Stevens Johnson Syndrome Foundation

Newsletter
January, 2005

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2005 the year of SJS Awareness

As most of you are aware SJS has been in the news a great deal. This is a a tremendous opportunity for all of us and we need to take advantage of it. The SJS Foundation has received numerous calls and emails from parents with questions and concerns about SJS. These are parents that **DO NOT HAVE A CHILD WITH SJS!** The public is visiting our website. They are educating themselves!

People are finding out about Stevens Johnson Syndrome before it finds someone they love!

Not the way most of us found out. They're are not standing at the bedside of their loved one, praying, crying and desperately trying to understand what has just happened.

We need to continue to educate the public, even after the media attention dies down. You can help by visiting our website. Print the SJS Fact sheet and take it to your doctors. Hand it out to your children's schools. Email the link to the SJS Foundation website: www.sjsupport.org to 10 of your friends, ask them to email it to 10 of their friends. Lets not lose the momentum. Together, we can make a difference. There are times when medications are definitely needed and beneficial, but through public awareness and education we can help the future SJS victims to receive a quicker diagnosis, and a proper treatment plan.

Children's Ibuprofen products in the News

As most of you are aware a lawsuit has been filed against the manufacturer of children's motrin in the case of a little girl that went blind.

The SJS Foundation has written to the FDA about Stevens Johnson Syndrome and children's ibuprofen products for over a year. We were told they have not seen an increase in SJS cases. The SJS Foundation has received reports of 2 new cases of SJS already this year to these products in children. We are only 2 weeks into the new year.

There have been more reported cases of SJS to ibuprofen then to acetaminophen. We are all taught not to give children aspirin due to the risk of Reye Syndrome. Yet there is no warning of SJS to the public in NSAIDS for children.

How fast do you really need a fever to come down? A fever is sign of an infection. Many doctors don't even consider a fever a concern if its under 101. We as

SJS Survey Form

If you have not completed our survey form in the past we are urging you to do so now. We need hard facts. Since the initiation of the survey form last year we have had 222 patients complete the form. The FDA's reporting system is not accurate. The only way we will get SJS out is the open is to prove that it is not rare. Not only will completing the survey help in that aspect but we will be able to accurately track certain drugs that have a higher incidence of SJS and lobby for warning labels. Your assistance in this project is greatly appreciated.
[Click here] to go the SJS Survey Form

SJS Awareness Month in your State

Once again it's time to write to your governor requesting that August be named SJS Awareness Month in your State. We have consumers deserve to be informed of the risk of dangerous sideeffects in over the counter drugs. When this medication was by prescription it carried the warning of SJS, yet when it went over the counter, readily available to all parents the warning was lifted. If you have a child that had SJS to ibuprofen, we urge you to complete the FDA online reporting form and the SJS Foundations Survey Form.

To view the response from the Food and Drug Administration please [http://sjsupport.org/pdf/FDA_Ibuprofen_Response.PDF]

Media Interviews

Since October 2004, the SJS Foundation has had the honor of being interviewed by the following news agencies. We would like to thank them for helping spread the word about Stevens Johnson Syndrome.

- The New York Times
- Washington Post
- News Day New Paper, NY
- WCBS NEWS RADIO 880 in NY
- The San Jose Mercury News
- The Killeen Daily Herald
- Reuters News Wire
- Dow Jones News Wire
- The Beaver County Times, Beaver, PA
- Wall Street Journal

SJS Patients and the Media

The SJS Foundation has been receiving numerous calls and emails from the media looking for SJS patients and families to interview. If you would like to be included in a future interview, please contact us by email at sjsupport@aol.com
Please add subject line : SJS INTERVIEW

Include the following information:

- Name
- Phone number
- Address
- Medication
- Year(s) of SJS or TEN
- Sideeffects

Also, if you have photo's it is helpful.
Thank you for your help

attached a link to a template letter to help you get started.

Your assistance as always is deeply appreciated.
[http://www.sjsupport.org/htmldata/sample_governor_letter.html, Template letter]

New Board Medical Advisor

Welcome Dr. Janis Cotter of Parkway Sclerals

It is our honor to welcome Dr. Janis Cotter of Parkway Sclerals to our medical advisory board. Dr. Cotter has been fitting gas permeable scleral contact lenses to diseased eyes for almost 20 years received her doctorate in optometry in 1985 from the New England College of Optometry. She completed a residency in hospital based optometry at the VA Medical Center in West Roxbury and Brockton, Massachusetts. From 1986 to 1992 she was manager of the Contact Lens Service at Massachusetts Eye and Ear Infirmary, Boston, Massachusetts. It was here that she developed her interest and commitment to the use of contact lenses as medical devices for eye diseases. In 1992 she became executive director of a nonprofit foundation that specialized in the use of corneal and gas permeable scleral contact lenses for diseased eyes. Doctor Cotter was a member of the team that developed the Boston Scleral Lens. She was responsible for the clinical care of more than 500 patients fitted with the Boston Scleral lens during her 11 year association with the foundation. Doctor Cotter has been published nationally and internationally as well as lectured nationally and internationally on the use of gas permeable scleral contact lenses. Patients she has fitted with gas permeable scleral contact lenses were featured on Good Morning America, Oprah, and in multiple articles over the years. Janis M. Cotter, O.D

Ocular Damage and SJS/TEN

by, Scheffer C. G. Tseng, M.D. PHD

Thank you to Dr. Tseng for taking time out of his busy schedule to provide the following article

