

Testimony

Thomas Hennessy, Jr.

Good Afternoon Chairman Snell, Dr. Wanda Jones, members of the [M.E.AC](#) committee, Ladies and Germs, as Charles Dickens once said, "These are the best of times. These are the worst of times...".

I want to PUBLICLY thank Dr. Wanda Jones and entire [M.E.Accountability Committee](#) staff all for scheduling this meeting on the 10th and 11th of May, so that advocates can both testify to the this committee AND try to meet with their respective senators and congressmen on May 12th, the 19th anniversary of ME/CFS/GWS/FMS/MCSS and Chronic Lyme disease Awareness Day.

Also, after more than 2 decades of requests from the patient community, HHS has finally made this meeting available on the Internet, so that the millions of sick people around the world can have access to these meetings. I thank you ALL on their behalf.

A lot has changed in the past six months. But, a LOT more needs to be changed. There IS enough research money. it is just going to the wrong places.

<http://report.nih.gov/rcdc/categories/> (if someone could get this page up on some kind of overhead projector by 4 pm, i would greatly appreciate it! thx. TMH)

Thanks To Dennis Mangan, Dr. Vivian Penn, Dr. Wanda Jones, Chairman Christopher Snell, NIH Director, Dr. Francis Collins, and HHS Director Kathleen Sebelius and all the folks who participated in the very informative "State of the Science" held at the NIH in April, all the key players now know that we are NOT a bunch of meretricious valetudinarians. We are very sick and in chronic PAIN!! The time for being treated as a piece of dog feces under the shoe of our medical officials and government bureucrats, and dishonest insurance executives is OVER! NO MAS!

The late, Great Eleanor Roosevelt once said, "You can NEVER be a second class citizen without your consent!" AMEN....

The time to be referred to as being "chronically fatigued" is Over!. NO MAS! If patients en masse REFUSE to accept the label "CFS" anymore, and the doctors refuse to DIAGNOSE UNDER THIS ASSININE LABEL, IT WILL DIE ON THE VINE! Myalgic Encephalomyelitis has had a valide W.H.O. code as a neurological illness for 40 years! USE IT!

There are NO more excuses. Slow people need to learn by repetition, so i again say, the theme for now and the future is "NO MAS!" Dr. David Bell once referred to this as "the disease of a thousand names".

I say the exact opposite. This is 1,000 disease entities under ONE name! Louis Pasteur said more than 100 years ago, "The antigen is nothing, the terrain is everything!"

As I said in my first speech to the very first International "CFS" meeting in 1989, "We are NOT sick of being tired, We are tired of being SICK!" There is a HUGE difference!! Webster's Dictionary says "to define is to make clear and distinct, to differentiate". If you do NOTHING else today, lock the doors and come up with an accurate definition and change the God Damn Name! If you do not have the courage to do this today, you will condemn untold millions of people from all over the world to lives of abject misery, premature deaths and a huge economic burden on our societies. Knock heads until you come up with an accurate definition and a proper name" That Date was April 15th, 1989. the day before my 35th birthday. Despite seeing some of the top doctors in the world, and trying more than 100 different medications, supplements, meditations, prayer groups and more. and I still have not been able to work ONE single 8 hour day in the past 23 years!

The good news is that we have a good definition, we need to adopt the Canadian Consensus Definition, by Carruthers et al TODAY and scrap every other definition in use anywhere in the world. Period! Go with the name Myalgic Encephalomyelitis, which is not a perfect name, but it describes a CIND (Chronic Immunological and Neurological Disease) which has had a WHO classification for 40 years. -The Canadian Consensus Definition must be adopted worldwide immediately. all other definitions and names need to become moot. Immediately.

The CDC "CFS" website must be taken down and rewritten immediately! the entire staff of the CDC "Viral exanthems" division from Dr. William Reeves and Dr. Elizabeth Unger, jim jones et al need to be fired immediately and given NO severance whatsoever. Their so called "work product" for the past quarter of a century has been abysmal. What they claimed to be affecting some 4,000 to 10,000 Americans in 1988, they NOW claim affects 1 Million to 4 million people! If AIDS, Heart Disease or Cancers went from 4,000 people to 4,000,000 people in 25 years and you worked for the "centers for disease control" in corporate America, they ALL be fired! no severance, no mercy, NO MAS!

