

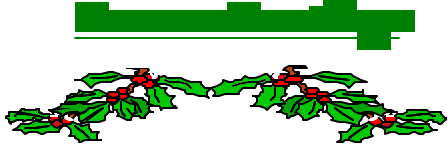
# Stevens Johnson Syndrome Foundation

PO Box 350333 - Westminster, Colorado 80035-0333

Phone (303) 635-1241 Fax (303) 469-2528 email: [sjsupport@sjsupport.org](mailto:sjsupport@sjsupport.org)

Website: [www.sjsupport.org](http://www.sjsupport.org)

December 2003



## SJS Awareness Month

August has been named SJS Awareness month. Please mark it on your Calendar and join us next summer as we spread the word about SJS/TEN!

## Girls Scout Gold Award!



Congratulations to Jeanette Schnitzer.

Jeanette had SJS when she was 6 years old from amoxicillin. This summer she chose SJS as her service project for the highest award a girl scout can receive. Jeanette spoke to daycare's and preschool's educating young parents into the signs of SJS. She and her mother Susan and sister Amber also helped man the SJS awareness booth at the Westminster Fair. Their support and hard work is greatly appreciated!

Great Job Jeanette!

## Children's Ibuprofen Products.

This spring we have has seen an increase in SJS cases to NSAIDS in children, especially young girls. Please spread the word about the signs of SJS. Pediatricians as well as dentists are recommending ibuprofen to pediatric patients. Remember to tell your friends and family that over the counter drugs can cause SJS also. You can find these products under the names, Children's Advil and Children's Motrin.



Emily, 6 years old and her 10 year old big sister Charlotte of Westmidlands, England

Little Emily Hawton developed Stevens Johnson Syndrome 3 year ago when she was just 3 years old. Her mother, Julie says that all Emily could talk about while she was recovering was Shamu the Killer whale at Seaworld in Orlando, Florida. Below Emily shares a beautiful picture that she made for us of Shamu!

Thank you Emily!



## SJS Volunteer needs your prayers!

Barbara Davis has helped the SJS Foundation with the newsletter for the past 5 years. This summer Barbara developed West Nile Virus and encephalitis. She has been in the hospital for 3 months. We are hoping she is able to come home in time for the holidays. Barbara has spent countless hours folding and addressing newsletters. We ask that you join us in sending her healing thoughts and prayers. You can send a card to Barbara in C/O the SJS Foundation PO Box 350333, Westminster, CO 80035 or

Email her at: [sjsupport@sjsupport.org](mailto:sjsupport@sjsupport.org)

## Great News!

Soon the Scleral Lens will be available to you without the expensive trip to Boston.

Dr. Janis Cotter has many years of experience in fitting scleral lenses. Dr. Cotter has relocated to her own practice making the scleral lens more available to more patients. Her website is under construction at this time and we will be providing a link to her site as soon as it is available. Dr. Cotter is an asset to SJS Patients everywhere.

Parkway Sclerals!  
Parkway Eye Center  
80 Broadway  
Revere, MA 02161

**Phone:** 781-289-7929



**In Memory of Bill Farrell**

Sept 26, 1931 - August 30, 2003

Bill Farrell was a well known commercial photographer and owner of the Photo Works in Boulder, Colorado He photographed my daughter Julie in the burn unit when she had SJS. He stood beside me and held me together when I was witnessing one of the worst nightmares of my life.He was one of the most caring and compassionate men I have ever met and I am proud to say he was my uncle. Bill's pictures have appeared in numerous medical journals as well as the SJS Brochure and website. He was an asset to the foundation and was dedicated to our cause. This summer we lost Bill to pancreatic cancer. He is deeply missed and will live on in our hearts forever. - *Jean Farrell McCawley.*

**OPPORTUNITY FOR MAKING OUR VOICES HEARD**

Lyn A. Veatch

I am a survivor of SJS. Others have lost their lives to SJS/TENS and no longer have a voice to speak out. Those of us that have survived must make our voices heard. Families and friends that have lost a loved one to SJS/TENS can speak out also.

The FDA (Food and Drug Administration) is in the process of drafting changes and there are specific things we can help them with by giving our input. I would like to suggest we take

the time to send brief written letters to our Senators and Representatives, in our own States, and request they be sent on to the appropriate departments with the FDA. Since our Congressmen represent us they are more likely to listen and take some action on our behalf. The following are requests that are relevant to the changes the FDA is undertaking.

Extend the post market research time on all new drugs.

Better reporting and gathering of statistics on Adverse Drug Reactions such as, Stevens Johnson Syndrome and Toxic Epidermal Necrolysis. (SJS/TENS)

More funding and research that relates to DNA and susceptibility to severe adverse drug reactions such as SJS/TENS.