SJS, especially when associated with TENS, is a horrible disease affecting the eye. As the medical director of Ocular Surface Center in Miami, Florida, I have a precious opportunity of seeing and taking care of quite a few patients in the last three years after I left the Bascom Palmer Eye Institute, University of Miami. The following are our progresses made and I would like to share them with you:

1. We have retrospectively reviewed clinical data from 38 patients with SJS, of which 27 with additional TENS. Our results showed that acute stage of SJS/TENS was characterized by tarsal conjunctival ulceration, an as-yet-poorly recognized finding. Keratinization of eyelid margin with variable degrees of meibomian gland dysfunction was observed in all cases. Floppy eyelid, trichiasis, partially or totally opened lacrimal punctum, symblepharon and aqueous tear deficiency were not significantly correlate with corneal complication. In contrast, there was a strong correlation between the severity of eyelid margin and tarsal pathology and the extent of corneal complications (Spearman r: 0.54, P= 0.0005). A multivariable regression analysis also showed that the extent of eyelid and tarsal pathology had a significant effect on corneal complications (Coefficient: 0.84, P=0.006). We thus conclude that Acute SJS/TENS patients are characterized by severe inflammation and ulceration of the tarsal conjunctiva and lid margins. If left unattended, lid margin keratinization and tarsal scar together with lipid tear deficiency contribute to corneal complications because of blink-related microtrauma. Attempts to suppress inflammation and scarring by amniotic membrane transplantation at the acute stage (preferably within the first week) and to prevent microtrauma at the chronic stage are vital to avoid sight-threatening complications. This paper is now accepted for publication in Ophthalmology in 2005. Please also visit my website www.ocularsurface.com for more information.
2. As a consultant for Bio-Tissue, Inc., a company that has manufactured and distribute cryopreserved amniotic membrane in the past, I

The SJS Foundation also welcomes: Dr. Scheffer Tseng to our Medical Advisory Board!

Dr. Tseng serves as Medical Director of Ocular Surface Center, providing the state-of-art to patients suffering from Stevens Johnson Syndrome and Toxic Epidermal Necrolysis. Dr. Tseng serves as Research Director of Ocular Surface Foundation, who are to be specialized in ocular surface biology, health, and diseases, and also director of Research & Development of TissueTech, Inc., Medical Director and Consultant of Bio-Tissue, Inc., and Director of Research & Development of Bio-Lipid, Inc., supervising a variety of directed to study the pathogenesis of ocular surface and tear diseases, and develop new tools and products for improving the diagnosis and treatment of these diseases.

New Board of Directors

It is our pleasure to name Mr. Tushar Khatri of Lafayette, Colorado, and Mr. Justin Hebert of Broomfield, Colorado to the SJS Foundation Board of Directors. Tushar and Justin have volunteered many times for the Foundation distributing SJS Fact Sheets to the public and have also helped with the SJS fundraisers. Tushar has a background in computers & management and Justin is presently working towards a degree in Nursing.

have helped to popularize this new surgical procedure in the last 10 years. Amniotic membrane transplantation has been approved by Medicare in January 2004. In the past two years, I have also helped Bio-Tissue to manufacture a "sutureless" amniotic membrane, called "Prokera", which has been approved by FDA as a medical device so that amniotic membrane can be applied to the patient's eye without the use of sutures. By doing so, this may facilitate the clinical use of amniotic membrane especially during the acute phase of SJS/TENS when there is a difficulty of bringing the patient to the operating room. Bio-Tissue will formally lauch this product in March 2005.

3. When SJS reaches a chronic phase, surgical reconstruction of scar-induced complication becomes necessary. One major hurdle is the severe adhesion between the lid and the globe, called symblepharon or obliteration of the fornix. We have developed a new surgical procedure to release such adhesion and to prevent its recurrence after surgery. This new surgical procedure is based on the use of amniotic membrane as a graft in conjunction with the intraoperative application of mitomycin C. The paper describing this procedure has been accepted for publication in Ophthalmology, 2005, and the video has been awarded as "the best show" in the last annual meeting of American Academy of Ophthalmology in New Orleans.
4. When SJS affects the cornea leading to the total loss of limbal stem cells in a state termed "limbal stem cell deficiency", restoration of vision relies on transplantation of limbal epithelial stem cells. One new approach is to transplant these cells expanded in culture on a piece of amniotic membrane from the limbal tissue obtained by a small biopsy. In USA, our center and TissueTech, Inc. are the first that receive FDA's approval to conduct a clinical trial to transplant such culture-expanded cells together with amniotic membrane for patients suffering from total limbal stem cell deficiency caused by a number of diseases including SJS. We have also received a grant support from National Institute of Health, National Eye Institute to help the manufacturing of such a tissue-engineered product to our patients (for more information, please visit website www.biotissue.com).

New and Improved SJS Foundation Website

We are very excited to present our new and improved website. Special thanks to our wonderful webmaster, Amit Khatri and content provider Jean McCawley (- *Founder of SJS Foundation*) for their hard work. Please take a few minutes to visit our website and see the changes and new information. Many people are contacting us to be added to the prayer list. We have an updated news section with all the latest SJS news in the media.

If the information contained in our website was helpful to you, please be aware that it has been made available for public access strictly through volunteer effort and funding. The **S**tevens **J**ohnson **S**yndrome **F**oundation is a 501(c)(3) non-profit organization dedicated to promoting public awareness to adverse drug reactions as well as to provide immediate information regarding treatment of those suffering from this devastating affliction. Please help us keep this website running. Your tax-deductible donations will help us to continue this good work.
[Click here] to make your generous contribution to **SJS F**oundation..!!