

The news and developments on XMRV are listed in descending order with the most recent first. Check out [XMRV Articles](#) for lectures & podcasts

August 24, 2010

In October 2009, a study was published associating Chronic Fatigue Syndrome with a particular retrovirus called XMRV. Four subsequent published studies failed to find XMRV in patients with CFS.

Yesterday afternoon, a new study was published by the U.S. National Academy of Sciences. This study again failed to find XMRV. However, XMRV is part of a broader family of retroviruses called Murine Leukemia Virus (MLV)-related viruses. The study found evidence of MLV-related viruses in 32 of the 37 patients they tested (86.5%), and in only 3 of 44 healthy volunteers (6.8%). This means that the retroviral theory for CFS is still very much alive. It has been expanded to looking at the broader range of retroviruses.

The position of the National ME/FM Action Network is that this announcement is very exciting. It has the potential to lead to a better understanding of CFS and to prevention and treatment strategies. Retroviruses may also be a factor in related illnesses like Fibromyalgia. However, we recommend that patients be cautious until more research is in place. The authors themselves identify the need for more research into

- whether the same strong association with MLV-related viruses is found in other groups of patients with CFS
- whether these viruses play a causative role in the development of CFS, and
- whether they represent a threat to the blood supply.

There is a need for much more research around the world but also here in Canada. The Canadian Institutes of Health Research (CIHR) is the primary funding organization for health research in Canada. CIHR maintains a data base showing the grants it has funded recently. The database shows over 6,000 grants worth over \$1.5 billion. Not a single grant descriptions even mentions Chronic Fatigue Syndrome. We encourage you to contact your Member of Parliament and ask for immediate funding for follow-through research.

We are monitoring the response of the Canadian media to this announcement. The release prepared by Associated Press has already been picked up by CTV, CBC and by the Winnipeg Free Press. We expect it to be picked up by other media. We encourage you to add your comments where possible.

Lydia E. Neilson, M.S.M., Founder and Margaret Parlor, President
Chief Executive Officer
National ME/FM Action Network

[Findings by Reno scientists confirmed by U.S. government Read full article](#)
August 16, 2010

In the News

FRED FRIEDBERG, PhD, PRESIDENT OF THE IACFS/ME SPEAKS OUT ON XMRV STUDIES

July 30, 2010

Science and the Hold on XMRV Studies

(July 2; <http://www.nature.com/news/2010/100702/full/news.2010.332.html>), one scientist familiar with the issue said that the journal's editor-in-chief sent the paper

out for further review after government agencies requested the publication delay. That review came back with requests for additional studies.

Stephen Monroe, director of the CDC's Division of High-Consequence Pathogens and Pathology, called the delay a "strategic pause" given the conflicting findings between the CDC's own XMRV negative study in CFS -- also put on hold but recently published in *Retrovirology* --and the positive XMRV findings of the NIH/FDA group (still unpublished). Of course, we're concerned about a full airing of the scientific data on XMRV. But it appears that the transparency and timely reporting that is so essential to science was not in evidence in this unusual government action.

Examining the Rationale of the Hold

Although the specific purpose of the hold was the subject of speculation among scientists and others, it was not clearly explained by any government official or journal editor. If the purpose of the hold was to re-examine conflicting data with an effort toward reconciling disparate findings, the approach taken here did not achieve this goal

(as of this writing). In my view, if the extraordinary step is taken to delay conflicting peer-reviewed studies accepted for publication, then both studies should be held until all further analyses are done.

Once all additional work is completed, the research groups should review each other's manuscripts. This should be followed, in one of the journals, with a thoughtful discussion among the investigators that examines the discrepancies between the studies with the goal of providing informed recommendations for subsequent research. Finally, both articles should be published simultaneously or as close to it as possible. This process has the potential to advance the science.

By contrast, the CDC article alone was published weeks ago without considering or even citing the findings of the PNAS paper. I argue that the CDC paper should have been held until its authors could respond to the NIH/FDA study when its additional work is completed. If there's still time, I would like to see the CDC and NIH/FDA research groups have a discussion of their conflicting findings with the aim of publishing their talks in the issue of PNAS that contains the NIH/FDA study.

Implications of a Second Positive XMRV Study

Once we get past the hold period, the publishing of the second XMRV positive paper is likely to change the nature of the debate. Prior to this second positive report, the original *Science* paper was becoming an outlier study that could be dismissed in light of several published failures to replicate. With the new replication, the XMRV link to CFS, whatever it may be, will become an ongoing controversy that demands resolution of key issues such as the differences in testing protocols for XMRV as well as the characteristics of patient groups that are tested.

