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## **Press Release: INCORRECT GOVERNMENT INFORMATION COULD BE HURTING CHRONIC FATIGUE SYNDROME PATIENTS, NEW RESEARCH FINDS**

November 20th, 2013 • [25 comments](#) • [Filed Under](#) • [by ABMN Staff](#)

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**PRESS RELEASE: NEW YORK, NY (11/20/2013)** – An untold number of New Yorkers, perhaps well over 100,000, who have been diagnosed with Myalgic Encephalomyelitis and Chronic Fatigue Syndrome (ME/CFS) could be at risk of relapsing and exacerbating their condition due to a course of a treatment suggested to them by the federal government, according to groundbreaking new research.

At a medical conference today sponsored by the New York ME and CFS Center at Mt. Sinai and held at the New York Academy of Medicine, researchers showed that a form of treatment called Graded Exercise Therapy (GET) which has been lauded by the UK's National Institute of Clinical Excellence (NICE) and recommended by the U.S. Centers for Disease Control and Prevention (CDC) may not help ME/CFS, but actually can make it worse. Unfortunately, the CDC has long been touting that certain exercise regimens can help manage the disease, even offering guidance on their website.

Dr. Derek Enlander, Dr. Eric Schadt, Dr. Miriam Merad, Dr. Christian Becker and a team of researchers at Mt. Sinai Medical Center have discovered new research on ME/CFS that could change the way the disease is treated. Their research shows that the disease is tied to the immune system much more than originally thought. A recent study showed patients can actually relapse when they partake in excessive exercise, and other therapies maybe more effective.

"We want to raise awareness about this disease, how it affects the body and the best way to treat it," Dr. Enlander said. "For too long, this disease has been misunderstood, leading to a poor quality of life for far too many patients. We hope to change all that."

Myalgic Encephalomyelitis was first identified in the mid-1950s, by Dr. Melvin Ramsay of London's Royal Free Hospital, after being suspected of outbreaks dating back at least two decades' prior. What is thought to have been an outbreak in Nevada's Incline Village in the mid-1980s, mirroring one in rural upstate New York's Lyndonville, led to the CDC officially recognizing a condition reduced Chronic Fatigue Syndrome in 1988 following the elimination of the Epstein-Barr virus as a potential culprit. The CDC has displayed an inconsistent track record ever since, diverting millions of dollars earmarked for research in the disease to other causes in a scandal uncovered some 15 years ago. Recent estimates suggest that hundreds of thousands of people in the U.S. suffer from CFS, although the CDC is thought to have both underestimated the severity of the disease, while overestimating the numbers, as they have reported a disease prevalence of 2.54% in the U.S. This figure is not accepted by experts in the field. Using the more-accepted figure of 0.4% would estimate the number of sufferers in the New York City Metropolitan area alone at over a half million patients, the majority of whom are likely undiagnosed.

The illness which afflicts women to a greater degree than men, causes severe immunologic dysfunction, profound loss of energy (sometimes referred to as fatigue, though in many cases patients would report that this term is inadequate as a descriptor), sleep disorders, neurological disturbances, pain, and other symptoms. Underlying causes and treatments for CFS have been elusive, but new research is shedding light on how the disease works.

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*Jill McLaughlin*

ME and CFS flips to ME/CFS? There is NO such disease as ME/CFS. If Incline Village was ME, then it was a missed dx and what the CDC defined is not ME, so no, CFS is NOT just another name for....

Whatever happened historically does not change the fact that currently CFS is defined very differently from ME and there is no valid reason to call or combine ME as/with CFS. ME is NOT CFS, so talking about ME/CFS is not only diagnostically inaccurate it makes no sense in any realm. This is the incorrect information that is harming patients.

- *Toby Vokal*

I want to thank you for being factual about the disease. We patients suffer and a lot and there is different ways that ME is portrayed. Hopefully more media will pick up on this. Could you please look into the HHS-IOM contract that is trying to redefine the disease? They are trying to prescribe exercise, CBT, and other harmful treatments.

- *lemonfoundation*

HIV-Negative AIDS: Is it CFIDS or AIDS?

Allied NATO Government is hiding millions of infectious NON HIV AIDS cases (like mine) under the "Chronic Fatigue Syndrome (CFS)" ICD-code.

