

The HUMMINGBIRDS' FOUNDATION for M.E. (HFME)

Fighting for the recognition of Myalgic Encephalomyelitis based on the available scientific evidence, and for patients worldwide to be treated appropriately and accorded the same basic human rights as those with similar disabling and potentially fatal neurological diseases such as Multiple Sclerosis.

XMRV, 'CFS' and M.E.

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There has been much media publicity lately over a small research study that claims to have made a connection between "CFS," or "ME/CFS", and a retrovirus. While many are touting this as a huge medical breakthrough, there is a large group of doctors, scientists, patients and advocates who look at this information with tempered enthusiasm.

Why? These people are well-versed on the topic, and realize that before moving forward with great jubilation, more information is required. We realize that this research in and of itself, means precious little, so we have not only adopted a more "wait and see" attitude, but are of the opinion that this research is most likely relatively unimportant in the scheme of things and would not place it anywhere near the top of the list in the arena of much needed new M.E. research. We also worry that this research, and the sensationalism with which it is being reported, will detract from the need for genuine M.E. research.

The following comments from M.E. researchers, patients and advocates may help you understand better the "wait and see" attitude these folks have, and why it is so appropriate.

Additionally, as you consider the following insightful comments, please keep in mind what the Whittemore Peterson Institute itself says about the blood samples used in their recent retrovirus study:

"Dr. Peterson has a repository of samples from the original out break in Incline Village, Nevada which also includes longitudinal samples taken from patients from the 1980's through 2005. None of these samples were used in the XMRV study."

[Reference link](#): WPI website

Thus we actually have no way of knowing if any M.E. patients were involved in the study at all, and that makes the results suspect to those of us who do have

M.E. Knowing what we know about the wastebasket label "CFS", it makes us feel that the results of this study may not ever come to have any real value at all for M.E. patients, nor for many of those given a 'CFS' misdiagnosis. Perhaps the following comments, taken from an informal group discussion, will shed some light on a few of the reasons we need to consider this research with a healthy dose of skepticism.

Quotes on XMRV by fellow advocates:

‘Here's what I think we know & don't know:

1. Patient population

- We know the blood samples were not 100% ME. Samples were from patients with `CFS' according to Fukuda & with `ME/CFS' according to Canadian Definition
- It's possible that some of the blood samples were from ME patients. Some ME patients may be included in the `CFS' group
- So the findings definitely do not apply only to ME. They might apply to ME as well as to other diseases.
- It's not clear what disease(s) the patient population represents.
- The media reports that this applies to ME (e.g. The Independent newspaper in the UK) are wrong.

2. Cause or effect?

- The media are claiming a possible `cause' of `CFS.' However, the article did not say Mikovits et al had found a cause, only that they had found an `association.' The article acknowledged that XMRV might only be a `passenger' virus.
- Mikovits said elsewhere that she is hopeful that XMRV might be the cause of `CFS,' and Cheney said it seemed likely - but they haven't explained why.
- No one has definitely said that XMRV is the cause of anything.

- It could be that XMRV infection is one of the things that is likely to happen when people are very ill, like RNase L dysfunction, like mitochondrial dysfunction, etc etc.

- For all the speculation, no one knows what the association of XMRV with 'CFS' means.

3. What disease?

- The findings is that XMRV is associated with 'CFS,' but it has also previously been associated with prostate cancer. XMRV is also associated with leukaemia and lymphoma. So XMRV seems to be associated with a whole range of diseases."

- Lesley

“Sorry to go on about this, but I was just thinking of the way that the study is getting endorsement/credibility from some people because a lot of the blood samples came from the same region as the originally-studied M.E. patients.

[Editor’s note: Note that soon after the initial WPI XMRV announcements, it was made clear that in fact, samples from the 1980s outbreaks in the US were NOT included in this study, as had been claimed.]

This made me think of the way in which "Swine Flu" really broke out in Mexico a few years ago (though I've heard reports that it had existed for some time before that, possibly elsewhere). The people in that particular Mexican region had been coming down with all kinds of things, because of foreign business that was operating in a particularly unsanitary way in their vicinity. So not only would they have tested positive to H1N1, but to many other things as well, because of environmental problems and the fact that getting sick with one thing tends to weaken your immune defences, making you more susceptible to other infections. But none of that would imply that H1N1 caused even the majority of the majority of these people's symptoms.

