



Hunter-Hopkins **ME-letter**
October 2009

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XMRV – Newly Discovered CFS-Related Virus

Researchers have just reported exciting news about a novel retrovirus that is associated with Chronic Fatigue Syndrome. This gives new hope that we can identify and treat Persons with CFS (PWCs)!

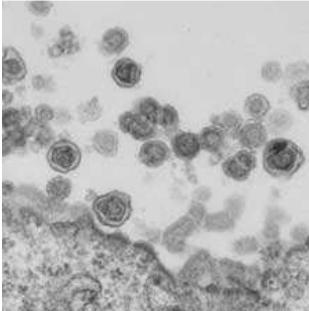
Writing in the October 8 issue of *Science*, researchers at the Whittemore-Peterson Institute, the Cleveland Clinic, and the National Cancer Institute reported finding the XMR virus in the blood of 67% of individuals involved in the original Lake Tahoe and Raleigh CFS outbreaks (about 1983-1985). XMRV, or Xenotropic Murine Leukemia Virus-Related Virus, is a gamma-retrovirus that reduces immunity via the RNaseL antiviral system and has mostly been associated with aggressive prostate cancer in men.

Because the RNaseL enzyme is involved in CFS, researchers at the Whittemore-Peterson Institute tested for XMRV in samples saved from the initial CFS outbreaks, and found that 68 of 101 samples contained the virus. An additional number of PWCs had antibody evidence of the virus, bringing the total number of positives to 95%, whereas the virus is found in only 3.7% of normal healthy individuals. A small number of positives have also been reported in persons with fibromyalgia, and other illnesses.

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 but is not currently available commercially.

XMRV is a human retrovirus (meaning that it transcribes in reverse, or “retro”). There are three other known human retroviruses: HIV (the AIDS virus), HTLV-1 (causes lymphoma), and HTLV-2 (causes leukemia).

XMRV can be found in blood (raising the possibility that it could be spread by blood products or bodily fluids), but is otherwise *not* known to be infectious or transmissible. Retroviruses can affect immunity and



Electron microscopy shows XMRV in the blood of a person with CFS – courtesy the Whittemore-Peterson Institute

activate latent organisms in the body, which could explain why many PWCs have evidence of ongoing viral or other infections.

There is no known treatment for XMRV although the experimental drug Ampligen may modulate the RNaseL system, and therapies are available for other retroviruses such as HIV.

Many of you will recall that in the late 1980's we had identified a novel retrovirus in Persons with CFS (PWCs), but the finding was later discredited by the CDC, the NIH, and others. We are hopeful that this will not be the case with XMRV. Note also that just because XMRV *occurs* in PWCs does not mean that it *causes* CFS. XMRV may just weaken the immune system permitting other organisms or biological mechanisms to cause CFS. Also, it is odd that XMRV is seen only in prostate cancer – strictly a male illness – whereas CFS is mostly a female illness. Nevertheless, Dan Peterson, M.D., medical director of WPI has optimistically stated, "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."

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We've Moved!

You may have notice the new masthead above. Our address has changed. On Friday, October 2, we successfully moved from our old office to bright new quarters on the corner of Carmel Road and Pineville-Matthews Road, just 1.5 miles from the previous office. We look forward to seeing you there!

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Ampligen Update

Hunter-Hopkins is one of two centers in the world providing Ampligen to Persons with CFS (PWCs). The other center is Dr. Dan Peterson's clinic associated with the Whittemore-Peterson Institute.

We have recently modernized our infusion facilities, and have just evaluated three more individuals to start Ampligen treatment under the cost-recovery (aka compassionate care) AMP-511 Protocol.

Interested individuals should consult the information on our website at www.drlapp.net/ampligen.htm .

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Tips From Other Patients

A Frequently Overlooked Analgesic

Those of you who cannot "stomach" ibuprofen, Advil, NMotrib, naproxen, Aleve, and the like, consider **Doan's Pills**™. Previously known as Doan's Little Liver Pills, these tablets contain magnesium (good for muscle and GI problems) plus salicylate. Salicylate is an analgesic also found in aspirin (which is methyl-salicylate), but combining it with magnesium instead of a methyl group reduces the stomach irritation. Give it a try!

Information on Fibromyalgia

Go to www.fibrocenter.com, a non-branded website for information on diagnosing and managing FM. We particularly like the "Living With Fibromyalgia" button, and Rhonda Britten's "Yips for Living with FM,"

at the very bottom. Rhonda is a nationally recognized life coach who provides 1-2 minute snippets on dealing with FM.

Lidoderm Substitute

Do you love Lidoderm but can't afford it? Many patients are getting similar benefits for less money by using generic creams, gels, and ointments containing lidocaine, the active ingredient in Lidoderm. Ask your doctor to prescribe one of these:

Lidocaine 4% Gel available over-the-counter from Amazon.com (\$30-\$40)

www.amazon.com/Zcaine-Fast-Acting-Anesthetic-Lidocaine/dp/B001F8HY0U

Lidocaine 5% ointment (15 gm \$12, 35 gm \$15)

https://www.getcanadiadrugs.com/view_product.php?ProductID=2036

Lidocaine 3% Lotion (6 ounces, \$60)

<http://www.drugstore.com/pharmacy/prices/drugprice.asp?ndc=68032010517&trx=1Z5006>

Lidocaine 4% Solution (50 ml or 2 ounces, \$17)

<http://www.drugstore.com/pharmacy/prices/drugprice.asp?ndc=00054350547&trx=1Z5006>

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