I have read 25,000 letters from all over the world. Hard working, ethical young men and women contract some type of Agent "X", which causes dysfunction of the autonomic nervous system. Many ignorant and arrogant Psychiatrists, most from the damn 'Simon the weasel' school in the UK have pushed GET and CBT theories to cure VERY PHYSICALLY SICK PEOPLE by forcing them to exercise their way out of being SICK. This is a crime against humanity! We are for the most part, HARD WORKING, ethical, often even athletic people who have pushed ourselves too hard already. We are NOT deconditioned because we are lazy or fearful of exercise. We are SICK! I have tried to push Chairman Christopher Snell behind the scenes to film EVERY patient that goes through their "Stevens Protocol". Insurance companies like UNUM Provident will continue to use outdated, dishonest criteria that they bribed weasals like Simon Weasally to "delay, deny, and hope you die!" as long as we let them. They are out to collect

premiums, and then "delay, deny, and Hope you die" when sick people make legitimate claims. Chairman Snell tells me These same patients almost always WIN their disability cases when they reach the Administrative Law Judge stage, which is often 2 to 3 years after filing their disability application. And since 40% of all Americans have net worth's less than \$2,000 this is a calamity which will only get worse!. I believe that most patients will gladly give permission to allow themselves to be filmed which will PROVE that we can NOT do any sustained physical or mental effort for one, two or three days in a row"

This group of conditions is caught between the Autism spectrum disorders in young, immature nervous systems, and Alzheimers on the other end of the spectrum. this is an International calamity that will bankrupt the Long Term Disability industry, so they have and they will continue to lie, cheat and steal premiums and then write in the small print in their contracts that if you are diagnosed with "CFS" or "FMS" you only get two years lifetime disability payments. Then they give "VULTURE awards" for the claims adjusters that deny the most "CFS" and "FMS" claims. they all should be given Rodney King style beatings every day of their lives until they "get it". We are no longer going to be the doormat of the medical industrial complex. We suffer from complex, devastating Neuroimmune diseases.

The joke in our community is that knowledgeable doctors who encounter new M.E. patients in their practice say "I have good news and bad news for you..." when the patient asks "what does that mean?"the M.E. literate doctor says....the "good news is that this disease probably won't kill you.....and the bad news...is that it probably won't kill you....."

Dr. Nancy Klimas who has treated AIDS, GWS, and M.E. patients and she said, If she had to contract HIV and AIDS or M.E. in today's world, She would choose to contract HIV!. Dr. Marc Loveless, who also treated more than 2500 patients with both diseases, stated under oath in front of the U.S. Congress that his "M.E. and CFS patients are more sick every single day, all day, than his AIDS patients are just two months before they die!" We are like dying Hospice patients every day of our lives and we have been treated as criminals and vagrants. This must end RIGHT NOW! Again, I say "NO MAS!"

I have heard strong, brave people give similar stories of abject misery to this committee and its forerunners for two and one half decades and they have all fallen on deaf ears until the now Infamous WPI SCIENCE paper of October 8th, 2009!.....Some group has to go to the WPI and repay the Whittemore family EVERY single dime they have invested in their WP Institute, for no other reason, than getting the HHS director Sebelius, NIH Director Dr. Francis Collins, and even President Obama to utter the words "CFS" and "serious, devastating, extremely debilitating in the same sentence". So, there are NO more excuses for delaying, denying and hoping that we will wither away and die! Ignorance as an answer...NO MAS!

I have heard patients who have lost their marriages, their careers, their families, their friends and far too often their very lives to the disease compare it to a life sentence in

solitary confinement, without parole. All the while being tortured every single day of their lives. NO MAS!

In 1989, I estimated annual GDP loss to the U.S. economy alone was more than \$9 Billion! Now, Lenny Jason and others estimate that the losses are somewhere between \$18 million and \$23 Billion...So, our medical establishment is not only cruel, they are STUPID!

Next, Medical Education! Many of the good doctors who have treated us are nearing retirement. With virtually NO curriculum regarding M.E. at major medical schools, this is a disaster that is going from very bad to a true crisis. We need to pay EACH Clinician like Dr. Susan Levine, Dr. David Bell, Dr. Paul Cheney, Dr. Nancy Klimas, Dr. Chuck Lapp, Dr. Dan Peterson et al, who have treated at least 1,000 M.E. patients in a clinical setting should be given a stipend of \$250,000 each and given ONE year to rewrite the CDC website and come up with pamphlets that give the Canadian Consensus Definition, and the most effective tests that need to be done, and the most efficacious treatments available. the CDC and NIH need a 24 hour a day hotline that is staffed with knowledgeable people who can answer questions for people who are too poor and too sick to travel to the acknowledged experts.