So this study *may* signify that people *from that US region* who had immunological or fatigue problems of some sort were more likely than those from other US regions, say, to develop XMRV. At this stage it's just hard to know what it tells us.

I do agree with _____ that the field of psychiatry as it is practised right now is often very much governed by the political interests it represents, and is hence not a particularly 'pro-health' discipline.

In terms of whether XMRV has anything to do with Myalgic Encephalomyelitis, I have to say that right now there's no evidence of that.

1. The patients whose blood samples were used were very probably not a solely M.E. group (and I'm not referring to the controls). The selection criteria used were the 1994 Fukuda "CFS" criteria, and the 2003 "Canadian Consensus" "ME/CFS" criteria. Neither of these criteria are the same as those of the original M.E. that was studied by Ramsay, Dowsett, Richardson and Hyde and has a WHO classification ("CFS", of course, has never achieved a WHO classification).

The Fukuda criteria describe little more than a fatigue syndrome, and the 2003 criteria are a little more complex, but still include those who don't have M.E.

2. Correlation does not equal causation. Therefore the greatly increased incidence of XMRV traces in the samples from the "CFS" patients, as compared to the controls, does not prove that XMRV is a cause of **anything**. Suppose for a moment that the subjects tested had all had M.E. Because M.E. includes phases of Th1/Th2 imbalance such that the patient has increased susceptibility to viruses, having M.E. can in itself make it much more likely for past evidence of **many** viruses to show up in patients. ****Other sorts of immune-compromised patients might also be very likely to demonstrate this effect.****

3. This sort of reporting can be very dangerous for the cause of M.E. rights as it actually encourages the continual conflation of M.E. and fatigue syndromes and hence takes attention, knowledge and funding away from actual M.E. The hype surrounding XMRV has also disguised the fact that M.E.'s being caused by a virus has been known for many decades. No, that's not the same as identifying which one in particular (which would be even more useful). But the many wrong statements surrounding this 'discovery' both make it less likely that accurate, scientific work on M.E. will be funded, and make it more likely that sufferers will focus their attention on the wrong thing - i.e. justifying "CFS" as always having a physical cause. This, because its definitions tend to be so vague, is quite probably wrong. (As it's likely that "CFS" groups together those with actual undiagnosed illnesses (including M.E.) and those who have "fatigue" due to depression.)

Here's a link to the HFME's "[A warning on 'CFS,' 'ICD-CFS' and 'ME/CFS' research and advocacy](#)"

As far as I know, the estimable Doctors Cheney and Peterson have done excellent work but do tend to conflate M.E. and fatigue syndromes.

<http://www.hfme.org/wcheney.htm> is an interesting link that discusses the question of what their work applies to.

I don't think the involvement/endorsement of these excellent doctors should blind us to the fact that those conducting the study themselves made it very clear what the selection criteria were - the 2003 "Canadian Consensus" "ME/CFS" criteria (not the same as M.E.) and the 1994 Fukuda "CFS" criteria (about as far away from M.E. as you could get).

I know it's tempting to hope but I really think that the interests of M.E.ites would be better served by clarity about who this study was about, in order for us to point out that research still isn't being done where it needs to be ...”

- Virginia

“It is entirely possible to use the "Canadian Consensus 2003 Criteria" and select a 100% non-M.E. group. It's possible and even likely since M.E. is just one very small group in CFS, after all. So using that criteria makes no difference, it may as well be the Fukuda definition. Neither selects a homogenous patients group or a strict M.E. patient group.

The claimed (and now proved to be false) link to old victims of outbreaks also seem tenuous, as many think they were part of outbreaks and had EBV, etc. or doctors now see EBV, etc. as part of this M.E. outbreak...as there were apparently EBV outbreaks at some time, so this is also unclear. Just saying something is linked to mid-80s outbreaks in the US does not at all mean that what is being discussed must therefore absolutely be 100% about M.E. Far from it.

Of course, we can't rule out that this thing will be shown to be relevant in the future, perhaps as a minor passenger virus which needs treating. Maybe. That isn't impossible. But to embrace it now, while there is no evidence at all of it being more than a passenger virus in some fatigued patient groups and many different illnesses is very premature. Of course, lots of people with a 'CFS'

misdiagnosis ARE ill, and do have immune system problems. Lots of them do. So finding immune anomalies in no way means the research (or anomalies) is about M.E. It probably affects M.E. patients and many, many others with weakened immune systems. Just like Rnase L.

