

**Message from Lydia E. Neilson, M.S.M., Founder
Chief Executive Officer
National ME/FM Action Network
NETWORK POSITION ON XMRV - WHERE DO WE STAND?**

As most of you know, 4 papers were published in the journal of Retrovirology while a 5th commented on them pointing out how easy it is to contaminate lab experiments involving the XMRV virus. The authors themselves disagreed on the interpretation of their data. One senior author stated that he just wanted to point out how easy it is to test positive for XMRV, even if the person is actually negative, if a tiny bit of the mouse DNA gets into the sample tested.

There is no need to get upset about these findings in the latest papers as it did not prove the other studies who did find the retrovirus wrong. It only means that those testing the XMRV samples need to be extremely careful because of the possibility of contamination. Something that researchers are very well aware of and don't need to be reminded of.

The way to look at the latest findings is that they are doing research and that for any negatives found, the researchers who are way ahead of this research, can easily rectify any negatives that are being thrown in the way of solving the problem of XMRV. No one would be going through all this trouble if they had actual proof that it doesn't exist.

Take pride in the fact that we are being taken seriously and research is ongoing. We know that both XMRV and MLV has been found. Scientists are hard at work to discover what these findings mean in regards to ME/CFS and what role, if any, it plays in the illness. Once that is established, the research on treatment can go full speed ahead.

Hang in there everyone, we are getting there.

Lydia E. Neilson, M.S.M.

**XMRV BLOOD TESTING?
Initial News of the XMRV Discovery in ME/CFS Patients**

Retrovirus - XMRV

Written by Administrator

Thursday, 24 February 2011 17:24 - Last Updated Saturday, 26 February 2011 07:33

As you are aware, the Whittemore Peterson Institute (WPI) announced that the XMRV retrovirus had been found in ME/CFS blood samples and also in FMS, although only a small amount of blood samples had been tested for FMS. This retrovirus was first discovered in some people who have prostate cancer.

As a precautionary measure, Canadian Blood Services announced that people with ME/CFS could no longer give blood donations. This affects all of Canada except for the Province of Quebec who has its own blood agency, HEMA Quebec, which is doing its own investigations.

The question has arisen, can a person be tested in Canada for XMRV and the answer is in the negative. Testing is being done in the U.S. and some Canadians have gone there at their own expense to get tested, with varying results.

It is important to remember, that this is research at the moment. Before we know what role XMRV plays with ME/CFS and FMS, the tests must be replicated by independent research and once that is done, then the next question becomes, is it the cause or another way of contracting the illness? We hope that these questions can be answered by the time we have the 2011 conference and we can move on to the next steps.

In the meantime, unless you are involved in a research study, to get tested for XMRV will lead to more questions than answers. Once you have been tested, what can be done with that information? What does it mean to your doctor? In addition, if you are on insurance disability and the test comes back negative, it may work against you and the insurance company may give you a hard time and cause you problems with your disability pension.

What XMRV has done is bring an interest in research and leading to funding That is a good thing. Due to the extensive research, a different outcome may occur than what we presently know.

Please rest assured that the National ME/FM Action Network is keeping a watchful eye on the situation and will keep you informed.

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Link between a retrovirus and ME/CFS was first reported in 1991 by [](#)Dr. Elaine DeFreitas, et al.