



Bergen ME/CFS-FM Support Group Newsletter

Meeting

There was no meeting in October since it coincided with the NJCFSA Conference. “NEW INITIATIVES IN TREATMENT, DIAGNOSIS, AND DISABILITY FOR CHRONIC FATIGUE SYNDROME (ME/CFS)” was a huge success with a near capacity crowd. Complete coverage of the conference will be included in the next issue of the NJCFSA Journal which will be sent to NJCFSA members when it is completed in late winter. The video version will hopefully be available for purchase from the NJ CFSA Library in the near future. Notice of its availability will be announced on the www.njcfsa.org website.

Study

For those who may not have seen or heard of the following study in the media, we are including the recent press release. It should be noted that other viruses have also been found to have associations with ME/CFS. What makes this news exciting is that the percentage of those in whom the virus was found is high. The implications of the results are not yet known and further studies will be needed. At this point, testing positive is not reason for treating. The publicity the study has garnered is very noteworthy.



EMBARGOED FOR RELEASE Thursday, October 8, 2009 2 p.m. EDT **Consortium of Researchers Discover Retroviral Link to Chronic Fatigue Syndrome** Whittemore Peterson Institute <http://www.wpinstitute.org>
Cleveland Clinic www.clevelandclinic.org National Cancer Institute (NCI) www.cancer.gov

Consortium of Researchers Discover Retroviral Link to Chronic Fatigue Syndrome

Scientists have discovered a potential retroviral link to chronic fatigue syndrome, known as CFS, a debilitating disease that affects millions of people in the United States. Researchers from the Whittemore Peterson Institute (WPI), located at the University of Nevada, Reno, the National Cancer Institute (NCI), part of the National Institutes of Health, and the Cleveland Clinic, report this finding online Oct. 8, 2009, issue of Science.

“We now have evidence that a retrovirus named XMRV is frequently present in the blood of patients with CFS. This discovery could be a major step in the discovery of vital treatment options for millions of patients,” said Judy Mikovits, Ph.D., director of research for WPI and leader of the team that discovered this association. Researchers cautioned however, that this finding shows there is an association between XMRV and CFS but does not prove that XMRV causes CFS.

The scientists provide a new hypothesis for a retrovirus link with CFS. The virus, XMRV, was first identified by Robert H. Silverman, Ph.D., professor in the Department of Cancer Biology at the Cleveland Clinic Lerner Research Institute, in men who had a specific immune system defect that reduced their ability to fight viral infections.

“The discovery of XMRV in two major diseases, prostate cancer and now chronic fatigue syndrome, is very exciting. If cause-and-effect is established, there would be a new opportunity for prevention and treatment of these diseases,” said Silverman, a co-author on the CFS paper.

Commonality of an immune system defect in patients with CFS and prostate cancer led researchers to look for the virus in their blood samples. In this study, WPI scientists identified XMRV in the blood of 68 of 101 (67 percent) CFS patients. In contrast, they found that eight of 218 healthy people (3.7 percent) contained XMRV DNA. The research team not only found that blood cells contained XMRV but also expressed XMRV proteins at high levels and produced infectious viral particles. A clinically validated test to detect XMRV antibodies in patients' plasma is currently under development.

These results were also supported by the observation of retrovirus particles in patient samples when examined using transmission electron microscopy. The data demonstrate the first direct isolation of infectious XMRV from humans. “These compelling data allow the development of a hypothesis concerning a cause of this complex and misunderstood disease, since retroviruses are a known cause of neurodegenerative diseases and cancer in man,” said Francis Ruscetti, Ph.D., Laboratory of Experimental Immunology, NCI.

Retroviruses like XMRV have also been shown to activate a number of other latent viruses. This could explain why so many different viruses, such as Epstein-Barr virus, which was causally linked to Burkitt's and other lymphomas in the 1970s, have been associated with CFS. It is important to note that retroviruses, like XMRV, are not airborne.

“The scientific evidence that a retrovirus is implicated in CFS opens a new world of possibilities for so many people,” said Annette Whittemore, founder and president of WPI and mother of a CFS patient. “Scientists can now begin the important work of translating this discovery into medical care for individuals with XMRV related diseases.”

Dan Peterson, M.D., medical director of WPI added, “Patients with CFS deal with a myriad of health issues as their quality of life declines. I'm excited about the possibility of providing patients, who are positive for XMRV, a definitive diagnosis, and hopefully very soon, a range of effective treatments options.”

Reference: Lombardi VC, Ruscetti FW, Gupta JD, Pfof MA, Hagen KS, Peterson DL, Ruscetti SK, Bagni RK, Petrow-Sadowski C, Gold B, Dean M, Silverman RH, and Mikovits JA. Detection of Infectious Retrovirus, XMRV, in Blood Cells of Patients with Chronic Fatigue Syndrome. Online October 8, 2009. *Science*.

The Whittemore Peterson Institute for Neuro Immune Disease exists to bring discovery, knowledge, and effective treatments to patients with illnesses that are caused by acquired dysregulation of both the immune system and the nervous system, often resulting in lifelong disease and disability. www.wpainstitute.org.