Of course XMRV isn't the cause of 'CFS.' It can't be. If you have abnormalities on testing, you no longer qualify for the diagnosis. So it's just silly to say XMRV could be the cause of 'CFS' as 'CFS' does not exist and is just a misdiagnosis, a wastebasket diagnosis.

XMRV is also not the cause of M.E. For one thing the incubation periods are all wrong, as Hyde has explained. There may or not be evidence some M.E. patients have XMRV infections, along with those with many other diseases, but that is very different to a cause. It's crazy so much attention given to what, if anything, is almost certain to be just yet another passenger virus.

It's like RNase L. Many said this was just happening in M.E. and trotted out the same old nonsense about this being 'first proof' of the disease. (As ridiculous as that is if you are talking about M.E.!) But as it turned out, even though yes it happens in M.E. it also happens in many, many, many other diseases where the immune system is affected, so it's useless information, really. It is extremely unlikely they had a solid, 97% single patient group involved here, so that makes it almost certain it's just another vague RNase L type thing doesn't it? Something that affects those with many different diseases. It falls into the category of just one of the many things that go wrong in an unwell body. It has nothing to do with causing the illness in any way. There is no evidence to suggest that at all. Yet that is what many involved in this are claiming. It's appalling.

CFS is a wastebasket diagnosis that be 'caused' by a hundred or more different things and so anyone can cherry-pick any type of patient group and find (or disprove) a new 'cause of 'CFS'' but it's all meaningless, as there is no such distinct disease as 'CFS.' It's comparing apples with oranges and grapefruits and lemons and the whole fruit basket. Each time you get a bizarre different mix of patients.

Instead of looking at the MANY ways this flawed 'CFS' research could harm patients and our fight for justice and recognition and trying to brace ourselves, many are sending money and praise to those involved in this. Have we learned nothing at all from RNase L, and the last 20 years? From EBV reactivation? It

seems not. Where is the most basic LOGIC here? What happened to looking at the actual facts before just believing any old hype you are given, just because it promises the world and looks really shiny and new?? How much worse does the abuse have to get before we wise up?

Also...doesn't the fact that this 'groundbreaking' 'CFS' research is being hugely supported by many or all ANTI M.E. campaigners, who have dedicated themselves to making fatigue illnesses the 'true ME/CFS' and making sure M.E. never gets separated from CFS, like Prohealth, Cort's Phoenix site, the Australian and New Zealand 'ME/CFS' groups and the CFIDS Association, give you a huge, huge clue that this is not in our interest, but instead THEIRS? They are committed strongly to maintaining the status quo. If it looks like a duck and talks like a duck... at least consider the mere possibility of duck-ness!

It's bizarre, so many newspapers are featuring articles saying 'first proof CFS is real' or 'first proof chronic fatigue is not all in the mind' or 'first proof M.E. is real.' The public are being told that M.E. is the same thing as CFS and chronic fatigue and this is good somehow???? Well, only if you live in bizarro world or know nothing at all of M.E. politics and 'CFS' history! And how is it helpful that the myth that there is no proof M.E. is a distinct and testable disease helpful? This sets our cause back so far. There is so much evidence supporting the facts of M.E., why are so many content for this to be ignored again and again? It is very hard to understand. We should be protesting these appalling fact-less articles, not applauding them. At the very least, why are so few looking at how potential damage to us and our cause can at least be minimised by all this, while we wait and see if there is anything to all the hype... instead of just attacking anyone who says the slightest negative thing about this research.

Sorry, I just can't believe that this nonsense is being hailed as the first proof M.E. is real, and as the first evidence we have to refuse CBT and GET, it's surreal. I just can't believe the reactions this is getting. Completely surreal.

I'm terrified we are about to lose another 10 or 20 years on this time wasting XMRV stuff, where all the focus goes on this and its impossible to get anyone interested in anything else more useful. By the time everyone works out it was a waste of time...the time will be gone and who knows how many more of us will needlessly be abused, neglected or killed."

- Jodi Bassett

“They have the fake CFS definition and "subgroups" that they can use to "fail to replicate" the findings, even if that virus is a big deal (for one of the patient groups studied).

Fred Friedberg is now talking about it (retrovirus) as being a contributing factor and how stress, genes, etc were the primary causes of illness

Bunch of crap, and I am so tired of people NOT GETTING IT. The real problem is still the cover-up of M.E. and all that goes with it (fake definitions, use of non-M.E. definitions and populations in studies, etc, etc, ETC).

