

In support of SJS Awareness campaign:

My name is Helen Milne and I am the proud mother of Ian, a 10 year old boy who had TEN's at age 3. Like every other parent of a child who has suffered a Stevens Johnson Syndrome reaction, every second of that period is burned into my brain forever. We too had never heard of this before, hence why the awareness drive is so important and I would urge you to take any opportunity to educate people as you go about your day to day.

Ian's story is similar to others in many ways in terms of the first presentation of his symptoms, misdiagnoses as chicken pox then hand foot and mouth disease, complete lack of proactive care and finally after 5 days of agony he was transferred to a burn unit. Within two days he was moved from the burn unit to Paediatric Intensive Care Unit. As soon as Ian was moved to PICU we were asked to leave the room for about 30 minutes and when we came back later, Ian had fallen into a coma and was wrapped from head to toe like a mummy - for any mother this sounds like a nightmare scenario, but in a strangely surreal moment my reaction was "Thank God they have stopped the pain!". It is this solitary moment that reminds me every day that Stevens Johnson Syndrome is an agonizing ordeal and very often pain management is overlooked in the initial period. It is one of the most inhumane experiences that a human being can have. Ian's eyes were very badly affected and he lost skin over 87% of his body. We nearly lost him on three separate occasions but thankfully he pulled through. As you are probably aware, too many SJS patients do not survive, and it was with this knowledge that we gratefully took him home, thinking it was all behind us with no idea that our lives were forever changed and a round of never ending battles was about to begin.

Like many SJS patients, hindsight (pardon the pun) is a bitter sweet experience, because had we known then what we know now, Ian's care plan would have been very different. Information was limited and we were left very much to our own devices in terms of finding medical care, most especially ophthalmic specialists who were experienced in dealing with SJS eyes. We have literally travelled the globe over the past seven years in finding care for Ian, however even that was not enough to save the sight in his right eye. Funny (not ha ha) how I can write that in one sentence when really it has been an ordeal in finding specialists, arranging financing, being stuck between disagreements between doctors and ultimately being left to make the most important medical decisions for our child with no real guidance. It just seems like it is a constant battle that has consumed our lives. Currently Ian has a dense cataract in his right eye and we hope to have surgery in Boston in October 2008 while at the same time having his scleral lens refit.

Above and beyond all that however, is my hero Ian. He is a child who has the most incredible sense of humor and a laugh that comes from his very soul. He works hard at school and has taught me many lessons in the way that he has endured years of light sensitivity and pain. There is no emotional pain worse than the pain of a mother watching her child suffer and like every other parent of SJS children, I would swap places with him in a heartbeat. He is determined to find fun in his life and I just love the picture of him buried in the sand at his school beach day. Without his scleral lens this day would have been an impossibility in terms of light sensitivity and dry eye. Ian is my inspiration for all that I do and it was on his behalf that we founded the **Milne Stevens Johnson Syndrome Society, a non profit organization** to fund his care and offer support to other SJS patients. I am proud to have been accepted as a facilitator for the **Stevens Johnson Syndrome Foundation, although the truth is that Ian could fill this role just as easily.**

As part of my awareness efforts, I have started a blog which you can visit at www.sightforsoreeyessjs.com - **Sight for Sore Eyes SJS**, a kind of a rolling diary of facts, experiences, tips and a little bit of humor to lighten the moment. At the time of writing this I am scheduled to meet with the Chief Medical Officer of Vancouver Island, a pediatrician and accomplished medical activist in Canada. I am hoping to discuss such topics as awareness campaigns for both the medical profession and layperson, reporting procedures, ophthalmic referrals, , with emphasis on establishing an ophthalmic treatment protocol across Canada. I have

to admit I am pretty nervous as I have never had an opportunity like this. Keep your fingers crossed, if we can prevent even one case of SJS / TEN or at least minimize the ocular sequelae then it will be worth the effort. I promise to follow up and let you know how it goes. Please join with me in spreading the word and supporting the August Awareness campaign in any way you can.

To Julie McCawley, Ian and every other SJS patient on the planet, I am humbled to be included in your world. I don't know if I would have the tenacity to achieve the daily victories that you claim each day. You are all champions of life.

I wish you all Health, Happiness and Healing.
Helen Milne