

From Tom Kindlon (tomkindlon@oceanfree.net or tomkindlon@gmail.com)

*(*This appears longer than it should be because I have appended my April submission below in green (Appendix 2) as well as 1440 signatures and comments from the petition complaining against the CDC's use of the "empiric definition" (Reeves, 2005). Most of the rest of the text is made up with the results from 10 ME/CFS surveys. The rest of the text is not that long (2881 words) *)*

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I would first like to thank you for the opportunity to make these comments. Unfortunately I have not been able to allocate as much time as I would like to the task. So in my main submission I am not going to repeat many of the comments I made in my two oral statements to the April 27 meeting on the CDC's draft research program which I wrote up and submitted in writing before the April 30 deadline (appended below in green).

I should say that I have had two letters published in high impact journals (the British Medical Journal and Brain) on the subject of Chronic Fatigue Syndrome (CFS) in the last year. So although unfortunately because of ill-health, I have not been able to reach my potential in terms of academic qualifications [I scored 1460 in the SATs in 1991 (i.e. before they were re-graded upwards, scoring the top percentile in both subjects); I became a member of MENSA with an IQ in the top percentile in 1990 and in the last exams I did in college before severe disability struck (2nd year, Mathematical Science, Trinity College Dublin)) I got all (6) firsts, I have shown I am able to make intelligent comment.

Given the CDC is now moving into the area of ME/CFS interventions and particularly the area of treatment recommendations for others, I plan to share some information, thoughts and analysis on the treatment/ management modality of Graded Exercise Therapy (GET) and if time allows, also Cognitive Behavioural Therapy (CBT) based on GET (given CBT is recommended for many conditions in medicine, not all forms of CBT are the same).

I will also give some information on the petition I set up on April 15, "CDC CFS research should not involve the empirical definition (2005)"
http://www.ipetitions.com/petition/empirical_defn_and_CFS_research .

I mentioned this before in my oral submission but the number of signatures has now increased to 1431, with many people giving comments which can be read at the site (more people have told me they gave comments but for some reason to do with the software of the site (I believe) they did not appear).

The safety of treatments and interventions is one of the most important issues, if not the most important issue in medicine. The ideas behind the phrase "First do no harm" are something that are inculcated in medical students around the world. As Wikipedia says (on the phrase), 'Another way to state it is that "given an existing problem, it may be better to do nothing than to do something that risks causing more harm than good."'.

With many interventions such as pharmaceutical drugs, there are mechanisms in place so that if adverse reactions occur, even after a treatment has been approved, this information is noted and attempts are made to collate the information. For example, in the UK (and perhaps elsewhere in the world) a yellow card scheme where either prescribing professionals or patients themselves can report adverse reactions. Drugs can often be taken off the market years after they were first "released" when it is discovered that they can cause adverse reactions

Unfortunately, with non-pharmaceutical interventions, such options are not there. So what is the next best thing? Using the information from patient surveys is the obvious answer. Later I will give some information from patient surveys about high rates of adverse reactions reported following the use of (i) Graded Exercise Therapy (GET) and (ii) Cognitive Behavioural Therapy (CBT) based on GET in the UK and indeed some other countries in ME/CFS patients.

The CDC, amongst other things, plans to begin *“providing the most current evidence-based information concerning CFS to federal, state, and local public health authorities, related government agencies, and HMOs and building long-term relationships with government and non-government agencies.”*

I am concerned that these plans may involve promoting potentially dangerous treatments: (i) Graded Exercise Therapy (GET) and (ii) Cognitive Behavioural Therapy (CBT) based on GET.

I am also concerned that information will not be passed on about adverse reactions, that have been reported by patients using these treatment modalities. There are plausible scientific reasons why people can be suffering adverse reactions to treatments which encourage increases in activity: there are numerous studies that show that the response to exercise in ME/CFS is unusual. The abnormal response to exercise is not restricted to intense exercise. It has also been noted in a study which measured the effect of the journey to the testing centre (White, JoCFS, 2005). An exercise test is like a trial of a high dose of a drug.

It is important that professionals are told of the abnormal response to exercise in ME/CFS.

It is also important that patients are given the risks associated with treatments. This does not seem to be occurring routinely at the moment in some places around the world where GET and CBT based on GET is “offered”. This means patients can not give informed consent to the treatments they are trying. Patients trying pharmaceutical agents are given information, so why not patients with ME/CFS when they are being prescribed treatments? This suggests that people with ME/CFS are being treated like second class citizens, not worthy of the protections that are offered to other patients. This needs to change with anything the CDC recommends.

