Stevens Johnson Syndrome Foundation

Newsletter
April, 2005

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Physicians List Recommendations

The SJS Foundation would like your help with our physicians list web page. Please share information regarding a doctor that has helped you deal with the aftermath of SJS/TEN. This information can help those who have recently been diagnosed in finding a doctor with experience in SJS/TEN sideeffects. Information we will need includes, doctors name, area of specialty, phone number, address, and email if available. We are looking for all areas, including but not limited to general practice, ophthalmology, ear nose and throat, pulmonologist, cardiologist, dermatologist and mental health. Please email information to sjsupport@sjsupport.org. Enter **Physician Recommendation** in subject line.

You're Lucky

by, SrA Tanner Claybaugh

On the morning of May 19th, 1993, I came downstairs after getting ready to go to school. My sister Mollie was sitting on the couch waiting for my mother to give her some medicine (children's Advil). My parents thought she had the common flu. She looked pale and about to throw up. Not wanting to go to school like any good kid I said to her "You're lucky." Striking back she said "No, I'm not." Looking back on it I wish I hadn't spoken those words. A short time later her lips turned purple and skin bleach white. What was to come I consider the end of my sisters life.

At the hospital they tried taking her blood but were unable to because it was too thick. The nurse gave her more childrens advil which in time made her condition worse. In a short while she developed blisters and rashes all over her body. She was put in the Intensive Care Unit (ICU) where there were countless machines keeping her alive. After about a weeks time she was put in the burn unit as if she had burns from a fire, but the allergic reaction was the cause of her third degree burns. Later that night my mother was sitting with my sister listening to the reassuring beep...beep...beep of the heart rate monitor. My sisters body let go of it's grip on life.

New Board Member

Welcome Maralee Bilotta to the SJS Board of Directors. Maralee is the Transient Sales Manager at the Millennium UN Plaza Hotel at United Nations Plaza. She is driven to spread the word about SJS and also participated in the SJS Candle Fundraiser. We are very happy to add her to our board. Thank you Maralee!

August is SJS Awareness Month!

Just a reminder, with August quickly approaching, we are asking once again for volunteers to write to your local Governor requesting a proclamation for SJS Awareness Month. Most states require a letter from a resident. Please help us spread the word nation wide. Your help is greatly appreciated! Click here for a sample letter: http://www.sjsupport.org/htmldata/sample_governor_letter.html

You can locate your Governors address through the following link: http://www.nga.org/governors/1,1169,C_GOV_ADDRESS,00.html

SJS 5K Walk/Run, August 13, 2005

Please join us for:

Hearing the flat line my mother pressed the red emergency call button that she had only glanced at hoping she would never have to touch it. Doctors and nurses rushed in to revive her. Back and forth she went from the burn unit to ICU. As soon as her condition improved it worsened.

It was always the same pattern entering ICU. Wash your hands with warm water and soap. Then put on medical mask and gloves. I was an 11 year old boy who had to do this just to watch my sister through a glass door of an isolation room. Her whole body wrapped in gauze to stop the bleeding blisters. The burn unit was the same. I remember sitting in her burn unit room watching two therapists lift her up and try to sit her in a wheelchair. Drops of blood falling to the ground originating from her burnt flesh. Her head had been shaved and blisters lined her body. All she could do is cry because her vocal cords had been burned, but I'm sure she was trying to scream out "Stop, it hurts." I was forced to leave thinking how this freakish transformation took place.

After five long months in the hospital she was able to come home. Our living area transformed into that of a hospital room. It had a ventilator for her tracheotomy, iv stand, stomach tube stand, heart rate monitor, and medications galore. Therapists came over everyday for her therapies. A nurse always by her side giving her care. Surgeries almost every other week to stretch her esophagus, ligaments in her feet and hands, and cornea surgery.

Before SJS, Mollie was a committed dancer. She loved dancing. She was suppose to perform in the opening show for the 1996 Olympics in Atlanta. She also auditioned for Show Stoppers and made it to the Nationals but was not able to go because she got sick. She won countless awards and beauty pageants. Mollie took lessons from the dance instructor that taught the Denver Broncos Cheerleaders. She even got me to try dance lessons, but being the hard-headed and stubborn kid I was I quit within a week. I was a sissy when it came to following through with things and she was the complete opposite. The room where she use to practice her dance moves, aerials, and back flips had now become her rehabilitation center.

