



Stevens Johnson Syndrome Foundation

Newsletter
December, 2005

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Out of the mouths of babes!

The Stevens Johnson Syndrome Foundation wishes you and your family a Happy Holiday Season! This newsletter is dedicated to SJS Children around the world. Our children are the future. They give us hope, wisdom and understanding. We hope that you will enjoy:

Out of the mouths of babes!

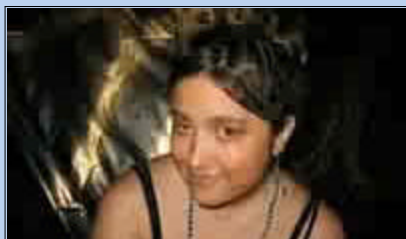


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MY SJS EXPERIENCE

by, Lindsay Estacio



Congratulations to new Mom

Danielle Gallo

Danielle Gallo has suffered with SJS and ongoing EM outbreaks for several years. She was on complete bed rest for the last 4 months of her pregnancy and on November 15th gave birth to a beautiful healthy baby boy weighing 7lbs 1oz and 19 inches long.

Welcome to the world little James Nicholas Gallo



SJS EXPERIENCE: At just 14 I was diagnosed with SJS. It started out with swollen lymph nodes, headache, and a fever. Two days after this occurred I woke up one morning with puffy, swollen eyes, blisters in my mouth, red bumps which started out on my stomach, then rapidly spread to my hands, legs and all other parts of my body. I was rushed to the Emergency room. From there, I was put on steroids which doctors hoped would've reversed the effect and make it stop. This was not the case. I was then transferred to another hospital where pediatrics were accepted to be watched for a few days. By this time my body started developing enormous blisters on all parts of my body. My skin was sloughing off. I was then transferred to yet another hospital. Hershey Med. Center, Hershey, Pennsylvania. By this time my body started burning up right in front of the Doctor's eyes. I was surrounded by at least 4 specialists. My body was at least 70% burns by that time. As time was running short, I was flown in the Life Lion helicopter to Crozer Chester burn center in Philadelphia, PA. The skin on my lungs was also sloughing off and closing my airway. I was put on a ventilator for 4 weeks. I was unable to see, talk, eat, or walk for 5 weeks. I was given 8 mg of morphine and ativan per hour for my 6 week stay at the burn center. Overall, my body was 95% burned.

After leaving the burn center, I couldn't return to school for my 9th grade year. I was too ill to go. I went to Physical and Occupational therapy to regain my strength. Some of my sweat glands were scarred closed, leaving me unable to exercise or sweat for at least a year. I am very sensitive to extreme hot and cold temperatures. I have minimal scarring on my chest and arms. I've lost all my fingernails and toenails, but one. My nail beds were scarred. The main problem I have today are my eyes. I don't produce any tears out of my right eye. I have to use refresh plus eye drops everyday. I have severe dry eye syndrome, and photophobia. I sometimes have lashes that grow in towards my eye, scratching the surface, and accounting for numerous visits to eye doctors at least several times a month. MY eyes are continually red, swollen, dry, and sore. I am currently investigating the Scleral lens. It seems to be my last hope. I am back to school now and in my senior year of high school.

SJS CHANGED MY LIFE: I would most definitely say that SJS changed my life. Because of my experience I have become so much stronger as a

3rd

My Story,

By, Arianna Crayton



I got sick when I was three and a half years old. I wonder what it would like to run around and when I see my brothers and sister jump on the trampoline I feel bad for myself. Have you had this before? At school I play with friends sometimes they ask me to run. I always wanted to be a cheerleader and a baseball player and a cook but I was always shaking a lot. When I go to sleep I sometime get sick at night it really hard on me. It hard when I stay up in school because I don't have enough rest. I had a lot of surgeries because I was 99% blind and the doctors told my parents that I would not be able to see again. But they kept praying that I could get better, and I did. God told me that he'll keep me safe and He did. Now I love God and people. I made it through SJS. I know I keep my mom up at nights when I get sick, and she has to go to school or work in the morning, she never complains, only when I bother her she would say I should call my dad the next time I get sick. I stayed a lot in the hospital, and my dad and brother and sister and my mom is always there with me so I feel a good when they are there. When we go out people always stare at me and me why am I crying, I always tell them I'm not I have allergies or I'm sick and I'm not crying, I have to carry oxygen with me where I go. One thing I do not like is the fact that I have to take a lot of medications everyday and sometimes I don't take them. I have osteoporosis that means my bones can break easily so I have to be so careful not to jump or play too rough because I can break a bone. I like when I go to the airport cause me and my mom get to pass all the people in the line and be the first to get on the plane, then I feel important. Now I am 10 years old and on the lung transplant

person. Although it sounds so cliché....its really true. "What doesn't kill you, will only make you stronger." And that it has. I have come to see people's inner beauty. I used to be so focused on peoples outward appearances that I never got a chance to know them. I have also become so much more appreciate of my life in general and how blessed I am to even be alive. And to all the things I have in my life. I am extremely grateful and after almost having your life taken away I've realized how important it is to live everyday as if it's your last. I think I've become more mature and wise and I've learned things in life that most people don't learn until their 30's 40's or if ever. I feel like I appreciate every little thing more. I do things now for the goodness of others, not myself. If there was a way for this not to happen to another person, I would definitely do it.

