

# Dr. Mikovits Chats on XMRV

by Cort on April 26, 2010

Dr. Mikovits has been in touch with patients more than any other researcher by several magnitudes and a couple of days ago I got to chat with her on a variety of topics.

Some questions had been raised about the WPI's two collaborators in the Science paper, the National Cancer Institute and the Cleveland Clinic. We hadn't heard a word from any of them since the just after the Science paper came out. Dr. Ruscetti of the National Cancer Institute did show up for the CFSAC meeting in late Oct of last year but they'd been laying low since. Were they backing away from CFS and XMRV? Had they dropped us in all the controversy? I asked Dr. Mikovits and she said both were still working on the CFS/XMRV connection with the NCI more focused on CFS than the Cleveland Clinic. I was just shown an email from Dr. Silverman of the Cleveland Clinic, however, to a CFS patient who promised that he was working hard on it. Neither of the WPI'S main collaborators, then, appear to backing away from the XMRV/ CFS connection – they're just laying low and keeping their nose to the grindstone -as researchers tend to do.

**WPI?** – but what about the WPI? We've heard that they are working feverishly away but was any of this going to show up in print? Were we going to see any papers in the near future? The answer to that is an emphatic 'Yes!' Dr. Mikovits reported they've submitted no less than 5 manuscripts (yes, that's 5 papers) since Feb. One has been accepted and they're waiting on word for the others. Papers generally take quite awhile to come out but they are in the pipeline.

**Papers, Papers** - We know that, in the end, that its ALL about the papers. We've heard (for over a month now!) that some papers are in press. Dr. Mikovits stated she knew Dr. Huber's and the CDC's papers were at the publisher and it sounded like she was feeling good about them. (Dr. Huber has recieved a great deal of funding from the CFIDS Association to look for active endogenous retroviruses in ME/CFS). Very early on she was reportedly very interested in XMRV. Because she is an endogenous retrovirus expert and some people have worried about endogenous retroviruses – it would be great to have a positive paper from her.

**Life in the WPI Lab** – what is the WPI actually working on? Well, they're apparently putting alot of effort into finding out how prevalent XMRV is in other neuroimmune disorders such as autism, FM and atypical multiple sclerosis. (Dr. Mikovits will talk at an Autism Conference this spring). They're refining their antibody (serology) test (see below) and their 'infectivity assay' (?) and developing treatment protocols involving existing anti-retrovirals (presumably raltegravir and AZT).

**Testing** - the testing/diagnosis news now all seems to swirl around antibodies- the immune factors B-cells make that clump to pathogens and gum their works and make them easier for the big guns of the immune cells – the cytotoxic T-cells – to 'blow up'. The big thing about the antibody tests is that positive results simply cannot be caused by contamination – antibodies are produced by the body in response to infection – not to a contaminant placed in a test tube. It is possible for antibodies to pick other viruses but as these researchers bear down on XMRV more and more its less and less likely that any antibody tests they develop are going to pick up something else. Dr. Mikovits reported in one of her earlier talks that Dr. Singh had developed an antibody test that picked up signs of infection in people who'd tested negative for the virus by PCR. We know the WPI is focused on antibody tests – I asked her whether they were using Dr. Singhs tests or one of theirs? Dr. Mikovits reported that the antibody test they were using was homegrown at the WPI...and she thought it at least as sensitive as Dr. Singhs and my sense was she thought it was probably more sensitive.

**DHHS Blood Study** - Its been what, five months or so since the DHHS announced they were going to look for the virus in the blood supply. The Washington Post reported that things were moving along – that they were close to coming up with a test but Dr. Mikovits is on the team overseeing the study and she reported that because the groups are storing the samples in a different way than the original study did – its taking longer to validate everything – don't expect the results in the immediate future.

