

STICKLER Involved People Newsletter

15 Angelina Augusta, KS 67010
Vol. 12, #4

316-259-5194
December, 2007

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COORDINATOR COMMENT

Time is close for another great set of holidays. I am one who removes EVERY item in my home (including curtains) and replaces it with Christmas decorations. If it cannot be removed, like light fixtures, I decorate it. When my "free labor" kids move out, I will have to hire help. Family and friends are a great part of the holidays. Remember to be extra good to all at this time of year and all times. Thanks for remembering your SIP friends.

CONFERENCE 2008
PLANS ARE IN THE WORKS
FOR A GREAT
CONFERENCE IN THE
NORTHEAST. WE ARE
WORKING ON LOCATION
RIGHT NOW. SAVE YOUR
VACATION TIME FOR JULY
11-13, 2008. WE ARE
PLANNING A FULL DAY ON
FRIDAY, AS OF NOW, WITH
PLENTY OF TIME FOR TALK.

Comment from 2007 Conference

"I just wanted to let you know how much we enjoyed the conference. It really was a blast. I was a little afraid that it was going to be a support group meeting with everyone sitting around in a circle talking about how terrible things were, but I was amazed at how upbeat, happy, excited, and funny everyone was! We met a lot of new friends, including a young couple currently in Minneapolis who are facing a lot of the same problems, questions, and concerns as we are. By the way, I hope you don't mind that we split from the group during mini-sessions! We were so excited to talk about our concerns in having children, and didn't want to disrupt the other groups. It was their first conference as well, and we were all very impressed. The speakers were of an amazing quality – all experts in their fields, well informed, and great speakers. We were lucky enough to have

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dinner with Mark. Mark's great sense of humor, independence, and amazing personality gives hope to anyone concerned with pending eye problems. I was also very impressed to learn all that Jan is doing to help educate the medical community, and I was glad to see it recognized this morning."

Organ and Tissue Donation for Stickler Research

If you wish to donate any/all organs and tissue to the National Institutes of Health/National Institute on Aging (NIH/NIA) to further research on Stickler syndrome, then all you need to do is advise a family member of your desire. When the time comes for the donation to be made, the contact number to coordinate the donation is 1.410.350.3950 at the National Institute on Aging. If you have a planned surgery, and would like to work with your physician to donate tissue for the NIH to study (and are not already a participant in the Connective Tissue Study being done by Dr.

Nazli McDonnell et al), then complete the study questionnaire on the NIH study website (see link below), prior to your surgery, and contact the study to give informed consent. Submission of this form needs to occur several weeks prior to your surgery date to be able to arrange for everything on time.

<http://www.grc.nia.nih.gov/studies/ctd.htm>

SIP News

Be sure to visit our newly redesigned web site: www.sticklers.org Rick Bishop and Mike Cermak have done a lot to improve the website and we all owe them a BIG THANKS!

Contributions Recognized

Since the last newsletter:

Robert Engel

SIP SCHOLARSHIP

Dr. and Mrs. Stickler donated the start-up money for a fund

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to provide high school seniors, who have a diagnosis of Stickler syndrome, with a four year scholarship. This year's winner is Elena Cox, for New York State. Applications are available on line and are due June 15. The winner is announced at the annual conference. Applications are on the SIP website.

CONFERENCE AID

The SIP Board is making a special effort to help persons come to our annual conference. We may have funds for airfare next year. We want to work with any and all to get you to the conference. Please contact sip@sticklers.org if you have thought "Gee, I would go, but for the cost." PLAN NOW to join us in 2008

NSGC

The SIP board, in order to promote recognition of Stickler syndrome, had a booth at the National Society of Genetic Counselors, in Kansas City, October 12-15. Thank you, Jan Helfer, for organizing and

manning this booth. Jan is also doing another mailing to targeted physicians, with our new brochure and information about the Stickler video. If you want your physician to receive a brochure, contact sipbrochure@yahoo.com

2008 Conference

As was mentioned earlier, there is a "movement" to have an additional day at the 2008 conference. One thought would be that we all bring our talents to offer at a "crafts show" to make money for Stickler Involved People. Those of us who come by plane could bring samples (or photos) and take orders for items we would offer for sale. We know of a great wood worker, and someone who tats and a great latch hook rug maker and one who makes jewelry. One of us used to make really cute stationary.

Think of your talents and think about what will work for you to present for sale at the

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conference. Maybe, you can offer child care for parents to go out on Friday or Saturday night, or Sunday after the conference. Maybe, you can

Mayo Clinic Nose drops?

"I was given this by a now-deceased ENT many years ago. It works. If you have a tendency toward sinus flare-ups, snuff this stuff up and blow at least twice a week. Here it is:

Go to your pharmacy and buy a sterile 8 oz. medicine bottle. Fill it with distilled water. Add 1/8 tsp. salt, 1/8 tsp. white vinegar, 1/8 tsp. bicarbonate of soda. Shake well. Using a medicine dropper, stick this stuff up your nose and snuff a couple times and then blow. Every time you do this, you can feel the pressure going away." From Mimi

Support from the List Server

"Now I know I would have been able to handle anything that came my way if she had been born with SS. But I was the same age I actually turned 24 on 10-16-91 so I was your age when I had her and was scared I was going to do everything wrong. The only thing I did wrong was underestimate myself. Enjoy him they grow up so fast before you realize it."

to thank each of you who has worked this year to make SIP what it is. If you are on the list server, if you told someone about Stickler syndrome, if you bought a video for your family or physician, if you offered conference help, if you worked with your child's school, if you attended a conference, if you sent in your membership, if you called for support, we thank you. Each of us makes a difference and all together we make improvements!

The Executive Board of
Stickler Involved People
would like to take this time