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**STICKLER INVOLVED PEOPLE  
JUNE 2013 NEWSLETTER**

**Flash: Find A July SIP Conference Registration  
Coupon At The End Of Newsletter**

**Coordinator's Comment**

May 31 was my final day "working for a living. I am now titled **RETIRED**. Someday, a job will come along that I will love and I will go with that for a while. For now, I am catching up with cousins, transporting grandkids, and figuring out which knitting project to start next.

**However, this is not the first time I retired and the first time was a lot scarier.** When our daughter went away to college, she decided to not tell anyone she has Stickler syndrome. She was 18 and retired me as the former "Chief General Contractor for Medical Issues." She took over my life long (her life) job as worrier, protector, advisor, scheduler, and coordinator for her health issues. Maybe, you remember becoming 18!

So, today, my advice to you (if you still have kids at home) is to realize that independence comes many ways and many times! I will let you KNOW as the career retirement progresses. The contractor retirement went well!

**Stickler DVDs**

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



## 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 are available on line and due June 15 each year.

Please consider making a donation to the Scholarship fund. The new address for the scholarship fund is:

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

## An easy way to help

[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 as you finish your Christmas shopping!

## Press Announcement

Lori Vickery sent this press announcement that the FDA approved the first retinal implant for adults with rare genetic eye disease.

[http://www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/ucm339824.htm#.UTYZ\\_0rvPxM.mailto](http://www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/ucm339824.htm#.UTYZ_0rvPxM.mailto)

**Please discuss this with your ophthalmologist who knows your eyes.**



## **A WEB SITE THANK YOU**

***Tomorrow my 18 year old son who has Stickler's is meeting with a Rehabilitation Counselor for the first time to evaluate the need for their services with job readiness and placement. While I was printing out some basic information about Sticklers for the counselor, I stumbled upon your website. I have never seen anything like it and I have tears of joy that you exist. We have documented fact that Stickler's has been in my family generations since before the Civil War. Everyone in our family expects blindness or near so before death. To know that there are others out there who understand about Stickler's, and to know of the wonderful webpage you have is so heart warming!***

***I can't wait to join your group and to receive newsletters.***

***But please do one thing. Please advertise. Get your webpage information out to eye specialists and clinics so that their patients may learn about you. Is it a regional thing? We're deep-south. I don't know of any of our many (many, many) relatives who are aware of your support group. Please get the word out! (You can't imagine how desperately we needed your help with IEPs in the last 18 years!)***

***Sincerely,***

***Brenda Majors McAllister, who has Stickler's  
whose father and grandfather and great-grandfather had Stickler's  
whose brother has Stickler's  
whose countless aunts, uncles and cousins have Stickler's  
who has 1 of 2 children with Stickler's***

***Thank you***



## **Dr. Ruth Liberfarb Announcement**

**Dr. Ruth Liberfarb has retired as of March 14, 2013. We have been assured that the Stickler Syndrome Clinic will continue. We are pleased to announce that Joseph V. Thakuria, MD, MMSc, Medical Genetics and Metabolism Attending Physician, Medical Director, Personal Genome Project at MGH Center for Human Genetics Research with the Massachusetts General Hospital has agreed to take over the clinic. He has agreed to speak at the Las Vegas SIP conference and share his new ideas about the clinic.**

**The clinic day may change so check with Sandy. We wish Ruth the best and give her a GREAT THANKS for all she has done for Stickler Involved People and for all persons with Stickler syndrome.**

**There are far too few heroes in our lives and Dr. Liberfarb is one!**

### **STICKLER CLINIC**

Patients will need to book the appointment with Sandy Massalski: 617-726-1561. The patient has to pre-register with Mass. General Hospital to give billing information, and to get a hospital number.

Dr Liberfarb's regularly scheduled clinic appointments are 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.

## 2013 Conference News



Time is running out to register for the 17<sup>th</sup> Annual Stickler Involved People's Conference July 12-13, 2013 in Las Vegas. We will use a slightly different format. We will meet on Friday night and all day Saturday. Lunch will be a "working" lunch and \$20 per person should be included with the registration fees. There will be no program organized on Sunday. Saturday evening and Sunday activities are on your own.

Another difference will be that room reservations will be limited. A contract has been signed with the Embassy Suites on Paradise Road which is close to the airport. So, you can make reservations now at [www.eslvcc.com](http://www.eslvcc.com). Be sure to request the Stickler Conference rate. Get more conference information at: <http://www.sticklers.org/sip2/content/view/9/11/>.

### STICKLER SURVEY

Some of you had the opportunity to help Eline Van Oostrum, an 18 year old with Stickler syndrome, complete her senior research project about Stickler syndrome. She received 100 responses and the data has been analyzed and edited for review. The link on our web site is:

[http://www.sticklers.org/sip2/images/stories/Surveys/  
ElinevanOostrumSurvey%201b.pdf](http://www.sticklers.org/sip2/images/stories/Surveys/ElinevanOostrumSurvey%201b.pdf)

## REMINDER

Please note that Jon Rodis, a specialist in disabilities, and his wife, a disability lawyer, have committed to joins us in Las Vegas and will present their disabilities session Friday evening!

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We will also have a round table discussion about where to take Stickler Involved People from here.



SEE YOU IN VEGAS BABY!!  
JULY 12-13, 2013  
REGISTER TODAY AT:

[Stickler Involved People - 2013 SIP National Conference](#)

**\*\*\*\*Coupon\*\*\*\***

**Register by June 15<sup>th</sup> and take \$10 off on your registration fee!**

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