Some other big clues this is bad news: Lots of anti-M.E. groups and individuals (Prohealth, Phoenix, CAA etc.) have been pushing and pushing this Whittemore/Peterson Institute (WPI), Buchwald testified to the Nevada legislature for them, asking for start-up money

The WPI and CAA are going around giving interviews. Just how great is this going to turn out? Will we get disability help now? Proper testing and diagnosis of M.E.? I think not.

WPI just uses ME, CFS/ME, ME/CFS, CFS interchangeably. makes them same thing. Hmm where have we seen that before? ME research is of primary importance. The CFS/ME, ME/CFS apologist "working together" tack OBVIOUSLY is not working.

Nothing has really changed, even if this (retrovirus) did turn out to be something significant, it is still not about M.E. Notice how now all the US press and government is ALL about "CFS/ME" and "ME/CFS", this gives them another brick in the wall of mixing it all up into a big confusing ball that helps no patients at all.”

- M.E. patient

“If the WPI study is right, then that means there are 10 million HEALTHY PEOPLE with XMRV infections in the US alone! Then there is the fact XMRV has been found in many other diseases. So it is very hard to see what possible value any test for XMRV could have for 'CFS' misdiagnosed patients or M.E. patients. Yet already patients are being talked into buying expensive XMRV

tests by some, the results of which mean almost nothing either way. All it means is you have a weakened immune system. It's crazy. Patients are so poor already and so desperate for REAL hope and help. As one doctor said 'False hopes are raised by false positive results when laboratory results are hyped prematurely.'

Many given a 'CFS' diagnosis will NOT have XMRV. Not everyone with this misdiagnosis has immune system weakness and so on, and some are only very mildly ill. So of course it will be very easy for research to be produced on a group of patients meeting 'CFS' criteria that do not have XMRV. Which is no problem at all, except that so many so-called advocacy groups have said CFS = XMRV and agreed seemingly that finally we have the 'cause of CFS'. So the studies showing no link with 'CFS' will make all of us, M.E. patients and advocates look like we are deluded or liars or like we don't have a leg to stand on scientifically as regards proof of the organic nature of our disease. When the truth is very different and there is a truckload of solid evidence we have had since the 1950s, that exists but is being ignored. Thanks a lot for that!"

- M.E. patient for over 10 years

“I think what most of us are waiting to get excited about (well, I can only speak for myself, really) is some true M.E. research. Some real, honest-to-goodness M.E. research. Not a muddled group of fatigue/immune suppressed people, some of which might have M.E., but real diagnosed M.E. patients in the test group.

We don't know that some of the group truly had M.E. Maybe some did, but we can't know that. Heck, some of the people in the group may have had diabetes too, but it doesn't mean that XMRV is related to diabetes too.

We are serious activists who have seriously educated ourselves about M.E. and the history of CFS and CFS research. Because of that, we look at this kind of research with a different eye, and try to see beyond the headlines and see what it will really mean for M.E. patients.

For us it isn't just a "healthy debate" like it is for healthy people, it's our lives. My remarks are only against the study itself. (Which is rife with serious, serious flaws.)

To me, this study is BAD news for us ME-ites and has the potential to be very dangerous. In fact, it is actually muddying the waters further for most people. It's validating the "CFS/ME" nonsense. One person actually said they think this will bring more validation to CFS/ME and other mystery type illnesses. (When M.E. is FAR from any mystery illness!)

This study was presented talking about the Fukuda CFS - which we know is not only a nothing illness, but we also know has a history of giving M.E. a bad name. "

~Sarah

What Dr. Byron Hyde has to say about XMRV research and its relevance to genuine M.E.:

“The Cause of CFS is a Retrovirus: In 2009, Dr Peterson, is probably one of the nicest and learned colleagues in the field of CFS, recently from the brand new, just opened, multi-million dollar Whittemore Peterson Institute in Reno Nevada, announced overwhelming evidence that the cause of M.E. or CFS, is XMRV retrovirus. The XMRV mouse retrovirus occurred in 68% of the CFS patient’s blood samples and only 4% of non-CFS patients. Pretty convincing!

