



Bergen ME/ CFS-FM Support Group Newsletter

Meeting Report

The meeting featured open discussion covering a wide range of topics, including alternative therapies. Gentle yoga and chair yoga have been helpful for some people, as has Tai Chi Chih (a gentle form of Tai Chi.) There was also discussion about some “natural” therapies that may or may not be beneficial or safe. You are urged to be cautious about the word “natural” which is not necessarily synonymous with “safe.” Many poisons are also “natural” - and it is quite common to be allergic to “natural” substances, such as peanuts and many others.

If you are considering a new therapy, there are a few strategies you might keep in mind.

- Check for information from a source not connected to the distributor or manufacturer.
- Look for articles in scientific journals. They often publish studies on alternatives.
- Discuss your interest in a therapy with your physician. Ask if he/she is familiar with it and ask his/her opinion.
- The decision to try a therapy is yours, but be sure to know the facts about how it may impact your overall health.
- Inform your physician – even if you are going against medical advice. Your doctor needs to know, so you can be monitored for interactions and/or side effects.

Also discussed was the possibility of appealing an insurance denial. One attendee asked if it was possible for us to provide a basic form letter that could be used for the appeal. A Google search revealed many samples of appeal letters. The Bergen ME/CFS/FM Support Group cannot endorse these sites nor vouch that the letters will be effective, but they may provide a starting point for those who wish to file an appeal. Below are links for a few of those letters.

<http://www.insure.com/articles/healthinsurance/claim-denial-appeal.html>

http://www.bankrate.com/brm/news/Financial_Literacy/Aug07_claim_denial_network_letter_a1.asp

<http://www.patientadvocate.org/index.php?p=36>

http://www.fixmyclaim.com/letters_of_appeal.php

http://www.pueblo.gsa.gov/cic_text/health/drugplan/drugplan.htm

http://professional.medtronic.com/wcm/groups/mdtcom_sg/@mdt/@neuro/documents/documents/dbs-reimb-ocd-appeal.pdf

http://www.pparx.org/en/prescription_assistance_programs/list_of_participating_programs

<http://www.gooddaysfromcdf.org/patients/process>

On behalf of the leadership team, may the New Year find you in better health.

Celebrate the New Year

Last year, the holiday party was moved to January. We realized that our members were already struggling with the activities of the season. The decision proved to be successful and those who attended enjoyed being relaxed and rested. We have decided to make it an annual event – the January Holiday Party. Members are invited to bring something for a sharing table. Finger foods are preferred, but whatever you wish to bring is great - desserts, hors d'oeuvres, small sandwiches, cheese & crackers, soda - whatever. It is your choice. For those who cannot bring anything, please come and be with the group. As always, you are welcome to bring a friend or family member. Coffee, tea and paper products will be provided.

Thank You

Barbara Comerford has asked that we extend “profound thanks” to all who helped her make Christmas special for a some children whose families could not afford to buy gifts.

ME/CFS in the News

There are exciting things happening at the NIH.

In a meeting last fall following the CFSAC (federal advisory committee) newly appointed Chair of the Trans-NIH ME/CFS Research Working Group, Dennis F. Mangan, Ph.D. announced that he would be using the ME/CFS acronym instead of CFS.

Just after Christmas, Dr. Mangan announced the formation of a team that will be preparing for a meeting to be held in April. It has been titled: “State of the Knowledge Workshop on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS).” He has been working with leadership representatives of groups across the country and NJCFSA’s co-presidents are among those who have been in dialogue with him.

Organizations were asked for nominations from known patients/patient advocates to fill 2 seats on the committee. Cort Johnson of Phoenix Rising and Mary Schweitzer, PhD – a long term patient and patient advocate were selected from those nominated. Dr Mangan also invited NJCFSA trustee, Ken Friedman to sit on the committee. Others on the committee include: Nancy Klimas, MD; Suzanne Vernon, PhD; representatives from the NIH, NIAID (National Institute of Allergy & Infectious Diseases), the CFSAC and other institutes and agencies. The first meeting was held on January 6th and the feedback has been very positive,

The following note is about a list serve, if you wish to receive updates from the NIH.

Dear ME/CFS investigators, patients, advocates, writers, families and friends:

An email listserv has been set up to enable information to be sent to you quickly and more frequently regarding NIH ongoing activities associated with ME/CFS research and the NIH ME/CFS Working Group activities. This will include informing you of new postings on the soon-to-be-released NIH Working Group website (still under construction).

If you wish to subscribe to this free list service, please do the following:

Send an email from your preferred computer address to LISTSERV@LIST.NIH.GOV

The text of the message should read: `SUBSCRIBE NIH_ME/CFS_WG-L {YOUR FIRSTNAME AND LASTNAME}`

You will then receive an email and must confirm your desire to join the list. You can unsubscribe from the list at any

time.

Please note that this is an information only email list service... not an Internet discussion forum.

All the best, Dennis

PS: please share this announcement with others on your email lists who might wish to join!