Better educational programs for Doctors and other health care professionals so they can recognize and diagnose severe adverse drug reactions and understand they are not "RARE."

Please make your voice heard, by writing to your Congressmen and requesting the FDA include our concerns in their drafting process.

**From the SJS Foundation!**

Please visit the SJS Foundation website. There are many new links to valuable information. You can now add your SJS Story to the sight. You can also translate the website into Spanish, French, Italian, Portuguese and German. Add you name and email to the SJS Friends link or post a question on the SJS Forum Board. We are presently updating the SJS Physicians page with contact information about doctors with experience in treating SJS related sideeffects

We are asking if you have a physician that has helped treat your after care of SJS, please contact us with their information so that we can add them to our SJS Experienced Physicians list.

As you are all aware it is very difficult to find doctors with this experience. We would like to be able to provide this information to others that are need of good medical after care If you know a good doctor that you would like to add to the list. Please email us at [sjsupport@sjsupport.org](mailto:sjsupport@sjsupport.org) or call 303 635-1241.

**SJS MEDIA BLITZ**

As we are all aware SJS needs public awareness and what better way to get it then through local news stories. We are looking for SJS survivors willing to help spread the word about SJS through the media. If you would like to participate in a news story please contact us at (303) 635-1241 or mail us your information including name address, phone number, what caused your reaction and best time time of day to reach you. You can also email your information to: [sjsupport@sjsupport.org](mailto:sjsupport@sjsupport.org).

We have recently had stories air in, Denver, Las Vegas, New York and Philadelphia. Thank you for your help!

**Donations**

As you know the SJS Foundation depends solely upon donations to continue our newsletters and information packets. We would like to extend a special thank you to The Kenneth Kendal King Foundation for their generous contribution this month for without it, this newsletter would not have been possible.

All contributions to the SJS Foundation are greatly appreciated!

### Never too late to be Alert!

There are some incidents in life we never forget. I had one of those incidents. It all started when I was 12 years old. I was studying 8th grade, I was enjoying life. I had dreams in my heart and goals in life to achieve. I had so many friends I could not count on my fingers. Just like everyone else I had one special one. For me she was beautiful, like a nymph. She had dark, long, black hair. She had beautiful deep blue eyes like the ocean.

Sometimes I felt like I just wanted to get lost in her eyes and be one with her. She had a cute little nose. She had the most beautiful smile I had ever seen. Once in while when she smiled at me, it took all the pain and sorrow out of me. Her lips were like petals of roses. When she spoke she had so gentle, beautiful and peaceful voice that I stopped my breath to listen to her. I was so crazy about her.

One day it was raining so hard every thing was closed. There were 5 inches of water on the road. All the sand on the side of the road was becoming mud and coming down to the road. I also got the news that the school was closed, but still I just wanted to have one look at her. So I put my raincoat on and rode my bicycle about 10 miles to my school and waited for her at the gate for 3 hours. I knew that she would not come, but I waited anyhow. I did not know that I would wait more then one year and that when she saw me again, that I would not be the same.

Now, there was a time for separation. In October we had 20 days of school vacation because the Diwali Festival was coming. Diwali is one of the biggest festivals in India. All different ages of people enjoy themselves, They light candles inside the house and outside of the house. At night the sky looks beautiful because of the fireworks. The festival goes on for seven days. . But people enjoy the festivals for 15 to 20 days. But there was this one child that would not enjoy himself because he had a fever.

I was suffering from malaria. I went to a doctor who gave me some medication. When I took the medications I felt better and then went to play with my friends. But within a few hours the fever started increasing so I had to take pills again. It went on for a few days and finally the day arrived that changed the rest of my life. The fever increased and I started vomiting and my body became red and small boils started popping out. The fever stayed so high it felt like I was burning inside out. Medication was not working at all. My loved ones thought that I had chicken pox. But within three days the boils on my body became bigger and bigger. Now they were in my mouth and throat. So I could not eat anything or take my pills orally because it hurts when I take a pill so I immediately spit out the pills. Looking at my condition my mother started crying because now I lost my hearing. I could not hear anything people said and the festival was becoming a disaster. My father immediately went to the doctor and requested him to visit me at home. The doctor also thought it was bad chicken pox so he gave me the same medication in liquid form. After two days it became very serious.

Now I lost consciousness completely. I was chanting the name of the lord and telling my parents, look, the lords of death have arrived to take my soul, So goodbye and I will see you all after a time." As soon as my mother heard those words she was overcome with grief and said "I want my son admitted to the hospital." Still my loved ones had no idea what happened to me. When the nurse first saw me at the hospital, she asked my parents why I burned myself: Then a doctor came and said, take your son to the biggest hospital because we cannot do anything. It is so serious that he will die in a couple of hours."

