

Hi Everyone,

I hope you all enjoying your July 4th weekend. My wife Kathy and I are staying put this weekend and relaxing. We are going to have a very busy July. In addition to attending and giving our Disability workshop at the NMF conference in Portland, we are also presenting and attending at the Turner Syndrome and Ehlers Danlos conferences.

As you saw by the subject line in the e-mail, I have decided to provide quarterly updates (starting with this update) and I promise to continue to provide detailed and informative updates on meetings, events and anything and everything in our Marfan and related Connective Tissue Disorder world.

I hope that you are able to attend one or several of the upcoming events. If you have never attended one, I assure you it will be worth the effort.-*Please mark your calendars*-.

The following are our Summer (July-September) MA Chapter Updates and Reminders::

1) Chase Community Giving Program on Facebook:

With your support, we were able to reach the list of Top 25 Charities and receive \$45,000 for the NMF's, early diagnosis initiatives. In these hard economic times, this is couldn't have happened at a better time. Awesome!!!!

2) Celebration of Marfan Life and History II- Celebrating Our 20 Years as a Chapter of the NMF and 30 years of the NMF:

As I reported in our last MA Chapter Update, we knew that we were going to equal the net profit of last year's event (\$5,000) and hoped to surpass it by a few hundred. Our final total for the event was a net profit of \$5,374!!!!!!

Proceeds from CMLH II are going to our MA Chapter Scholarship Program to assist families who need financial assistance in attending the 2012 NMF Conference in Chicago. (Proceeds from CMLH I helped 5 families attend this years conference in Portland.)

For anyone who would like to donate to the MA Chapter Conference Scholarship Program or any of our other worthwhile programs and causes, please do. All checks should be made out to the 'MA Chapter of the NMF' and you can put in the memo section where you would like it to be used or include a note with your check. You can mail your checks to: Jon Rodis, President-MA Chapter of the NMF, 45 Pearl Ave, Unit # 3, Winthrop, MA 02152.

We appreciate everyone's help and generosity in raising funds and spreading awareness of Marfan syndrome, Loeys-Dietz and all related connective tissue disorders. With your

support, we are able to do so much and make a difference in so many peoples lives.
Thank You!!!!!!!!!!.

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

I hope that some of you are able to come to this year's conference in Portland. It truly is a wonderful experience in so many ways. I know some of you are going to attend next year's conference in Chicago because it's closer and you'll have a year to plan and budget for it. (quite understandable)

For those of you who are not very familiar with the NMF's conferences here is a short description that will help you learn more:

-If you want to attend workshops and presentations by world-renowned doctors and researchers, receive medical assessment by some of the top Marfan specialists in the country, share experiences with others who know and understand what you and your family deal with, and have a fun-filled and educational weekend, then go to the NMF's web site at www.marfan.org for more details.-

Note: At this year's conference, we are donating a signed picture of Martha Stewart for the Heart Mart on the MA Chapter's behalf.. Last year, Kathy and I donated a signed picture of Jack Nicholson for the Houston Heart Mart. All money raised at the Heart Mart go to next years national conference scholarship program.

4) NMF Membership Dues for July 2010-June 2011:

Don't forget to submit your membership dues to National-\$35 for individual membership or \$50 for family membership. The annual dues help the NMF to continue many of the national programs and initiatives it undertakes on all our behalf.

For more information go to www.marfan.org or call 800-862-7326.

5) Call for Volunteers:

-Hey MA Chapter NMF members, would you like to be a volunteer in a future MA Chapter event? Would you like to become a member of our chapter's 'Physicians Awareness Committee'? What about helping with the marketing and social media initiatives that has become mandatory in these fast paced, technically driven times?

If so, please feel free to contact Harrison Farnsworth (Secretary-Board of Directors) at harnsworth413@gmail.com and let him know what you would be interested in helping the Chapter with.

We have come a long way and with your support, we can continue to make a difference in raising awareness, supporting one another, and taking our chapter to 25 and beyond.

6) July 31st-Heart to Heart Meeting

Our next Heart to Heart meeting will be held at Children's Hospital Boston in Waltham, 9 Hope Avenue, Waltham, MA. The Heart to Heart support meeting begins at 11 AM. All are welcome!!!

This is a great opportunity for MA Chapter members to meet and discuss anything and everything in our Marfan and related connective tissue day to day lives.

Please let us know if you are planning to attend. You can e-mail me at jrmarfan58@aol.com..

Also, check out our MA Chapter Web Page for a listing of all our 2011 meetings and events at: <http://www.marfan.org/marfan/3844/massachusetts-chapter> .

6) August 4th-Board of Directors Meeting

The Chapter's Board of Directors Meeting will be held on Thursday, August 4th from 5 PM to 7 PM at Advanstar, 600 Union Park, 4th Floor, Woburn, MA.. All BOD meetings are open to the MA Chapter membership.

7) August 21st-MA Chapter Barbecue

This year's MA Chapter's Barbecue will be held in Methuen (Northern MA) on Sunday August 21st, starting at 1 PM at the home of Randy and Jennifer Levesque.

Randy and Jennifer Levesque's address is:

13 Deering Ave

Methuen, MA 01583

jennifer.levesque@verizon.net

Please RSVP Jennifer at her e-mail (listed above) by **August 12th**. Please send your name and the number of people attending.

We will provide the hot dogs, hamburgers and drinks. Please bring a dish to share and a lawn chair for yourselves. If you have children please bring toys, balls, Frisbees, etc.

We look forward to seeing some new faces, sharing information and making some new friends!!!

Note: There will be no RAINDATE due to our Annual Gathering the next month.

8) September 24th-MA Chapter Annual Get Together:

On September 24th, my wife Kathy and I will host the MA Chapter's Annual Get Together/Meeting at our home in Winthrop from 1 PM to 5 PM. We hope you can come.

---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

President-MA Chapter of the NMF

Chair-Physicians Awareness Committee

Chair-CMLH I and II

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

NMF Website: www.marfan.org

JR Website: www.jrmarfan58.com