

Hi Everyone,

I hope you all are doing well and looking forward to Spring that is just around the corner. As you will see by the information listed below, we have quite a lot going on and I hope that you are able to attend one or several of the upcoming events. Please mark your calendars.

The following are our most recent MA Chapter Updates and Reminders::

1) 3rd MA Chapter Marfan Raffle Results

--I want to thank everyone who bought tickets this year, as well as the last 2 years. We sold a total of 280 tickets (\$2,800) and minus the cost of the raffle items and the printing costs, we made close to \$2,000 for our awareness/support efforts.

Here are the winners of our 3rd MA Chapter Raffle:

Grand Prize: Apple iPad ----- Mr/Ms Hong

2nd Prize: Kindle Reader and \$50 Gift Certificate ----Kathy Patton

3rd Prize: \$100 Best Buy Gift Certificate ----Terry Walsh

2) Marfan Presentations/Meeting With Doctors from Childrens Hospital Boston and Brigham and Womens Hospital Boston Marfan Programs

--I wanted to let you all know that our MA Chapter Meeting with Childrens Hospital Boston and Brigham and Womens Hospital doctors has been set.

Here are the Details:

Date: April 7, 2011 (Thursday night)

Place: Brigham and Womens Hospital in Boston
Bornstein Ampitheatre (**on main level across from Cabot Atrium**)
45 Francis Street

Time: 6:30 PM - 8:30 PM

Topics to be covered:

1) CHB and BWH Marfan and Related CTD Programs

--How far have they come-where are they going-
--**Q & A**-(maybe have questions before hand)

2) Losartan Clinical Trial-Status

--Where are we now?

--The finish line and what that may entail.

3) New Diagnostic Criteria (Nosology) and What It Means To Us

--Important things to know.

-Q & A to follow presentations.-

--**Please let me know if you are planning to attend.** It is going to be a very informative presentation and an excellent opportunity to learn and share information with the heads of both Marfan and CTD Programs at Childrens Hospital and Brigham and Womens Hospital. We are grateful to Dr's Ronald Lacro, Michael Murray and Michael Singh for their time and continued support on all our behalfs.

3) ~Celebration of Marfan Life and History II-May 14, 2011-Celebrating Our 20 Years as a Chapter of the National Marfan Foundation~

In a little more than two months from now, the MA Chapter of the National Marfan Foundation is going to host our second 'Celebration of Marfan Life and History' fundraiser on May 14, 2011 at the American Legion Post 440 in Newton, Massachusetts from 7 PM to 11 PM. This year we will celebrate our 20th year as a Chapter of the National Marfan Foundation and the NMF's 30th year anniversary..

We are in the process of calling and e-mailing people to ask for early ticket purchases. This way when everyone comes to the event on May 14th, they can spend money on raffle tickets, silent auction items. etc. The tickets for the event are \$25 and \$30 at the door.

I am encouraging everyone to talk to their family, friends, colleagues, business contacts, medical contacts. etc to see if they would like to come and/or donate to the event. All checks should be made out to the 'MA Chapter of the NMF' and please put in the memo section of the check, 'CMLH II Fundraiser'.

All checks should be mailed to my address: Jon Rodis, 45 Pearl Ave, Unit # 3, Winthrop, MA 02152. Tax exempt certification is available for all company donations.

~Proceeds will go to our 'MA Chapter Conference Scholarship Program'.

Please feel free to call or write me with any questions. I appreciate everyone's help and support in our efforts to raise awareness of Marfan syndrome and in doing so, help save lives.

4) NMF National Conference 2011 in Portland, Oregon--July 14-17

-If you want to attend workshops and presentations by world-renowned doctors and researchers, receive medical assessment at one of the top Marfan clinics 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.

5) Our next BOD and Heart to Heart Meetings will be on **Sunday, April 17** at Spillane Law Offices located at 1140 Washington Street, Hanover, MA. The BOD meeting starts at 9 AM and the Heart to Heart begins at 11 AM. All are welcome!!!

This is a great opportunity for MA Chapter members who live on the South Shore 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> .

---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

Director-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