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To my friends with ME/CFS,

I would like to put out a personal appeal for funds to be sent to the Whittemore-Peterson Institute (WPI) in order to speed up the progress of the current research. Here is my reading of a very complex situation.

Medical authorities, educational institutions, governmental agencies, and most practicing physicians have disrespected and minimized CFS in just about every way possible, from creating an insulting name for the illness to advising extreme caution in treatment, except cognitive behavioral treatments.

It is easy to dismiss my remarks to follow by saying that I am biased. And it is true, I am very biased and for twenty five years I have quietly sat on the sidelines believing that science will win out and true progress will be made. I am beginning to think this has been a great mistake. The profession I love has failed miserably.

In 1985 an outbreak of CFS hit Lyndonville NY and affected 210 persons, 60 of whom were children. The official response from the CDC and the New York Health Department was that this was mass hysteria. No one talked with a single patient. In 1990 I worked with Dr. Elaine DeFreitas and Dr. Paul Cheney and a retrovirus was found and the material published(1). A second paper had been accepted by PNAS and contained a photograph of C-type retroviral particles from a tissue culture of spinal fluid of one of the children in the Lyndonville outbreak. This paper was suddenly pulled and not published after a couple of flawed negative papers. A complete description of these troubled times is in [Osler'sWeb](#) by Hilary Johnson. The funding for our studies was pulled and all work on this abruptly stopped.

I think the same tactics are being employed to hamper the current work on XMRV by the WPI. The WPI is a private organization and, as I understand it, no federal grants or funding has been forthcoming. There have been three negative PCR-only studies which have established only that CFS can not to be superficially studied. At this time no study that has attempted to replicate the WPI study has been heard from. Many CFS research organizations have declared publically that "XMRV is a dead issue."

Nothing is farther from the truth. I cannot predict the future, but my fear is that the current political and scientific organizations who do not want to see retroviral involvement will attempt to stifle studies on XMRV in CFS. Huge amounts of money are spent on studies on cognitive therapy, and studies proving that CFS is heterogeneous (you can argue that polio is heterogenous).

We have not heard from the CDC, other than the inappropriate comment that this was not likely to turn out to be anything, made right after the *Science* paper publication in October 2009. We are now eight months later and not a peep. Maybe they are finding XMRV and want to be very careful. Maybe they haven't looked and are assuming that this heretical idea will blow away. Eight months? And the Band Played On.

It is possible that thirty other labs are finding XMRV in CFS or that no one else in the world is even looking for it. Science requires that labs do not disclose their findings prior to publication and I agree with this rule. But is the WPI going to be isolated by the scientific community and wither away because of lack of funding? Is XMRV going to become more of the compost of CFS research?

But there is an alternative. We cannot wait ten years for science to grind out its conclusions. Every person in the world who believes that CFS is important should send \$10 to the WPI. I plan to send \$10 today. It may not be much, but it is a start. There may be 10 million persons in the world with CFS. Lets see, that's...I need a calculator. May 12 is our day. Lets do this.

After 25 years of work in this field I do not have much. But I have my integrity. I feel that WPI has made an important discovery and I feel they are an ethical organization, they are not padding their pockets. But I also have my fears. And the greatest fear of all is that their discovery may not be appropriately followed up.

For the 9,999,999 other people out there who think CFS is both real and important, send \$10 to: Whittemore Peterson Institute, 6600 N. Wingfield Parkway, Sparks, NV 89436. Thank you.

David S. Bell MD, FAAP

1. DeFreitas E, Hilliard B, Cheney P, Bell D, Kiggundu E, Sankey D, et al. Retroviral sequences related to T-lymphotropic virus type II in patients with chronic fatigue immune dysfunction syndrome. *Proc Natl Acad Sci.* 1991;88:2922-6.