Stevens Johnson Syndrome Foundation

Newsletter
September 17, 2004

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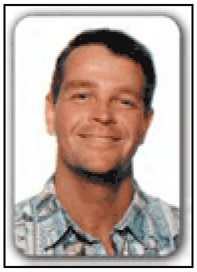
Our Prayers To:

SJS Foundation **B**oard of **D**irector **L**eroy **C**alvert, from Glenhead, Long Island, diagnosed with bladder and liver cancer. Our love and support are with him and his family at this difficult time.

Dr. **S**tephen **B**yrnes suffered a stroke on June 10, 2004, and passed away on Thursday, June 17th, 2004. Dr. Brynes authored the article "**F**atal **R**eaction, the **H**orror of **S**tevens **J**ohnson **S**yndrome." He was the first person to have an article published about the **SJS F**oundation. We will greatly miss him. Our thoughts and prayers go out to his family.



My SJS Experience, by Don Smith

October 13, 2003, I underwent a tonsillectomy and biopsies in other areas on the left side of my throat, due to a lump that was found by my primary care physician. It was diagnosed as cancer and surgery was performed to remove the infected lymph nodes and some muscle on the left side of my neck, on October 27. On December 8, I started radiation treatments on my throat.

On January 21, I went for my thirtieth of thirty-three radiation treatments, but the doctor told me that I needed to check into the hospital, instead. She took me to the Emergency Room, to be admitted and they took vital signs. Suddenly, I was put on oxygen and told that I had to be sent to another local hospital, because they weren't equipped to handle my needs.

On the fifteen minute ambulance ride, I tried to get the paramedic to have the driver turn on the lights and siren, to make the ride more exciting, but she wouldn't do it. At the same time, my girlfriend, Heather, and my primary care doctor were being

Miracles Do Happen, by, Katie Pennell

May 1995, I had been suffering from Interstitial Cystitis and reoccurring yeast infections. I went to my urologist to see about the IC. I happened to mention to him that I thought the yeast infections were making the IC worse. He told me that we would take care of the yeast first and then tackle the IC. He put me on a 28 day---100mg a day dose of Diflucan. Diflucan is a by-mouth yeast infection drug. (Come to find out later, I should have been given 1 - 150 mg. pill!) I took Diflucan, 15 pills, over 18 days. Below is the account of what happened next.

This summer was the “summer lost.” On Saturday, June 10, I attended one of my daughter’s softball games. I got a little sunburn. I decided to color my hair that evening. On Monday, June 12, I woke up with my eyes crusted shut and blisters on my sun burnt neck and on my right arm. I went to (my allergist). He took me off Diflucan, a medication I had been taking for a yeast infection. On Tuesday, June 13, I woke up with my mouth covered in blisters. I felt it would go into my throat, so my called and told that I probably wouldn't live through the night.

I recall being taken into my room and IV's started. The next thing I was aware of was that, when I woke up, I was very weak and I was taken for a bath and dressing change. For the next couple of days, I wondered why everyone kept saying, "You look great," whenever they saw me. There was a mirror in the room and I saw some of the damage that had been done to my skin from my face to my legs, by Steven-Johnson Syndrome. I didn't look great, at all.. When one of the doctors mentioned how much better I looked than when he had seen me nine days before. I remind him that I'd only been there less than a week.. When I mentioned this to Heather, she told me that this was my second week in the hospital. Even now, I have no memory of the first week, whatsoever. The nurses said it was due to some of the medications I'd been given, during the first week.

I was in the hospital for fifteen days and was discharged only because Heather, who lives over three hundred miles away. had arranged to stay in Grand Rapids to take care of me, for the first two weeks. Arrangements had been made to have the food for my feeding tube, the pump and other supplies delivered the evening that I came home. The nurse instructed Heather in handling all of that because I wasn't alert enough to follow her instructions...or to do it, at that time. Heather took very good care of me during the time she was here and made sure I understood how to handle everything before she left. I didn't realize how much help she'd actually been, until I had to do everything for myself. It wasn't until that two weeks that Heather was with me, that I understood everything I'd gone through. She told me of the phone call from the doctor, and how she'd called the Burn Center before I even arrived. I was most impressed with their treatment of Heather because she had called every hour on the hour, during that first night and day and they, in her words, were, "Wonderful with me."

After the first couple of hours, they told her that there was no reason for her to rush over, so she could take care of obligations at home, before coming to Michigan. Whenever she called, if they hadn't seen me recently, they'd check on me, and let her know how I was doing. They even gave the 800 number, to the desk, so that she didn't have to pay long distance charges. When I went back for a follow up appointment, I was greeted warmly by all of the staff who saw me come in. Those who hadn't seen me arrive, dropped by the examination room to