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XMRV Comment

Turning Today's Discoveries Into Tomorrow's Cures

http://www.wpinstitute.org/news/docs/WPI_XMRV_010111.pdf

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XMRV: A Human Retrovirus with Unknown Pathogenic Potential, Not a Lab Contaminant

The recent proclamation that “XMRV is not the cause of CFS,” came from an individual who did laboratory experiments to show how PCR experiments can become contaminated. These results have nothing to do with the reality of a disease or the methods used by those who have detected XMRV in the blood and tissue of patients found to be infected. The positive studies, which cannot be explained away by PCR experiments, are those which have used multiple methods to show that XMRV is a live replicating gamma retrovirus in human blood and tissue samples using the gold standard methods of viral isolation and antibody testing, in addition to PCR.

Unsupported conclusions, such as the one offered by the Wellcome Trust spokesman, often create sensational headlines but do little to move science forward. Authors of the positive XMRV studies have been extremely careful not to claim causality, realizing that more scientific research is required to make such a statement. However, one fact still remains clear. Not one of the negative studies changes the results of the scientific research done by Lombardi et al., Lo et al., Urisman et al., and Schlaberg et al.

The WPI-led scientific study, which rigorously ruled out contamination, revealed high associations of gamma retroviruses with physician-diagnosed CFS patients, using four different methods of detection. Recent commentary associated with the negative research papers on XMRV, which used only one testing method, claimed that these studies proved that XMRV was not the cause of human disease. On the contrary, what the authors of the “contamination studies” confirmed is something that most experienced scientists already know; there are risks associated with using PCR if one does not properly control for contamination. They cannot conclude that other research groups had the same problems or that “XMRV is not the cause of CFS”.

Most significantly, the recent *Retrovirology* publications failed to address the most important pieces of scientific evidence of human infection in the previous XMRV studies, including the fact that XMRV positive patients produce human antibodies to gamma retroviruses, XMRV integrates into human tissues, and infectious virus has been cultured from the blood of hundreds of patients with a diagnosis of Chronic Fatigue Syndrome and M.E. Humans do not make antibody responses to mouse DNA sequences from contaminated lab experiments. The *Retrovirology* studies only point out that XMRV research cannot be done in a mouse laboratory without extreme caution and should not rely solely on PCR methods.

Many researchers realize that the question of gamma retroviruses and human disease cannot and should not be dismissed lightly. Retroviruses integrate into their host's DNA causing lifelong infection. Human retroviruses, such as HIV and HTLV-1, are causative for immune deficiencies, neurological disease and cancer. Animal studies involving XMRV demonstrate that the virus moves quickly away from the blood to various organs within the body, such as the spleen, lymph nodes, GI tract, and reproductive organs. This helps to explain why the virus is difficult to detect in blood even as it replicates in the tissues of those infected. Other studies using mouse models of Murine Leukemia Virus

infection, a close relative of XMRV, have shown significant tissue involvement soon after infection, resulting in many physical symptoms of disease including cognitive deficits and immune deficiencies, symptoms which are well documented in patients with XMRV associated diseases.

Many anxious patients have asked, “Where do we go from here?” and “Is this the end of XMRV research?” The answer to the second question is an unequivocal “no.” As to the first question, a quick check of the status of ongoing research in various labs confirms that the research groups who have been working on XMRV over the past year are still hard at work developing better assays to check the world’s blood supply for the new retrovirus, finding correlates of immune dysfunction, engaging in animal studies, extending their findings to other groups of patients, and in general, enthusiastically continuing their research. They understand that novel scientific discoveries, which threaten current dogma, will continue to be challenged until the evidence can no longer be denied. For instance, there are still those few who question the fact that HIV is the cause of AIDS. It took Nobel Prize winner, Dr. Barry Marshall, 17 years and three trials in which he infected and then cured himself of H-Pylori associated ulcers, before the medical world would accept the fact that the bacterium causes the disease. Today we are engaged in a new battle to prove that human gamma retroviral infections, such as XMRV, are underlying pathogens in neuro-immune diseases and untold cancers.

It is clear that more research must be done to clarify the role of gamma retroviruses in human disease. However, when a pathogen such as XMRV is found in over 80% of those tested with the same diagnosis, causality is clearly a reasonable hypothesis that begs further scientific and medical research. It is a known fact that important questions of causality can often be answered through well designed clinical trials. For those who have suffered for years from these debilitating diseases, novel drug trials cannot begin soon enough.

WPI’s collaborative research projects are revealing the infectious and inflammatory nature of neuro-immune diseases, providing strong evidence against the use of CBT and exercise therapy as rational “treatments” for those who are ill. Such knowledge underscores the urgent need for much more private and federal funding of biological research to provide diagnostic tests and effective drug therapies for the millions who are ill, stop the spread of infectious retrovirus(es), and end the devastating cycle of disease.

Annette Whittemore
President
Whittemore Peterson Institute

Next Meeting

The next meeting will be held on January 16th. The January meeting is the annual holiday party. See note elsewhere in this newsletter for details

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: Nancy Visocki at ngv.njcfsa@verizon.net, Judy Machacek at judymachacek@msn.com, Pat LaRosa at pcl.njcfsa@gmail.net or leave a voice message at the NJCFSA HelpLine 888-835-3677 during business hours.

WEATHER or EMERGENCY – *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.*