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STICKLER INVOLVED PEOPLE
MARCH 2015 NEWSLETTER

Coordinator's Comment

"I sit on my deck and watch flocks of many kinds of birds. They vary from hummingbirds to bald eagles. I watch the different flight patterns, from those who flap wing all the time, to those who seldom move more than to rise to a soar. Nature has many styles. We who deal with a chronic disorder also have patterns. Some of us attack the problem hummingbird style and others handle situations as Eagles. Neither is "better", just different. Just be aware that you have choices and make a decision about what works for you.

Now is the time to make the decision to join us for our annual conference in Philadelphia. It will never be cheaper and may never be closer."

Refer to www.sticklers.org for more information about the 19th Annual SIP Conference July 10-12 2015 in Philadelphia.

ANNUAL CONFERENCE NEWS

Philadelphia, PA is the location of our **2015 19th Annual American Stickler Involved People's Conference** to be held July 10, 11 & 12, 2015. We are meeting at:

Embassy Suites Philadelphia – Airport, (←-Click Here)
9000 Bartram Avenue
Philadelphia, PA 19153
Phone No. (215) 365-4500.

The special SIP rate is $129 plus tax (about $20) per night. Contact the hotel directly for your reservations. This special rate includes free parking and free breakfast for two per morning. They also have free shuttle service to and from the Philadelphia airport. More information and the conference Registration Form is located at our web site and is due by June 1, 2015. After June 1st the registration fee jumps to $100, so register early.

Special thanks to Amy Leonard-Sako for her great assistance to help line up our Speakers.

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 Amazon Smile.

4. The Facial Recognition Study team will attend our conference in Philadelphia and if you wish to participate please bring your diagnosis conformation and/or at least the physician or clinic's name and address who diagnosed you.

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. CoRDS will have a representative at our Philadelphia conference in July. You will be able to register with them on site if you like. Just check the box on page one of the registration form if you are interested in signing up.

SIP and the H&R Block Nonprofit Referral Program!

By partnering with H&R Block last year, your organization raised money while helping your members, associates and supporters get exceptional tax preparation services. We thank you for your participation and look forward to working with you again in the coming year. Your organization will be automatically enrolled in the H&R Block Nonprofit Referral Program for 2015 by completing a few steps using the link below.

The program details remain the same. For each new client your organization refers to H&R Block, we'll provide a $20 reward to your organization. The more new clients you refer, the more money your organization can make!

To access updated materials and set your goal for 2015, log into your secure account here. 2014 referral history will be available for your reference, so be sure to set a new goal and track your progress during tax season. If you do not remember your login information, you can request a password reset by clicking here.

Thank you for your participation and the good work you're doing in the community. Please call 1-800-843-7347 or your local H&R Block contact if you have any questions or need assistance. We look forward to working with you again this year!

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.

The 3D Facial Recognition Team is Back

The Anschultz Medical Campus – Denver, CO research team will be at our Philadelphia conference once again 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). Note:

IMPORTANT NOTE: Participants need documentation of diagnosis (molecular whenever possible; if you have had testing but don't have the report, then they will need info as to where it was done so they can ask for that item of medical records). The photo session will take ~5 minutes per person and you will be selected during Saturday’s conference presentations.

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.

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, 2015:

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

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.

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.

SIP's Doctor's Referral List

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.

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 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 my son....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!!!

SIP Member's Corner

Lori Vickery is a member of the "Mixed Connective Tissue Disease" (MCTD) Facebook group and is inviting anyone interested to check it out and join the group. This group is for all people with the MCTD diagnosis: those who have been diagnosed; those who suspect they should be diagnosed; those with related disorders. They welcome family and close friends. Also, anyone seeking to gain more understanding or support for what connective tissue patients go through and those wishing to offer support. First, log onto your Facebook account then Click here for their Facebook page.

2014 SIP Conference