XMRV and the Ottawa 2011 Conference

Our Sept. 2011 biennial conference in Ottawa will devote a full session to XMRV. And we will put together an expert discussion panel representing different points of view about XMRV. This is the kind of scientific forum that we need to constructively address this ongoing research issue.

Fred Friedberg, PhD

President

IACFS/ME

DELAY IN RELEASE OF STUDY ON CFS PROMPTS OUTCRY

July 14, 2010

David Tuller of the Tuscaloosa News reported that researchers at the National Institutes of Health (NIH) and the Food and Drug Administration (FDA) stated they needed to re-evaluate their data and have therefore delayed publication of a new study believed to provide evidence of a link between CFS and XMRV. This already peer-reviewed study was to appear in the Proceedings of the National Academy of Sciences.

Federal officials stated the publication was delayed

because the findings contradicted those of the Centers for Disease Control and Prevention (CDC) who had conducted their own study on CFS and XMRV and had found no connection. The CDC study had initially been held up because of the discrepancies but was eventually published on July 1, 2010 in the journal of Retrovirology.

NIH refused to comment but Dr. Harvey Alter, an author of the unpublished study and an NIH infectious-disease expert stated "My colleagues and I are conducting additional experiments to ensure that the data are accurate and compete," adding "Our goal is not speed, but scientific accuracy."

**FOOTNOTE BY THE NATIONAL ME/FM ACTION NETWORK:
*The value of research is defeated when it can be influenced and stopped from being published.***

STATEMENT BY WPI REGARDING CENTERS FOR DISEASE CONTROL XMRV STUDY:

- Whittemore Peterson Institute Statement regarding Centers for Disease Control XMRV Study Contrary to the WPI study published in Science in October, 2009, as well as studies done by

others, including the NIH and FDA, Mr. William Switzer of the Centers for Disease Control reported that his research team was unable to detect XMRV in CFS patient samples. This negative finding is in

contrast to the WPI study in which we detected XMRV

in 67% of CFS patient samples. To correctly replicate scientific studies it is imperative that researchers use the same methods and patient criteria to ensure accurate results. The methodology used by the CDC was not the same as that used in the WPI study nor was the patient selection criteria. In September 2009, WPI sent the CDC twenty confirmed positive samples and the appropriate methodology to help them develop a clinically validated test. However, this team chose not to do this. Until researchers use clinically validated tests to detect XMRV in patient samples, as WPI and their collaborators have successfully done, an accurate association of XMRV to any diseased population cannot be made. For this reason, WPI researchers and many others are currently validating more sensitive clinical assays to assist federal agencies in their search for the true prevalence of XMRV in the human population. WPI will continue its core mission to deliver answers to patients with neuro-immune diseases by supporting the development of accurate diagnostics and providing effective therapeutics and clinical care.

- Absence of Evidence of XMRV in CFS and Healthy Controls in U.S. Population -

On July 1, 2010, the U.S. Centers for Disease Control and Prevention (CDC) reported results from researchers and colleagues of two institutions in which they found no evidence of infection with xenotropic murine leukemia virus-related (XMRV) among patients with chronic fatigue syndrome (CFS) and healthy controls in the United States.

The CDC led team tested archived blood specimens from CFS patients and healthy controls. The blinded testing was performed at CDC and two other laboratories with negative results. The CDC concluded that these data do not support an association between XMRV and CFS in their study population. Their report was published in an open-access journal *Retrovirology* 2010, 7:57 (July 1, 2010) By William Switzer, Hongwei Jia, Oliver Hon, et al. See <http://www.retrovirology.com/content/7/1/57> for summary.

It can be seen in its entirety on Provisional at <http://www.retrovirology.com/content/pdf/1742-4690-7-57.pdf>

To evaluate a possible association with XMRV with CFS, the CDC tested blood specimens from 51 persons with CFS and 56 healthy persons and were from previous study groups of people who had taken part in population-based studies of CFS in Wichita, Kansas and in Georgia. Patients in Georgia had been referred by physicians to a registry of fatiguing illness and had met the criteria of the

1994 International CFS Research Case Definition.

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"The rumor mill surrounding the XMRV pseudo-replication studies can finally be put to rest... The line in the sand has been drawn." Annette Whittemore