It also appears likely that the effectiveness of these treatments will be hyped.

For example, Bill Reeves at the May 2009 CFSAC meeting said: “CBT/GET is not the cure for everybody - nobody knows how many it is - it probably applies to a subset.”

But where is the evidence from the literature that GET is a cure for anybody with CFS? I am unaware of any.

And where is evidence that CBT based on GET is a cure for anybody with CFS? Few studies have made such claims. To the best of my knowledge these have used unsatisfactory definitions of recovery such as a patient being considered “recovered” or “fully recovered” if they didn’t score in the low percentiles for certain self-rated questionnaires [such as the 85th percentiles for the definition of “full recovery” in Knoop (2007) (although some of patients actually scored in a lower percentile on one of the questionnaires and were still considered “fully recovered”]. These are very unsatisfactory definitions of recovery but I fear that because of the influence of people like Peter White and Gijs Bleijenberg who hype these treatments’ effectiveness, official CDC literature will be talking about these treatments leading to recovery in some.

It is generally accepted that CFS is a heterogeneous condition. In particular, few if any researchers would say that CFS as defined by the “empiric definition” (Reeves, 2005) represents a homogeneous condition. However for some reason Peter White despite recognising that CFS is a heterogeneous condition, believes that with regard to treatment CFS should be regarded as homogeneous (sample reference: RSM lecture, April 2008). This is a potentially dangerous belief to promulgate especially given all the adverse reactions that have been reported with regard to GET and CBT based on GET. I hope that the CDC will not use such lazy constructs and will make clear when discussing CFS with regards to treatments (and, in particular, with regards to GET and CBT based on GET) that CFS should be considered as heterogeneous with regards to the effectiveness of treatments. Not everyone has shown the same results in clinical trials as well as surveys so until more is known about CFS, heterogeneity should also be mentioned in the context of treatments.

As I understand it, the CDC has largely been depending on information from Peter White to gain information on the situation in the UK. A major problem with this is that I do not recall hearing or reading Peter White informing readers or audiences the percentages that have reported adverse reactions with regards to GET and CBT based on GET in surveys and the like. As I have said, with no formal method for reporting adverse reactions to non-pharmaceutical modalities such as GET and CBT based on GET, the results of surveys take on a larger importance so I will give some information on these in a moment. I have read people suggest that Peter White hypes the effectiveness of GET and CBT based on GET and downplays any risks because of his connections with the insurance industry. I remain to be convinced by arguments based solely on money, although I do think it is important that the CDC reports these interests in the same way that it would be expected to report individuals interests in pharmaceutical agents. I think Peter White has taken an approach not suitable for clinical medicine and simply ignored information and data (on the issue of adverse reactions) that does not fit with his pre-existing theories.

Anyway, to move to some numerical data, here are the results of some numerical data from surveys of patients.

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Survey 1: (UK) Action for ME (2001)

In the UK, the Chief Medical Officer (CMO) (i.e. a government job somewhat similar to the position of Surgeon General in the US) set up in 1999 a working group to report on the area of “CFS/ME”.

Amongst other things, when they reported in 2002, the report included the following data from a survey.

Therapy*	Respondents	Helpful	No change	Made worse
Drug medication for pain	1394	61%	28%	11%
Drug medication for sleep	1300	67%	17%	16%
Pacing your activities	2180	89%	9%	1%
Graded exercise	1214	34%	15%	50%
Diet changes	1864	65%	32%	3%
Nutritional supplements	1953	61%	36%	3%
Rest, including bed rest	2162	91%	8%	1%
Cognitive Behavioural Therapy	285	7%	67%	26%
Other	878	76%	11%	14%

*Not all the respondents experienced each treatment approach
(Action for ME Membership Survey, 2001. 2338 respondents in total)

This data was then included in the Full NICE Guidance on CFS/ME (Page 95 of 317):

Helpful	No change		Made worse
Drug medication for pain	61%	28%	11%
Drug medication for sleep	67%	17%	16%
Pacing your activities	89%	9%	2%
Graded exercise	34%	16%	50%
Diet changes	65%	32%	3%
Nutritional supplements	62%	36%	3%
Rest, including bed-rest	91%	8%	1%
Cognitive behavioural therapy	7%	67%	26%
Other	75%	11%	14%

[Aside: there are three changes by 1% from the figures given in the CMO Report - these are on “occasions” when the first numbers did not add to 100% but with the changes, the numbers all added to 100%. Somebody presumably thought they need to be changed. Due to rounding, the numbers do not need to add to 100% to be accurate, so I believe the first set of figures should be considered the most accurate data]

As one can see, Graded Exercise Therapy had a terrible safety profile in this data – 50% of 1214 people reported being made worse – that’s the equivalent of 607 reports of adverse reactions! CBT had the second worst safety profile with 26% reporting being made worse by it. But this was for a smaller number of patients (285) than GET, so is equivalent to 74 reports of adverse reactions.

