

Hi Everyone,

I hope this e-mail you all in good health. I have been going through some rough bumps in the road (health wise) the past few months but I think I have found a few answers and already are seeing some improvement. As the song goes, 'I get knocked down but I get up again, nothings going to keep me down!' : ) (I know a lot of you can relate.)

As promised, I am going to provide the latest information and updates on meetings, events and anything and everything in our Marfan and related Connective Tissue Disorder world.

***The following are our October-December MA Chapter Updates and Reminders:***

**1) July 14-17-National Marfan Foundation Conference 2011 in Portland, Oregon:**

I hope that some of you were able to come to this year's conference in Portland. It was really a great experience and I highly recommend attending a national conference in the future..

Next year's conference will be held in Chicago from August 2<sup>nd</sup> to August 5<sup>th</sup>. Don't forget to check the NMF's website in January/February for more information. Also, if you need financial assistance in attending, apply to the NMF's Conference Scholarship Program. Over the last 2 years, the MA Chapter's CMLH I & II events have raised funds to assist families from all over the United States to attend conference.

*Note:* At this year's conference, we donated a signed picture of Martha Stewart for the Heart Mart on the MA Chapter's behalf.. Next year, I am working on a list of celebrities that the teens and young adults gave me. I have my hands full for sure. The Cast of Glee? Beyonce?...hmmmm. : )

All money raised at the Heart Mart goes to the following years National Conference Scholarship Program. (Los Angeles-2013)

**2) August 21<sup>st</sup>-MA Chapter Barbecue**

This year's MA Chapter's Barbecue was held in Methuen at the home of Randy and Jennifer Levesque. Randy and Jennifer were great hosts and their hospitality seemed to play a role in fending off the showers that were forecasted.

Along with Massachusetts Chapter members, we had several members from the NH/VT Support Group in attendance. Having the barbecues in different parts of the state has made it easier for more members to attend. (As we also do with the Heart to Heart meetings.)

**3) September 24<sup>th</sup>-MA Chapter Annual Get Together:**

On September 24th, my wife Kathy and I hosted the MA Chapter's Annual Get Together at our home in Winthrop. Once again, we had the benefit of good weather but this time I don't think it was due to Kathy or I but the good food and company that everyone enjoyed.

For more details on the day, check out our MA Chapter Webpage. (link is below)

#### **4) October 15<sup>th</sup>-17<sup>th</sup>-American Academy of Pediatrics Conference-Boston**

From Saturday, October 15 through Monday, October 17, volunteers from the MA Chapter and the NH/VT Support Group helped Jennifer Buffone (Director of Support Services) man the NMF Exhibit table. It was a wonderful opportunity to talk to pediatricians from all over the world about Marfan syndrome and related disorders.

I want to thank Rene Jones, NH/VT Support Group Leader and Kaddy Ackroyd, a fellow MA Chapter BOD member in helping Jennifer and I answer questions from all attendees and make more physicians aware of the NMF and it's many resources.

#### **5) MARFANDX-Mobil Site**

One of the newest resources that we promoted at the AAP Conference was the MarfanDX, which is a mobile site that is designed to put the revised diagnostic criteria right in the hands of healthcare professionals involved in making the diagnosis. It is designed to be used on android and iPhone smartphones. It is also compatible with Nook Color, iPad, and on desktop PC's and Macs using Firefox or safari internet browsers.

Take it from me, this is a great tool for ALL medical professional should have. Please share this with all you healthcare providers and everyone you know that could benefit from having the ability to review the criteria for diagnosis.

For more information and to find out how to access MarfanDX, visit <http://www.marfan.org/marfan/5498/MarfanDX-Mobile-Site> .

#### **6) October 23<sup>rd</sup> -Heart to Heart Meeting & Ehlers Danlos Meetings**

This past Sunday, we had our quarterly Heart to Heart meeting at Children's Hospital-Waltham. In addition to having a nice meeting, several of our members stayed for the Ehlers Danlos support meeting that followed our meeting. There was over 30 people in attendance at the meeting.

For those of you unfamiliar with Ehlers Danlos Syndrome (EDS), it is also a connective tissue disorder that has several similarities to Marfans. In fact, some people with EDS are first told they have Marfans to later finding out they have EDS. The key difference in the two syndromes is that Marfans has a fibrillin mutation and EDS has a collagen mutation.

I plan on helping the EDS Support Group raise the level of EDS awareness and in doing so, help unite our common goals in improving the quality of our day to day lives.

**7) Next Heart to Heart Meeting-January 22, 2012**--It will be held at Spillane Law Offices, 1140 Washington Street, Hanover, MA. The Heart to Heart support meeting begins at 11 AM. All are welcome!!!

As always, this is a great opportunity for NMF members to meet and discuss anything and everything in our Marfan and related connective tissue day to day lives.

Please let me know if you are planning to attend. You can e-mail me at [jrmarfan58@aol.com](mailto:jrmarfan58@aol.com).

**8) MA Chapter Webpage**-check out our MA Chapter Web Page for a listing of all our 2012 meetings and events at: <http://www.marfan.org/marfan/3844/massachusetts-chapter> . I will continue to update it as more information become available.

**9) MA Chapter E-bay Site:** If anyone would like to donate an item to our E-bay site, please contact BOD member Shauna Morrissette at [slmorrissette@aol.com](mailto:slmorrissette@aol.com) . To date, we have raised over \$700 in net profit from the site to benefit our MA Chapter awareness programs. Here is the link to our page:

[http://shop.ebay.com/mass\\_chapter\\_nmf/m.html?\\_nkw=&\\_armrs=1&\\_from=&\\_ipg=25](http://shop.ebay.com/mass_chapter_nmf/m.html?_nkw=&_armrs=1&_from=&_ipg=25)

---Well that's it for now. Please, always feel free to write or call me with any questions, suggestions or anything you would like to discuss or need help with.

My Best,

Jon Rodis

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Chair-Physicians Awareness Committee

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Member-Winthrop Disability Commission

Home: 617-846-4975

MA Chapter Web Page: <http://www.marfan.org/marfan/3844/massachusetts-chapter>

MA Chapter E-bay Site:

[http://shop.ebay.com/mass\\_chapter\\_nmf/m.html?\\_nkw=&\\_armrs=1&\\_from=&\\_ipg=25](http://shop.ebay.com/mass_chapter_nmf/m.html?_nkw=&_armrs=1&_from=&_ipg=25)

NMF Website: [www.marfan.org](http://www.marfan.org)

JR Website: [www.jrmarfan58.com](http://www.jrmarfan58.com)