

## Adverse Drug Reactions.

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When I was 11 months old I was diagnosed with Pediatric epilepsy. I was taken to a neurologist that prescribed Phenobarbital to control my seizures. My mother asked the doctor about side effects and he told her the only side effect was drowsiness. Two weeks later my eyes swelled shut and I started running a high fever. My mother rushed me to the pediatrician who told her I had an ear infection, conjunctivitis in both eyes and strep throat. Before we left the doctor's office I started breaking out in a blistering rash and so the doctor then added chicken pox to the long list of diagnosis. She also said because I was running a high fever to give me Tylenol alternating with Children's Motrin and to make sure I did not miss my dose of Phenobarbital as I could have a febrile seizure.

Over the next 12 hours my condition changed drastically and I was now covered from head to toe with blisters that ran together. My mouth and down my throat were also covered in blisters and my mother desperately tried to give me fluids with an eye dropper. She took me to the hospital where they put me in an isolation room to protect other patients from catching the chicken pox. I was also given Phenobarbital in my IV as I was unable to take anything by mouth. After a long day in the emergency room they decided to admit me for a case of severe chicken-pox. I was taken to the third floor where I would stay in a reverse isolation room to prevent spreading it to other patients. Of course I would continue to receive my seizure medication intravenously.

This continued for four more days and I wasn't getting any better. Finally my nurse spoke up to the doctors and said I was having a severe reaction to the Phenobarbital called Stevens-Johnson Syndrome. They called for an infectious disease doctor to examine me and he

agreed saying “Stop the Phenobarbital”. My mother was very relieved saying at last we know what’s wrong with her! This was just the beginning of a nightmare that would affect me for the rest of my life. I spent twenty seven days treated in the burn unit with blisters that covered over eighty percent of my body and on a feeding tube for nutrition. I was debrided daily and on a morphine drip to undergo these traumatic procedures. My eyes were severely damaged and I have since had fourteen eye surgeries due to this horrific drug reaction.

My mother was told we would never hear of another person with Stevens-Johnson Syndrome also known as SJS as it is extremely rare. She researched at medical libraries and checked the side-effects of every drug advertisement she saw in magazines. She then started a nonprofit organization, the Stevens-Johnson Syndrome Foundation to share the information she had compiled with other parents and SJS victims. She started with a small homepage on the internet and within days of launching it emails started pouring in from thousands of other Stevens-Johnson Syndrome patients and their families.

Though statistics say that SJS is rare we have heard from hundreds of thousands of people from around the world. But why do they say SJS is rare? The food and drug administration has an adverse drug reaction reporting system however it is up to the patient to report these post marketing events. Most people have no idea they can do this therefore SJS continues to go under reported and often misdiagnosed.

The pharmaceutical companies now advertise their wonder drugs on television encouraging patients to ask their doctor to prescribe these medications. They give 20 seconds of why a drug is good for you and then speed read a barrage of side effects many life threatening. The one side effect they fail to mention is Stevens-Johnson Syndrome. They refer to it as a rash! This rash can kill you. SJS victims and their families are rarely compensated as the pharmaceutical companies spend hundreds of thousands of dollars on their defense fund. They

are a multibillion dollar industry that will protect their products at all cost and literally bury their mistakes.

Almost anyone can get Stevens-Johnson Syndrome from almost any medication including over the counter ibuprofen products. As consumers don't we have the right to make an informed decision when purchasing a product, especially for our children? Children have no say in the medicines they receive. They rely on their parents to protect them, they in turn trust their doctors to prescribe safe treatments for their children.

The FDA should make reporting of adverse post marketing events mandatory by physicians! Pharmaceutical representatives wine and dine doctors and offer huge perks to prescribe their products to their patients. Doctors rarely warn their patients of adverse drug reactions especially SJS as they are taught that Stevens-Johnson Syndrome is extremely rare, and they will probably never see a case in their entire medical career. When they do see it they typically misdiagnose it because of this. Most SJS patients are turned away from the hospital two or three times before they are properly diagnosed. A quick diagnosis and removal of the offending drug is the key to survival. Proper treatment plans include Intravenous fluids, feeding tube for proper nutrition and Immunoglobulin treatment.

Drug reactions are a very serious issue. I'm not saying we don't need medicine. On the contrary, medicines are very beneficial and needed, however pharmaceutical companies and physicians owe it to the public to provide us accurate information regarding adverse drug reactions and when these reactions do happen they should step up to the plate and offer a compensation fund as their victims lives are forever changed.

Victims of Asbestos reactions that suffer from Mesothelioma are now compensated for their pain and suffering. The tobacco companies are no longer allowed to advertise on TV and

are required to add warnings to the cigarette packages. The Pharmaceutical companies should be held to the same standards. The FDA is supposed to be watching them, but who is watching the FDA? The pharmaceutical companies have them in their back pockets. They also pour millions of dollars into political campaigns. Therefore it's up to us to do our homework and be proactive in our healthcare. Research all medications and learn the signs of adverse reactions. The life you're saving could be your own.

Please watch the below Youtube made by a former pharmaceutical rep! You will find it very interesting:

[http://www.youtube.com/watch?v=AazObF\\_pHSU](http://www.youtube.com/watch?v=AazObF_pHSU)