husband took me to the ER at our local hospital. I was given two shots and sent home. On Wednesday, June 14, I was no better and continuing to get worse. Mom took me to (the allergist) again. He gave me several things and Nizoral. Nizoral is in the same family as Diflucan. By Saturday night I was miserable. The blisters were so hot that some on my back even burst. I called (the allergist.) Took him away from a concert. (He was not happy!) Told to stop taking Nizoral-given more prendisone on Sunday. Monday morning, I was about 50% covered in blisters on my legs, arms, and back. These blisters were sizes from a dime to a dollar and filled with fluid. I actually sloshed when I walked. Went to see (allergist) on Monday, June 19th. Cried. He said I should see an infectious disease doctor. He asked me what he could do for me. I lost it. Please put me in the hospital. I went in around 4 p.m. We called my sister and told her what was happening. She took the first flight out of Greenville/Spartanburg and arrived around 8 p.m. No orders given. Tried IV six times. ER doctor got one in my left arm. Had to have an arm board to keep it still. 11 p.m., still no orders. Nurse calls new doctors answering service. The doctor on call gives orders. By Tuesday, June 20, I was 75-80% covered in blisters. They were on my arms, legs, feet, hands, neck, back, hair, face, mouth, and private areas. Because I was very dehydrated and required antibiotics, morphine and other medications, a wonderful doctor put in a central line. What a neat person. Very caring. I was later told that if I had waited one more day to enter the hospital, I would have been dead. The central line was easier to deal with. I have vague memories of the first week. I remember that my feet swelled so bad that I could not walk. They put a portable toilet next to me so I wouldn't have to go far to go to the bathroom. My day looked something like this: Wake up, after being awakened several times during the night to be checked, get a warm washcloth from my sister or my husband. Use one warm washcloth to open my crusted eyes. Even with my eyes open, my vision was so blurry that I couldn't see well. We tried eye drops, but they only helped a little bit. Get another warm washcloth and use it to open my crusted mouth. Try to eat something. Finally I convinced them that I really couldn't eat. They put another bottle of stuff on my IV pole and told me it was food. At least I didn't have to try to eat anymore! I was to have twice-daily whirlpools. They hurt so badly. After I returned to my room, from the whirlpool, my husband, sister, and or the nurses would slather Aquaphor on my skin and wrap me in gauze bandages. I looked something like a real life mummy. My skin was debrided, blisters removed, once a day by a dermatologist. He told me one see how I was doing and to say, "Hello." It was the same extra caring and concern that I'd received as a patient, in their care.

Realizing that they had literally brought me from Death's Door, to recovering as well as I had been, I wanted to show my gratitude in a way that acknowledged them forever. On March 29, I dedicated one of my favorite paintings, "Incongruity," to the Burn Center staff who had treated me.

The dedication statement reads: "This painting is dedicated to the wonderful staff of the Spectrum Health Regional Burn Center in appreciation for the highly professional care that Mr. Smith received during two weeks in January and February of 2004. â€œEven after discharge, during follow up visits, their care and concern were still evident. They are truly exceptional,â€• said Mr. Smith." The dedication, on March 29, was one of the most meaningful events of my life. None of the staff knew that I'm an artist and that was brought up to me, very pointedly, by a couple of them. A printout of the painting had been posted on the bulletin board and the colors were way off, besides being too dark. They were very happy with the actual painting. A room is being remodeled, as a Burn Center pediatric waiting room and the painting will hang there. I was told that the interior designers had been stumped as to what colors to use and were very excited about the colors in the painting. Perhaps that will be the color scheme of the room. The painting will fit, perfectly, I was told, because it will appeal to children and adults, alike. I'd expected everyone to rush back to work, immediately after the presentation of the painting but there were cakes and coffee, afterward. Again, they were showing that flair for giving extra caring attention, when it wasn't required. We spent some time, chatting and snacking, although I couldn't have any, because I'm still on a feeding tube. There are some in the freezer, to enjoy when I can eat normally. When I left, it was a very satisfying feeling, knowing that the people who probably saved my life, will never forget me, either

SJS Awareness Month

night that I had an amazing faith considering what I was going through. I hated what he was doing to me, but I looked forward to seeing him. He was a very kind, gentleman. After the debriding, I would be slathered again and bandaged. I was treated very much like a burn victim. (They talked about moving me to a burns unit in Cincinnati, but the doctors and my sister felt it was too risky.) The biggest fear was that some of the open skin would become infected. They tested my open areas often to make sure I wasn't developing any infections. I did develop a few, but they either upped my antibiotics or put bacetracin on them. I was evidently suffering from sleep deprivation. Finally given something to help me sleep. The whirlpools were still awful! So much pain. The doctors tried to find a pain medication that would make my whirlpools feel better. They tried Ativan. I thought I was being chased by my IV pole. They tried Demerol and I thought I was a cartoon character and I hallucinated that buildings outside of my room were jumping around. They tried Haldol. That one was the worst. I got down to the whirlpool and my jaw started locking shut. I told my sister I was having trouble breathing. She told the PT people to call upstairs and tell them to call my doctor immediately to reverse the effects of the drug. Months later she told me that she thought I was going to die right there! Thank goodness for Morphine. As a last resort they tried morphine. It worked and gave me few side effects. Although I did tell my sister that I saw her running a marathon in her underwear. I also told my husband to watch out for the car; all the while he was sitting on my bed. During this time, visits from my daughters were bad. They had to wear gloves and a mask. I was in a room that allowed me to breathe only my own air. It was an isolation room. My youngest cried and told me that I wasn't her mother. My oldest didn't know what to do. On Monday the 26th I evidently flipped out. I remember seeing my husband in a red and white shirt, on top of me. He held me down for 3 hours, 11 p.m.-2 a.m. Months later, I asked him what I was so flipped out over. He said that I called him the devil and that I was fighting the devil. I slept through the 27th-my oldest’s birthday. By Wednesday morning I was alive again. My doctor gave me a stern talking to. He basically told me to get my act together and start healing. I was terrified to go to the whirlpool. (Terrified doesn't even do the idea justice. I was scared out of my mind at the mere thought of going to the whirlpool again.) The chaplain layperson came in and prayed with me. Then a priest my family knew came in. He and the layperson prayed over me to give me strength. I made it through the whirlpool and things started turning around. From that point on, I continued to get better. My sister, bless her heart, dropped