FUTURE GOALS: I have my heart set on being an adolescent psychologist, and/or helping those who suffer from SJS and diseases like it, which change the outward appearance. I really feel like I'd be able to empathize with them, and truly know EXACTLY what they're going through. I'd be able to help them from my heart, not from a psychology textbook. I feel like there is no better feeling then knowing you made a difference for the better in someone's life.

Lily!

As told by her mother Tami



Lily! As told by her mother Tami.

Our world changed on September 17 this year. Having 2 FASD/Bipolar adopted children we are used to the chaos and the surprises we get every day. It is a constant battle for "normalcy" and good behaviors. A day without some twist and turn is almost unheard of here.

Lily woke up with scratchy eyes Saturday, by that afternoon her eyes were swollen and oozing. The worst pink eye I had ever seen. Sunday morning she crawled in bed with us and said "she fell" and

list, and I have to go to California every 3 months to see Dr woo and the other doctors who are doing my transplant. I also get the see Dr. Milligan for my ears, and Dr Oneil and Dr Heinz for my eyes and Dr Woodward for my lung and Dr. Redleaf all the time. I still have a lot of problems but when I get my transplant I can do everything including running for field day. I am very talented I like to sing and write and read. it is hard for a kid to be as sick as I am but, there are some who are worst than me. I love my Daddy.

Love Ari

Help the SJS Foundation!

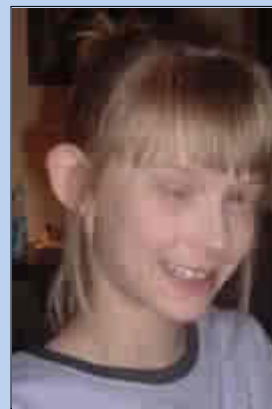
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What if ...up to 30% of each purchase you made went to Stevens Johnson Syndrome? Your shopping at hundreds of online stores helps a cause close to your heart with each purchase! It's all free & private. Join today and change online shopping for good.

Surviving SJS

By, Julie McCawley



My name is Julie McCawley, I'm 12 years old. I had Stevens Johnson Syndrome when I was 11 months old. I don't really remember having SJS. I do remember all the things I have been through since. I've had lots of doctors appointments for my eyes and ears. I hate the ear appointments the most they hurt really bad. I have had a lot of eye surgeries too. I know that SJS has changed my life. I had two great big blue eyes one wasn't even foggy looking at all. I know because I have seen pictures of

her lip hurt. Her lips and inside of her mouth had swelled at least 3 X larger. She was miserable. For a child with an abnormally high pain threshold, she told her daddy "I don't feel well". ER visit by 8 am that day, he sent us home with conjunctivitis and stomatitis diagnosis and instructions to return if decrease fluids etc. etc. The following 20 hours were a blur as she developed a fever and the funniest little red rash on her face. She also quit drinking around 8 PM. Monday am, 48 hours from first symptom we were at our Pediatricians. Two hours later she was fighting and screaming as they started IV's, X-rays and Respiratory treatments.

On Wednesday she was transferred to the children's hospital here in town and her "official" diagnosis of Stevens Johnson Syndrome was given. The deciding cause of SJS was Lamictal. Our 7 year old Lily had been taking this medication for almost 12 weeks for her seizure disorder and as a mood stabilizer for her Early Onset Pediatric Bipolar Disorder.

Her treatment consisted of IVIG (3 treatments), PICC line to administer her TPN and medications, wound treatments (which were a joke as she wouldn't leave a bandage on for more than 5 minutes), catheter as she was so inflamed in the genital area and unable to urinate, at least 200 wash clothes and 50 sheet changes a day due to all of the open wounds plus the ones she used to keep her mouth empty...

The IVIG treatments stopped/slowed the progression of the lesions to about upper mid thigh area but she is losing her finger nails now and the bottom of her feet have peeled twice. She came home at 3 1/2 weeks but was admitted again 3 days later because she quit drinking again and was sent home with another PICC line and TPN at home. She then developed severe anemia (7.0 HGB) and was admitted again. This time they found a duodenal ulcer and many in her digestive track that were healing.

We never heard of SJS until September 19th. For our beautiful little girl the scars are obvious, the damage to her eyes still unknown and she lives with a constant "itch" to her skin. Two and a half months down this road and we have seen a glimpse of our old Lily. She has even asked about her "spots" and if she is going to "die".

