



15 Angelina
Augusta, Kansas 67010
316-259-5194
sip@sticklers.org

STICKLER INVOLVED PEOPLE

Founders: Bill & Pat Houchin

March 1 2020

www.sticklers.org

WHY JOIN THE MARFAN FOUNDATION?

Twenty some years ago Bill and Pat Houchin started the Stickler Involved People's not-for-profit support group from their home in Agustas, KS. Over the years they helped nurture it to a very popular grassroots support group in America. Pat put together an annual conference for members to get together and exchange their experiences. It Started in Iowa City, Iowa in 1996 and prospered until 2019. After 22 years of conferences, we could not find a way to keep it going due to financial and volunteer shortcomings. We dearly miss our annual grassroots' gatherings. Pat Houchin and Rick Bishop have retired from organizing the SIP conferences but came up with an alternative for our members. Why not join the Marfan Foundation.

This idea was first mentioned by our friend Jon Rodis who is a Marfan patient and started the Boston Marfan support group years ago. More recently, Rick needed Aortic Heart surgery and Jon recommended he have experts at Stanford Medical University Health Center perform his surgical repairs. Rick soon met Stanford cardiologist Dr. David Liang who recommended surgery be performed by surgeon Dr. Craig Miller. Both Doctors were very familiar with



Connective tissue disorders and specialized in Marfan patients. All went very well for Rick and he is grateful for Jon's suggestion.

At his follow up visits with Dr. Liang, Rick learned how both doctors played an important role in the Marfan Foundation research and protocol studies at the University. Dr. Liang was interested in how Pat and Bill started the Stickler Involved People support group. Rick explained how difficult it is to raise money for conferences and get new research funded etc. Dr. Liang mentioned that he sits on the Marfan Foundation Board and would like to see if they would extend an invitation for SIP to join their foundation to help us keep this wonderful SIP grassroots support group going. Dr. Liang knew how difficult it is to start such important and helpful patient groups and to keep it growing.

Rick discussed this option with Pat & Bill at length and we decided to present it to the SIP Board. We see a potential to be part of valuable research pertaining to connective tissue disorders as well as opportunities to raise funds for future meet ups for the group. Here are some pointers about the Marfan Foundation:

- 1. They share with other connective tissue Groups.**
- 2. Like Marfan syndrome, Ehlers-Danlos syndrome is caused by a defect in the body's connective tissue. Unlike Marfan syndrome, the fragile tissues and skin and unstable joints found in Ehlers-Danlos syndrome are due to defects in a group of proteins called collagen, proteins that add strength and elasticity to connective tissue.**

3. **Loeys-Dietz syndrome is a genetic disorder of the body's connective tissue. It has some features in common with Marfan syndrome, but it also has some important differences.**
4. **Stickler syndrome is a genetic disorder caused by mutations in genes that are responsible for forming collagen, proteins which add strength and elasticity to connective tissue. Stickler syndrome affects connective tissue throughout the body, but most notably in the eyes (it is the most common cause of retinal detachment in children), ears, face, and joints.**
5. **As a result of the Marfan Foundation's long-time commitment to advancing their research, they have turned the tide for Marfan research. They work with world-class scientists who are equally dedicated to goals of creating a brighter future for people living with Marfan syndrome **and related disorders**. And, through their research grant program, they have grown the number of researchers studying Marfan syndrome and advancing research that improves diagnosis and treatment for all different body systems affected by these syndromes.**
6. **They continue to move forward research for both Marfan syndrome **and related conditions** because advances in fighting Marfan syndrome helps us take steps toward victory in related conditions, and vice versa. Through their grant program and other commitments, they funded \$1.5 million dollars in**



research this year. As a result of their efforts, grants will help researchers study eye issues in Marfan syndrome and **other connective tissue conditions.**

The above points are edited from the Marfan Foundations website: <https://www.marfan.org/about/related-disorders>

As you can see, we benefit from joining their Foundation and the SIP Board agrees. The Board of Directors will stay in service and the not-for-profit SIP charter will be renewed and not dissolved. Pat and Rick have agreed to stay on the SIP Board for two years to help move the transition forward and advise the Marfan Foundation as needed.

SIP is currently working to join the Marfan Foundation and our first meet up is tentatively set for the 2021 Marfan conference in Chicago. We plan to have a separate meeting room in conjunction with their conference. More information will be forthcoming.

We are invited to join the Marfan Foundation's Victory Walk fundraisers across the continent throughout the year. Please visit their Victory walk page: <https://www.marfan.org/get-involved/fundraising-events/walk> for additional information. If you are interested in raising funds for SIP, this is an easy set up to help SIP through the Marfan Foundation.