SIP
Stickler Involved People

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STICKLER INVOLVED PEOPLE
March 2014 NEWSLETTER

Coordinator's Comment

I am in the midst of making a presentation on elder bullying. First time I heard of this subject, it hit me as funny. Kids abuse other kids. Then suddenly, names of folks in the Senior Sunday School, or people attending senior centers where I have spoken, came to my mind. I realized that elder bullying is a heavy subject.

We, Stickler Involved People, are another heavy subject. The SIP board reads every conference evaluation with sincere interest. We weigh cost vs. group interest. We debate the future and the directions we want to go.

Dr. Stickler was very good at asking the questions to make me choose "a way to go", just one of the many reasons I miss him. He would ask what I wanted for SIP, then figure out a way for it to happen. One of my concerns that he did not get to, is the expense of genetic diagnosis.

The SIP board is very excited to give you the opportunity to solve an expensive problem for persons with Stickler syndrome. You can read about the special research project in Denver that will accompany our conference this year. Your efforts could save a person $6000- $9000. What a gift you can give to all Stickler involved people!!!!

It's that time of year, to make plans for the annual SIP conference! This year SIP has been invited to participate in a 3D facial recognition diagnosis research project in Denver. More details are in this newsletter under the "*Annual Conference News*" heading below.

SIP SCHOLARSHIP

Dr. and Mrs. Stickler donated the start-up money for a fund to provide high school seniors, who have a diagnosis of Stickler syndrome, with a four year scholarship. Applications and requirements are available at our SIP web site (click here). Please send your completed scholarship application with all the required paperwork to this address no later than June 15, 2014:

Stickler Involved People
Gunnar B. Stickler Scholarship Award
PO Box 775
Cologne, NJ 08213

Note: **Cappex.com** is a resource where students can apply to thousands of additional scholarships. Check it out for your student. First, click on their “Start Now” button and register to get into their site.

ANNUAL CONFERENCE NEWS

We have selected Denver, Colorado as the location of our **2014 Annual American Stickler Involved People’s** conference to be held July 11, 12 & 13, 2014. Our meeting is being held at the **Courtyard by Marriott Denver Airport**, 6901 Tower Road, Denver, CO 80249.

For hotel reservations, call **800-321-2211** or book online **by clicking here.** Be sure to ask for the Stickler Syndrome special rate. We have a limited block of hotel rooms reserved starting at $109/day plus taxes. Parking is free and this room rate includes two free breakfasts each day.

A team from the University of Colorado’s School of Medicine at the Anschultz Medical Campus will be at our conference to explain and process a 3D Facial Recognition diagnosis research project. All Stickler patients who want to participate must have some proof of a genotype diagnosis. Bring medical summary records, particularly genetic records of molecular genetic diagnosis (they need to correlate facial structure findings with specific gene involved and even specific gene mutation, if possible).

We need everyone who has a genetic diagnosis for Stickler syndrome to attend this conference to participate in this project. If you are first time conference attendee with a genetic diagnosis and need some financial assistance please send a request to sip@sticklers.org for the Board to consider. **NOTE**: Not all requests can be honored.

2014 Conference Registration

For more conference information and to print our registration form, please go to www.sticklers.org or click here: **Conference Registration Info**.

IGIVE.COM is an easy way to help SIP

IGIVE.com has sent Stickler Involved People over $900 since it started. When you buy from the web, please remember to start with IGIVE.COM and make some money for us. There are some places that have special offers for IGIVE.COM subscribers. We get $5 for each new person who places an order through IGIVE.COM. So, now is the time to look it over, subscribe, give Stickler Involved People as your cause, and place an order. You are helping SIP and may save yourself some money and time. REMEMBER IGIVE.COM as you do your shopping!

Survey Request for an Honorary Thesis Project

My name is Kelsey Shinnick, and I am a senior undergraduate psychology student at the University of Southern Mississippi. I am working on my honors thesis that is titled, “Parenting, Assistive Technology Use, and Independence with Routines among Children with Physical Disabilities.”