Today my sister Mollie cannot walk, see, or talk very well. She is fed through a stomach tube and it's hard for her to breath. 100% of her body was

The First Annual Stevens Johnson Syndrome 5K Walk/Run

Fundraising Event to Benefit the Stevens Johnson Syndrome Foundation
August 13, 2005
Westminster City Park Promenade

Date: August 13, 2005
Check in time: Check in will start at 7:00am
Begin time: Run Will Begin at 9:00am, Walk Will Begin at 9:10am
Duration of walk/run: 9am - 12pm
Donation to Walk/run: $25.00 (includes T-Shirt, drinks, and snacks)

(Additional Donations are Greatly Appreciated and Needed)

[http://www.sjsupport.org/sjs_walk/sjswalk_form.html] to complete registration form: The First Annual Stevens Johnson Syndrome 5K Walk

For more information contact Penn Street at 1-800-634-8401 email: penn@mosesstreet.com

OR the SJS Foundation at 303 635-1241 email: sjsupport@sjsupport.org

[http://hotel-guides.us/colorado/westminster-co-hotels.html] for the list of hotels located in the Westminster area.

Preventing SJS Could Become a Reality!

A team of researchers from Taiwan's Academia Sinica has recently discovered 2 genetic markers (variations) among Chinese SJS patients whose SJS was from Tegretol or Allopurinol. They are now in the process of developing an inexpensive test, so (Chinese) people could be tested for these markers BEFORE they take these 2 drugs, in order to avoid getting SJS in the first place!

Now the researchers will be turning their attention toward finding genetic markers among all ethnic groups, for these and other drugs that commonly cause SJS/TEN. This is not an overnight process, but ultimately has the potential of deterring people from taking the drugs that would cause them to develop SJS/TEN!

If you are able to participate in this research please call Donna J. Nelson at 641-472-9994, or email her at djnelson3@gmail.com. All DNA and information is kept burned from the inside out and the scars on her skin still remain. My mother has become a nurse so she is able to take care of her. Since the healthcare budget cut my sister is not able to receive any more therapies. There is also limited funding for stem cell research which could improve my sisters condition if perfected. Stem cells could help my sister see again. Mollie is smart, quick witted, and remembers things from our childhood that I don't even remember. I love my sister.

Everyone needs to be aware of the potential for disaster this drug has. I, for one, have never taken any drug containing ibuprofen in fear that I will develop the same allergic reaction. Every time I go to any medical clinic I make sure they know that I am allergic to ibuprofen. I'm not taking any chances and neither should you. So, next time you're handed any drug containing ibuprofen remember, "You're lucky."

Montel Williams Show

Betty and Clarke Guilliams just returned from a trip to New York, where they filmed a segment for the Montel Show. Betty had TENS in 1998. Her story appeared in our December newsletter. We are very happy that her story is going to air soon. Special thanks to Betty, Clarke and the Montel Show for spreading the word about SJS/TEN.

SJS in the News!

By, Jean Farrell McCawley

So far 2005 had brought quite a bit of awareness to Stevens Johnson Syndrome. I am sure many of you have been following the news regarding NSAIDS. Recently Bextra was taken off the market due to an increase in adverse events in particular a severe skin reaction. SEVERE SKIN REACTION???

This year the amount of Stevens Johnson Syndrome cases has escalated. We have seen a huge increase in NSAIDS in adults and children. It was my honor to travel to Maryland this February to join 7 year old Sabrina Brierton Johnson and her attorney Browne Greene, of Green, Broillet & Wheeler of Santa Moncia, CA,

in the strictest privacy, and used only for this specific research. Academia Sinica is an academic/research institution. Thanks to Jean for helping with this!

along with Joan Claybrook of Public Citizen for a press conference held during the FDA Hearings regarding the joint meeting of the arthritis advisory committee and the drug and safety Risk Advisory Management Committee.

We discussed an increase in SJS among children to ibuprofen products. Little Sabrina was the first citizen to testify at these hearings asking that the warning label of Stevens Johnson Syndrome be returned to these products. Time was limited to a 2 minute statement. If you went over your time limit the microphone would be shut off. Sabrina through her Mother Joan, made great use of her 2 minutes. Great job Sabrina!

The Stevens Johnson Syndrome Foundation submitted written testimony to the panel. Our statement was entered into the docket and can be viewed at the following link: [http://www.fda.gov/ohrms/dockets/dockets/04n0559/04n-0559-c000003-01-vol1.pdf]

Since the hearings we are relieved to see the FDA finally moving in the right direction by placing warnings on over the counter NSAIDS. It is our hope it will clearly state Stevens Johnson Syndrome and not risk of serious skin reactions. We have also asked the FDA to implement a National Reporting system to get an accurate count of the incidences of SJS/TEN. How can anyone say that SJS/TEN are rare when there is no reporting system in place? We will continue to update you on our progress.

Related story: [http://www.sjsupport.org/topstory_archive/old/HealthScoutNews]

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. [http://www.donateforcharity.com] 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 **S**tevens **J**ohnson **S**yndrome **F**oundation 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 F**oundation..!!

Information for Donors: The Stevens Johnson Syndrome Foundation is a 501 (C) (3) tax-expempt corporation. All donations to the SJS Foundation are tax-deductible. [Click here] for Tax information.