

## Testimony

Thomas M. Hennessy, Jr.

Dear Dr. Jones,

As a 24 year bed bound M.E., FMS and CFS patient, and an attendee of most of these meetings from the inception in 1994 of the first CFSCC (that we FOUGHT for for 5 years, with Dr. Phil Lee from SF, CA, the ASST. Sec. for HHS under Donna Shalala to get the first one started) until 2004 or 2005. I finally gave up because the head of HHS either never READ the recommendations of the HONEST members of the panel, or never acted on them!

When Dr. Phil Lee pushed Congress to create the first CFSCC, it was the ONLY such committee dedicated to only ONE disease in the Entire government! The very first charter called for the person in Dr. Lee's seat (the number two person in the entire US health services. At the time this included ALL Social Security, ALL Medicare, All medical departments of the US government. Dr. Lee and Donna Shalala were in charge of \$662 BILLION per year. this was Twice the Pentagon budget at the time!) to CHAIR the meeting twice a year.

I heard some government employess complaining during a coffee break that they had NEVER seen such a committee dedicated to a single disease before, and they went on to say that it must have been because of the "clout" of the CFS patients. HAH! we have soo much clout, that out of a \$32 billion NIH budget, we don't get enough money to purchase paper clips for a single study, let alone anything close to what 17 million or more sick, homebound and many bedbound patients around this big world need and deserve.

Because of the newfound interest in this brutal condition with XMRV ressearch at WPI and other centers around the world, and also, because I have watched YOU, Dr. Jones on YOU TUBE actually try to run a fair meeting, I would like to request a speaking slot for 5 min. i have a little apple computer with a tiny camera that could be used on video testimony if you have a set up for it. or i can type something up and email it in. i am stuck in a nursing home in Florida. I don't have a printer close by. or large envelopes to mail in my testimony. if someone could print out my testimony in your office, maybe that would suffice. So, i can phone in my testimony, or email it in, or give it over a video link from my little personal computer. i am destitute and recovering from a broken back, cracked ribs, crushed sternum, cracked occipital bones and crushed vertebrae in my neck from a little auto accident i had where i blacked out on the way to the ER and I hit the back of a broken down semi tractor trailer near For Lauderdale, Florida.

I was recovering from a 4 day visit to a local hospital in which the insurance company that i contracted with to help cover some costs that Medicare didn't cover, and they put me through half a dozen tests because of my severe high blood pressures 187/117, and weird heart spasms I was going through because i was to ill to attend daily detox treatments that the insurance company might pay for because of the extreme neuropathies probably related to lyme disease, which is often a co-factor in M.E., FMS,, CFS, GWS and related disorders. Like many other M.E. patients, my illness has worsened over the years. I call it Myalgic Encephalomyelitis, which was the name given to this condition by people who actually KNEW something about this

condition. There has been a WHO code 93.3 for neurological M.E. for about 40 years. The truly Awful CDC "CFS" definition of 1988, called the Holmes Criteria, was a garbage diagnosis put together mostly by NON experts, when the REAL experts refused to sign off on the work product that the mid level government bureaucrats tried to force upon the real M.E. experts back in 1987. The Holmes criteria for "CFS" was put into the annals of Internal medicine way back in March of 1988. I have been VERY sick, every single day since i first collapsed on October 23, 1987. good timing! This disease is cruel beyond the imagination of most mere mortals.

Since we M.E. patients have had TERRIBLE luck with many of the "CFS" personal at HHS over the years, I must mention that i have heard quite GOOD reports about you from my friend Marly Silverman from PANDORA and other sources. I have heard that you have pushed for phone or email submission of patient speeches to be more accomodating to some of the sickest patients on the planet. Thank you for that. Regarding the videocasting of the meetings and allowing more people to give testimony. THANK YOU for that!

For years, i lived in the basement of my late father's home in Potomac, Maryland and i used to drive in with the testimony of half a dozen sick people from around the country. People who were too sick to make it to Washington, D.C. or too broke to afford a ticket to DC, would email me their testimony so that it could be read OUT LOUD to the CFSAC committee. Supposed summations of patients' testimonies were supposed to make it into the record, but this rarely happened in the early days.

And EVERY darn Time, over the years from the late 1990's to the mid 2000's, the staff from the CDC or NIH or HHS, would make it HARDER to give legitimate testimony, not easier. These people should have been PROSECUTED for the harassment they gave me and other patients. First, they accused me of MAKING up testimonies of various people who i did NOT know , who had been seeking me out on the internet, becuae i had offered to READ the actual testimony of sick patients. Then, on a subsequent meeting, I was told at the last minute, that i had to have a SIGNED and Notarized statement saying that i was allowed to give the testimony of that person. This was a completely new and arbitrary rule. I was already bedbound and was simply trying to allow people who were too ill or too poor to come to D.C. in person to just participate in their legal and legitimate attempt to get the care that their Tax dollars had paid for.

And what did i get for these efforts to help my fellow very sick colleagues?  
Harrassment in the extreme!

The behavior of members of the HHS, CDC and NIH staff was criminal!