- Dr. Lorraine Day was on Riley's THE POWER HOUR (9/12): "...HIV-Negative AIDS cases falsely reported and treated as CFS cases may be one of the biggest cover-ups we have seen."

- In 1992 "...Newsweek made an even more shocking announcement: ...CFS patients who had the same immune system deficiencies as the NON-HIV AIDS cases..."

- Dr. Judy Mikovits stated on In Short Order (11/12) about CFS & Myalgic Encephalopathy (ME):  
"...consider this as NON HIV AIDS."

– Neenyah Ostrom's book "America's Biggest Cover-up: 50 More Things...CFS & Its Link To AIDS" cites: "Some CFS Patients May Be Non-HIV AIDS Cases."

My case goes up through the NIH, CDC, White House, WHO, to the UN. I testified federally in Washington-DC, and am published 18 times on 4 continents.

<http://www.ukprogressive.co.uk/the-aids-like-disease-seldom-mentioned/article20891.html>

I hope that you will spread-the-news too.

Or simply google "NON HIV AIDS"

- *nush*

Very accurate reporting. I like to add that ME does not only affect adults, it also affects children as young as two years old. The misinformation surrounding ME and CFS has led to many tragic events where children and young adults are removed from their parents care and even incarcerated into mental institutions against their will. The consequences are horrendous; children mistreated with graded exercise and forced to school are ending up bedridden and have to be tube fed for years. Some died. The latest case is a young girl from Denmark, who was forcibly removed from her home and is held against her and her parents will in a psychiatric ward, treated by psychiatrist, Nils Balle Christensen with graded exercise and CBT. Please read about her case and report! We need all the help we can get by news agencies to raise awareness . <http://voicesfromtheshadowsfilm.co.uk/2013/karina-hansen-is-a-severely-ill-danish-patient-who-was-forcibly-taken-from-her-home-update-may-2013-9th/>

- *Smith*

Karina Hansen is the 20-something-year-old woman who Danish police and psychiatrists forcefully removed from her home. She's been held around eight months now and denied legal representation and access to her immediate family. <https://www.facebook.com/JusticeForKarinaHansen>

- *Fred Smith*

Right – because the mitochondria are damaged, and can't regenerate energy quickly like normal, exercise is harmful. The hallmark symptom of ME/CFS is exercise intolerance causing post exertion exacerbation of all symptoms. These can last for days depending on how far you overdid it – just the activities of daily living are enough to over do it, much less adding actual exercise on top of that. Patients should be pacing their activities so they don't over do.

- *Smith*

Huffington Post has just featured a story on an upcoming film on the ME experience, called "Canary in a Coal Mine" by ME patient and director Jennifer Brea. [http://www.huffingtonpost.com/jennifer-brea/myalgic-encephalomyelitis\\_b\\_4303725.html?utm\\_hp\\_ref=fb&src=sp&comm\\_ref=false](http://www.huffingtonpost.com/jennifer-brea/myalgic-encephalomyelitis_b_4303725.html?utm_hp_ref=fb&src=sp&comm_ref=false)

- *lquitos*

Thank you for some of the most accurate reporting on this disease I have ever seen. That ME has been recognized since 1969 by the World Health Organization, with CFS a synonym for it, has been ignored by the US health bureaucracy (CDC and NIH) is worse than a scandal.

And big thanks to Dr. Enlander and the Mt. Sinai researchers for doing so much with so little support. It really gives those of us who have been sick for decades a little hope that, maybe, others may not have to have their lives ruined by this devastating disease, even if it's too late for us.

- *tonnyb2*

First I'd like to thank you for the accurate reporting.

MATH ERROR: 500,000 is .4% of 125 million. NYC metro has ~24 million people. I would love to see the corrected numbers. Thanks.

- *tonnyb2*

There is an attempt in the research community to separate ME from CFS, defining ME as exercise intolerant and CFS, not as much. In fact the WHO has classified ME as a neuro illness since 1969. The US however had ignored it and finally added it to a collection of undefined fatigue issues under the CFS banner in 1988. The new ICD-10, scheduled to go into effect in late 2014, gives ME it's own diagnostic code G.93.3 (WHO's code) and, for the first time since 1988, specifically separates it from CFS.

- *disqus\_Rv8tqVZbOP*

Yes the research community wants separation, but technically they are separate. It is the "ME/CFS" groups that are pushing to combine them and flood everything with ME/CFS misinformation.

