

Hi Everyone,

I hope you all are doing well and that you enjoyed your three day weekend.. 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) April 7th-Marfan Presentations/Meeting with Doctors from Childrens Hospital Boston and Brigham and Womens Hospital Boston Marfan Programs:

First of all, we would like to thank Dr. Lacro, Dr. Murray, Dr. Singh, Monica Giovanni and Martha King for their wonderful presentations and their time and commitment to this event.

We had a very good turnout for a weeknight and the attendees were not only able to hear the most up to date information on the clinical trials on Losartan, a clearer understanding of the new diagnostic criteria for Marfan syndrome and more information on both Marfan Programs at Childrens and Brigham and Womens Hospitals, but also were able to ask questions on all these topics and whole lot more.

We look forward to future presentations and welcome more of your input on what subjects you would like to have covered.

2) April 15th-Clinical Research News

Science Daily-- <http://www.sciencedaily.com/releases/2011/04/110414141402.htm>

3) May 7th-Disability Resource Faire-Winthrop, MA

On Saturday, May 7th from 1 PM to 4 PM at the Winthrop Senior Center at 35 Harvard Street, the Winthrop Disability Commission is holding a Disability Resource Faire. At the event, there will be 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.

For more information on the Faire, contact Commissioner, Lee Dzedulionis at lee1040@aol.com.

4) May 14--Celebration of Marfan Life and History II- Celebrating Our 20 Years as a Chapter of the National Marfan Foundation~Newton, MA:

In a little less than a month 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..

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

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.

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.

5) May 21st-Phillips Family Fund Benefit-Grafton, MA:

The Phillips Family Fund was started for Joshua Phillips and his family. Josh is a husband, father, son, brother, Grafton resident as well as many other things. He had his first surgery 3 years ago to repair his Ascending Aorta, there were no complications and he was back to work in 8 weeks. The next surgery was on March 11th 2011. After 20 hours of surgery to repair his Descending Aorta he was left paralyzed from the waist down. After being in the hospital since the beginning of March, he is hopeful to be home by the end of April.

The apartment he lives in with his wife and 2 young children however cannot accommodate him. His mother has offered to have Josh and his family move in with her into her ranch house that with work can be assessable to him. This is where your help is needed. This benefit is to raise money for these renovations as well as any equipment he may need that the insurance will not cover.

The family is asking for donations for the fundraiser. Donations could be Gift Certificates and/or products that can be used in a raffle as well as food that can be sold to the guests and paper products for serving food. Any kind of donations are appreciated and will help the family reach their goal. The Phillips Family Fund has been started with Citizen's Bank; monetary donations can also be made directly to the bank as well.

The event is at The American Legion, 69 Worcester St, Grafton MA 01519 from 3pm-8pm The tickets are \$10. per person and food and raffle tickets will be available for purchase.- For more information, call Carla Phillips at 508-887-0622 or e-mail her at ibleaveinmiracles@hotmail.com .-

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 for more details.

8) The NMF-30 Years-What It Means To Me

The NMF is seeking 30th Anniversary Marfan Stories:

Were you diagnosed with Marfan syndrome in or around 1981? Were you born in 1981 and diagnosed at birth or later with Marfan syndrome? If so, we want to hear about your Marfan story.

The NMF is collecting stories about people who meet the above criteria. As part of our 30th anniversary celebration, we want to highlight you on our website, in our media outreach and in other ways.

Interested? Please send us your Marfan story – no more than 500 words – via email. Tell us your name, age and your diagnosis story, who else in your family is effected and how the NMF has helped you in your Marfan journey. Include your contact information as we may want more information. You can send your submission to publicity@marfan.org.

9) July 31st-Our Next Heart to Heart Meeting will be at Childrens 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> .

---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