



Stevens Johnson Syndrome Foundation

Newsletter
December, 2004

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Happy Holiday's...!!



Wishing you and your family a Happy Holiday Season!

Betty's story

In 1998, I was Director of Athletics at a school for learning different children, a basketball coach, and a field hockey referee. My husband worked for a computer company and our three children were in 8th grade, a freshman at the University of North Texas, and a junior at the University of Texas. Life was good.

I had taught at my school for 7 years and it was by far the best teaching position I had ever experienced. It was my second family, my best friends were there and it was a school full of magic with teachers who could work miracles with children who learn differently from the rest of us.

In November of 1998, after a season of officiating field hockey and organizing the fall athletic teams; I bent over to pick up a volleyball in the gym and felt a sharp pain in my right knee. Immediately I knew what had happened. I had torn the meniscus cartilage in my knee - the cartilage that cushions the knee joint. I had done this several years back and had arthroscopic surgery.

FDA Letter Writing Campaign

The Food and Drug Administration is being investigated by a congressional committee. Now is our chance to let our voices be heard. Please write your SJS/TEN story to:

SENATOR CHARLES GRASSLEY
135 Hart Senate Bldg.
Washington, DC 20510 - 1501
Heading up committee on putting safety first.

SJS is not rare. We need public awareness of this devastating reaction. I hear from families and patients every day suffering from this nightmare. There is nothing more heartbreaking than to hear a person's cries and anguish over losing a loved one to a medication, or to listen as they suffer blindness, lung damage or many of the other debilitating side-effects from SJS/TEN. They all ask the same question. WHY? Why didn't anyone tell us about this? Why weren't we warned? I don't know the answer to that, but I do know this, together we can get it out in the open. We can get results. One voice alone is not enough. We need your help!

There are over 1000 people on our mailing list. Yet only a handful, 10 at the most join with us in writing. It only take 10 minutes or so of your time. You owe it to yourselves to get the word out. We owe it to the future SJS victims. I am begging you, PLEASE HELP! Please send a written letter by postal mail. Emails are usually disregarded.

So off I went to my orthopedist and explained what happened. One x-ray later confirmed my diagnosis and I thought I would have my knee scoped again over the Christmas holidays. My doctor decided instead to give me a non-steroidal anti-inflammatory drug to see if that would relieve my symptoms and avoid another surgery. I started taking the medication.

Two weeks later on Christmas day, I started to feel like I was getting the flu. Three days later after several visits to doctors and emergency rooms, I was seriously ill, breaking out in a rash and then blisters all over my body. My husband took me to the emergency room at our local hospital. I did not know what was wrong however, I knew it was serious. It was really frightening when I became aware the doctors didn't know what was wrong either. I was having trouble swallowing and was in pain. Finally, a dermatologist looked at me and said that I had Steven Johnson Syndrome.

I was rushed to Parkland Hospital in Dallas where a team of burn specialists were waiting for me. I had been put on morphine in the ambulance because the pain had become so intense. The emergency room doctor told my husband that I might not make it through the night. The last thing I remembered was telling my husband to call my good friend in Chicago. She was a nurse and I knew she would come and take care of my kids and him.

I was admitted to the intensive care burn unit at Dallas Parkland Memorial Hospital where the doctors and nurses tried everything they could to save my life. I had 11 operations and almost died several times. My husband had the doctor in charge of my case call a specialist in colon surgery. My abdominal cavity had become infected. I made it through that surgery and at that point, everyone thought I was going to be ok.

But it didn't turn out that way. Over a hundred blood transfusions helped me along, and a respirator helped me breath when I developed pneumonia. The drugs they gave me were narcotics that caused

January is SJS Senator Awareness Campaign. Your same letter to Senator Grassley's Committee can be sent to your local senator. The more we hit our public officials with the reality of SJS the better our chance to get new safety labeling. To access your Senators address please go to: [[Click here](#)]

If you are not in the United States, please do not feel left out. Write your story to Senator Grassley as well. SJS is a worldwide issue. Hundreds of people from other countries have contacted us, saying doctors don't know about this syndrome over here. I beg to differ, they most certainly do. They, just like here in the states, sweep it under the carpet. We hear from the United Kingdom at least twice a week. India has a huge amount of SJS. The Netherlands and Japan have their own support groups. Why? Stevens Johnson Syndrome is not rare. Let us shout it from the Himalayas to the Rocky Mountains, from the Empire State Building to the Eiffel Tower. We are here and we will be heard. We will not be silenced! Together we are one voice that will not go away.

