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**STICKLER INVOLVED PEOPLE  
JUNE 2014 NEWSLETTER**

## **Coordinator's Comment**

I do not know how involved you are in Facebook. I find it very cyclical, busy some days and slow others. A certain person will be very active for a while and then fade. This is true on my personal FB and on the various Stickler pages. Today, on FB, I compared life to the stock market, with its ups and downs. Wouldn't it be interesting to graph life as analysts do?

Recently, the Genetic Alliance asked me for the number of persons over 18 years of age from our SIP group, who might be interested to fill out a survey. This got me to thinking about the cycles of Stickler life. If you are a parent of a newly diagnosed, or trying to get a diagnosis yourself, the cycle is VERY busy. Then, getting educated on the disorder and finding specialists, begins another cycle. There comes a time when we are at peace and have a slow cycle. Then, with all old age, a cycle of medical issues comes along.

So, as I always say, this too will pass. Enjoy the good times and know that the rough days will also change. Please remember that this year's SIP conference will be one of the times you can really make a big change in the Stickler world!!! Don't miss the articles about all the conference activities in Denver this year. Hope to see you next month!

**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 heading, "Annual Conference News"**



## 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

Denver, Colorado is the location of our [2014 Annual American Stickler Involved People’s](#) conference to be held July 11, 12 & 13, 2014. We are meeting 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 Anschutz 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). 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](mailto:sip@sticklers.org) for the Board to consider.

For more conference information and to print our registration form, please go to [www.sticklers.org](http://www.sticklers.org) or click here: [Conference Registration Info](#).

## [IGIVE.COM and AMAZON.COM shopping helps SIP](#)

[IGIVE.com](http://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](http://IGIVE.COM) and make some money for us. There are some places that have special offers for [IGIVE.COM](http://IGIVE.COM) subscribers. We get \$5 for each new person who places an order through [IGIVE.COM](http://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](http://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

Mass General Hospital is extremely fortunate to attract Dr. Paula Goldenberg MD, MSW, MSCE, from Cincinnati as their new Clinical Director of Medical Genetics. She has just started and will be taking over the Stickler Clinic. We look forward to her attendance and presentation at our annual SIP conference in Denver, CO July 11-13, 2014. Her e-mail address is: [pgoldenberg2@partners.org](mailto: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](mailto: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](mailto: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**

[Barb Lockey Shea](#) (mother of Stickler young adult) made a personal comment after reading Pat Houchin's March 2014 Facebook posting:

Pat is 110% spot on.....a Sticklers conference will change your life....we have been lucky enough to have been to 8 ....our son has Sticklers and I will never forget walking into that room in Iowa City with him and instantly feeling at home ... And he has benefitted so much from the help and education that we have gained....If you can take advantage of this opportunity, do it!

**[Here is Pat's posting \(edited\) on FB that Barb responded to:](#)**  
**[Pat Rickords Houchin](#)**

We are getting plans finalized for Denver. [The hotel does have our GREAT rates (\$109, includes 2 free breakfasts) in their system now].

If you have not attended a conference, you have no way to know what a great impact it makes on your life, to be with fellows who understand what you say, who accept your feelings and pains as true, who know you like you know yourself.



You may have heard this before and will probably see it again, but this may be THE conference where you may make a greater impact in the lives of future Stickler persons, even than on your life. We participated in the University of Iowa Eye study, our first conference. We helped researchers at Wills Eye Hospital during our third conference. We worked with the NIH Stickler study at our first Boston conference.

This year, we will get the chance to let a geneticist use this new study we will participate in, to make a visual comparison for diagnosis. Imagine that you can save others from spending \$8000 for a diagnosis, save them from having to wait 6 weeks to 6 months for a diagnosis. That will be the contribution to the future you can give, if you know your gene mutation location!!! Bring your papers and come make a difference.

**Register now for the Denver SIP conference and join your extended family for a weekend of sharing and learning. Help us get the 3D facial recognition research project off to a great start!**

## 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.**

Hello I was wondering if you had any information on magnifying sheets of music. I know this is probably an abnormal thing to be asked but my son has stickler and he is blind in his right eye from the retina detachment. He has very poor vision in his left eye. So when he goes to play his instrument (trumpet), he has to be right on top of his music. I have bought the sheet magnifying [device] but they really do not work. He loves to play music and is excellent in art. I just would love to do something that would help him enhance on what he truly loves. Any information would be greatly appreciated.

Reply: (edited) use a copy machine (i.e., FedEx store) to enlarge the sheet music to his liking.

Response to reply: As for now the enlarging is working. I want to thank you for getting back to me. I have read a lot of information on your site. Especially when we found out Reiss had stickler it was very helpful! Thanks again.

Afterthought: We have since learned that you can find large print sheet music on the internet (i.e., Amazon.com).

**[See the Listserv button on our website to register and then you can participate on it.](#)**