

Finally a solution!

The Stevens Johnson Syndrome Foundation (The Julie Foundation For Allergic Drug Reactions) a non-profit organization based in Westminster Colorado, was founded in 1994 by Jean Farrell McCawley after her 11 month old daughter Julie contracted SJS from the anti - seizure drug Phenobarbital .

The primary function of the foundation is to bring public awareness to this devastating and life threatening illness.

Stevens Johnson Syndrome (SJS) and TENS (Toxic Epidermal Necrolysis Syndrome) - another form of SJS- are severe adverse reactions (ADR's) to medications, prescription or over the counter, taken exactly as prescribed.

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 150,000 are never released, they die.

Keep in mind Hippocrates born in 460 BC on the island of Cos, Greece, known as the Father of Medicine, and the author of the Hippocratic Oath where he states "First Do No Harm" didn't have a drugstore on the corner. He used all natural remedies such as roots, herbs and minerals that were available at that time.

Most of today's major pharmaceutical companies were founded in the late 19th and early 20th centuries. Key discoveries of the 1920s and 1930s, such as insulin and penicillin, became mass manufactured and distributed. Switzerland, Germany and Italy had strong industries, followed by the UK, US, Belgium and the Netherlands.

SJS was first discovered in 1922 by 2 pediatricians A.M. Stevens and F.C. Johnson after diagnosing a child with severe ocular and oral involvement to a drug reaction.

Since then legislation was enacted to test and approve drugs and to require appropriate labeling. Prescription and non - prescription drugs became legally distinguished from one another as the pharmaceutical industry matured.

In the 1950s due to the development of systematic scientific approaches, understanding of human biology and DNA and sophisticated manufacturing techniques the industry grew.

During the 1950s and 1960s many new drugs were developed and mass produced.

There are now more than 200 major pharmaceutical companies, and they are more profitable than any other industry, and employ more political lobbyists than any other industry. With advances in biotechnology and the human genome project there will be more sophisticated, and more individualized, medications. With each new drug manufactured, and distributed, the risk of SJS/TENS increases.

We recognize that the use of prescribed and over the counter medications are necessary and beneficial to our wellbeing and help many people, but because each persons 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.

The Stevens Johnson Syndrome Foundation has sent newsletters and information packets worldwide, and was instrumental in establishing the Stevens Johnson Syndrome Foundation in Japan.

The Japanese government sent a news team from Tokyo News to Colorado to do a television interview in October of 2000 which has aired several times on the Japanese version of 20/20. There have also been numerous articles in the Japanese newspapers.

It's ironic, that the Japanese Government and Japanese Ministry of Health takes the time and initiative to educate the people of their country about SJS/TENS, and the United States, the greatest, most affluent country in the world will not inform its citizens.

The biggest offender is the FDA, the watch dog of the drug industry. They label SJS/TENS as rare, and refuse to institute a mandatory reporting system to show the actual number of cases each year. Their reasoning is they currently have the MedWatch system in place.

MedWatch is a voluntary reporting system that allows consumers and healthcare professionals to report serious problems with medical devices they dispense or use. The problem is this system is not only difficult to navigate, but is almost impossible to understand. This type of reporting is ineffective at informing consumers and medical professionals of severe reactions that may be caused by prescription and over the counter drugs.

Let's not forget about the medical community, the doctors, nurses and hospitals. They are our first line of defense; these are the people we go to with our health problems. These are the people we trust.

The problem is the doctors and nurses know little, or nothing about ADRs, and if you asked them more than 90% would tell you they never heard of, or saw a case of SJS/TENS, one of the most severe drug reactions.

Numerous cases are misdiagnosed as chicken pox, measles, scarlet fever or flu. Many cases are never reported.

Every day The Stevens Johnson Syndrome Foundation receives emails, and or calls from victims and their families, asking for information about the disease, and where they can find doctors and hospitals for treatment. If possible they are given the names of doctors or facilities in their area that are familiar in treating SJS/TENS. In many cases the foundation will contact, and fax information packets and treatment plans to hospitals that are not familiar with the disease.

Regrettably the foundation has limited funds and resource, but makes every effort to help as many people as possible.

Last, but not least we have the multi - billion dollar pharmaceutical industry, with over 200 companies developing and distributing thousands of prescription and over the counter drugs.

Each year 25 new chemical entities are approved for marketing, and the cost of developing a successful new drug is estimated at 1 billion dollars, add to that 19 billion a year on promotion and advertisement and you can begin to understand how enormous and lucrative this industry is.

A medium size company may employ 1000 drug representatives. The larger companies have tens of thousands of representatives. There are approximately 100,000 pharmaceutical sales reps handling some 120,000 pharmaceutical prescribers.

Drug companies spend 5 billion annually sending representatives to physician offices. The physicians are the ones that write the prescriptions that will be used by the patient. Influencing the physician is the job of the drug reps and the majority knows little or nothing about pharmacology or the drugs they are promoting.

Let's give the devils their due. The pharmaceutical industry develops and markets many good and beneficial medications that really help people, and do the job they are designed to do, such as relieve pain, lower cholesterol, correct erectile dysfunction and are also instrumental in extending life.

These drugs are developed in a laboratory and are a combination of chemicals, and because everyone's body chemistry is different what is beneficial to one person may be fatal to another.

It would benefit the pharmaceutical companies to allocate a portion of their advertising budget to support the Julie Foundation for Allergic Drug Reactions, AKA, Stevens Johnson Syndrome Foundation.

The foundations collectively would maintain accurate records of the number of reported ADRs and the offending medications. It would also provide information to those who suffered an injury by taking these drugs, treatment needed and where they can go to receive it. And, when necessary offer financial assistance to the injured parties. It would also provide information and assistance to medical professionals.

The goodwill a program like this would generate would more than pay for it, and go a long way in eliminating many frivolous law suits.

In closing I would like to remind you of the immortal words of Hippocrates.

“FIRST DO NO HARM”