Let us make 2005 the year that SJS becomes public knowledge!

With warmest regards,
Jean Farrell McCawley

!! New !! **Comforting Kids**

In the past few months we have sent out numerous bears and blankets to our little SJS victims. For a \$30.00 donation you can sponsor a Bear & Blanket to comfort an SJS child. Your donation is tax deductible and very much appreciated.

Please make checks payable to **SJS Foundation**
enter: **SJS Kids Comfort** in the memo section of your check.



Kids Meeting Kids!

me to have horrible hallucinations, which I cannot even begin to describe. They were so vivid and traumatic that I remember most of them today. One of my doctors prescribed a medication to stop the hallucinations and I had a reaction to that drug as well and wound up back in intensive care almost dying again. All the while, my blood pressure was pole vaulting over my bed, my hair was falling out and my skin was coming off my body. I must have looked like the Borgue Queen.

Throughout it all, my family rallied the wagons. My husband was there every day encouraging me to fight. He literally drug me through the agony and pain and pleaded with me not to give up. My daughter dropped out of college and came home to help take care of me. She knew her dad was going to need some moral support and she just couldn't stay in Austin while all hell was breaking loose in Dallas. My middle son came to see me and became so upset the nurses had to take him out of my room to calm him down. He persevered in college even though he was worried that I might die. My youngest child was left to fend for himself. He fixed his own breakfast and came home to an empty house. But when his sister came home, he was able to cope a little better. My brother came to see me from Virginia and spent time with the boys. His children and wife came as well. The upheaval that my illness caused my family still bothers me to this day

My school chipped in with food; they cleaned my house; mowed the yard, took the kids out to lunch and, of course, came to the waiting room to sit with my husband. They were allowed to see me when I was lucid. I was in the intensive care burn unit for five months and then on the rehab floor for two. Every day one of my friends from school came to see me. My good friend, Vicky, even slept in my room one night.

Eventually my husband told me I had lost my left eye and the function of my tear ducts. I had so much trouble with my eyesight I thought I would never have a normal life again. I lost my colon and spleen and probably several other things I don't know about. I had to learn how to swallow again which was extremely

Through the Stevens Johnson Syndrome Foundation we heard about Tiffany, a girl the same age as our daughter Mari, who also suffered from SJS. Incredibly enough she also lives in South Florida, about 15 minutes from where we live. After a few phone conversations, both sets of parents decided the girls needed to meet. Mari was very excited and wanted to buy something for Tiffany and I guess Tiffany was also on the same page because when she arrived at our house she had a gift for Mari. They played for a little while, but Mari wasn't feeling all that great and she fell asleep but woke up in time to see Tiffany off. The next time they saw each other was at Dr. Tseng's office (eye specialist) on Oct 6th, and they hugged each other like they had been best friends since the day they were born. They exchanged stickers and it was very hard to get them to say goodbye to each other. Mari is very happy to have met Tiffany and viceversa. As you can see from the picture theirs has been a match made in heaven!



SJS Candle Fundraiser



A very special thank you to those who participated in the Candle Fundraiser. The fundraiser ended on November 15, And we are happy to say that 228 candles were sold. We appreciate your help and dedication.

Volunteers:

Bill Sarosky
Maralee Billota
Janey Links
Amit Khatri
Surendra Khatri
Tushar Khatri

swallow again which was extremely frustrating and difficult. The rehabilitation was absolutely the most excruciating experience in my life. I would come back to my room in tears. But my therapists would not let me give up. I finally stood up one day with three therapists holding me. It was the most physically demanding thing I had ever done. Having been a kinesiology major and a coach I knew how important the rehab was so I tried as hard as I could. Deep down, though, I didn't think I would ever walk again.

My rehab doctor was great, my therapists were great, my surgeon was amazing -- she came in my room one night and scratched my back for fifteen minutes because I had broken out in another rash. My eye doctors came to see me every day. They were worried that I might develop an infection in my right eye. They worked really hard to keep that from happening. The nurses who took care of me and consoled my family are angels on this earth: I just can't see their wings. But I did memorize their voices and knew which one was in my room. They took turns putting up with me.