Pacing and rest (including bed rest) had both the highest rates of people reporting they were helpful (89% and 91%) and also the lowest rates of adverse reactions – just 1% for each (note: as I say, the first set of data appears to be the most accurate one with the second data having being adjusted to add to 100%).

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Survey 2: (UK) ME Association (2009)

The UK’s ME Association recently organised possibly the largest ever survey of people with ME/CFS. In its Spring 2009 magazine, it included data on 25 therapies. Yet again, Graded Exercise Therapy (GET) had the highest rates of adverse reactions with a whopping 56.5% of people reporting being made worse by the intervention:

Graded Exercise Therapy
906 replies:
Made much worse: 33.1%
Slightly worse: 23.4%
No change: 21.4%
Improved: 18.7%
Greatly improved: 3.4%

The related treatment modality of physiotherapy (i.e. therapy provided by a physical therapist) also had a high rate of adverse reactions (32.8% in total):

Physiotherapy
862 replies:
Made much worse: 15.7%
Slightly worse: 17.1%
No change: 36.7%
Improved: 27.0%
Greatly improved: 3.5%

Cognitive Behaviour Therapy (CBT) had a lower but still significant rate of adverse reactions 19.5% or 194 out of 997 cases:

Cognitive Behaviour Therapy (CBT)

Made much worse: 7.9%

Slightly worse: 11.6%

No change: 54.6%

Improved: 27.0%

Greatly improved: 3.4%

CBT also came very low (21st of 25) on the table of treatments based on the percentage of people helped by them. The only treatments below them were Imunovir (which had only being tried by 62 patients, the lowest number of the 25 treatments) (25.8% reporting it helped them), NADH and Graded Exercise Therapy.

The treatment with the highest percentage of people saying it helped was pacing of activities:

Pacing

2137 replies

Made much worse: 1.2%

Slightly worse: 3.5%

No change: 24.1%

Improved: 59.6%

Greatly improved: 11.6%

Pacing also had one of the lowest rates of people saying they were made worse by the treatment.

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Survey 3: (UK) 25% ME Group (2004)

In the UK, there is an ME charity specifically for severely affected patients with ME, called the 25% ME Group.

It conducted a survey of its members which got a response rate of 66% or 437 replies.

This is a direct quote from their report where they quote the statistics i.e. out of 170 patients who had tried **Graded Exercise Therapy (GET)**, 139 had been made worse by it!

“By far the most unhelpful form of treatment was considered to be Graded Exercise Therapy (GET). This is a finding that may surprise some readers, given the current medical popularity of this approach. However, these patients’ perceptions are supported by data from previous experience: of the 39% of our members who had actually used Graded Exercise Therapy, a shocking 82% reported that their condition was made worse by this treatment. On the basis of our members’ experiences we question whether GET is an appropriate approach for

patients with ME. It is worth noting that some patients were **not severely affected before trying GET**. Thus, it is not only people with severe ME who may be adversely affected by this form of treatment.”

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Survey 4: "Scotland M.E./CFS Scoping Exercise Report" (October 2007)

With Section 16b Funding through The Scottish Government, Action for ME produced a report: "Scotland M.E./CFS Scoping Exercise Report" (October 2007)

"In total 564 people with M.E. were sent a questionnaire (510 sent hard copies, 54 electronic versions). 399 completed questionnaires were received which represents a 71% return." (Page 8)

Table (Page 9)

Treatment	Helpful	no effect	made me worse	didn't try
CBT	15.5%	17.5%	7%	60%
GET	5%	6%	32%	57%
Graded Activity	18%	8%	30%	44%
Pacing	77%	8.5%	3.5%	11%

Translating these percentages into percentages solely based on people who had actually tried a treatment (more interesting figures, I think most people would agree), would give the following figures (the actual figures may have been a tiny bit different because of rounding):

CBT

Numbers Tried: 160

Helpful: 38.75% (=15.5/40) (62)
No effect: 43.75% (=17.5/40) (70)
Made me worse: 17.5% (=7/40) (28)

GET (i.e. Graded Exercise Therapy)

