STEVEN'S-JOHNSON SYNDROME / TOXIC EPIDERMAL NECROLYSIS
visit the stevens-johnson syndrome foundation online at sjsupport.org

The following is an article about Stevens-Johnson Syndrome (also Toxic Epidermal Necrolysis) that can be found in the September 10, 2004 issue of The Golden Eagle. A local newspaper printed and distributed at NAS Lemoore, California. The article is about my family – the young boy suffering from this condition is my little brother. By posting this article and spreading this story around I'm hoping more people will become aware of what this condition is, how badly it effects the person who has it and how easily it can be prevented in the future if people are just made aware of its existence.

One thing I would like to say first: There is a woman in our church who had signs of this condition shortly after my brother had been released from the hospital. The doctors did not know what was going on with her – it's common to misdiagnose some of the early symptoms as something other than what they are. The pastor from our church had visited my brother many times during his stay in the hospital and afterwards he also visited this other woman while she was in the hospital. And from what he'd seen with my brother and what he was seeing now with this particular woman, he was able to recognize the condition and inform the family.

It's great to be able to know exactly what is wrong or what to expect, having the knowledge of a condition and feeling comfortable with the care you are receiving for it. But it would be even better if we could prevent it from happening entirely and doing this is so simple.

SJS: It Could Happen To You
By Tammy Ragonese
Golden Eagle Staff Writer

When we get sick, we go to the doctor and trust that the medicine will make us well. For some people, the very medicine that is supposed to make them well can cause a horrific and even fatal reaction called Stevens-Johnson Syndrome (SJS).

SJS is a severe allergic reaction to commonly prescribed drugs, including antibiotics, anti-convulsants, painkillers and even over-the-counter cold medicines, this leads to blistering of the skin and the moist surfaces of the body (lips, mouth, eyes, esophagus, stomach). An extremely painful disease, SJS commonly causes blindness and can even result in death in 10 to 30 percent of the cases diagnosed properly. Because many physicians and emergency facilities are not familiar with the symptoms, treatment is frequently delayed, further worsening the condition.
With SJS, a patient’s reaction to medication usually develops one to four weeks from the onset of starting the medication. For some, allergic reactions can happen as quick as hours or days and include a mild rash, lesions, fever, hives and swelling of the eyes, tongue and mouth. Kim Franklin, retired military dependant, knows all too well the horrors that SJS can cause. Her 14-year-old son, Allen, who attends Akers School on board NAS Lemoore, was diagnosed with SJS on June 24 and spent seven weeks in Children’s Hospital Central California in Madera.

“SJS, although rare, does affect a lot of people. I want the public to be aware of this horrible disease. It can happen to anyone, any age, and any background. No one is immune to this,” explained Franklin. “My son was close to death. Every day he is with us is a blessing.”

The Franklin’s nightmare began just weeks after Allen started his seizure medication. On June 22, Allen developed what was initially diagnosed as an eye infection (pink eye). The doctor wrote out a prescription for antibiotic eye drops.

Still unaware that Allen was experiencing an allergic reaction to the seizure medication and following doctors instructions, the eye drops were administered; both medications containing sulfa. This would be key in the events that would unfold.

Just two days later, Allen, having no known allergies to any medications, was rushed to the emergency room with swollen lips and eyes. Not responding to treatment, Allen was transferred to Children’s Hospital in Madera just hours later.

“When I arrived at the hospital, I didn’t recognize my son. His face was swollen and blistered. I wanted to faint and cry, but knew I had to be strong for Allen. I was in shock,” explained Franklin, who is also the mother of Allen’s fraternal twin, Alex and 21-year-old sister, Alana. Allen had a severe case of SJS as it was discovered he was allergic to Sulfa drugs. All doctors can do is treat the symptoms (medical maintenance) while SJS runs its ravaging course through the body.

A breathing tube was inserted to keep an airway open for Allen and he was placed in a drug-induced coma as his body burned (blistered) from the inside out. There was nothing Franklin could do but watch in horror as her son became more and more unrecognizable.

“Patients with SJS are placed in burn unites because their bodies are burning with blisters from the inside out. Allen’s
skin was burning off his body and his eyelids were stuck to his eyeballs. He had no eyebrows or eyelashes, “said Franklin. “Something nobody should have to go through.”

Children’s Hospital became Franklin’s new home for the next seven weeks as her son fought to live. She stayed at the Ronald McDonald House and relied on prayers to see her through.

“Courage is fear that is said as prayers, which means I had to let God handle it,” said Franklin. “We had so many people praying for Allen and us.”

Allen is a fighter and after many setbacks including a collapsed lung and temporary blindness, Allen won the battle and was released from the hospital one day before his 14th birthday on August 13.

“His body is still adjusting. His nails are now falling off, another symptom of SJS. His skin is scarred from SJS and is still growing back. His bottom eyelids are adhered to his eyes. It was a long road back and we are so thankful he is not blind and that he is alive and still with us,” explained Franklin. “He still has some possible surgery ahead of him and has to wear a hat and sunglasses to protect his eyes.”

Franklin’s church donated $2,500 to the Ronald McDonald House and after living through the horrible nightmare of SJS, the Franklin family is ready to give back to those who helped them through their ordeal.

“We have so much to be thankful for and need to pay it forward by donating our time to our church, the Ronald McDonald House and Children’s Hospital,” explained Franklin.

Allen is just thankful to be home and out of the hospital. He is bothered by the loss of his skin color, but wants people to know that he is a survivor.

“I lived through a disease that could have killed me. I want to tell my story so other people with reactions to medicine will have hope and I want them to never give up,” said Allen.

SJS is all too real for the Franklin family. Their story is one of survival and one that can happen to anyone. SJS does not discriminate and anyone taking medication is at risk.

“I don’t want to alarm anyone by sharing our story, but want the public to be aware of the warning signs and to not take
them for granted,” explained Franklin. “I would advise that people read the medication inserts given by the pharmacy and watch your child and/or yourself closely while on the medication and know your family history. If you or your child develop any adverse signs at all, stop the medication and seek medical attention immediately.”

If you’d like more information on Stevens-Johnson Syndrome and Toxic Epidermal Necrolysis (TEN) please visit www.sjsupport.org, the SJS Foundation site. If you’d like to send your well-wishes to my brother or the rest of the family, please email allen@lemoorons.com.