This retrovirus theory comes with a history: It was first raised as a possibility by the gay community at a symposium I attended in San Francisco in 1987 and again by Florida based researcher Dr DeFreitas in the early 1990s. Dr DeFreitas discussed this retrovirus theory in our textbook, *The Clinical and Scientific Basis of M.E.*

At the very least, this retrovirus discovery is great free advertising for the Whittemore Peterson Institute. It will possibly bring them in many millions of dollars from, patients willing to be separated from their assets, generous charities and governments before the retrovirus theory is once again thrown into the garbage bin. I should add that incubation period of XMRV is up to 21 days which makes it impossible to cause an epidemic illness.

One theory to explain this “new” finding is that XMRV is a mouse virus and since many research institutes have tens of thousands of mice, cross contamination of specimens are inevitable.

The Cause of CFS is Human Herpes Viruses 6 & 7: In June 2008 I was paid by the Swiss pharmaceutical company, ROCHE to attend a symposium on CFS in Baltimore, Maryland. There were well over 100 “eminent” speakers from around the world, all the speakers except for a salaried researcher from the Canadian Government Viral Detection Laboratory in Winnipeg stated they found Human Herpes 6 & 7 in the 70-80% of all CFS patients but not in healthy controls. Now I am under the opinion that the technology for demonstrating HHV 6 & 7 may be under copyright to a USA laboratory. It is also possible they give cash or free travel grants to University researchers who can prove the HHV-CFS association but not to those who do not find this association. It is my belief that the US laboratory which sponsored this Symposium has the copyright of this test.

Whether money is changed hands or not, if I am correct, such a symposium with over 100 research papers could ultimately bring in several million dollars or more a year of royalties to this laboratory. Also, Roche Pharmaceuticals who paid my way along with 10 of the other researchers, one from the Whittemore Peterson Institute, were offering a carrot of 30 million dollars in research grants to the ten researchers and myself who would treat CFS patients with their new Herpes Virus anti-viral. Dr Peterson, the Whittemore- Peterson researcher was one of the ten at this private meeting with me. He too stated that he found conclusive evidence that the cause of CFS was HHV 6 & 7. I was the only invitee who told the Roche representatives that they were wasting their money.

If ROCHE had funded the Whittemore Peterson it might have been financial suicide, to then state that the XMRV retrovirus was the cause of CFS.

The Cause of CFS is an Enterovirus: In 2007, the son of California Infectious Disease specialist, Dr John Chia fell ill with M.E. He also complained of stomach pain. Dr Chia examined his son’s stomach and saw an infection that when biopsied, turned out to be a Coxsackie enterovirus. This is a virus in the same family as poliovirus. This is the same virus family associated with the Akureyri Iceland epidemics in 1947. It is the same group of viruses associated with the M.E. pandemic in Canada in 1984-1986. There is no money to be made with this virus since there is no patent on it and it is difficult to recover. In

four of the sixty M.E. Epidemics an enterovirus was recovered. In over 50 other epidemics, no virus was recovered but the average incubation period of the infection in these epidemics was 3-6 days, as it is in all enterovirus infections. HHV6 has an incubation period of 10-12 days. The EBV incubation period is 40 days.”

Clearly then, when M.E. is mixed in with 'CFS' it is easy to come up with many different theories about causation, as 'CFS' describes a heterogeneous patient group. When pure M.E. patient groups are studied, the evidence for enteroviral causation becomes very clear, however.

For more information on why ME and CFS are not the same, and why CFS research is not the same as ME research etc. see the section below:

Understanding M.E. and CFS - A Brief History

The following is a brief, factual history of what M.E. is, and how and when the term and definition of CFS came into existence.

M.E. (Myalgic Encephalomyelitis) is a distinct neurological disease that has been recognized by the World Health Organization (WHO) since 1969. It is classified in the current WHO International Classification of Diseases with the neurological code G.93.3. This recognition emerged from meticulous clinical observation and examination. It occurs in epidemic and sporadic forms, and over 60 outbreaks of M.E. have been recorded worldwide since 1934. The term M.E. was coined in 1956, and has been confirmed by findings of brain damage and spinal cord inflammation in autopsies of M.E. patients.

The primary symptoms of M.E. are neurological, cardiac, cardiovascular, cognitive, metabolic, respiratory, hormonal, immunological, gastrointestinal and musculo-skeletal. It is a testable and scientifically measurable disease, and there is a large body of mutually supportive research and clinical information on the disease.

