

I expect this email to be provided to participants during the CFSAC meeting in October.

Dr. William Reeves of the CDC/CFS program MUST be removed and replaced with someone acceptable to the CFIDS community NOW. The latest study on XMRV, the fourth human retrovirus recently discovered, provides further evidence that CFIDS is in fact a "real disease" and not a psychocrap illness that Reeves, his CDC associates, and his contractors can not refute. Reeves and his associates should be prosecuted by the law and put in jail for their deliberate destructive activities during Reeves stint as the head of the CDC/CFS program. Investigations have been under way by the Inspector Generals of the CDC, NIH and DHHS. We have also requested that Reeves and the CDC be investigated, yet again, for possible funding issues with the CDC/CFS contractors (Emory University Mind-Body Program and ABT Associates). We do expect that Congressional action will begin soon.

Reeves and his CDC associates MUST BE REMOVED NOW. Enough is enough. The damage that this greedy, stupid man has done to millions of sick people is beyond criminal. Reeves is directly responsible for thousands of deaths to heart disease, the cancers that are seen in high proportions in the CFIDS population, and the suicides of those that could no longer "live" a life of pain and despair. Those that took their own life were not weak or mentally ill. Instead, they were so sick and with no where to turn and no one to believe them or help them saw no choice but to end their own suffering. Thousands of deaths sit on the head of Dr. William Reeves. May he burn in hell for eternity.

Sharon Stapleton
Richard Kugler.

Inside the Labyrinth

<http://www.oslersweb.com/blog.htm?post=638469>

OUR VIETNAM WAR ENDED TODAY
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Tags: [THE FOURTH HUMAN RETROVIRUS; DO YOU HAVE XAND?](#)

Our Vietnam war is over. Our Gu antanamo has closed. The world has flipped. It took one human generation, but it turned right side up today.

If you know what happened this afternoon, read on. If you don't know,

here is the [link](#). Then, if you want to talk about it—if you are not too busy crying or screaming or calling your best friend or praying to your God or simply struck numb—come back here.

A nova has appeared in the constellation. We knew it would appear some day—but in our lifetimes? Many of us, having given up on recovery, had merely hoped we might live long enough to understand the scientific basis of our suffering. Thousands, perhaps hundreds of thousands, of us didn't make it, or simply gave up. Between the time Dr. Judy Mikovits of the Whittemore Peterson Institute and her collaborators at the National Cancer Institute and the Cleveland Clinic submitted their paper to *Science* and today, we know at least one woman, the British citizen Pamela Weston, chose assisted suicide rather than go on; in the note she left behind she wrote that she hoped her choice would, in some part, move the UK medical research forward. Might Weston have hung on had she known about XMRV? We grieve for those who couldn't wait, couldn't hang on, and acknowledge their bravery. For the rest of us, this is a day to celebrate.

We don't know for certain what is going to happen next. We only know—we *must* understand now—that some great piece of our suffering has ended.

All those petitions we signed in the tens of thousands over the decades? All the hope that was bound up in those petitions, our pleas for mercy? Just part of our suffering, part of the trail we had to walk, like refugees, through our private war zone. Only we knew what it was like.

This nova will redefine the relationships among the stars. Astronomers' maps are being redrawn as I write this. From the doctors' we visit, to the insurance companies that have mercilessly controlled our access to medical care and disability support, to research laboratories at major universities and in the laboratories of federal health agencies—change is coming.

A generation of quacks and sub-par investigators will be in retreat, as well. Let them pursue their study of "chronic fatigue syndrome."

The real scientists have arrived and they'll be studying XMRV-associated neuro-immune disease, a.k.a., XAND.

The name ginned up in Atlanta in 1988 to make sure disability insurers would not be required to pay out on disability policies and the public would assume the malady was a new category of mental illness? One can imagine, or simply hope, that the phrase is about to be jettisoned into outer space where one can fantasize it entering the band of space trash circling the earth. For months, the team at WPI has been playing around with names. In lighter moments, their favorite became "I.T.V.S.," the acronym for, "It's the Virus, Stupid."

Thank you Harvey and Annette Whittemore; thank you Daniel Peterson of Sierra Internal Medicine; thank you Judy Mikovits and Francis and Sandy Ruscetti and your collaborators at the National Cancer Institute; thank you Robert Silverman of the Cleveland Clinic. Anyone who knows the immense backstory here will appreciate the profound cosmic justice of today's revelations.