Another time, they called my home at 7:15 pm on a Friday night, before a monday morning meeting to say that the new Asst. Sec for HHS had just called them and told them that No ONE was allowed to read other people's testimonies any more, for ANY reason, unless the writer of the speech was in attendance. Since it was snowing at the time. and it was after 7 pm on a friday night, I KNEW for a FACT that there was NO Asst. Sec for HHS in his or her office on a friday night when it had been snowing since noon. So, i KNEW that the staff member who was calling me, was lying. All the local TV stations were saying how schools and government offices were shutting down early for the weekend since noon time, so that people could go and pick up their children for the day. This supposed meeting had taken place at 6:30 pm on this Friday night, when we had school closings and government office closing bulletins, since 12 noon. the ENTIRE reason for the phone call was to harass and disorient me. But the fool who called forgot that our family had lived in the DC area for 30 years, and i knew how the town worked. especially government offices.

No person that high up the HHS food chain would even know who spoke about what disease, let alone care enough to stifle a troublesome advocate on a Friday night, over a snowy weekend. The newly appointed asst. Sec. for HHS would not even CARE who read who's testimony at some meeting for a committee that the particular HHS big shot had not even attended the meeting that was called for in the CFSAC charter. These people NEVER listened to or responded to the testimony of the professional members of the CFSAC, let alone the sickest of the sick anyway! It was heartbreaking that many very, very sick Americans, and their friends around the world, would work for weeks or months on their 5 minute testimony, hoping and praying that it might make a difference. And those of us who KNEW better, knew that these great speeches would end up in the circular file, destined to become liners for the recycle bins, rather than being kept as a legitimate document on how we might actually help some very sick people find treatment for one of the most vicious medical conditions in the world. Many of the people who wrote to me, could not feed themselves. or sit up to eat. Many drank their meals through straws. The debility of this condition is just amazing. Between emails, post cards, hand written letters and beautifully typed Resumes and 10 page missives about how their once brilliant career was ruined, I have read more than 22,000 such letters. I would not believe it myself, if I did not live through it.

Even last week, I witnessed some portly buffoon, a Dr. Stoye, who was in charge of the Q and A for the first XMRV meeting at the NIH. He couldn't have been more rude and condescending if he tried. I have lived outside America for more than 5 years, and I am fairly worldly, but to have someone who is NOT American running a meeting at the NIH, where the New Director, of the NIH, Dr. Francis "the singing doc" Collins opened the meeting saying that it was a "momentous" time and that "great things" were expected from this panel, it was a less than auspicious display. Director Collins charged Dr. Anthony Fauci of the NIAID, with dispensing the top virus hunter in our country to work with these Retrovirologists to get to the bottom of the XMRV mystery and whether it does or does not cause all or part of this vicious disease.

The world wide press was interested enough to run more than 325 media articles in the past two weeks because a top NIH and top FDA researcher had mostly backed up the work of the Lombardi et al group from the WPI last year, that claimed that the newly discovered XMRV retrovirus, only the third known retrovirus in the world after HTLV-1 and HIV, MIGHT have something to do with the misery experienced by at least 17 million people around the world who suffer unbelievable nerve and muscle pain, cognitive impairment, completely non-restorative sleep, AND the distrust and derogatory smears from former friends and family alike. Most of us can NOT get even barely adequate medical care. There are very few palliative care items available for even minimal care, even after at least 30 years of top government officials KNOWING that this is a serious medical condition.

It has been DISGRACEFUL by any stretch of the imagination.

Dr. Jones, we are not a bunch of meretricious valetudinarians. It is a crime to be so sick and to be treated SOO badly by the very government officials that are charged with taking care of us, and getting to the bottom of what is causing all this misery should be Agenda Item #1. Back in 1989, I claimed that we were losing at least \$9.1 BILLION in government revenues PER YEAR from just lost tax revenues from what these sick folks would be paying, if we were not so sick. Dr. Jones, I repeat, That was way back in April of 1989. That number now is closer to \$20

Billion per year!. and what do we spend on researching M.E. and CFS? a mere 3 or 4 million...and most of that has been siphoned off to pet projects of other researchers.

All the while, those of us who speak up are exposed to the kind of harassment i just described from the very people that our taxes pay to help fix our health problems. It is immoral and it should be illegal. Until you came along, Dr. Jones, this was NOT the exception, this was the rule.

I was in the room, lying on my foam pad when Dr. Phil Lee, who has been a friend of mine since 1987 , two years before i collapsed, openly chastised these people, but nothing ever happened. To be soo sick and then to get hassled for simply trying to testify before a meeting of people who were trying to do good work, but who were totally ignored by our government leaders was disheartening in the extreme. I hope that with the discovery of XMRV things will change for the better. But, sadly, i am not as sanguine as our newbies are. Fool me once, shame on you! Fool me twice, shame on me!

Until i see serious amounts of money and top researchers assigned to this terrible plague, I will have to be counted as a skeptic.

I sincerely, hope and pray that you will prove me wrong.  
Thank you for your time.

Sincerely,  
Thomas M. Hennessy, Jr.