There was an outbreak of M.E. in Lake Tahoe (US) in the 1980's. Sadly, at that time, a group of US scientists was convened, and they came up with not only a new name for an old disease, but a new definition as well. Thus, in 1988, the CFS label was born. Not content with simply changing the name to CFS, the

scientists involved also changed the case definition, instead of focusing on the testable findings and defining symptoms of neurological and cardiac origins, they actually shifted the focus on to an "unexplained" fatigue.

In so doing, the researchers took away any medical significance CFS could possibly have - if a patient is found to have something organically wrong with them causing the fatigue (anemia, depression, thyroid dysfunction, cardiac disease, etc) they no longer qualify for a CFS diagnosis. CFS is only "medically unexplained fatigue". In defining it this way, researchers have made it a wastebasket diagnosis that means nothing. According to the case definition, if you have something wrong with you, you don't have CFS, conversely, if you have CFS, there is nothing wrong with you. Clearly, a CFS diagnosis according to that definition is harmful to everyone.

For this reason, it is not simply an issue of using the right name or label for this disease, as the actual definition of the illness was changed. It's the definition (or diagnostic criteria) that is the key issue for patients and doctors. By redefining the illness in such a vague way, the CFS patient population is now a mish mash of fatigued people, rather than patients who have been thoroughly diagnosed with the same distinct disease process. The CDC itself has admitted that ambiguities in the CFS research definition contribute to inconsistent case identification, again demonstrating that the problem is not an issue of names or labels, but rather an issue of improperly defining an illness.

Properly understanding these issues has a big effect on how we all view the research being done on CFS or M.E. Are such researchers investigating people with a specific, distinct disease? Are such researchers investigating people who are simply fatigued healthy people? Are researchers investigating people who qualify for the broad, wastebasket diagnosis of the invented CFS protocol, but truly have any number of other diseases and disorders? Can the research actually amount to any kind of reliable result?

The following referenced excerpts provide a bit more information on the subject. They will also show that what we should be concerned about isn't the label, or name, put on an illness. We should be concerned with how an illness is defined. The definition of the artificial construct CFS was never meant to be treated as a disease entity, sadly however, it has been treated as such, and in so

doing, patients diagnosed with CFS and patients with M.E. have all been misunderstood and mistreated.

"It is the CFS definitions themselves that give rise to this inaccuracy. Consider the following:

1) What other physical disease definitions essentially state that if you discover the patient has any physical injury or disease, then the patient does not have the illness CFS? In other words if you have CFS then it does not result in or cause any major illness. What else could CFS then be but any number of various psychiatric, social, hysterical or mendacious phenomena?

2) The various CDC administrations dealing with the subject have clearly stated that CFS is a physical, not a psychiatric disease. However, is there any other definition of any physical disease that is not provable by scientific and clinical tests? Only psychiatric diseases are not clearly verifiable by physical and technological tests.

3) What other physical disease definition requires a 6-month waiting period before the illness can be diagnosed? Any physician knows that to treat a disease adequately you have to be able to define the disease at its onset and treat it immediately in order to prevent chronic complications from arising. To my knowledge, in the entire history of medicine, there are simply no other disease definitions that have ever been assembled with a structure similar to the CFS definitions.

4) If you are still not convinced, check the Internet for the definition of: DSMIII Somatization Disorder. (DSM) You will find that there is little substantial difference to distinguish the DSMIII definition from the 1988 and 1994 CDC definitions of CFS. It is difficult to believe that the CDC medical bureaucracy is not aware of this similarity. It is thus understandable why the insurance industry, as well as some psychiatrists and physicians, have simply concluded that CFS, if it exists, is a somatization disorder."

Reference link: The Nightingale Definition of M.E. by Dr Byron Hyde

"The physician and patient alike should remember that CFS is not a disease. It is a chronic fatigue state as described in four definitions starting with that

published by Dr. Gary Holmes of the CDC and others in 1988 (Holmes, Kaplan, Gantz, et al., 1988; Holmes, Kaplan, Schonberger, et al., 1988). The definition created by Lloyd, Hickie, Boughton, Spencer, and Wakefield (1990) is also widely used in Australia. There are two subsequent definitions. The Oxford definition of 1991 (Sharpe et al., 1991) and the 1994 NIH/CDC definitions (Fukuda et al., 1994) are basically, with a few modifications, copies of the first definition. Where the one essential characteristic of ME is acquired CNS dysfunction, that of CFS is primarily chronic fatigue. By assumption, this CFS fatigue can be acquired abruptly or gradually. Secondary symptoms and signs were then added to this primary fatigue anomaly. None of these secondary symptoms is individually essential for the definition and few are scientifically testable. Despite the list of signs and symptoms and test exclusions in these definitions, patients who conform to any of these four CFS definitions may still have an undiagnosed major illness, certain of which are potentially treatable.