Public Education! Patients who are doing their best to cope under impossible circumstances are subjected to verbal and Physical abuse by people who have been persuaded by the powers that be that patients are either lazy or crazy and can be cured by thinking happy thoughts and rising Lazarus-like from their beds. "Just go back to work!, GET and CBT will cure you." absolutely criminal... NO MAS!

Some 90% of us have one or more documented sleep disorder. When the body can not get to deep restorative sleep, it can not repair itself, which disrupts the autonomic nervous system even further. Sleep disorders need to be diagnosed and treated by any and all means necessary.

We need DRAMATIC INCREASES IN FUNDING! Not one penny less than \$250 Million per year, until we catch up parity with other serious illnesses. Anthrax research has gotten close to a BILLION dollars in NIH research money since 9/11 and yet the "CFS" budget has decreased. maybe six to 10 people have been injured by Anthrax...and yet, Anthrax has gotten close to a billion dollars in the past decade! Pat Fero's excellent presentation at the State of the Science meticulously dissected the misallocation of taxpayer funds at the NIH over the past 25 years. a copy of her speech is on our website at www.rescindinc.org

The funding for M.E. is NOTHING at the NIH. and the dismal funding for the "CFS" crap is less than 1/10 of 1 percent of the annual cost to the economy of having us lying in agony in our beds and contributing nothing to society. If you can get us back to work, we will make that back in income taxes in under a month!

The Centers of Excellence have been defunded. We need to RE-FUND them. The WPI must be re-imbursed for every dime that the Whittemore family has INVESTED to help find the causes and treatments for Neuro-Immune Diseases.

When I asked fellow patients if they wanted me to make any specific comments to you six months ago, the biggest response I got was "Why Bother?" This group has made leaps and bounds improvement in the past six months. Keep it up!

So, In conclusion i say the cu NO MAS!!!

- #1. Adopt the Canadian Consensus Definition TODAY! Discontinue every other "Definition" on the planet. Declare them null and void.
- #2. Join the almost 10,000 names on the M.E. Definition that has a link at our Rescindinc.org website. if you have not signed yet, do, so. When we hit 10,000, we are taking the signed petition to the White house in a giant Wheelbarrow.
- #3. Demand NIH funding of not one penny less than \$250 Million for fiscal year 2012. Take the money from the ANTHRAX budget. that is just slush fund for the Pentagon anyway, and Anthrax has sickened less than a dozen people since 9/11. We have close to 1,000,000 homebound or bed bound people suffering from WHO, neurological and Immunological disease of Myalgic Encephalomyelitis.
- #4. Get clinicians and researchers who have seen at least 1,000 patients in a clinical setting and give the top ten a stipend of \$250,000 to completely rewrite the CDC website and decide WHERE and how to spend the \$250 Million coming out of the Anthrax budget at the NIH.
- #5. Reimburse the WPI for every penny spent so far by the Whittemore family, and fund trials PROPER replication trials for XMRV and the National CFIDS association of Gail Kinsky's ciguatera isotope found by Dr. Hokama, one of the top marine biologists in the world. virtually every serious M.E. patient they have tested has been positive.
- #6. Fast Track Ampligen. Look at Mary Schweitzer and Bob Miller. they are living proof that this drug can help people. Dr. Carter and company are poor managers. I say that the Pentagon should declare this disease group a national emergency and they should nationalize HEM and give Dr. Carter a royalty for every treatment of Ampligen, and use the Pentagon funding to do trials on sick gulf war veterans and any patients who want to enroll.
- #7. Refund the Centers of Excellence for Dr. Jose Montoya at Stanford, and Dr. Klimas in Miami, Dr. Komaroff at Harvard, Dr. Lucinda Batemen in Utah, Dr. Susan Levine and Dr. Derek Enlander in NYC, and until they are proven WRONG, reimburse the WPI for every penny they have invested. they have gotten us MORE press and medical attention in the past 2 years than in the past 20!
- #8. Fire the entire CDC "Viral and Exanthems branch" and start hiring competent people immediately.
- #9. Give a round of applause to Dr. Nancy Klimas, Dr. Lenny Jason, Dr. Susan Levine, Dr. Vivian Penn, Dr. Wanda Jones, Dennis Mangan and all the others who tried to make a silk purse out of a sow's ear over the past 2 decades, and congratulate them on their NEW name of the M.E.A.C. the Myalgic Encephalomyelitis Accountability Committee....

#10. Initiate a class action lawsuit against all Long term disability companies who have used bad faith, bribery and outright fraud to "delay, deny and hope you die" to tens of thousands of very ill people over the past 25 years.

Thank you for your time!

Sincerely,

Thomas M. Hennessy, Jr.