The Lerner Research Institute is home to Cleveland Clinic's laboratory, translational and clinical research. Its mission: to promote human health by investigating in the laboratory and the clinic the causes of disease and discovering novel approaches to prevention and treatments; to train the next generation of biomedical researchers; and to foster productive collaborations with those providing clinical care. More than 1,200 people in 11 departments work in research programs focusing on cardiovascular, cancer, neurologic, musculoskeletal, allergic and immunologic, eye, metabolic, and infectious disease. The Institute also is an integral part of the Cleveland Clinic Lerner College of Medicine of Case Western Reserve University.

The National Cancer Institute (NCI) leads the National Cancer Program and the NIH effort to dramatically reduce the burden of cancer and improve the lives of cancer patients and their families, through research into prevention and cancer biology, the development of new interventions, and the training and mentoring of new researchers. For more information about cancer, please visit the NCI Web site at <http://www.cancer.gov> or call NCI's Cancer Information Service at 1-800-4-CANCER (1-800-422-6237).

Surviving the Holidays

<http://www.americanchronicle.com/articles/view/80675>

Ten Holiday Survival Tips For the Chronically Ill

Lourdes Salvador

November 09, 2008

The holidays can be a stressful time for nearly anyone. But for those with chronic illness, the schedule, social demands, and additional things to do can simply be impossible. People with multiple sclerosis, multiple chemical sensitivity, chronic fatigue syndrome, fibromyalgia, and other invisible illnesses appear normal, but have a disability which makes day-to-day living difficult. The increased demands of the holidays can easily become overwhelming and frustrating, especially when family and friends do not understand the extent of an invisible disability. Here are ten tips to surviving and enjoying the holidays.

1. Start planning and shopping early by making a to do list.
2. Avoid the stress, crowds, exposures, and hassles of shopping by employing alternatives such as buying gifts online.
3. Take care of yourself by sticking to your normal foods and routine.
4. When entertaining, stipulate the rules on party invitations. If no fragrances are allowed, provide safe clothing and shower access for guests to use when arriving. If you don't want to entertain all night, be sure to specify the time the party ends. Ask guests to bring a pot luck dish to reduce energy expended cooking and cleaning up. Ask guests to help out.
5. When going to a gathering away from home... If dietary needs may not be met, bring a dish of food that you tolerate to eat and share with others. Bring your own vehicle and make a short appearance at a gathering if you are unable to stay for the duration or your family wishes to stay longer. If fragrances are of concern, wear layered clothing or a cover-up and bring a mask. A paraplegic would not show up without a wheel chair. You should not show up without your medical equipment either.
6. Plan to do nothing or lighten your schedule a few days before and after an event.
7. Just say no. It's okay to pass on activities and outings, especially if accommodations will not be made for you. Your first priority is you.
8. Speak to your friends and family in advance to outline your needs and make plans.
9. Avoid making commitments you may not be able to keep. This will lessen the pressure you feel and you'll win more points if you say maybe and no show than if you say yes and no show. And if you happen to show up in spite of "maybe", everyone will be delighted.
10. Pace yourself. It's better to enjoy only one activity than be in bed for two weeks because you attempted several activities.

This article originally appeared in the MCS America News, November 2008 Issue. <http://mcs-america.org/november2008.pdf>. For more articles on this topic, see: [MCSA News](#).

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Sharing Holiday Joy

There are many children for whom the holidays are not like the pictures portrayed in the media. Without angels, many of them might not receive any gifts. Each year, Attorney Barbara Comerford works very hard to make sure some children have wonderful memories to treasure by hosting parties and distributing gifts. Last year some of you helped her efforts by donating toys. I asked Barbara if she would like us to reach out to you asking for help. Barbara replied that this year she would be providing gifts for young homeless children at a location in Newark and also at a small struggling mission in another town. "Any toys would be greatly appreciated. Thank you!" Donations can be brought to the Bergen Support Group November meeting and the December luncheon. You can also contact us at pcl.njcfsa@gmail.com for other arrangements.

Staying Healthy



An Ounce of Prevention

Wash hands often with soap and water. Wash between fingers, under nails, wrists and backs of hands. Wash for at least 20 seconds – enough time to sing Happy Birthday twice.

Use paper towel or air dry. Do not shut off water or touch door handle/knob with clean hands. Use the paper towel or elbow.

In a hand-washing areas used by more than one person (including your home) paper towels are preferable to fabric ones to avoid the spread of germs.

Use hand sanitizer frequently when soap and water are not available. It will not remove dirt – for that you need soap and water. Hand sanitizer must be at least 60% alcohol to be effective. Be sure to include backs of hands, between fingers, fingernails and wrists. Keep the sanitizer out of the reach of small children. Avoid use on children and infants who put their hands in their mouth.

Do not use near people with Multiple Chemical Sensitivity.

Cough or sneeze into a tissue, or into your upper elbow or upper sleeve – instead of your hand. Discard used tissues immediately in trash.

If you feel ill, are coughing or have a fever – STAY HOME.

2009

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 decide 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 lunch gathering. This is an informal gathering, an opportunity for people to gather and chat with other members.*