They immediately admitted me to a bigger and better hospital. In the hospital they diagnosed me with Stevens Johnson Syndrome (SJS).



They kept me in intensive care unit and they told my parents that they couldn't do anything until 72 hours passed. I was fighting for my life. It was a battle where death took over life. I passed 72 hours and then they started giving me medical treatments.

Now, the boils on my body were filled with fluid. There was no spot on my body where there was not a hot fluid boil. Nurses had a hard time giving me an I.V. because they could not see the vein. I could not eat anything at all. And I could not stop vomiting. When I vomited the skin from inside my body came out. When I tried to sit up on the bed the sheets stuck to my back, so the nurse had to pull the sheet off. When they tried to pull the bed sheet, the blood came out and my skin came off. I lost all the skin from top to bottom, and tongue to anus. Not just that, I lost my hair, teeth and nails. My parents asked the doctor if I would have any skin left on my body. The doctor said, he will heal back but it will take a long time. For one and a half months I was in the hospital. My relatives visited me at the hospital but I could not see them. All I could hear were their voices but I could tell their names by hearing their voices.

Then I realized who says life is not fair? If a person loses one sense, then he will use another sense.

Finally the day came and the doctor told my family that I could go home. I thought the disaster was over and I could go back to my normal life.

But I forgot that I could not see or open my eyes and my eyes were light sensitive. For one year I stayed in a dark room where not even a fraction of light came in.

I could not see or do anything by myself so my parents had to take care of me. For me it was like I was born again. Whatever I did it felt like I was doing it for the first time. When I ate something, it felt like I had never eaten that particular food before. If I walked, it felt like I needed someone to hold my hand, otherwise I would fall down. It was a completely different experience.

My mother had to take me to the shower, my brother had to feed me and my father comforted me saying, everything will be all right. We will go to the best eye doctor and you will be on your own in no time.". While I was sitting in one room of the house, I could hear the other children playing. I was just 12 years old and I felt so much pain in my heart with guilt asking only one question: Why me? For one year every day and night I tried to tell myself how good it will feel when I meet her again and see the beautiful smile on her face.

I remember when that day arrived. After one year I went back to school with little vision but everything else had changed. I cannot believe to this day that so many friend that I could not count on my fingers were now so few. My friends left me alone. They did not want anything to do with me. There was this one word, which was following me every moment. That word was disabled. In school at lunchtime I spent hours and hours sitting under the trees by myself. No one wanted to talk to me or play with me but there was only one thing that kept me going. and that was she. I was thinking that she would accept me for who I am, not for how I look.

I saw someone walking towards me. When a shadow came near I realized it was she. I was dying to see her one smile.

But what I saw was a big question on her face. We looked at each other for a few minutes, then she said, I am sorry and then she left. It felt like the big sky had just crashed on earth and it was taking me down with it. I fell on my knees and wanted to cry out loud, but I did not shed a single tear. I started recognizing a change in myself and a change in other people. When people look at me they do not look at the person but at the disability. But I did not sit and cry. I used my ability to do something in my life. In school my instructors were worried because I could not read or write. All I could do was hear. How would I keep up with the other students? At home my mother read all the books to me and I listened. Then I went and took exams and still I was getting A grades. All the instructors in school were so surprised that I was using my ability to complete my life.

But there is only one thing. When I tell people I have Stevens Johnson Syndrome (SJS), as soon as they hear syndrome they think that it is contagious, but it's not. This is not a part of my body that I can cut and throw out. This is something I have and it will be like this for the rest of my life, They don't look at me as a person who has a heart and feelings, they look at me as a person with a disability.

Sometimes I wish I could have a normal life. I could do all the things that normal people do. Where were all my friends when I needed them the most? Where is the beautiful smile when I needed to see it most? I wish I could have someone to talk to, someone to say, " I love you. But it seems like it's just a dream. There are dark clouds on my side of the sky, but I know there is someone behind those clouds. All I am waiting for are the clouds to clear and I can see who is hiding behind them.

## **Amit, My Friend** **By Jean Farrell McCawley**

One summer day in 1998, I received a phone call from a young man that had SJS as a child. We talked for a while and I found out he did not live very far from me. I drove to his house that afternoon and delivered him an SJS information packet. That was the day that I met my friend Amit. He and his family had just relocated to Colorado.

Amit's family was told that we had the technology here in the United States to help restore his sight. I wish that were true. Amit ended up having 7 cornea transplants, mucous membrane grafts, vitamin A ointment, his left eye removed and being fitted for the scleral lens. Amit is miracle. He is a determined, intelligent man.

Amit volunteers his time to the SJS Foundation as our web designer. He redesigned our website and it is fantastic! With very limited vision he sits closely to his computer screen and continually updates the Website. He is truly an exceptional person. He is outgoing and funny with a warm personality. He is now 24 years old.

