



Stevens Johnson Syndrome Foundation

Newsletter
September, 2005

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First SJS Awareness 5k Walk/Run

The first SJS Awareness 5 K Walk/Run was held on August 13, 2005. With months of careful planning what could go wrong?

The day before the walk was a sunny, beautiful, Colorado day. Last minute errands were run including picking up water from Eldorado Water Company, renting a helium tank and purchasing balloons. We filled runner's bags with SJS fact sheets, homemade awareness ribbons made by survivors, SJS water bottles and snacks. We even worked until 1:00AM hanging banners around the park leaving 5 minutes of sleep before returning at 6:00am to set up the registration booth.

At 3:00am we awoke to a cold front! This can't be happening! At 5:00am it was pouring. We loaded up our cars and trucks and headed off for the park. We had people flying and driving in from around the country. We couldn't let them down.

Under rainy skies we headed for the park. We looked at each other thinking no one will come. Thank goodness we were wrong. Within 5 minutes of arriving at the park, volunteers from Federal Express started driving up. We struggled in the wind to set up canopies. About 7:30 SJS walkers started showing up. We made a make shift registration booth right out of the back of June Eggleston's mini van handing out t-shirts and bags.

Suddenly miracle happened! The rain stopped. The sky was gray and overcast but not a drop of rain came down the rest of the day. Over 100 people came and walked. Many wore cards and walked in honor of SJS victims that could not be with us or walked in memory of those that lost their battle with SJS. The day ended with Bronco cheerleaders selecting winners of door prizes.

Survivors came from around the country to participate in the walk. All the way from Florida Stacey Pevzner and from New York were Wendy Rosow and her son Christopher Simpson. We were also joined by people from Oregon, and the western slope of Colorado. We are thankful for all of our participants.

Special thanks to all the volunteers who helped make this event such a success. To all the employees at Federal Express in Denver, Tim Bowden, June, Jeanne, & William Eggleston, Leslie & Anne Farrell, Elizabeth, Carolina & Catherine Finch, Trina Hoag, Amit Khatri, Julie Lankford, Dan & Julie McCawley, Penn Street & Jeanette Schnitzer.

Thank you to our sponsors: Advocare Energy Drink, Burg Simpson Attorneys at Law, City of Westminster, Dr. Janis Cotter of Parkway Sclerals, Einstein Bros Bagels, Eldorado Springs Water Company, Embroidery by Design, Robert Landsperg Board of Director SJS Foundation, Moses Street Photography, Muttleys Maid, Team Davis/United Property Brokers, Wylaco Supply Company of Denver, & American Medical Response Team

We would also like to thank the following companies for their donation of door prizes: Black Eyed Pea, Carrabba's, Cheesecake and Such, Chillis, Honey Baked Ham Store, Moses Street Photography, Olive Garden, On the Border, and The Wave Car Care Company

It was a wonderful day and we look forward to next August at the 2nd annual SJS Awareness Walk. Hope

to see you there!

For photo gallery of First SJS Awareness 5k Walk/Run
[http://sjsupport.org/Images/sjs_5kwalk_05/index.php]

Support Group Facilitator

Each day the Stevens Johnson Syndrome Foundation hears from people around the world. No one should go through the horror of Stevens Johnson Syndrome alone. We are currently in the process of looking for volunteer support group facilitators. If you would like to be a contact person for your area please complete the SJS Volunteer form: [http://sjsupport.org/htmldata/facilitators/support_group_facilitator.pdf]

Support group facilitator list will be available by state on the SJS Foundation website.

SJS AWARENESS SHOP

Over the past several years the Stevens Johnson Syndrome Foundation has received numerous requests for T-shirts, hats and pins. As a non profit organization with very limited funding we were unable to manufacture these products. We are very excited to announce the SJS Awareness Shop at: www.cafepress.com/sjsupport. You can shop online for SJS Survivor and SJS Awareness items. We have several different designs to choose from including the SJS Foundation Logo, Awareness ribbon, SJS Foundation mascot and SJS Survivor products. Cafepress makes the items for you so the foundation doesn't have to stock inventory. Your purchase is shipped directly to you and 25% of all purchases are donated to the SJS Foundation.

Thank you for your continued support!.

SJS Mascot



The Stevens Johnson Syndrome Foundation would like to thank John Bilotta for designing our SJS Mascot. Stevie Johnson Seagull. John is a professional cartoonist and has done a fabulous job. This little mascot was printed on the front of the 5K walk/run shirts and was a big hit.

A Family History of SJS,

- By Joyce Breen

Our first child, Michael, was only eight months old in 1953 when we noticed a strange rash on his arm. When it seemed worse the next day we took him to the family doctor. After a brief check-up, the doctor suggested that we take him in to Children's Hospital in Milwaukee to see a pediatrician. He commented that Mike's condition was something he had never seen.

After a brief examination, the pediatrician excused himself and was gone for about fifteen minutes. He returned, apologizing, saying that he had consulted his text books. He said Mike had Stevens-Johnson's disease? a rare skin condition. He had never seen symptoms so early in their development because usually at this stage the family doctor was still treating it as 'just a rash'.

The pediatrician wanted him to be hospitalized immediately, saying that Mike would be much worse before he got better. These fifty-three years later, I can still recall my feelings as a nurse came, took my baby and carried him down the hall screaming and stretching his arms out to me over her shoulder.

Back in those days parents were not allowed to stay with their small children who were hospitalized. In fact, we were advised not even to come to see him for three or four days. We were horrified!

We were allowed to go to his room to see him before we left the hospital, but that was even more shocking. He had been placed in a tiny isolation room and his entire body had been covered with gauze saturated with solutions to help pain control and promote healing. Tiny slits were left for his eyes, nose, and mouth. He just lay there, not crying, not recognizing us.