Numbers Tried: 172

Helpful: 11.63% (=5/43) (20)
No effect: 13.95% (=6/43) (24)
Made me worse: 74.42% (=32/43) (128)

Graded Activity

Numbers Tried: 224

Helpful: 32.14% (=18/56) (72)
No effect: 14.29% (=8/56) (32)
Made me worse: 53.57% (=30/56) (120)

Pacing

Numbers Tried: 298

Helpful: 86.52% (=77/89) (258)
No effect: 9.55% (=8.5/89) (28)
Made me worse: 3.93% (=3.5/89) (12)

A few proponents of GET have tried to say that figures from surveys are somehow not significant because we don't know whether the people did Graded Exercise Therapy under a professional or not. Firstly surveys 5 and 6 (below) show that the evidence isn't there to show that doing these treatments under a specialist is safer. Also the fact remains that GET is like an "over-the-counter" drug. People will try it if information is put out that it is an effective treatment either under a professional or by themselves. Which means promoting it as a treatment for ME/CFS risks damaging people's health.

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Survey 5: (UK) Action for ME (2003)

Action for ME in 2003 wanted to follow up on its previous survey to see whether changes were occurring with regards to members' experiences of treatments. It restricted responses to treatments received over the previous three years so that the results would not overlap with a previous survey. 550 patients were sent a questionnaire, "your experiences", with 354 people responding (a response rate of 64%).

List of results for people who did GET broken down by the practitioner:

Under a Physio:

Negative 12 (67%) Neutral 0 (0%) Positive 6 (33%)

Under an OT:

Negative 6 (100%) Neutral 0 (0%) Positive 0 (0%)

Under a Doctor:

Negative 3 (27%) Neutral 1 (9%) Positive 7 (64%)

Under a Behavioural Therapist:

Negative 1 (25%) Neutral 1 (25%) Positive 2 (50%)

Gym:

Negative 3 (100%) Neutral 0 (0%) Positive 0 (0%)

No Professional:

Negative 1 (8.33%) Neutral 4 (33%) Positive 7 (58%)

With regard to this group the authors of the report say:

"Had NO professional input (had they therefore paced themselves ?) - mostly with positive outcomes"

If one combines

Under a physio + Under an OT + Under a doctor + Under a behavioural therapist, to get a figure for under a professional:

Negative 22 (56.41%) Neutral 2 (5.13%) Positive 15 (38.46%)

So those who did GET under a professional had much higher rates of adverse reactions.

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Survey 6: (UK) Action for ME/Association for Youth with ME (2008):

This is another large survey, with 2763 patients with ME or CFS in the UK responding to a questionnaire which asked about people's experiences of treatments over the last three years (to avoid overlap with other surveys Action for ME had undertaken).

It found that of 699 who said they'd tried Graded Exercise Therapy, 34% said they'd been made worse by it compared to 45% who said they'd been helped and 21% who said it made no difference.

The contention that people would not have being made worse by a treatment if they had done the treatment under specialist supervision, is not backed up by the data from this study.

In this study patients were asked who provided the GET treatment. 567 answered this question (i.e. 132 did not). 181 (31.92%) of these said it had made them worse compared to 276 (48.68%) who said it helped and 110 (19.40%) who said it made no difference.

335 of these 567 patients said they had done the management strategy under an "NHS specialist". 111 (31.27%) of this group said they'd been made worse compared to 162 (45.63%) who said they'd been helped and 82 (23.10%) who said it made no difference.

So you can see that a similar percentage of people were made worse by GET who had done it under an NHS Specialist as those who had not, so doing it under an NHS specialist did not reduce the rate of adverse reactions.

So a large proportion of patients in the UK have experienced adverse reactions for trying Cognitive Behaviour Therapy (CBT) and in particularly Graded Exercise Therapy (GET). However it is my experience from reading Peter White's writings and hearing him talk that he does not inform people of this information.

Given the seriousness of the issue, I feel it would irresponsible if the CDC allows Peter White to be the only representative from the UK.

Suggestions for others on the ground who are not in denial of the issue of adverse reactions from GET (like Peter White appears to be) include: Charles Shepherd MD charles.c.shepherd@btinternet.com ; Ellen Goudsmit PhD CPsychol AFBPsS (a Chartered Health Psychologist) ellengoudsmit@HOTMAIL.COM ; Abhijit Chaudhuri DM MD PhD FACP FRCP (a consultant neurologist) chaudhuria@gmail.com ; Neil Abbot MSc PhD (Operations Director, ME Research UK) Neil.Abbot@pkavs.org.uk and William Weir MD (an infectious disease consultant who ran an NHS clinic for ME for a number of years – I don't have an E-mail address at the time of writing but he can be contacted through his practice at: +44-207-467-8478 (i.e. from the US: 00-44-207-467-8478). All of these five professionals have published in the area and been in the area for over 10 years – I think Dr William Weir is in the area for approximately 20 years and Drs Shepherd and Goudsmit for over 20 years. Drs Chaudhuri and Goudsmit did their PhDs in the area.

