SIP Stickler Involved People
15 Angelina
Augusta, Kansas 67010
316-259-5194
sip@sticklers.org

STICKLER INVOLVED PEOPLE
SEPTEMBER 2014 NEWSLETTER

Coordinator’s Comment

One of our members recently asked me if we could raise funds by doing an ice bucket challenge. My suggestion on how we can spread the word about Stickler syndrome without infringing on the brilliant ALS ice bucket challenge campaign going on around the world is as follows.

Each of us can take a couple of minutes to tell all of our FB friends about Stickler syndrome. If you like to cut and paste, try this explanation:
"I am a person involved with a genetic disorder called Stickler syndrome. My hope is to share some information with you which could save another person's sight. If you know family or friends having vision and joint problems, or a child born with Pierre Robin syndrome, refer them to www.sticklers.org for more information and support for these ailments.”

Rick and I will work up a FB post, with our logo and we will post on October first. We all can start our own personal posts shortly thereafter.

In a follow up post, you can talk about how you got the diagnosis or anything that might help someone increase awareness. I cannot even do the math, if I tell my 100 FB friends and each of you share with yours, we have reached many, with little effort from each of us. Forward to our email, SIP@Sticklers.org, if you get responses that we need to know about.

If you do not have Facebook, send the sentences above to all your email friends. You can even do both. This message does not say you have Stickler syndrome. The message is not to share horror stories, or to step on ALS toes, or to make money. We just need to use the free resources we have available to help get the word out about Stickler syndrome.

Reminders

1. Remember to contact CoRDS for your registration for potential researchers. See the article in this newsletter.

2. Stickler Involved People (SIP) has signed up as an organization that can receive donations through H&R Block. So, remember if you get your taxes done there, be sure to tell them that you want $5 of your fee donated to SIP. It cost you nothing and could add a lot of $$$ over the years.

3. Also, remember to use Amazon smiles as your primary purchase page. If you sign up as SIP as your organization, we get a percent and you get a smile. Even Amazon Prime works with AmazonSmile.

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

2014 AWARD*:** The Scholarship Committee is pleased to report that we have reached a consensus as to the winner of the 2014 Gunnar B. Stickler Scholarship: Congratulations, ***Jonathan P. Hunter from Muskogee, OK. He is attending the University of Oklahoma this fall, working towards a Chemical Engineering major.

SIP JOINS CoRDS at SANFORD RESEARCH

Stickler Involved People (SIP) is fortunate to partner with the "Coordination of Rare Diseases" (CoRDS) at Sanford to launch a patient registry for our rare disease. Liz Wheeler attended our Denver Conference and presented the purpose of CoRDS and what our participation would mean to us as individuals and as a group. What does all this mean exaxtly?

Based at Sanford Research in Sioux Falls, South Dakota, a not-for-profit research institution, CoRDS is a centralized international patient registry for all rare diseases. The goal of the CoRDS registry is to connect as many patients and researchers as possible to help advance treatments and cures for rare diseases. The CoRDS registry is free for Stickler syndrome patients to enroll and for researchers to access. They work with patient advocacy groups, individuals, and researchers to coordinate the advancement of research into the 7,000 rare diseases.

Patients who are diagnosed with Stickler syndrome and individuals who have not yet received a diagnosis are eligible to enroll in CoRDS. If you want to enroll, you can complete the CoRDS Screening Form by clicking here: CoRDS Registry Form.

After submitting the form, you will receive a unique username and password which you can use to log in and enroll by the secure platform. Participants will be notified of opportunities to participate in clinical trials and other research. CoRDS personnel will also contact participants annually to update your information.

With SIP being a partner with CoRDS, we have investigated their mission statements, reputation and security measures already. We hope you will take the time to join. For more information about CoRDS, go to: http://www.sanfordresearch.org/CoRDS.

DR. KEVIN DEAN, 2014 CONFERENCE FOLLOW UP

Kevin Dean, MD, Ph.D. Associate Professor of Medicine, Division of Rheumatology at the University of Colorado School of Medicine, wanted to follow up with our group about a question asked at the Denver conference.

A person in your audience asked a question about 'growing pains' in her 6 year-old. In particular, her doctor had recommended vitamin D.