Amit wrote "Never too late to be alert" for a college course he is taking at Community College in Boulder, Colorado. It was printed in the Hour Glass Magazine, a college publication. Amit's parents and brother Tushar have distributed brochures in medical offices and hospitals in Boulder, Colorado as well as written to many SJS patients in India. Thank you Amit for all your do for the foundation and for being my friend!

In August the SJS Foundation participated in 13th annual Westminster fair in Colorado. The fair features crafts, rides and entertainment and draws approximately 8,000 visitors. The SJS Awareness Booth was a huge success. Volunteers passed out brochures and fact sheets to over 600 local residence. In September we held an awareness booth at another local fair called Broomfield Days. Many people told us they had a friend or relative that had SJS. Some took extra fact sheets to pass out at day cares and local schools. Thank you to all the volunteers that helped man the booths,

Special thanks to the Westminster High School Drama Club, Anne Farrell, Trina Hoag, Nicole Milliard and Luke Schimpf, and our SJS Survivors, Amit Khatri, Jeanette Schnitzer, Julie McCawley, and Danica Robison!

Jean Farrell McCawley



Julie McCawley



Trina Hoag & Anne Farrell



Nicole Milliard, Luke Schimpf and the wonderful Mr. Amit Khatri our SJS Foundation Webmaster!



Racheal Callaway, Jeanne Eggleston, and Janet Robison

The Stevens Johnson Syndrome Foundation is a non profit organization. We rely solely on contributions help us continue to provide information packets, brochures and newsletters to patients and their families suffering from these severe reactions. Your donations are tax deductible and very much appreciated. .

**Our special thanks to those people listed below for their generous donations:**

**In Memory of 3 year old Heather Rose Kiss**

Joem & Gloria Schmey  
DeLzon & Jane Kingett  
Michael & Mary Clifford  
Richard & Lisette Lospinoso  
Kathleen Prout  
Dadon & Kathryn Lester  
Richard & Lois Meyers  
Joan Guiditta  
Rochelle G. Metroka  
Lisa Reynolds  
Henry & Elisabeth Artczak  
Robert & Jeanne Levit  
Marshal & Maxine Haykin  
Daniel & Alia Ramer  
Walter & Margaret Coston  
Ryan, Beck & Co.  
Deborah E. Roomey  
Lloyd Road School PTO  
Victor & Mary DiMartino  
Timothy Christian School  
Joann & Warren Downey  
Aberdeen Morris Club

Drs. Noah & Cynthia Gilson  
Claire Borrelli  
Joann Toto  
Rori & Hal Ottenstein  
Frank & Cathleen Kingett  
Rochelle Leventhal  
Teresa Libro  
Eileen Salemo  
Carole Thumann  
Edward & Deborah Long  
John & Robin Quartararo  
Maria Sarantino  
Evelyn Ford  
James Bowman  
Amy Metroka  
MM Thomas Rojy Jr. MD  
Rodney & Joan Van Natta  
MM Thomas Rojy Sr.  
Joann & Warren Downey  
Frank Antonides School  
Dr. & Mrs Ryan Lake  
Drs. Noah & Cynthia Gilson  
Michael & Lauren Clifford

Dr. & Mrs Ryan Lake  
Ronnie & Hal Ottenstein  
Jane Felding  
Walter & Janet Kain  
Marilou Kiss  
Scott & Dana Haykin  
John & Marie Byrne  
Diane Thompson  
Marilou Kiss  
Andrew & Darlene Kiss

**In Memory of Scott Schmitz**

Desota Nursing Associates  
Robin & Chad Svendsen  
Jessioca Hedquist  
All Saints Guild  
Joanne Schmitz  
MM John Hansen  
Kristen Schmitz  
Jerry & Cathy Schmitz  
Dan & Robin Harris  
Les, Rachel & Greg Schmitz  
Teresa Libro  
Luke & Mary Lewy  
John & Carrie Lewy

Village Pine Needlers  
Carole & Rudolph Thumann  
Jim & Michelle Boushee

**Donations:**

Arnit Khatri  
Deborah Kaplan  
Renee Smith  
Allstate Giving Campaign  
Wendy, Jerry & Christopher Simpson  
Delton & Lyn Veatch  
Luke & Mary Lewy  
Edith Simpson  
Eva Araiza  
Rodney & Joan Van Natta  
Robin Dziczek  
Harold Landsperg  
Rob & Teri Bartoli  
James & Karen Mohan  
The Kenneth Kendal King Foundation  
James Barber  
Marlene Kerber  
Robert R. Landsperg  
Theda Bilota



**Stevens Johnson Syndrome Foundation**  
**PO BOX 350333**  
**Westminster, CO 80035-0333**