Surveys from other countries:

The 6 above surveys are from the UK. I have information on some surveys undertaken by local groups in the UK which would also report high rates of adverse reactions both from CBT and especially GET.

However reports of adverse reactions are not restricted to the UK.

Gijs Bleijenberg PhD is a Dutch psychologist which the CDC has worked with. I fear he will not have shared with the CDC or others results of surveys of patients which show a somewhat different picture to the studies he has published.

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Survey 7:
Koolhaas et al (2008/2009)

*Majority of ME/CFS patients negatively affected by Cognitive Behaviour Therapy***
(From: <http://listserv.nodak.edu/cgi-bin/wa.exe?A2=ind0803A&L=CO-CURE&P=R647&I=-3>)

To the best of my knowledge, this was presented at the 2009 IACFS/ME conference by Dr Van Hoof.

The following summary is from page 4 of the Dutch-language study.

<http://home.planet.nl/~koolh222/cgtbijmecvsvanuitperspectiefpatient2008.pdf>

Cognitieve gedragstherapie bij het chronische vermoeidheidssyndroom (ME/CVS)
vanuit het perspectief van de patiënt

Drs. M.P. Koolhaas, H. de Boorder, prof. dr. E. van Hoof
Date: February 2008
ISBN: 978-90-812658-1-2

The Netherlands

SUMMARY

*Background

*In recent years, Chronic Fatigue Syndrome, also known as Myalgic Encephalomyelitis (ME/CFS), has been getting a lot of attention in scientific literature. However its aetiology remains unclear and it has yet to be clarified why some people are more prone to this condition than others. Furthermore, there is as yet no consensus about the treatment of ME/CFS. The different treatments can be subdivided into two groups, the pharmacological and the psychosocial therapies. Most of the scientific articles on treatment emphasize the psychosocial approach.

The most intensively studied psychological therapeutic intervention for ME/CFS is cognitive behaviour therapy (CBT). In recent years several publications on this subject have been published. These studies report that this intervention can lead to significant improvements in 30% to 70% of patients, though rarely include details of adverse effects. This pilot study was undertaken to find out whether patients' experiences with this therapy confirm the stated

percentages. Furthermore, we examined whether this therapy does influence the employment rates, and could possibly increase the number of patients receiving educational training, engaged in sports, maintaining social contacts and doing household tasks.

*Method

*By means of a questionnaire posted at various newsgroups on the internet, the reported subjective experiences of 100 respondents who underwent this therapy were collected. These experiences were subsequently analysed.

*Results

*Only 2% of respondents reported that they considered themselves to be completely cured upon finishing the therapy. Thirty per cent reported 'an improvement' as a result of the therapy and the same percentage reported no change. Thirty-eight percent said the therapy had affected them adversely, the majority of them even reporting substantial deterioration. Participating in CBT proved to have little impact on the number of hours people were capable of maintaining social contacts or doing household tasks. A striking outcome is that the number of those respondents who were in paid employment or who were studying while taking part in CBT was adversely affected. The negative outcome in paid employment was statistically significant. CBT did, however, lead to an increase in the number of patients taking up sports.

A subgroup analysis showed that those patients who were involved in legal proceedings in order to obtain disability benefit while participating in CBT did not score worse than those who were not. Cases where a stated objective of the therapy was a complete cure, did not have a better outcome. Moreover, the length of the therapy did not affect the results.

*Conclusions

*This pilot study, based on subjective experiences of ME/CFS sufferers, does not confirm the high success rates regularly claimed by research into the effectiveness of CBT for ME/CFS. Over all, CBT for ME/CFS does not improve patients' well-being: more patients report deterioration of their condition rather than improvement. Our conclusion is that the claims in scientific publications about the effectiveness of this therapy based on trials in strictly controlled settings within universities, has been overstated and are therefore misleading. The findings of a subgroup analysis also contradict reported findings from research in strictly regulated settings.

