



Bergen ME/ CFS-FM Support Group Newsletter

Meeting

Weather forced the cancellation of the holiday gathering in December. The members of the team hope you each had a happy & healthier holiday season.

The social gathering has been rescheduled for the meeting on January 17th. As with the December celebration, you are welcome to bring something for the sharing table. In the past, members have brought a wide variety of goodies to the table, from appetizers to desserts. You are welcome with or without donating toward the sharing table. It is a nice time to socialize with other members.

2009 News in Review

The news that brought perhaps the largest spotlight to ME/CFS during 2009 was the publication of Whittemore Peterson Institute paper on XMRV. At this time, the significance of the relationship of XMRV to ME/CFS is unknown. At present, there is no change in diagnostics or treatment. Several researchers will repeat the study.

Dr. Derek Enlander of New York and Dr Jonathan Kerr of London are jointly conducting a similar XMRV study. Dr. Enlander is seeking research volunteers both ME/CFS patients and controls. Interested people should contact Joy by email ENLANDERCFS@YAHOO.COM asking for an appointment so that blood can be drawn. The study is a nine month double blind study and it is FREE. Specimens will be frozen and sent to London. Contributions to help with the freight would be appreciated.

Dr. Enlander shared a bit of information. Individual tests may be available from the Nevada lab, but it is expensive. He thinks they charge \$600. His advice is not to spend your money on the test as there is no confirmation of the study or new treatment based on the result, at this moment.

Sharing Holiday Joy – Thank You

Donated toys were delivered to Barbara Comerford for her Christmas charity event in Newark. She was very thankful and appreciative. Barbara asked us to please pass along her thanks to everyone who donated toys! Barbara thanks you very much!!

Info on XMRV

Dr. Donnica Moore, a popular authority on Women's Health and a frequent guest speaker on TV shows, recently addressed ME/CFS on both Good Morning America and The Dr. Oz Show. Below are the links to those presentations. Information about Dr. Donnica can be found at www.drdonnica.com/display.asp?document=Bio. While at the site, you can do a "search" for Chronic

Fatigue Syndrome to read some of Dr. Donnica's work. Dr. Donnica is also a past board member of the NJCFSA.

- "Good Morning America Health" segment on "What is CFS?"
<http://abcnews.go.com/Video/playerIndex?id=8664151>
- "Good Morning America Health" segment on the Science paper from WPI discussing the XMRV/CFS findings: <http://abcnews.go.com/video/playerIndex?id=8864348>
- The Dr. Oz Show segment about XMRV & CFS http://www.youtube.com/watch?v=_WEUC7hRXzM
- Companion article to Dr. Oz Show segment <http://www.doctoroz.com/videos/what-chronic-fatigue-syndrome-and-how-xmr-v-related>

Coming Events

- The NJCFSA Conference is set for Sunday October 17, 2010. The program line-up will be announced in the near future. Mark your calendar. It will be a great day.
- Watch for the announcement of an additional NJCFSA event this spring. Information will be sent as soon as the details are completed.

Next Meeting

The next meeting will be held on Sunday January 17th. Agenda – rescheduled holiday social.

This newsletter is intended for CFS & FM patients in the area of this support group. The purpose is to share information and support. If you have questions about meetings please contact: Pat LaRosa at pcl.njcfsa@gmail.net, Nancy Visocki at ngv.njcfsa@verizon.net, Judy Machacek at judymachacek@msn.com or leave a voice message at the NJCFSA HelpLine 888-835-3677 during business hours.

***WEATHER** – In the event of bad weather, or other emergency, we encourage you to check your email before leaving for Englewood. If it has been decided that a meeting will be canceled, an email will be sent via the yahoogroups list. The Hospital will also be notified of the cancellation. The email posting also applies to a cancellation of the First Wednesday of the Month luncheon which is an informal gathering, an opportunity for people to meet and chat with other members.*

May 2010 bring more acceptance of ME/CFS and FM in the medical community
and
may we find ourselves a step closer to treatment and a cure.