Although the authors of these definitions have repeatedly stated that they are defining syndrome and not a specific disease, patient, physician, and insurer alike have tended to treat this syndrome as a specific disease or illness, with at times a potentially specific treatment and a specific outcome. This has resulted in much confusion, and many physicians are now diagnosing CFS as though it were a specific illness. They either refer the patient to pharmaceutical, psychiatric, psychological, or social treatment or simply say, "You have CFS and nothing can be done about it."

"The CFS definitions have another curiosity. If in any CFS patient, any major organ or system injury or disease is discovered, the patient is removed from the definition. The CFS definitions were written in such a manner that CFS becomes like a desert mirage: The closer you approach, the faster it disappears and the more problematic it becomes..."

Reference link: The Complexities of diagnosis by Dr Byron Hyde

"There is no such disease(s) as CFS. Fatigue is a common component of normal life not always relieved by 'rest' unless that means a prolonged holiday or stay in a sanatorium/asylum - ask any harassed mother of a large family!"

Fatigue is a common component of any infectious disease eg: Bacterial (tuberculosis) or Viral (influenza) and thousands of others including AIDS, Lyme disease, syphilis, Hepatitis A etc.

Fatigue is a common component of any prolonged physical stress (lack of sleep, care of the seriously ill, shift work etc)."

Reference link: Differences Between M.E. & CFS by Dr. Betty Dowsett

"The disease category of `CFS' was created in a response to an outbreak of what was unmistakably M.E., but this new name and definition did not describe the known signs, symptoms, history and pathology of M.E. It described a disease process that did not, and could not, exist..."

The new name and case definition for `CFS' was created in the US in 1988 by a board of 18 members, few of whom had either looked at an epidemic of M.E. or examined any patients with M.E. Two of the most experienced members of the board refused to sign the final document and withdrew from the (CDC) definitional committee because the proposed new name for the illness and the definition that went with it were just too different from the Myalgic Encephalomyelitis with which they were so familiar (Hooper et al. 2001 [Online])...

Chronic Fatigue Syndrome is an artificial construct created in the US in 1988 for the benefit of various political and financial interest groups. It is a mere diagnosis of exclusion (or wastebasket diagnosis) based on the presence of gradual or acute onset fatigue lasting 6 months. If tests show serious abnormalities, a person no longer qualifies for the diagnosis, as `CFS' is `medically unexplained.' A diagnosis of `CFS' does not mean that a person has any distinct disease (including M.E.). The patient population diagnosed with `CFS' is made up of people with a vast array of unrelated illnesses, or with no detectable illness. According to the latest CDC estimates, 2.54% of the population qualify for a `CFS' (mis)diagnosis. Every diagnosis of `CFS' can only ever be a misdiagnosis..."

Reference link: Who benefits form 'CFS' and 'ME/CFS' by Jodi Bassett and Lesley Ben, on HFME

Conclusion

Knowing these facts about the history and invention of the CFS label can help us to view even the most current research in its appropriate context. Please note the following, clarifying points that patients and patient advocates have mentioned in reference to the latest retrovirus study.

For more information on the need to be well versed on these topics when considering any kind of research, advocacy and everything they each entail, see the article "[A warning on 'CFS,' 'ICD-CFS' and 'ME/CFS' research and advocacy](#)"

Some of the most common myths about XMRV and M.E. include the following:

MYTH: Evidence exists which suggests or shows that M.E. is caused (partially or completely) by XMRV infection, and this theory fits all the major facts of M.E. (with no big 'holes')

MYTH: The recent XMRV 'CFS' research was conducted on a distinct and 100% M.E. patient group. This research clearly separates M.E. patients from those with 'CFS.'

MYTH: The recent XMRV 'CFS' research shows promise in providing a unique test for M.E.

MYTH: Evidence exists which suggests or shows that anti-retroviral treatments (perhaps specific to XMRV) are the treatment breakthrough that M.E. patients have been waiting for, for so long. This type of treatment represents real hope (or certainty) of a cure for M.E. patients.