**The Letter** - Annette Whittemore penned a rather strong letter to Dr. McClure a couple of weeks ago. In it we learned that the collaboration between the WPI and the Kuppeveld and Groom study groups was much more extensive than we'd thought. In fact it turned out that samples sent from those groups to the WPI tested positive for XMRV at the WPI's lab. Those groups, however, rejected the WPI's findings and didn't mention them in their report. Dr. Mikovits reported that 3 of the 10 samples Kuppeveld sent to the WPI tested positive and one of those was from a healthy control. After Kuppeveld ran his own tests and couldn't find XMRV, he concluded that contamination had occurred at the WPI.

**A Collaboration In Trouble**- Dr. Kerr had been collaborating with Dr. Mikovits on another project but it's possible, given how upset the WPI was about the way they felt they were treated by the Groom group, that that collaboration is at an end. She felt the Groom group should have attempted to reconcile the discrepancy between their results and the WPI's before they published. She also felt that the WPI should've been kept in the loop about the Grooms groups inability to duplicate their results. As it turned out they were informed of the study results only a day before the paper was published. It's, of course, possible that Dr. Kerr was under constraints of his own. In any case, it's a unfortunate situation.

We obviously don't have Dr. Groom's or Dr. Kerr's or any other researchers take on why things turned out as they did. Even in the CDC/DeFreitas saga – which churned up so much controversy – the two groups were talking about their methodology frequently. This was definitely a one sided interaction.

**Those Negative Studies** – the negative studies have had an impact. Doors that were pretty open aren't closed yet but it appears that projects outside of the WPI that were going to pretty quickly gear up have been put on hold until the dust settles. The WPI is in kind of a strange situation; they have lots of work to do – more work than ever – yet, until XMRV is validated they'll have difficulty getting big federal grants they need. Private donations of the magnitude that they probably need, are difficult to come by in this economy. Money from the diagnostic tests is certainly helping but the research is very expensive and what they need are grants and clinical trials. Six months after the Science paper they have not received ANY federal funding. Dr. Mikovits noted that the federal government was spending billions of dollars on HIV, which affects less than 1 million people in the country yet the NIAID (National Institute of Allergy and Infectious Diseases), the huge pathogen Institute at the NIH, has done absolutely nothing but XMRV.

**The UK Study** – on a more positive note – 50 of the 200 patients in the UK study have had their blood drawn and they are a very interesting group indeed. About 50% are homebound and presumably never been anywhere near Dr. Wesseley and his cohort. It will be interesting, indeed, to see how often XMRV shows up in these very ill patients.

**Funky Virus** – Whatever the problems with the earlier validation studies some of them did contain well known retrovirologists who, as one commentator put it, “do know how to do PCR”. So how could they be getting such different results? One possibility, of course, is that XMRV is trickier to find in the blood than researchers have suspected and that small differences in different studies methodologies have made a difference. Another concerns the composition of the virus itself. I asked Dr. Mikovits if slightly different strains of XMRV in Europe could be part of the problem and, she said, after noting that HIV has two strains, and HTLV no less than four (!), that it would be ‘arrogant’ to exclude that possibility. She also noted that the fact that the XMRV antibody tests sometimes find the virus where PCR tests do not, suggest that a different strain of XMRV could be managing to elude the PCR's grasp. In fact she stated there was a 50% false negative rate on PCR tests at VIP Dx (ie 50% of the tests negative for XMRV by PCR were positive by other tests).

**Still Confident** – Dr. Mikovits is clearly frustrated at the lack of positive findings, the financial stress that being placed on the WPI, and the lack of federal funding but she is still confident in the WPI's results stating again that she does not see any way contamination could have played a role in their findings. The WPI is doing two types of antibody tests; one, which is apparently the ELISA test which measures antibodies to the whole virus and is less precise than the Western Blot test which looks for antibodies to a specific protein on a virus. The Western Blot test is essentially a check on the Elisa test and Dr. Mikovits reported both tests were providing similar findings; ie this is XMRV they are finding.

**Busy, Busy** – Dr. Mikovits was finishing up two Department of Defense proposals and then was off to Europe to talk to the British Hematological Society, then it was over to Spain to work on XMRV study there, and then to a 100th anniversary of the discovery of retroviruses. That Science article, by the way, should be out in about two weeks.