. He said it's very safe with no known side effects (and no reported cases of sjs), all natural. Of course anyone should check with their eye doctor first, and for dosage also. I have taken it for about 4 yrs now. It is important to get a good brand from health, vitamin section of store. It can take about 2-3 weeks of taking it 2-3 times a day before you will notice a difference so don't get discouraged right away.

I hope you can pass this info on, as it may help many SJS patients greatly, if you didn't already know about it.

Thanks, M'lissa  
[starmagik76@aol.com](mailto:starmagik76@aol.com)

anyone could have.

Today, was a day that became very difficult for me. I stood in my friends kitchen, by myself, and out of no were, it hit me, I just started to cry my eyes out, someone came in and said, are you ok? It was wonderful to be able to say, yes, I am fine, I was just thinking of my Dad.

I never was one to say, yes I am doing great. I would tell a stranger if I was not having a good day, or miserable. I have chosen to change and reprogram my brain that is what has brought my cup to become over flowing today.

I could go on and on and on. I seek out people who want good things in lives and make healthy choices for themselves. We all learn from each other. I have friends and the people that are in my life, who are not negative people, they will only drag you down, and I sure found out, life is short, and can be taken from any of us at any moment.

And I want to hold onto are the good things in my life today, we cannot get yesterday back, nor our old life's before SJS. However we can learn from our new destiny, you can choose to happiness, or misery.

In spite of my many doctor's visits, and days of pain, I would not trade life for death, I worked very hard and was very not going to allow myself to endure any more emotional pain. I had enough to last me a lifetime.

That is a gift in itself, being left with ones toughest challenge and still feeling this way. I am no longer angry, and I no longer hate doctors After all, how are they truly going to know, that we are going to ignite from medicine. Their training was just not perfect, and neither is life.

I know that many people may disagree with my thoughts, and that is ok and just fine with me. Today I can honestly say, that we can all agree as adults to disagree and still be friends and civil to one another. Anger does not hurt them, but will sure kill us. I truly have accepted my life, just a different road that there is no college course that teaches us, how to endure this one. It is hands on.

I will close with this. I met this man once, and I will never forget what he told me when we were

speaking of life's hardships. He said to me, life is a mystery to be lived not solved. Is that not the truth or what! I will never forget his words, and he was so right.

None of us know what tomorrow may bring, and why miss the good things in life that we have today. And I am forever grateful for my life today, in spite of pain, loss's and challenges, that I truly can say, I hold my head up with the grace of a woman, and not the grief of a child. That is what TEN gave me!

Wishing everyone a happy holiday season!  
Marlene

## How you can help SJS Foundation?

Special thank you to the following for their generous donations! [[Click here](#)] for the list.

**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.

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