

Hi Everyone,

I hope you all are doing well and that you are as ready as I am to see the sunshine. It has been not only gloomy but the weather has been a real 'pain' for most of us with joint and muscle issues.

As you will see by the information listed below, we still 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) Chase Community Giving Program-Vote for \$500,000 on Facebook:**

Details on the vote were sent to everyone in a separate e-mail today. It is important that we all vote for the NMF and increase our chances of winning the \$500,000 for early diagnosis initiatives.

**2) May 7th-Disability Resource Faire-Winthrop, MA**

On Saturday, May 7<sup>th</sup> at the Winthrop Senior Center, the Winthrop Disability Commission held its first Disability Resource Faire. At the event, there was information and resources from several state and federal organizations dealing with everything from social security disability issues to a wide spectrum of special needs/services for adults and children who have a variety of conditions/disorders that require assistance.

At the Faire, we were able to provide information on Marfan and Loeys-Dietz Syndrome to several healthcare organizations who attended as well as exhibited. We also spoke to a representative from House Speaker Robert DeLeo's office and answered their questions.

**3) May 14th-Celebration of Marfan Life and History II- Celebrating Our 20 Years as a Chapter of the National Marfan Foundation:**

The Massachusetts Chapter of the National Marfan Foundation hosted our second 'Celebration of Marfan Life and History' event on May 14, 2011.. This year we celebrated our 20th year as a Chapter of the National Marfan Foundation and the NMF's 30<sup>th</sup> year anniversary as well.

Among the highlights of our celebration of our 20th year as a Chapter of the National Marfan Foundation, we had a live performance of Jonathan Larson's 'Tick Tick Boom' , a 'Silent Auction' that included a seven night stay at the Manhattan Club in New York City valued at \$2,500, a Southwest Airlines Voucher for two worth \$800 and a Boston Bruins Jersey signed by the entire team valued at \$1,200, and a commemorative poster of the Chapter's history (which can be purchased-details to come) as well as a timeline of the NMF's 30 year history.

To commemorate the event, Richard Saltus (who was President of the MA Chapter from 1991-2003) read a letter from the National Marfan Foundation's President and CEO, Carolyn Levering congratulating us on our 20 years. In addition, my wife Kathleen (in my stead) read a letter from Priscilla Ciccariello (who is considered by many to be the mother of the NMF) that honored the efforts of everyone who was a part of this chapter's rich history.

In regards to how we did overall, I am happy to report that we are definitely going to equal the net profit of last year's event (\$5,000) and more than likely surpass it by a few hundred.

For anyone who hasn't donated and would like to, there still is time. We are keeping the books open till May 31<sup>st</sup>.. 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. 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.

We appreciate everyone's help and support in our efforts to raise awareness of Marfan syndrome and in doing so, help save lives.

#### **4) MA Chapter Conference Scholarship Program**

With the proceeds from CMLH I, the MA Chapter will be sending and helping to send five families to Conference this year in Portland, Oregon that otherwise would not have been able to attend.

I want to thank Vice-President, David Donato and Board member, Richard Saltus for their work in heading the Massachusetts Chapter Scholarship Committee. I also want to thank Jennifer Buffone, Director of Support Services and Development of the NMF for all her help and support in this endeavor

With next year's Conference being held in Chicago, we look forward to using our funds from CMLH II to assist even more families from Massachusetts and around New England to attend

#### **5) May 21<sup>st</sup>-Phillips Family Fund Benefit-Grafton, MA:**

As I reported in last month's chapter update, the Phillips Family Fund was started for Joshua Phillips and his family to fund renovations to the apartment he lives in with his wife and 2 young children.

The Phillips Family Fund was set-up to raise money for these renovations as well as any equipment he may need that the insurance will not cover.

On behalf of the MA Chapter, the Board of Directors voted unanimously to donate \$500 to the Phillips Family Fund.

Once I receive an update from the Phillips Family on the benefit they had yesterday, I will send an update to the chapter.

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

-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](http://www.marfan.org) for more details.

**7) 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 [hfarnsworth413@gmail.com](mailto:hfarnsworth413@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.

**8) July 31<sup>st</sup>-Our Next Heart to Heart Meeting** will be 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](mailto: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

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)