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Survey 8: Survey of 3 Dutch ME/CFS patient organizations (December 2008):

3 Dutch ME/CFS patient organisations published in December 2008 at:
<http://www.nivel.nl/pdf/Rapport-draagvlakmeting-CVS-ME-2008.pdf> the results of a large survey they undertook. Following the link, one can see the questionnaire that was used.

Table 2.1 numbers of sent questionnaires and responses returned to the patients' associations

Number sent: 740

Total number of responses: 449

% response rate (gross): 60.7%

Number of filled in questionnaires: 412

% Net response rate: 55.7%

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(Rough) Translation into English of the results tables from a large survey of the membership of three Dutch ME/CFS patient organisations (part 2 of 2)

Table 4.10 Treatment or accompaniment/support/management concerning the diagnosis ME/CFS and the impact experienced of that treatment or accompaniment/support

Treatment or accompaniment/support/management

Column 1: % that has had (the) treatment

Column 2: Number of those that have answered

Column 3: Impact: After (i.e. because of) the treatment, improved

Column 4: No impact

Column 5: Impact: After (i.e. because of) the treatment, disimproved

- Diet 65,2% n=251 50,2% 43,8% 6,0%

- Homoeopathy 64,6% n=247 30,8% 62,8% 6,5%

- Physiotherapy 52,4% n=203 36,9% 41,9% 21,2%

- Vitamin B12 48,2% n=184 32,1% 63,0% 4,9%

- Psychotherapy (not CBT), Psychological support 46,1% n=169 33,1% 60,9% 5,9%

- Management based on trying to have a balance of rest and activity 44,2% n=172 57,0% 33,7% 9,3%

- Antidepressants 43,0% n=165 32,7% 36,4% 30,9%

- Carnitine 40,9% n=156 37,2% 53,8% 9,0%
- Melatonin 38,0% n=146 32,9% 50,7% 16,4%
- Graded Activity/Exercise Therapy 37,3% n=142 43,0% 23,9% 33,1%
- Painkillers 37,0% n=138 47,1% 47,8% 5,1%
- Cognitive Behavioural Therapy (CBT) 29,9% n=115 30,4% 42,6% 27,0%
- oefentherapie (I think this is a cross between physiotherapy and the Alexander Technique) 27,0% n=102 20,6% 42,2% 37,3%
- Herbal Medicine 26,7% n=97 28,9% 61,9% 9,3%
- Bed-rest 11,7% n=45 48,9% 44,4% 6,7%
- Participation at a rehabilitation centre 10,2% n=40 45,0% 35,0% 20,0%
- Immunological therapy 7,7% n=25 44,0% 40,0% 16,0%
- Neurofeedback 3,8% n=14 35,7% 57,1% 7,1%

To summarise the data here for GET/GAT, CBT and Physiotherapy in a way that is easier to read

The results for Graded Activity/Exercise Therapy were:

142 respondents

Improved: 61 (43.0%)

No impact: 34 (23.9%)

Disimproved/Made worse: 47 (33.1%)

Physiotherapy

203 respondents

Improved: 75 (36.9%)

No impact: 85 (41.9%)

Disimproved/Made worse: 43 (21.2%)

Cognitive Behavioural Therapy (CBT)

115 respondents

Improved: 35 (30.4%)

No impact: 49 (42.6%)

Disimproved/Made worse: 31 (27.0%)

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Tabel 4.10 Behandeling of begeleiding in verband met de diagnose ME/CVS en het ervaren effect van die behandeling of begeleiding

Behandeling of begeleiding % dat

Column 1: % dat behandeling heeft gehad

Column 2: aantal dat vraag naar effect heeft beantwoord

Column 3: Effect: Het ging daarna beter

Column 4: Geen effect

Column 5: Effect: Het ging daarna slechter

- dieet 65,2% n=251 50,2% 43,8% 6,0%
- homeopathie 64,6% n=247 30,8% 62,8% 6,5%
- fysiotherapie 52,4% n=203 36,9% 41,9% 21,2%
- vitamine B12 48,2% n=184 32,1% 63,0% 4,9%
- psychotherapie (niet CGT), psychologische begeleiding 46,1% n=169 33,1% 60,9% 5,9%
- begeleid zoeken naar een balans van activiteiten en rust 44,2% n=172 57,0% 33,7% 9,3%
- antidepressiva 43,0% n=165 32,7% 36,4% 30,9%
- carnitine 40,9% n=156 37,2% 53,8% 9,0%
- melatonine 38,0% n=146 32,9% 50,7% 16,4%
- begeleide opbouw van activiteiten 37,3% n=142 43,0% 23,9% 33,1%
- pijnstillers 37,0% n=138 47,1% 47,8% 5,1%
- cognitieve gedragstherapie (CGT) 29,9% n=115 30,4% 42,6% 27,0%
- oefentherapie 27,0% n=102 20,6% 42,2% 37,3%
- kruidentherapie 26,7% n=97 28,9% 61,9% 9,3%
- bedrust met begeleiding 11,7% n=45 48,9% 44,4% 6,7%
- opname in revalidatiecentrum 10,2% n=40 45,0% 35,0% 20,0%

