



Stevens Johnson Syndrome Foundation

Newsletter
April, 2007

[Go to Website](#)

[Email Us](#)

[Make a donation!](#)

[Click here for printable PDF version](#)

SJS Prayer List

This winter has brought many new SJS patients. Please take a moment to visit our website and say a little prayer for those who so desperately need them.

SJS TIPS: DEALING WITH PHOTOPHOBIA

by Bud Telchin

Nearly everyone who gets SJS/TENS has moderate to serious problems with their eyes, and something that occurs right away is photophobia, or sensitivity to light.

When I had SJS at age 11, I was so light sensitive, especially in the morning, that I couldn't tolerate the light in the bathroom or in the kitchen. Sunglasses provided little benefit, and going outdoors was something to fear and avoid. It took years for me to cope better, and I want to pass on to you the benefit of my learning experiences. For some people the pain is so bad that they become effectively crippled.

Why is this so?

My theory is that the nerves from the eye to the brain can handle just so much information. For normal people, bright light is translated into information to the brain, and is handled with no problem.

To view full article please: [\[click here\]](#)

New Scleral Lens Provider

Michigan residence can now be fitted for scleral lenses without traveling out of state. We are pleased to add Dr. Dalia K. Warner to the list of scleral lens providers.

Dr. Warner is an optometrist and director of the contact lens clinic at Michigan Cornea Consultants. Dr. Warner fits mini and full size Scleral lenses. She is originally from England where she studied under Ken Pullman and has seen SJS patients at Moorsfields Eye Hospital in London as well as patients in Michigan. She joins three well respected cornea surgeons; Dr. Steven Dunn, Dr. David Heidemann and Dr. Christopher Chow.

Michigan Corneal Consultants has three offices at the following locations:

29201 Telegraph Road,
Suite 101, Southfield,
Michigan 48034-7630
Phone: 248 350-1130

21000 E Twelve Mile Road,
Suite 103, St. Clair Shores,
Michigan 48081
Phone: 586 447-8939

19853 West Outer Drive,
Suite 102, Dearborn,
Michigan 48124
Phone: 313 565-6102

Please visit the following link for a scleral lens

SJS Physicians List

The SJS Foundation needs your help. If you know a physician with experience in treating the aftermath of SJS please help us by adding their name and contact information to the physician list. We are looking for doctors in all fields. This information will assist other SJS victims with their recovery.

Please email us at sjsupport@aol.com add for SJS Physicians list in subject box.

We appreciate your participation in this project important project.

provider near you:

<http://www.sjsupport.org/scleral.shtml>

SJS Survey

The Stevens Johnson Syndrome Foundation has surveyed 1137 SJS and TEN Patients. The Foundation receives calls each day regarding after effects. Many patients will suffer one or more life long disabling conditions as a result of SJS/TEN. Below is a list of results pertaining to residual side effects secondary to Stevens Johnson Syndrome and Toxic Epidermal Necrolysis.

To view full article please: [[click here](#)]

SJS Support Group Facilitators

We now have support group facilitators in 8 states and 4 countries.

Patients receive encouragement by meeting others who have overcome SJS challenges like your own. Most patients have been told that they will never meet another person that has had Stevens Johnson Syndrome. We hope that more people will volunteer to support other SJS patients locally.

If you would like to volunteer to be a SJS Support Group Facilitator please download the support group application located at: [[here](#)]

and mail to:

Stevens Johnson Syndrome Foundation
PO BOX 350333
Westminster, CO 80035

If you have any questions please contact us at: (303) 635-1241 OR email us at: sjsupport@aol.com

August is SJS Awareness Month

Once again the SJS Foundation is asking for your assistance. Each year we write to the United States Governors asking them to proclaim August SJS Awareness Month is their state. However many states want a letter from a local resident. Please help us by writing your state governor.

If you are a resident of another country we would like your help also. Please write to your appropriate government official. We would like to see August recognized world wide as SJS Awareness Month!

A sample letter is available on the Stevens Johnson Syndrome Foundation website at: [[click here](#)]

To access your governors address: [National Governors Association](#)

How you can help SJS Foundation?

Now you can donate your vehicle to help the SJS Foundation Through Vehicles for charity, the SJS Foundation will receive a check once the car is repaired and sold at auction. Your donation through vehicles for charity is tax deductible. [[Click here](#)] for more information on how you can help.

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 **Stevens Johnson Syndrome Foundation** 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 Foundation**..!!

Articles or advertisements referring to specific programs, services and/or products do not constitute endorsement by the Stevens Johnson Syndrome Foundation. Articles involving medical aspects of SJS are not intended to be medical advice and readers are cautioned not to make any changes in their treatment based in information without consulting with a physician.

Information for Donors: The Stevens Johnson Syndrome Foundation is a 501 (C) (3) tax-exempt corporation. All donations to the SJS Foundation are tax-deductible. [[Click here](#)] for Tax information.

© Copyright 1997. All rights reserved. Contact Webmaster: [Amit Khatri](#)