MYTH: XMRV is believed to be an important and absolutely vital scientific lead to follow, by all of the M.E. community.

For more information about M.E. myths, see [The myths about M.E.](#) page.

Jodi Bassett, 2010

The HUMMINGBIRDS' FOUNDATION for M.E. (HFME)

Fighting for the recognition of Myalgic Encephalomyelitis based on the available scientific evidence, and for patients worldwide to be treated appropriately and accorded the same basic human rights as those with similar disabling and potentially fatal neurological diseases such as Multiple Sclerosis.

myalgic

A one-page summary of the facts of M.E.

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Taken from www.hfme.org



- Myalgic Encephalomyelitis is a disabling neurological disease that is very similar to multiple sclerosis (M.S.) and poliomyelitis (polio). Earlier names for M.E. were 'atypical multiple sclerosis' and 'atypical polio.'
- Myalgic Encephalomyelitis is a neurological disease characterised by scientifically measurable post-encephalitic damage to the brain stem. This is always damaged in M.E., hence the name M.E. The term M.E. was coined in 1956 and means: My = muscle, Algic = pain, Encephalo = brain, Mye = spinal cord, Itis = inflammation. This neurological damage has been confirmed in autopsies of M.E. patients.
- Myalgic Encephalomyelitis has been recognised by the World Health Organisation's International Classification of Diseases since 1969 as a distinct organic neurological disease.
- Myalgic Encephalomyelitis is primarily neurological, but also involves cognitive, cardiac, cardiovascular, immunological, endocrinological, metabolic, respiratory, hormonal, gastrointestinal and musculo-skeletal dysfunctions and damage. M.E. affects all vital bodily systems and causes an inability to maintain bodily homeostasis. More than 64 individual symptoms of M.E. have been scientifically documented.
- Myalgic Encephalomyelitis is an acute (sudden) onset, infectious neurological disease caused by a virus (a virus with a 4-7 day incubation period). M.E. occurs in epidemics as well as sporadically and over 60 M.E. outbreaks have been recorded worldwide since 1934. There is ample evidence that M.E. is caused by the same type of virus that causes polio; an enterovirus.
- Myalgic Encephalomyelitis can be more disabling than MS or polio, and many other serious diseases. M.E. is one of the most disabling diseases there is. More than 30% of M.E. patients are housebound, wheelchair-reliant and/or bedbound and are severely limited with even basic movement and communication.

- *Why are Myalgic Encephalomyelitis patients so severely and uniquely disabled?* For a person to stay alive, the heart must pump a certain base-level amount of blood. Every time a person is active, this increases the amount of blood the heart needs to pump. Every movement made or second spent upright, every word spoken, every thought thought, every word read or noise heard requires that more blood must be pumped by the heart.

However, the hearts of M.E. patients only pump barely pump enough blood for them to stay alive. Their circulating blood volume is reduced by up to 50%. Thus M.E. patients are severely limited in physical, cognitive and orthostatic (being upright) exertion and sensory input.

This problem of reduced circulating blood volume, leading to cardiac insufficiency, is why every brief period spent walking or sitting, every conversation and every exposure to light or noise can affect M.E. patients so profoundly. Seemingly minor 'activities' can cause significantly increased symptom severity and/or disability (often with a 48-72 hour delay in onset), prolonged relapse lasting months, years or longer, permanent bodily damage (eg. heart damage or organ failure), disease progression or death.

If activity levels exceed cardiac output by even 1%, death occurs. Thus the activity levels of M.E. patients must remain strictly within the limits of their reduced cardiac output just in order for them to stay alive.

M.E. patients who are able to rest appropriately and avoid severe or prolonged overexertion have repeatedly been shown to have the most positive long-term prognosis.

- Myalgic Encephalomyelitis is a testable and scientifically measurable disease with several unique features that is not difficult to diagnose (within just a few weeks of onset) using a series of objective tests (eg. MRI and SPECT brain scans). Abnormalities are also visible on physical exam in M.E.
- Myalgic Encephalomyelitis is a long-term/lifelong neurological disease that affects more than a million adults and children worldwide. In some cases M.E. is fatal. (Causes of death in M.E. include heart failure.)

For more information, and to read a fully-referenced version of this text compiled using information from the world's leading M.E. experts, please see: [What is M.E.? Extra extended version](#). Permission is given for this unedited document to be freely redistributed. Please redistribute this text widely.