

Hi Everyone,

I hope you all are staying warm and enjoying the break from the snow. I don't think I have ever looked more forward to warmer weather than I do now. Let's all think warm thoughts. :)

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

1) MA Chapter Meeting with Doctors from CHB and BWH 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 behalves.

2) MA Chapter 3rd Annual Raffle

We are now underway with our 3rd Annual Raffle for our February Marfan Awareness Month. Last year, with your support, we raised over \$2,030 for our local chapter and it's awareness efforts. We have kept the ticket price at \$10 each to keep it affordable for everyone to purchase one or several tickets.

Here are the raffle details:

There will be three prizes in total including the following: *Grand Prize: I Pad* (worth \$500), *Second Prize: Kindle w/\$50 Amazon Gift Certificate* (worth \$189), and *Third Prize: \$100 Best Buy Gift Certificate*.

-The number of tickets sold as of March 5, 2011 will determine the odds of winning.

-The winning ticket will be drawn on March 7, 2011, in Winthrop, Massachusetts by one of the town's commissioners.

-All checks should be made out to the 'MA Chapter of the NMF' and please put " Raffle Tickets" in the memo section. Send your checks to my attention: Jon Rodis, 45 Pearl Ave, Unit # 3, Winthrop, MA 02152.

~As always, I deeply appreciate your continued support in our awareness work. Please feel free to write or call me if you have any questions.

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

In less than four months, 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.

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 the my address: Jon Rodis, 45 Pearl Ave, Unit # 3, Winthrop, MA 02152. Tax exempt certification is available for all company donations.

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) 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