- immunologische therapie 7,7% n=25 44,0% 40,0% 16,0%

- neurofeedback 3,8% n=14 35,7% 57,1% 7,1%

Survey 9: Norway (2009)

[Patients' experience with treatment of chronic fatigue syndrome.]

[Tidsskr Nor Laegeforen.](#) 2009 Jun 11;129(12):1214-6

[Article in Norwegian]

Bjørkum T

Wang CE,

Waterloo K.

torunn.bjoerkum@helse-forde.no Sogndal BUP Postboks 184 6851 Sogndal.

<http://www.ncbi.nlm.nih.gov/pubmed/19521443>

BACKGROUND: Chronic fatigue syndrome is a highly debated condition. Little is known about causes and treatment. Patients' experience is important in this context.

MATERIAL AND METHODS: 828 persons with chronic fatigue syndrome (ICD-10 code: G93.3) were included in the study. They were recruited through two Norwegian patient organizations (ME-association and MENiN). The participants filled in a questionnaire on their experience with various approaches to alleviate their condition.

RESULTS: Pacing was evaluated as useful by 96% of the participants, rest by 97%, and 96% of the participants considered complete shielding and quietness to be useful. 57% of the participants who had received help to identify and challenge negative thought patterns regarded this useful. **79% of the participants with experience from graded training regarded this to worsen their health status.**

Overall, the results were similar, irrelevant of the severity of the condition.

INTERPRETATION: Most participants in this study evaluated pacing, rest and complete shielding and quietness to be useful. The experience of the participants indicate that cognitive behaviour therapy can be useful for some patients, but that graded training may cause deterioration of the condition in many patients. The results must, however, be interpreted with care, as the participants are not a representative sample, and we do not know the specific content of the approaches.

Survey 10: (US) The CFIDS Association of America 1999 Reader Survey:

The largest survey of ME/CFS patients that I am aware of in the US was published by the the CFIDS Association of America in 1999 (questionnaires were also distributed that year).

I can send a copy of the page of results of 28 therapies on request. Unfortunately, I do not have time to type in all the results at present.

820 readers filled in the questionnaire.

The results for Graded Exercise Therapy were:

462 respondents

Helped a lot: 111 (24.0%)

Helped a little: 170 (36.8%)

No effect: 51 (11.0%)

Harmful: 130 (28.1%).

Numerically this was the highest rate of adverse reactions. Numerically the second highest rate of adverse reactions was reported for antidepressants:

Antidepressants

539 respondents

Helped a lot: 163 (30.2%)

Helped a little: 154 (28.6%)

No effect: 104 (19.3%)

Harmful: 118 (21.9%).

In terms of percentages, Graded Exercise Therapy had the third highest rate of adverse reactions. Two treatments, Beta-blockers and colonics, which I think the CDC is unlikely to recommend, were marginally higher:

Beta-blockers

172 respondents

Helped a lot: 33 (19.1%)

Helped a little: 39 (22.7%)

No effect: 45 (26.2%)

Harmful: 55 (32.0%).

Colonics

131 respondents

Helped a lot: 14 (10.7%)

Helped a little: 38 (29.0%)

No effect: 42 (32.1%)

Harmful: 37 (28.2%).

CBT had a lower rate of adverse reactions compared to the rates seen in other surveys. This may be because CBT in the US currently is not simply based on GET – there are different

forms offered, some which might encourage the pacing of activities. However this might change if information from the form of CBT that tends to be used in the UK and the Netherlands is highlighted by the CDC.

CBT

160 respondents

Helped a lot: 48 (30.0%)

Helped a little: 60 (37.5%)

No effect: 38 (23.8%)

Harmful: 16 (10.0%).

The treatment with the best results was Pacing of activities. It had the lowest rate of adverse reactions (1/601 or 0.2%) and the highest helpful percentage (i.e. the sum of the percentages for helped a little and helped a lot)

Pacing

601 respondents

Helped a lot: 423 (70.4%)

Helped a little: 167 (27.8%)

No effect: 20 (3.3%)

Harmful: 1 (0.2%).