Please help me in the completion of my Senior Honors Thesis by assisting me by completing my online survey. The participants I am seeking to recruit are the primary legally responsible adult caregivers of children with physical disabilities (without a mental impairment) aged 6 to 12. Each participating caregiver will be entered into a drawing for one of four $25 gift cards.

My passion for research concerning individuals with physical disabilities stems from the fact that I am physically disabled myself. I am diagnosed with Charcot-Marie-Tooth Disease (CMT), which is a neurological condition that affects the extremities. My goal in academia is to assist other individuals with physical disabilities in the form of research.

Please contact me at Kelsey.Shinnick@eagles.usm.edu if you wish to participate in my research and survey. Thank you!

Stickler Syndrome Clinic News

Mass General Hospital in Boston is extremely fortunate to attract Dr. Paula Goldenberg from Cincinnati as their new Clinical Director of Medical Genetics at MGH. She has just started and will be taking over the Stickler Clinic. We anticipate her attendance at our annual SIP conference in Denver, CO July 11-13, 2014.

TO VISIT THE STICKLER CLINIC

Patients will need to book the appointment with Sandy Massalski at: 617-726-1561. The patient has to pre-register with Mass. General Hospital to give billing information, and to get a hospital number.
Regularly scheduled clinic appointments are usually on Thursday afternoon from 1-5pm. The clinic can see 3- 4 people. The patient needs to submit medical records in advance. The Genetics Unit has a training program for physicians doing fellowships in Med. Genetics. Some of these "fellows" might want to participate in the clinic.

The clinic is not free, but it is a “dream come true” for persons with Stickler syndrome. Recently, I was able to answer someone that this is THE one place to visit with all the experts you need. Be sure to make your needs known when you call for an appointment.

Two SIP Public Service Announcement Videos

SIP has two YouTube public service announcement videos entitled, “Stickler Syndrome” and the second one “Baby Graham Elder’s Story”. We need more viewer hits on both videos so please take the time to visit them and help us get the word out about Stickler Syndrome to the general public. Click on the above links to view them.

NEW Doctor’s Referral List **NEW**

A member of the stickler list serve has compiled a list of specialists, to share with those interested in finding a physician in their area. If you have specialists whom you consider knowledgeable about Stickler syndrome (even if you trained them), send an email to:

Doctorlist949@gmail.com

Please include your email address (which will not be shared), the doctor name, address and phone, AND the type of specialist they are.

You can now request specialists, in your area, recommended by someone in the group by contacting Pat Houchin at sip@sticklers.org. She will respond to you with listed specialist(s) in your area. Not all major Cities are represented at this time.

Stickler DVDs

The 1st film is now available on http://www.sticklervideo.org , for free. The 2nd film, "Finding Hope" is also easily found on the same website.

Newsletter Praise

I just wanted to thank you for all that you do with the newsletter for SIP- I recently had my second retinal detachment 6 weeks after my brother had his second retinal detachment- mine is healing, his is not doing too well. The SIP newsletter offers so much information and also helps us remember that we are not alone with this condition. I did sign the petition, both my brother and myself are worried about our children's and grandchildren's future- I have a 26 year old that is already blind in one eye and so afraid of another detachment, he was recently diagnosed with a cataract in his good eye and I know with the removal comes added risk as it did with my eye- This condition is more serious than even physicians realize if they even know what it is- so keep up the good work and maybe more doctors will know how to treat our children and grandchildren in the future-
Monica

Additional Resources

(click on blue heading for more information)

Sibling Support Project The Sibling Support Project is a national effort dedicated to the life-long concerns of brothers and sisters of people who have special health, developmental, or mental health concerns.

Tips for Protecting your Knees exercise that can help reduce knee pain and stiffness, strengthen the surrounding muscles, and improve your flexibility and range of motion.

NEW tablet-based Pediatric Family Health History Tool this is an electronic pediatric family history tool. It is designed to support the provider in family history risk assessment and genetic evaluation. Also to Identify additional evaluation, preventative services, or personalized management for children who are at increased risk for health conditions based on family health history.