

Stevens Johnson Syndrome Foundation
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The Honorable Governor Deval Patrick
Massachusetts State House
Office of the Governor
Room 280
Boston, MA 02133

MAR 25 2013

Dear Governor Patrick:

My name is Tara Stepanian and I am a resident of the state of Massachusetts. I am writing to you on behalf of the Stevens Johnson Syndrome Foundation, a nonprofit organization and a partner organization based in Massachusetts, Boston Foundation for Sight.

Stevens Johnson Syndrome (SJS) and TEN (Toxic Epidermal Necrolysis) - another form of SJS - are severe adverse reactions (ADR's) to medication. I am sure most people are aware that heart disease, cancer and diabetes are the three leading causes of premature death in America today and these conditions are almost 100% avoidable.

According to the New England Journal of Medicine, over 2 million Americans fall ill and are hospitalized every year from taking these recommended drugs. And of the 2 million that are admitted, over 140,000 are never released, they die. That's equivalent to crashing a fully loaded 747 aircraft every day.

SJS is one of the most debilitating ADR's recognized. It was first discovered in 1922 by 2 pediatricians A. M. Stevens and S.C. Johnson after diagnosing a child with severe ocular and oral involvement to a drug reaction.

Almost any medication including over the counter drugs, such as ibuprofen, can cause SJS. Most commonly implicated drugs are anti-convulsants, antibiotics (such as sulfa, penicillin and cephalosporin) and anti-inflammatory medications.

Although SJS affects people of all ages, a large amount of its victims are children. There have been numerous cases reported due to the use of Children's Ibuprofen products. Many of these children have been left blind and several have died. Unsuspecting parents are not warned of the danger from these seemingly safe products readily available to us in our local grocery store. One of the first signs of SJS is a high fever. Parents then administer more of these products desperately trying to reduce their child's fever unknowingly giving them more of offending drug. More female cases of Stevens Johnson Syndrome have been reported than male. However it does not discriminate against anyone. The SJS Foundation hears from people around the world who from SJS and TEN. On average, three cases are reported to the foundation every day.

Recognizing the early symptoms of SJS and prompt medical attention are the most invaluable tools in minimizing of the possible long-term effects SJS may have on its victims.

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Our biggest problem is in public awareness. The pharmaceutical companies and the medical communities are under the impression that incidences of SJS/TEN are rare, but this is not the case. Numerous cases are misdiagnosed as chicken pox, measles, scarlet fever or flu. Many cases are never reported.

We recognize that the use of prescribed and over the counter medications are necessary and beneficial to our wellbeing and help many people, but to because each person's body chemistry is different, what may be beneficial to one may be fatal to another.

The only way to combat this devastating problem is through public awareness. The pharmaceutical companies, FDA, AMA and the media can and should take the responsibility to educate the public and the medical community, the doctors, hospitals and nurses.

SJS and TEN are life threatening. If left untreated they can result in death. Complications can include permanent blindness, dry eye syndrome, photophobia, lung damage, chronic obstructive pulmonary disease (COPD), asthma, permanent loss of nail beds, scarring of the esophagus, and other mucous membranes, arthritis, and chronic fatiguesyndrome. Many patients' pores scar shut, causing them to retain heat. These are some of the side effects that have been reported.

The SJS Foundation has been existence since 1995 after Jean Farrell McCawley's daughter, Julie, suffered SJS at 11 months old from Phenobarbital.

On a personal note, I work at a nonprofit eye healthcare organization in Needham, MA – Boston Foundation for Sight – who is on the front line of the battle. We treat patients suffering with SJS, help them regain their sight and reclaim their lives. In 2010, pediatric survivors of SJS and their families were brought together for the first time for the only event of its kind, SJS Kids Week. Since 2010, it has been held annually at the end of July/beginning of August and is dedicated to the treatment of complex corneal disease and the emotional support of pediatric SJS patients and their families. We have had the honor and privilege of working with Jean McCawley to help raise awareness and have treated her daughter in our clinic.

Information on SJS Kids Week can be found on our website: bostonsight.org/News/SJS-Kids-Week.

I am writing to ask you as Governor to issue a proclamation declaring the month of August 2012 "Stevens Johnson Syndrome Awareness Month".

Respectfully yours,



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