

GORDON MEDICAL ASSOCIATES

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XMRV Related to Chronic Fatigue Syndrome (CFS)

By now, you may have heard about the new retrovirus that has been associated with CFS/ME (Chronic Fatigue Syndrome/Myalgic Encephalomyelitis), prostate cancer, and possibly other diseases. On October 8, 2009, scientists from the Whittemore Peterson Institute (WPI) announced that the infectious retrovirus, XMRV (xenotropic murine leukemia virus-related virus), was found in 67% of CFS patients they tested. Their groundbreaking paper is published in *Science*, a highly respected journal of original scientific research, global news, and commentary. The paper, "Detection of Infectious Retrovirus, XMRV, in the Blood Cells of CFS Patients," is a major breakthrough in understanding this disease, containing the possibility of hope for many.

After the paper was originally submitted for publication, the researchers refined their testing, and are now finding the virus in 95% of all CFS/ME patients tested. Only 4% of controls show the virus in their blood. "This finding clearly points to the retrovirus as a contributing factor in this illness," says Judy Mikovits, Ph.D., leader of the team who discovered the connection of XMRV to CFS/ME.

This landmark study was the first to isolate XMRV particles from the blood, and to show it can be transmitted between blood cells. XMRV was first discovered in the prostate cancer tissue of men with a specific genetic defect. A similar immune system defect in CFS/ME sufferers led researchers to look for the virus in banked blood samples from several medical practices in the United States. Other retroviruses, such as HIV and HTLV-1, are known to cause cancer and immune deficiencies in humans.

This study showed that XMRV can be found in human blood cells and is infectious. Researchers have confirmed this retrovirus is transmitted through body fluids and is NOT airborne. While there is the possibility of transmission, Stuart Le Grice, director of the National Cancer Institute's Center of Excellence in HIV/AIDS and Cancer Virology, emphasized that traces of the virus had been found in blood samples preserved for as long as 25 years. "This is not associated with a new and spreading disease. We are not on the verge of an epidemic," he said.

Dr. Judy Mikovits attended our April 2009 symposium for international researchers of chronic neuro-immune diseases, organized by Gordon Medical Associates. These researchers have formed a loose affiliation, operating under the name the Sonoma Working Group (SWG). Since April the SWG, connecting some of the top names in CFS, Lyme, Autism, MCS and other neuroimmune diseases, has continued to pool information, benefitting patients around the world. GMA has been privileged to assist Dr. Mikovits in determining prevalence of this retrovirus in people with Chronic Fatigue Syndrome, Fibromyalgia, and chronic Lyme disease. We were able to provide samples to Dr. Mikovits from our patients and staff in order to expand the data pools the researchers are testing for XMRV.

Dr. Mikovits and her group are working hard to make sense of what the next step should be. She expects to have a good, commercially available test for XMRV within the next several months, possibly even sooner. Currently the best test is only available for research purposes. We suggest you wait until the best testing is available.

Some patients have also asked about the test available for RNASE panels at VIP lab, which tests for the original immune defect that pointed to XMRV. We found this test does not have clinical value, nor does it seem to show whether a patient is likely to have XMRV. A recent study of 38 CFS patients at GMA, tested with the RNASE panel, found it was not helpful in directing treatment at this time. Dr. Mikovits' study on CFS patients also found the RNASE panel did not indicate who would have XMRV. We do not recommend that you spend money on this test. As soon as there is a good XMRV test available, outside of research opportunities, we will let you know!

As yet, no specific treatment protocol has been worked out. While XMRV has some similarity to HIV, in that they are both retroviruses, we don't know whether HIV treatments will be useful, nor do we know if our CFS/Lyme/FMS patients would be able to tolerate them. The Sonoma Working Group, in addition to Dr. Mikovits, are focusing a great deal of attention on possible treatment protocols. As soon we know more, we will let you know!

It has been tremendously exciting to see the level of cooperation develop in the SWG, between a group of clinical practitioners and researchers. Research into CFS has been notoriously contentious. Seeing everyone working to pull the various theories together to support this finding underscores the importance of the discovery of XMRV. GMA feels incredibly fortunate to be intimately involved with the future of this research.

Until more is known, take heart!

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For more Information on XMRV:

<http://www.wpoinstitute.org>