- **NIH & FDA CONFIRM XMRV STUDY** <http://www.nih.gov/researchmatters/october2009/10192009cfs.htm> 06/22/2010
- [Whittemore Peterson Institute Throwing Down the Gauntlet](#) 04/12/2010
- [XMRV Novel Assay](#) 04/2010
- [Glaxo Smith Kline XMRV study announced](#) 04/02/2010
- XMRV "can spread through blood even though the virus replication rate appears to be very low."
[The prevalence of XMRV in prostate cancer patients and healthy controls in Japan.](#)
- The XMRV story may be over in Holland but it appears to be gathering steam in Utah.
[A Light in the Darkness: Good News Ahead for XMRV?](#)
Cort Johnson, Phoenix Rising 03/28/2010
- [XMRV Caution](#) - Dr. Enlander, ESME 03/2010
- "Secret Weapon" of Retroviruses That Cause Cancer
ScienceDaily 02/17/2010
A "virulence factor" that inhibits the host immune response and allows the virus to spread throughout the body identified. This factor is a sequence of amino acids that is located in the envelope protein of the virus.
<http://www.sciencedaily.com/releases/2010/02/100215130341.htm>
- [XMRV Assay](#)

- [XMRV study shed light on cancer causing properties of retroviruses](#)
02/17/2010
- Whittemore-Peterson Institute Response to UK Validation Studies
02/18/ 2010
"We look forward to the results of studies which replicate the methods used used in the original study..." [Read more](#)
- Further Doubt Cast on Virus Link to Chronic Fatigue Syndrome
Feb. 16, 2010 ScienceDaily
<http://www.sciencedaily.com/releases/2010/02/100216142328.htm>
- "At the present time, we have accepted blood donations from donors who report a history of CFS but are now well. Donors who are not well may not donate blood. Given the lack of clarity around XMRV, we are changing the way we manage donors such that any donor who has a medical history of CFS will be indefinitely deferred from donating blood." [XMRV - Canadian Blood Supply](#)
Dana Devine, Ph D, Vice President, Medical Scientific & Research Affairs, Canadian Blood Supply, Quest Winter 2010
- Whittemore Peterson Institute Announces Renowned Health Expert, Dr. Donnica Moore, As New Spokesperson Feb. 8, 2010
Widely known as "Dr. Donnica", she will join WPI in its efforts to help raise awareness and funding for its research of XMRV and associated neuro-immune diseases, including Chronic Fatigue Syndrome (CFS). http://www.wpoinstitute.org/news/docs/WPI_pressrel_020810.pdf
- <http://www.drdonnica.com/news/00012771.htm>
- Whittemore Peterson Institute Announces Availability of Updated XMRV Testing - UK Study Publication Does Not Impact XMRV Research
Press Release - Jan. 14, 2010
www.wpoinstitute.org/new/docs/WPI_pressre_011410.pdf
- Official Statement from the Whittemore Peterson Institute Regarding UK Study about XMRV Virus 01/2010
The Whittemore Peterson Institute (WPI) has reviewed the paper entitled "Failure to Detect the Novel Retrovirus XMRV in Chronic Fatigue Syndrome." This study did not duplicate the rigorous scientific techniques used by WPI, the National Cancer Institute and the Cleveland Clinic, therefore it cannot be considered a replication study nor can the results claim to be anything other than a failure not just to detect XMRV, but also a failure to suggest meaningful results.
[Read More](#)
- Top 100 Stories of 2009 - #55 - Virus Invades Human Genome and Causes...Chronic Fatigue? Jan - Feb 2010
"Clever sleuthing finds a connection between a virus associated with cancer and mysterious "yuppie flue". By Jill Neimark
Discover- Science, Technology & the Future, Health & Medicine
<http://discovermagazine.com/2010/jan-feb-055>
- *"What on earth do the King's College clinic's patients have in common with those of Dan Peterson at Incline Village, NV?"*

Written by Administrator

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[Pay Attention to the Data Set](#)

Mary M. Schweitzer, Ph. D. 01/2010

- *"Both studies included CFS patients defined by the 1994 case definition criteria, but this is where the comparability ends."*

[XMRV Negative Results Emphasize Need for Robust Replication Study](#)

Suzanne Vernon, Ph D, CFIDS Association of America 01/2010

- "Those who portray ME as a somatoform illness are fully aware that using patients who do not fit strict selection criteria will obviously skew results."

[Invest in ME Statement on BBC News Article "Research finds no proof that a virus is the cause of ME".](#) 01/2010

- [Cleveland Clinic Conference puts spotlight on XMRV link with CFS](#)

Angela Townsend, The Plainsman 11/24/09

- [Independent confirmation of the relationship between XMRV and ME/CFS in Sweden](#)

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