In less than two years and with a million dollars--most of it private, philanthropic money because both the NIH as well as the CAA refused the institute's requests for grant support--Mikovits et. al. appear to have solved our problem.

Science magazine held the paper, submitted in May, through the summer while federal scientists in Bethesda worked on their roll out strategy for the discovery that XMRV, the fourth human retrovirus, had been found in the blood and saliva of 67 percent of "CFS" patients. Today, Mikovits is finding XMRV in 98 percent of the patients tested. She and her colleague in Reno, Vincent Lombardi, have found the virus in patients from multiple outbreaks, multiple geographic regions, and in patients' blood samples that have been frozen since the mid-1980s.

Will anyone with "CFS" *not* be positive for XMRV? Certainly. Of course! I suspect there will be negatives among CDC's patients in Macon County, Georgia; same goes for the CDC's cohort in Wichita. Just a guess .

As far as the scientists in Nevada are concerned, "chronic fatigue syndrome" is of little further import. Let the CDC's finest--Bill Reeves, James Jones and their contractors, the psychiatrists like Chris Heim at

Emory--pursue their study of adults with histories of sexual molestation.

"Chronic fatigue syndrome" is over, except maybe in Witchita, in Macon County, Ga. and in Bill Reeves' head.

Overnight, the Whittemore Peterson Institute and its collaborators have turned a 20-year crime story back into a science story.

XMRV, the fourth human retrovirus (HIV was the third) is the first infectious human retrovirus to be linked to disease in twenty-six years. In September, Ila Singh at the University of Utah reported in the *Proceedings of the National Academy of Sciences* that XMRV could be found in the tumor cells of the most aggressive prostate tumors. Earlier, in April, this infectious pathogen was found in human semen. Could XMRV, like Human Papilloma Virus, be a sexually transmitted infection that causes cancer? They're working on it.

The virus was discovered by Robert Silverman, a cancer biologist at the Cleveland Clinic's Lerner Research Institute, in collaboration with Joseph DeRisi and Don Ganem of the Howard Hughes Medical Institute at UCSF in San Francisco. The group reported their discovery in February of 2006. XMRV generated tremendous interest among virologists, but raised hardly an eyebrow in the mainstream press until now because it had yet to be definitively associated with any specific disease or diseases. Silverman is also among the network of scientists who collaborates with investigators at the Whittemore Peterson Institute.

XMRV is a gammaretrovirus, as opposed to HIV, which is a lentiretrovirus, from the Latin for "slow." Lentiretroviruses may take years to cause symptoms after infection. Not so gammaretroviruses. They've long been known to cause neurological disease, cancer and immune deficiency in animals. Until 2006, scientific dogma held that gammaretroviruses infected only animals.

XMRV has been in the human population—and we can assume, in the nation's blood supply—at least since 1984. Mikovits found XMRV in a sample of frozen blood that had been saved by Dan Peterson as long

ago as 1984. The blood happened to have had been drawn from a patient who went on to die of mantle cell lymphoma, another disease XMRV is suspected of causing.

Today, there are an estimated one million people sick with XMRV-associated neuro-immune disease in the United States and ten million infected, or 3.7 percent of the U.S. population, with a virus of "unknown pathogenic potential."

CSI: Atlanta

Given that Dr. Mikovits, her team at the Whittemore Peterson Institute, and her colleagues at the National Cancer Institute have determined a human retrovirus may be at the heart of this disease, the failure of the Centers for Disease Control to respond professionally and rationally when presented with a novel retrovirus in patients and their close contacts in 1991 by Elaine De Freitas of the Wistar Institute needs to be revisited immediately.

We've known since early 1996, when *Osler's Web* was published, about the CDC's fiscal malfeasance and lies to the Congress and, in partnership with the organization CAA, to the public, as regards this disease. We've monitored the agency's willful ignorance of—indeed, their extreme hostility to—the science in this field. We've recognized their propagandistic agenda. We've never lost sight of their bio-ethical failures. But if it turns out their failure to replicate Elaine DeFreitas's findings of a novel retrovirus in this disease, followed by their attempt to destroy her professional reputation, was purposeful, or even incompetent, then the multi-billion dollar complex of buildings in Atlanta known as the CDC is as much a crime scene as it is a federal science agency.