Here is a link to some good information about 'growing pains' in kids.
http://news.psu.edu/story/141240/2007/11/05/research/probing-question-are-childrens-growing-pains-real

Also, I've attached to an article about vitamin D and growing pains that might be helpful to your group.
http://www.sticklers.org/sip2/images/stories/SIPArticles/Growingpains_Morandietal_2014.pdf

Feel free to give out my e-mail. I am happy to answer any further questions. Dr. Deane's power point presentation can be seen our SIP web site.

Kevin Deane, MD, Ph.D.
Kevin.Deane@UCDenver.edu

ANNUAL CONFERENCE NEWS

Philadelphia, PA is the location of our **2015 Annual American Stickler Involved People's** conference to be held July 10, 11 & 12, 2015. We are negotiating a location and thanks to Amy Leonard-Sako, we have most speakers lined up already.

More information will follow in the December newsletter.

IGIVE.COM and AMAZON.COM shopping helps SIP

IGIVE.com has sent Stickler Involved People over $1,000 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!

Amazon Smile helps in ADDITION to your use of iGive. The cause you choose to support via Amazon Smile may be the same as you're supporting via iGIve, or can be completely different.

You will need to choose a cause from the Amazon Smile list to get the added benefit of their program. Every time you shop through http://www.iGive.com/Amazon you'll be helping twice as much!! Please try it.

Stickler Syndrome Clinic News

Dr. Paula Goldenberg MD, MSW, MSCE, from Cincinnati is the new Clinical Director of Medical Genetics at MGH in Boston. She has the exciting duty of taking over the Stickler Clinic. She provided an excellent presentation at our recent annual SIP conference in Denver, CO. We are posting her power point presentation on our SIP web site. Her e-mail address is: pgoldenberg2@partners.org.

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.

Facebook Praise

July 17th: My 17 year old daughter had the cleft of the soft palate and Pierre Robins her cleft was real bad she had nothing thankfully we had a great surgeon I have 6 kids and 4 of them have SS same as me my mom and brother a few off my aunts and uncles and some cousins and my grandma the best advice I can give you is go to the website "Stickler Involved People" and print out as much info as you can and take it with you to every doctor appointment hospital visit and etc. it makes it easier when you try to explain what it is.

July 20th Randall wrote: "Reasons I liked my first conference this year and will be attending the 2015 SIP Conference: I'm 52 and known I've had Stickler for over 30 years but it opened up communication with myself, wife and daughter (who's affected) and got us on the same page. It's just something we deal with but don't really talk about normally. I UNDERSTAND more because of the conference. Treatments are being developed all the time so it's good to hear from specialists what's out there to diagnose and fix issues. This empowers us to be advocates for ourselves and our children to find therapies that will help our quality of life. We learned to cope better by meeting others who have coped with various issues already. We learned what to look out for and catch issues to avoid long-term disability. It helps my kids and grandkids by being involved and educating them and my getting involved in the research programs. It was affirming to new parents that their children can be VERY successful because other Stickler kids are successful despite challenges. I met new friends that I want to see again. There wasn't a PITY party anytime during the conference.

I remember crying when my middle son's eye exam showed he was legally blind at around 3 years old. With glasses he functions pretty well. I didn't feel the guilt but I did feel sadness that he would be limited by something that I passed on to him. It is what it is. But my son really isn't limited at all. We prepared him as best we could for the world out there and he is being successful. Worry and guilt aren't really emotions we spend much time on. Preparedness and action are much more effective. :) I can see the SIP conference as being a key to being more prepared and able to take action in the future." Randall

ListServ Question & Comments

Remember to use the SIP ListServ for any questions, tips, news or follow up comments on Stickler syndrome topics. Here is a recent listserv inquiry that may also help other Stickler patients.

Why should you come to a Sticklers conference?? I just arrived home from my third SIP conference with my son, Ian who has Sticklers. I remember our first conference like it was yesterday. The fear of the unknown was a taste in my mouth I will never forget. At this year's conference I saw what I felt with my first conference in several families' faces. The love and support you get from everyone in our SIP family is something that is almost indescribable. Even though my *family* ****knows**** what we go through with Ian....they don't REALLY know like my SIP family knows. The stories while different are mostly the same. You learn of new things to try, what didn't work for others, what not to do, what to do. The main reason for going....the LOVE and support. A smile, a hug they all go a long way. You learn things you didn't know from speakers, some things you did know but you can share your experiences with others to help them. The conference is a blessing…. Jennifer

See the Listserv button on our website to register and then you can participate on it.

"It's great to be unique but it stinks to be rare!"
Shelley Bowen

2014 SIP Conference – Denver, CO