SJS Awareness Month

Once again the **SJS F**oundation participated in the Westminster Fair, located in Westminster, Colorado. Our Awareness booth was a huge success. The Government Proclamations were displayed as well as SJS photos and information on 3 display boards. We distributed over 500 SJS Fact sheets from 10 AM until 5:00PM. It was a long day but well worth the time. SJS survivors Amit Khatri, Penn Street and Julie McCawley volunteered their time to help pass out information. One woman knew a little girl in California that is a member of our support group. Many people stopped and asked questions and thanked us for being there. Special thanks to the volunteers that helped to man the booth. We couldn't have done it without you!
To see the slide show of Volunteers in Westminster Fair 2004 [Click here]

Fundraiser for the SJS Foundation
!! New !!

We need your help! The **SJS F**oundation has been offered a great fundraising deal through Home and Garden Party. We will be selling 10 oz. jar candles.

<u>If the customer buys:</u>

1 candle....the price is $8.00

2 candles....the price is $7.00 each

3 or more candles....the price is $6.00 each

These 10 oz. jar candles have a 50-hour burn time. They are fully wicked and scented from top to bottom and provide a nice, even surface burn, not to mention a wonderful fragrance! There are a total of 18 fragrances available, and they make wonderful gifts!

Please contact us by email at sjsupport@aol.com If you would like to participate. We will then send you Pamphlets and order forms and SJS Fact sheets.

everything and flew up on June 19th to be with me. Through her efforts, I feel she saved my life. My best friend came to see me almost every other day. She took care of the girls several times. She gave my oldest daughter a birthday breakfast and cake. My husband - What a trooper! He did things for me I know no other husband could have done! I am so lucky and so blessed. He was there constantly. He was caring for the girls, caring for the house, and visiting me. During all this, he was interviewing for Principalships. He got his job with Milford, all the while spending the night in the hospital. I came home on July 5th. I was a little scared of what life held in store for me at home. I tired so easy. Just walking to the kitchen was a chore. Eating was still not fun. Thank goodness for Jamocha shakes. I worked hard to get my stamina back, but it was hard. I wasn't able to go to Orff II or be in the Summer Band. I had to rest a lot. By August I was feeling some better. My skin had finished peeling by then. My sister and her family came for a visit. She told me many things I didn't remember. Funny things I had said when I was out to lunch. Her husband took pictures to document my scars.

I remember one night during the first week I was in the hospital. I saw my sister crying. I thought she was upset because she missed her son. She said no, she was crying because she was afraid. She didn't want to say it, but she was afraid that she wouldn't be able to do enough to save me. Years before she had been a mobile nurse with Humana Hospital in Louisville. They had sent her to a burns unit outside of Atlanta for six weeks. She hated every moment of it. The pain. Little did she know that because of that experience she was able to communicate that knowledge to the nurses and my husband at the hospital. This knowledge saved my life! Oh, He works in mysterious ways.

I continued to go to my dermatologist long after I got out of the hospital. He checked me twice weekly and then once weekly basis for quite a while. Close to the last visit he asked me if I fully realized what I had been through. I of course said yes. He then told me that I was more than a little lucky; I should be pushing up daisies. The two conditions I developed can be fatal. Stevens-Johnson's Syndrome and Toxic Epidermal Necrolysis are very serious reactions to drugs. TEN has a high rate of mortality. Sometimes as high as 90%, according to the research I have done. Patients with TEN also have a 90% chance of severe eye damage as a result of the condition. I have the same prescription as I did before this all happened.

Yes, I still have scars, dry eyes and nails that look

This is a great way to raise funds and awareness into SJS. We appreciate your help in this worthwhile cause.

Special Thank You from **SJS F**oundation.

Giving a kid a hug!

Thanks to Christopher Simpson and the Knights of York for their generous donation to the Give a Kid a Hug Fund. Thanks to their generosity we have been able to purchase SJS Teddy Bears to send to our littlest SJS victims. These 20 inch bears are made of soft material and are very huggable. Each bear wears an SJS T-shirt with the light house logo on the front and we also send a handmade fleece blanket for them to wrap themselves in for a hug from the **SJS F**oundation.

funny, but I am here enjoying my life. How lucky and blessed I am.

!! New !! SJS NewsLetter ON LINE

As most of you are aware the **SJS F**oundation 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. **T**hank 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 **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.