Indeed, in light of the *Science* study released today, what may have seemed like sheer incompetence and political maneuvering in the early 1990s needs to be re-examined by the U.S. Congress. It's not a minute too soon to utter the words, "Class action lawsuit," either.

Maybe the real question now is, Who will inherit the scientific real estate that used to be the CDC?

I hear my mother scolding me that this is not the day for bickering and pettiness--but, I can't help myself: If you ever needed evidence of the true nature of the CFIDS Association of America, the McCleary/Vernon shop in North Carolina, observe closely how they respond to this finding. Will they call for a congressional investigation of the CDC's handling of this epidemic? Or will they be CDC apologists? Will they admit to the fact that DeFreitas had to end her work in this field because the CAA decided to pull the plug on her funding? Will they assure patients there is still no evidence for transmission? Will they admit to the tragic waste of research dollars during the last 25 years, a phenomenon they participated in like pigs at the trough?

More recently, CAA used \$35,000 the NIH gave them and held a meeting at the Banbury Center. Another snooze fest. As recently as October 1, 2009, or eight days ago, CAA published their conclusions from Banbury: among those conclusions, there was "no evidence for retroviral infection" in this disease.

To cap it off, when they learned of the Whittemore Peterson study and its imminent publication in *Science*, Kim McCleary and Susanne Vernon chose to violate a strict scientific embargo and sent copies of the paper to members of their board. The move can be construed as contempt for scientific protocol and disrespect for the scientists who labored to deliver this work. In the future, watch them gyrate and twist to find a way to claim this discovery, however indirectly, for themselves, to use it to promote their organization and to raise money for themselves. And if they can't claim it, I imagine they're going to start trashing it. Twenty years out, these folks are just so predictable. Is it time for a clean break with the haunting, failed agendas and strategies of the past? Isn't some part of success in life knowing the difference between your friends and your enemies?

History is shifting. The pundits, the people who are paid to ask why, will finally ask the questions they should have asked twenty-five years ago: why medicine is so obtuse, its practitioners so willfully ignorant. How could our government and the governments of other nations dismiss and then ignore millions who suffered from "An infectious disease of the

brain,” as Hilary Koprowski of the Wistar Institute called it publicly in 1992. Koprowski was an expert in neurological diseases—he knew one when he saw one.

They will talk about the dangers of scientific bias and the strange, near-criminal manner in which a disease could be defined, for so long and in spite of so much contrary evidence, as a personality disorder, its victims whiney yuppies who were, in the words of Johnny Carson, “too tired to tie their sweaters around their necks.” Carson never knew how close he got—the part about the sweaters? Slam dunk.

Mikovits and her collaborators may have changed the course of medical history. This discovery may lead in many important directions, explaining, for instance, why immune system cancers lymphoma and leukemia—have been on the rise for the last twenty years. It may explain why inflammatory cancers of the breast, prostate and pancreas are becoming more common, too. And it may explain autism, atypical MS, and fibromyalgia—even amyotrophic lateral sclerosis. Certainly, it has very probably explained the pathophysiology of our disease. Why we are riddled with co-infections—herpes viruses, enteroviruses, mycoplasmas. Why we have NK deficiencies. Why we have encephalitis. Why we get lymphoma, thymoma, and acute lymphocytic leukemia. Why we are sick for decades, not days.

Word spreads fast these days and secrets are hard to keep, especially secrets as fascinating as this one. *Science* was forced to move up their publication date, originally set for October 16th, due to the rumors and gossip on Internet chatrooms, blogs and websites that began two weeks ago. The news was spreading virally, if you will. With over a million Americans sick, this news was never going to be secret for long.

Let’s make sure this horrific chapter in medical history is not forgotten. The years of our lives during which thousands of research papers were written by psychiatrists or wanna-be psychiatrists purporting to explain away a life-destroying disease with discussions of personality disorders, exercise and activity phobia, malingering, hysteria, stress, sexual abuse, school phobia, Type A behavior, attention-seeking behavior, and any other kind of behavior, must be respected, the papers saved for posterity. Princeton English professor Elaine Showalter’s book equating this disease with fantasies of alien abduction probably deserves its own

shelf in this pantheon of the grotesque. And, rest in peace—if you can—
Stephen Straus, father of the movement. All these works will be
examined, in time, by researchers who seek to understand the human
capacity for delusion, ignorance and greed.

Sometimes, music [is](#) enough.