We have worked so hard as the parents of this little Alcohol/Drug Exposed/Developmentally Delayed/Seizure Disorder/Asthmatic/Bipolar little girl whom we adopted at birth. Our biggest

myself before I got sick. I can't see out of my right eye and I have a lot of scarring. The light hurts my eyes so most of the time I wear sunglasses and a hat inside and out. I have to carry eye drops with me all the time and sometimes I forget they are in my pocket and they go through the washing machine. I have had a hard time in school. Last year they tried to make me move to a school for the blind. It was really far away and I cried about that a lot. My Mom had a lot of meetings with the school and the school district and I got to stay where I am. I didn't want to leave my friends and family. I would have had to live at the school and come home on the weekends. It has been hard for me to make friends. Kids have always made fun of me but now I have some friends that stick up for me. Since my Mom runs the SJS Foundation I have been really lucky to meet a lot of people that have SJS. They can relate to me and I can relate to them. I met my first SJS friend when I was 18 months old. Her name is Danica and she was 7 years old. I still know her today. When I was four I went to Boston and met my friend Stephanie from New Jersey. She was 3 and we became really good friends immediately. I also met Joe Zienowicz. I remember he took us to a seafood Restaurant and I had fish sticks and he had lobster. He was really funny and he had a cool car and it had a built in dog cage in the back because he has dogs but I never got to meet them. I have been really lucky to meet a lot of SJS friends. I went to the hospital to see Arianna when she came to Denver for some tests. She was really nice to me and my sister and we like her a lot! If I never had SJS I wouldn't have gone to Boston I wouldn't have met so many people. I guess there are good things about it too. I have learned a lot about it and I have helped give out SJS Fact Sheets and I also walked In the first SJS 5K walk. My grown up friends are Penn Street and Amit Khatri. I have a friend named Joe in Ohio. He emails me and we are pen pals. His uncle passed away from SJS. I can't say I like SJS because it is not a fun thing. I know that lots of people have died from it. I am glad to be here with my family. I know that I almost died and God had a reason for me to be here so I know I am a lucky person. I love my little sister Kerry. She is 5 years old and she has type 1 diabetes. Kerry has had to have shots every day since she was 21 months old. If I could wish anything in this world it would be for my little sister to be cured of diabetes. When I grow up I would like to be a veterinarian. I love dogs and cats. I have 2 dogs Molly and Chloe and 3 cats, Snowball, Simba, and Ali. Every night my sister and I pray for everyone that has had SJS to get better.

Love, Julie

heartbreak has been that she has lost almost all of the skills we taught her. I carry a diaper bag again, daily living skills are a chore and the regression of her social skills is devastating.

Would we have done anything different? We are not sure. Her medical needs called for a good prescription. If I had read the entire Lamictal insert and seen the SJS at the bottom, would it have made a difference? NO. I didn't know what it was. We do now...

I do see Lily becoming more and more aware of life again. Even though she doesn't recognize herself in the mirror she will ask about being sick. She tells me she loves me, and even has reached out to her dad for comfort. She walks around outside, plays with the dogs, and will color every once in awhile. She has come along way, and has a long road ahead.

The pain and terror we saw in face during the first few weeks of SJS is something no parent should live with. All of this caused by a drug. A drug that was supposed to help her cope with life. We will pick up the pieces and she will find her way again.

Thank you for letting us share a small part of Lily's Story.

Tami and Clarence Kent & family....especially Lily

When I had SJS

by, Mariaelena Burgess 8 years old



My name is Mariaelena Berges and I had Stevens Johnson Syndrome. I was really sick when I had Steven Johnson Syndrome. How I had Stevens Johnson syndrome is that I had an ear infection and I took a medicine that I was allergic to but no one knew I was allergic to that medicine. So when I went to the doctors office and when my mom told the doctor about my ear infection they told me that I had to take the medicine again and I shouted don't give me the medicine but while I was shouting the doctor put the medicine in my mouth and I got more sicker and my color started getting red and hard and by that moment my skin fell of and my mom called the ambulance and by the time I got in the ambulance truck I was out and I burned my eye I was really scared because I thought I was going to die. My mom was really scared. I arrived at the hospital all the nurses were really nice to me. My doctor said that in 30 days I would go home. On the 30th day I was happy because I would get to see my family but when I got there I hugged everybody , but when I was going to hug my cousin Ashley she ran away from me and when she ran away from me I felt like a Monster but now I am better and she likes me and I am happy.

SJS Volunteer Support Group Facilitators

The Stevens Johnson Syndrome Foundation would like to thank the following people for volunteering as Support Group Facilitators.

Marla Daniels - Las Vegas, Nevada

Gina Brancado - East Northport, New York

Mary Niemeyer - Austin, Texas

Pam Shields - South Carolina

Edgard Devaux - France

If you would like to volunteer as a Support Group Facilitator, please www.sjsupport.org/sjsupport_group_facilitators.shtml and download the facilitator application and return it by mail to the SJS Foundation. Our goal is to have support groups around the world. No one should go through SJS alone. Your assistance is greatly appreciated.

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