- *tonnyb2*

I don't see it that way. Much of the research is indistinguishable. They have been conflated for a long time. They are not separate in the literature or media.

- *disqus\_Rv8tqVZbOP*

Which is what has caused the problems. These US "ME/CFS" groups (Pandora, Phoenix Rising etc) have lead the charge to try to officially combine them by changing ICD codes. We literally have "advocacy" that works against us. These so called patient groups have greatly contributed to the conflation and confusion and deliberately switch around terms (the "it's just a name" game). These groups write articles and literally change terms from what was used in the original research, or within an article switch from CFS patients to ME/CFS research to ME studies. It is unscientific, sloppy and embarrassing. And much of the research IS distinguishable. Read Lenny Jason's comp def papers.

- *Jill McLaughlin*

ME/CFS misinformation is rampant and pushed/promoted by patient groups. There is no such illness as ME/CFS (no WHO recognition or ICD code). WHO does NOT say that CFS is a synonym for ME. WHO does not even recognize CFS as an illness. It is not included in the tabular disease listings, only in the alphabetical index as a term.

The term M.E. was coined in 1956 and means: My = muscle, Algic = pain, Encephalo = brain, Myel = spinal cord, Itis = inflammation. Chronic Fatigue Syndrome means Chronic Fatigue Syndrome. Sound the same? ME predated CFS by several decades so were not merely different names.

CDC states in CME courses: "ME is accompanied by neurologic and muscular signs and has a case definition distinct from that of CFS." <http://www.cdc.gov/cfs/education/wb1032/chapter1-1.html> ...

This is true. ME IS ACCOMPANIED BY NEUROLOGIC AND MUSCULAR SIGNS. CFS is not. There is no validity or science to the bogus ME/CFS. ME/CFS research means NOTHING as there is no way to know what patient group was being studied.

This ME/CFS definition has become a turf war. There should be no ME/CFS definition as there is no such disease. This is only making up something that they will call ME/CFS. There can be no definition that is best or even works for what are and should remain different things. The real issue is that ME patients want an ME definition. CFS people can figure it out (rename, redefine CFS etc), not borrow or hijack ME.

- *tonnyb2*

Your link is no longer available.

There should be no ME/CFS. However at this time it still exists as a manufactured construct. With the growing awareness of the conflation of the terms, the efforts by some experts to disentangle ME from the CFS moniker, the distinction made in ICD-10, where ME is separated from CFS, and with ICD-10s implementation on 10/1/14, the separation will be complete and ME will get the attention it deserves.

Dr. Enlander is interested in ME as described by Dr. Melvin Ramsay, observer of one of the most definitive ME cluster outbreaks, the 1955 outbreak at London's Royal Free Hospital.

There is also the documentary, Canary in a Coal Mine, that among other things, intends to disentangle ME from CFS. <http://www.kickstarter.com/projects/959776320/canary-in-a-coal-mine>

- *disqus\_Rv8tqVZbOP*

If Dr. Enlander is interested in ME then he should use the correct terminology and not play the ME/CFS shell games. Hoping that the documentary would tell the truth about ME (not just a name for CFS), but the well known ME/CFS suspects are being featured so this makes people wonder.

- *tonnyb2*

If he uses the correct terminology he will be dismissed by the media and his peers since ME has yet to be established in all circles involved.

- *disqus\_Rv8tqVZbOP*

And it never will be established in all circles involved if we keep this up and keep making excuses. Frankly this "oh vee haff to..." nonsense is the "ME/CFSers mantra but a poor excuse. This is only contributing to and further entrenching the problems. And the media is nothing but press release journalism so no, they simply do not care and wouldn't even notice.

- *lemonfoundation*

Chronic Fatigue & Immune Dysfunction Syndrome (CFIDS) is a syndrome, hence its name.

Acquired Immune Deficiency Syndrome (AIDS) is also a syndrome.

CFIDS & AIDS are not diseases. ->

A syndrome is a syndrome.

Allied government mindfully left the "ID" out of CF(ID)S to create the silly, belittling Orwellian name, "CFS."

Myalgic Encephalomyelitis (ME) is a disease, just like malaria or MS ~ with specific hallmark diagnostic biomarkers.

CFIDS is AIDS-like (syndromes)

ME is MS-like (diseases)

“CFS/ME” is not interchangeable, or accurate.