I can remember just laying in bed day after day with tubes everywhere, and needles and blood tests, a central line, and shots, shots, shots.. Waking up in the middle of the night and thinking it was during the day was very distressing. The more I began to be weaned off the narcotics, the more I realized what I had been through. I started worrying about my husband and children. My anxiety level went up along with my irritability. They sent a psychiatrist in to see me daily because I was developing a depression. But all the hard work of my doctors, family and the support from my school motivated me to keep trying.

Finally, the respirator was removed, the feeding tube was removed, the central line and IV's were removed, the foley was gone and I started to understand just what a horrible illness Stephen Johnson Syndrome is. The day came when I finally went home. I stopped by my school on the way and everyone came out to see me although I could not walk so I stayed in the car. Things were not great at home. My husband was afraid he wasn't going to be

June Eggleston
Dan McCawley

October Safety Month at Walmart



Thank you to Cyndee Callaway at the Westminster Colorado Walmart store for inviting us to participate during Walmart Health and Safety month. Our wonderful volunteers spent October 2nd and 3rd passing out SJS Fact Sheets to over 1000 people.

Volunteers:

Amit Khatri
Jeanne Eggleston
Lindsay Callaway
Racheal Callaway
Julie McCawley
Dan McCawley

In Loving Memory of Leroy Calvert



It is with great sadness that we announce the loss of Leroy Calvert. As you may remember from our last newsletter, Roy was suffering with bladder and liver cancer. He lost his battle very quickly. He passed away at home on October 22. He was 81 years old. Roy was a member of the SJS

Foundation Board of Directors

He strived to get the word out about SJS. His dedication to our cause was exceptional. He was a retired employee of the Long Island Rail Road. Roy leaves behind his loving wife Kay and daughter Pam and grandchildren and great grandchildren. He was preceded in death by his son, Robby.

Our prayers and condolences are with his family. He will be sadly missed.

able to take care of me. I missed my job; I was still in rehab and came home crying every day. I had neuropathy in my legs and feet and that is very painful. I still have it to a degree, but not as bad as it was. I hated being a burden to my husband, he was so kind and patient and always up. He never let me see him down although I know that at times he was frantic.

Looking back on it now - five years later, I am still angry at times for all the days I spent away from my family and for having them go through the insanity of it all. Losing my job was a very difficult and sad experience. But I found a wonderful doctor in Boston who fitted my right eye with a sclera lens which totally changed my life. I read constantly now. I am coaching field hockey again and even officiated a game last week which goes to prove the saying true that referees are really half blind!

I saw both my children graduate from college and the "baby" graduate from high school. All my children are doing well in spite of their mother. My daughter graduated from law school and in January she gave me my first grandchild (whom I plan to spoil rotten). My middle son is an artist and his paintings are a joy to see. My youngest is starting college and has finally let me back in his life. For so long he was afraid to believe that I was going to be all right.

Although there were days; both in the hospital and when I returned home I thought I would have been better off dying, I am very glad to still be here. So those of you who have those blue days when the "bad guys" come out to get you, just shoo them away. Life is precious and we need to seize every moment and try to find happiness, although at times, I have found that difficult to do. I have a psychiatrist still and go to see her often. She is another one of those angels in my life whose wings I cannot see. And she gets after me when I start feeling crummy. Sometimes she makes me really mad, but I know the advice she is giving me is right. Somehow she has located my brain and has figured out how it works (or not).

Steven Johnson threw a big curve ball in

my life. I will never understand why something like that has to hurt so many people. When you almost lose your life and everyone you love, it changes your perspective on so many things. I know I will never be the same.

I have learned how important my family is and how much I cherish them. I have learned who my friends are. One of my neighbors came to see me at home every day. She brought me flowers and read to me. I have learned the incredible sacrifices that doctors and nurses make to help the sick. I have so much respect for them and sometimes I feel like they are my best friends. I have learned the meaning of "in sickness and in health." . I have learned that somewhere out there is a force that sees us through the worst of times. I have learned to love and appreciate those who pass through my life and am grateful to them for believing in me.



!! New !! SJS NewsLetter ON LINE

As most of you are aware the **SJS** Foundation is a non profit organization. We depend on grants and donations to survive. Due to a lack of funding, we have been forced to make some changes. While **SJS** cases are on the rise, the stigma **RARE** is still associated with it. Newly diagnosed patients and their families are in dire need of SJS information packets. Unfortunately a decision had to be made to distribute the newsletter that was more cost effective. This will help us to continue to provide information packets to those in need. Thank you for your understanding and continued support.

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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