The doctor had talked to us about a new experimental drug now on the market that might cut Mike's healing time in about half. We signed a release form allowing cortisone, the new drug, to be given to him. It did help.

We visited him each day, just to look through the

Governors Issue Proclamations!

Governors across the USA this year issued proclamations declaring August Stevens Johnson Syndrome Awareness Month. We are pleased to announce Kentucky, Tennessee & Massachusetts joining the states of Colorado, Connecticut, Louisiana, Michigan, Nevada & Wisconsin...

We need your help. Please write to the Governor of your state for next year. Our goal is to get a National Proclamation issued by the President of the United States. Please ask them to send the proclamation to the

SJS Foundation
PO BOX 350333
Westminster, CO 80035-0333

For a template on key issues to be included in the wording of the proclamation please visit the following link: [http://www.sjsupport.org/htmldata/sample_governor_letter.html]

Your assistance is greatly appreciated.

From a loving mother for my angel

By, Lisa Jirak

Dakota was born September 19, 1995 in Las Vegas, Nevada at UMC Hospital. He weighed 6 pounds 8 ounces and was the most beautiful baby boy I have ever seen. I was told he was perfectly healthy. When we went to take him home I noticed something seemed to be wrong with him. He wouldn't look at me when I talked to him. He didn't move at all. So I took him to his doctor who said he was fine and give him some time. About an hour after we got home he had a grandmal seizure. I rushed him to the clinic in Mesquite and they told me to take him to the hospital in St. George. When we got there they gave him Phenobarbital and did a CAT scan. He started to get little red bumps like a heat rash. The doctors came in and told me he had septo-optic dysplasia

Dakota developed a fever of 106.8. Within 20 minutes he was blistered on over 90% of his body. They called life flight to transport him but life flight went to Phoenix instead of St. George so they had to take him by ambulance to Las Vegas Trauma Center. When they got him there they were doing so many things to him I didn't know what was going on. I was only 19 years old, I didn't understand and they made me leave the room. An hour later they let me back in. They had broken the Blisters and had tubes coming out of him everywhere. They couldn't get reading on him because his temperature was so high so they put

glass and watch him as he lay wrapped up like a mummy. The nurses assured us that he was 'doing well.' We did not see his skin at its blistered stage.

On the fifth day when I arrived, he had been moved to a general ward and the bandages had been removed. What a wonderful experience that was for me. At one end of the ward was a circle of rocking chairs. Each was occupied by a volunteer rocking a baby. One of those babies was Mike, who got all excited when he saw me walk toward him.

The next day we took him home. But the trauma was not quite over.

Shortly after being put to bed that first night we heard awful sounds of him gagging and throwing up. The contents were huge clumps of what we later found out were the mucous membrane lining of his stomach. The hospital staff had neglected to tell us ahead of time that this was to be expected. Fortunately, we had a phone number to call at the nurse's station, and she reassured us that he would be ok.

Within just a few days he was his old self, eating well, laughing, and not showing any signs of the ordeal he had endured.

Interestingly, Mike has been the healthiest of our three children. He almost never gets colds or flu despite the fact that he works as a school psychologist and is in daily contact with many children. I have sometimes wondered if the SJS had given him special immunity.

At the time of his hospitalization, I do not recall ever being asked if Mike had been on any medication. I do know that he had no infection at the time he got the rash. However, I also do recall that almost all doctors in our area prescribed a purple, grape flavored sulfa pill when any child had an earache or sore throat. Mike had taken them for earaches, but I do not know how long before he developed the SJS.

After forty-two years of typical family living we had our second experience with SJS.

My father had been an exceptionally healthy man except for allergies. He knew he was allergic to penicillin and sulfa. He had gotten a severe hive reaction to those two drugs.

In 1985, when he was ninety-nine years old he

him in a drug induced coma on life support. They gave him so many different drugs and didn't tell me all of them.

I couldn't hold him for three months. He wasn't getting better. I finally told them " Let God take him back." They finally let me hold him until he died 8 ½ hours later. I told him don't hold on just for Mommy. I would be ok and go back to God. Dakota went to Heaven on January 6th, 1996 at 8:17pm. When he left, he let out one Breath and one tear to say thank you Mommy. I love you Dakota!

moved into a nursing home. His allergies were recorded on his chart.

One Sunday his nurse noticed a bit of drainage from one ear and Dad complained of pain. The nurse called the doctor on call, and he prescribed amoxicillin. The nurse said he was allergic to penicillin, but the doctor assured her it would be ok, and to give him some benedryl if he got a rash.

In the morning the staff called his family doctor who stopped the drug. By afternoon of that day his body was red and blistering. The staff tried everything within their means to give him relief, to no avail.

The next day he was transferred to the Burn Center of the University of Wisconsin Hospital. He was immediately diagnosed with SJS.

Is SJS passed on genetically? Should our children, grandchildren and future great-grandchildren be warned about sulfa and penicillin? Should we be warned about drugs like Bextra that contain sulfa? Is SJS most common to infants and the elderly (as we were told) or are those of us in between those ages at risk also? Why aren't doctors better informed about SJS?

Joyce M Breen

SJS Awareness Booth 2005

This was our third year to participate at the Westminster Fair in Westminster, Colorado. There was a great deal of interest in Allergic Drug Reactions and many people stopped by to pick up an SJS fact sheet. We would like to thank the following volunteers for helping man the booth, Jeanne & Will Eggleston, Leslie Farrell, Amit Khatri, Dan McCawley and Jeanette Schnitzer. As always your help is appreciated.

Please [http://www.sjsupport.org/htmldata/slideshow_fair_05.html] to view the slide show from the fair:

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 **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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