ME patients do not have CFIDS. While many do, not all CFS patients qualify for a ME diagnosis (by International Consensus Criteria (ICC)).

Just like a CFSer cannot just wake-up and decide “hey, I have malaria.” A CFSer cannot just wake-up and arbitrarily decide that they have ME. A CFSer stating that they have ME is the equivalent of an AIDS patient stating that they have MS → it is wrong. Until the day comes when a doctor diagnoses you with ME, then you have CFS → a syndrome.

Syndrome or disease, patients suffer and die of both.

E.g., AIDS (syndrome) patients die all the time.

People ignorantly talk about AIDS like its one thing, but by present-day definition, there are 29 separate and distinct DISEASES under the AIDS SYNDROME umbrella (everything from TB, malaria to lung and cervical cancers); Only every 29th AIDS patient is alike.

There have to be 29 types of CFS. {1 type being ME}

There is only one type of ME.

CFIDS & AIDS (both syndromes) are 100% political paradigms.

ALLIED NATO GOV'T SOLD-OUT

GLOBAL PUBLIC HEALTH FOR SAKE OF →

INDUSTRY, OIL, & ORWELLIAN GREED

<http://www.cfsstraighttalk.blogspot.com>

- *Gabby Klein*

The title of this article says it all. One million Americans suffer from Myalgic encephalomyelitis/chronic fatigue Syndrome (ME/CFS). This is a very serious, complex debilitating disease. It has rendered me disabled for eleven years now. One of the hallmark of this disease is that exercise not only exacerbates the disease, it can permanently bring about further damage and has rendered many patients bedbound forever. THE HHS?CDC has been ignoring this fact and the CDC actually promotes exercise for patients on their website. To make matters worse, HHS has recently contracted with the institute of Medicine (IOM) to re-define the disease and to further promote their damaging views on this disease. This contract has been violently opposed by the ME/CFS community resulting in an open letter to HHS from 50 worldwide experts in ME/CFS urging them to cancel the IOM contract. This has been followed by a letter signed by 171 patient advocates asking for the same. HHS is ignoring all this and forging ahead

with their damaging agenda. We need the world to know what is being perpetrated by the government against this very ill patient group.

- *Jill McLaughlin*

There is no such disease as ME/CFS. CDC studies CFS. CDC clearly states that research is done using the Fukuda definition, which is for CFS. NOT ME. CDC IS telling the truth. ME/CFS is patients false illness beliefs that they are the same or that CFS research should apply to ME. These so called "ME/CFS" patient groups are just part of this turf war and vastly overrepresent themselves (any blog, discussion list or website calls themselves a group). These "groups" are working against ME patients (and ban and censor any honest and open discussion that would thwart THEIR "ME/CFS" agenda). The ME/CFS cabal does not tell the truth that ME patients are opposed to this entire ME/CFS scam. ME patients do not have CFS (in the medical/diagnostic sense), do not want to play the "ME/CFS" shell games and are not part of this bogus "ME/CFS" community.

- *Sprinter1*

Thanks for correctly reporting that the problem is the CDC, not awareness. It's a political turf fight. If the CDC would listen to the doctors who treat the patients, the misinformation would disappear.

- *I dont hate you*

So still we are not allowed to give blood, still parts of the Royal Free out break are subject to the UK official secrets act for eighty years!

It is blindingly obvious there is a cover up. Do the people hiding the truth, insurance, politicians and probably most disturbing of all...the Military ! Care that their names will be mud at some point for their future family to see.

If the wider public knew the truth, they would sure to goodness care!

I'd also like to show my full respect to the author who presented the information in a conscientious manner. It very much appreciated.

- *tonnyb2*

Except almost all the patients fully recovered. How is that related to ME?

- *I dont hate you*

Because the ones that did not recover could be considered as having M.E. While the others recovered from the original outbreak. This could be a pattern where an unknown virus effects an area and not everyone recovers.

I'd also like to take up the point that exercise has caused me permanent unfixable issues. Exercise is dangerous for M.E patients if forced. A relapse some years ago after forcing myself to exercise left me with swallowing , toilet and balance problem. It is clear to me that unfixable nerve damage is done during these relapses. In fact you can feel your are and back of my legs went dead during these relapses, then they recovered some what but left me with damage and loss of feeling in my hips also. I was given a a Spinal tap to look for M.S or Tumour, nothing obvious was found.

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