As I have pointed out, Peter White has strong views on Graded Exercise Therapy (GET). He has also got strong views against Pacing and at the last moment resigned from the CMO group on CFS/ME (2002) (mentioned above) as it had placed Pacing on the same level as GET and CBT. People involved in the committee were annoyed at this as people had made a lot of concessions to try to get a document people like him would sign.

This is relevant when one is talking about an “international consensus on management.” Basically by selecting Peter White for such a committee, it is very likely that the document will recommend GET with few caveats or warnings; alternatively Peter White will resign. His views would not be representative of a lot of the opinions in the UK or internationally, so it would not really be an international consensus if he was on the sole UK representative.

As I mentioned before, I believe you need people on any panel who are not in denial about the adverse reactions from GET (like Peter White appears to be). Here are my suggestions again: Charles Shepherd MD charles.c.shepherd@btinternet.com ; Ellen Goudsmit PhD CPsychol AFBPsS (a Chartered Health Psychologist) ellengoudsmit@HOTMAIL.COM ; Abhijit Chaudhuri DM MD PhD FACP FRCP (a consultant neurologist) chaudhuri@gmail.com ; Neil Abbot MSc PhD (Operations Director, ME Research UK) Neil.Abbot@pkavs.org.uk and William Weir MD (an infectious disease consultant who ran an NHS clinic for ME for a number of years – I don't have an E-mail address at the time of writing but he can be contacted through his practice at: +44-207-467-8478 (i.e. from the US: 00-44-207-467-8478). Without individuals who are willing to challenge Peter White on such a panel, I believe one is likely to

get a document which hypes the benefits of GET and CBT based on GET and does not give much if any information on potential risks. To me, this would seem like a very irresponsible thing for an agency like the CDC to do.

The other point I want to re-iterate is my problems with the way the CDC CFS team have “operationalized” the Fukuda definition with the “empiric definition” (Reeves, 2005).

I have previously mentioned virtually all the points I would like to make on the topic as comments on papers that involved the definition. They are appended below in green (as they were included in my last submission).

Frustrated with both the lack of feedback and the CDC’s continued use of the definition, I set up a petition on the issue (see Appendix 1). Despite the petition’s text not being very “catchy”, there are 1440 signatures.

I am appending the signatures below along with comments they made (more people me they made comments but for some reason some comments never showed up – given these are people signing a petition against the definition, these would not have been positive comments).

As I said in my (written) testimony to the May 2009 CFSAC meeting: “If one has a heterogeneous group of patients, it can mean that in intervention trials, if “true” CFS patients only make up a tiny fraction of the cohort, useful interventions could come up as showing no effect (or even being detrimental); alternatively, interventions may come up as being useful for CFS when in fact if one had only looked at those with “true” CFS, the intervention may have made no difference or may even have been detrimental.” Given that the CDC is now moving towards intervention studies, this is a particularly important issue.

The CDC’s response to this criticism might be that using subsets can deal with this issue. However the definition has been broadened so much by the empiric definition that it is far from clear that this is enough. The prevalence rates from CDC CFS studies went up from 0.235% to 2.54%. That means that on average, patients satisfying the Fukuda definition as the CDC was previously using it would only make up 9.25% of the patients covered by the “empiric definition”. And of course due to the nature of probabilities, the actual figures could well be lower. And even if 9.25% were inducted into a study, on average in a trial which had at least two “arms”, one of the arms would have a cohort with less than 9.25% of the individuals satisfying the Fukuda definition as the CDC was previously defining it. And of course, even at the earlier stage, it was recognized that even the Fukuda definition captured a heterogeneous population.

Of course, this point is true in general with the “empiric” definition – the definition has become so broad that it may now be impossible to find the subsets that make up CFS.

One other point: as far as I can see, the only virus group specifically referred to in the CDC’s long 5-year Strategic Plan is HHV6.

It would be good if some of the CDC's (not inconsiderable) CFS research budget could be used to investigate enteroviruses in CFS. In 2007 a study involving enteroviruses[4] resulted in much excitement in the media on the subject. It found, in a sample of CFS patients who had gastrointestinal symptoms, that 135/165 (82%) biopsies stained positive for VP1 within parietal cells, whereas 7/34 (20%) of the controls stained positive ($p < 0.001$). Earlier studies have demonstrated circulating antigen of enterovirus, raised antibody titres and viral RNA in the blood and muscle biopsy specimens of patients with CFS[4-8]. John Chia does recognize that other infections could be playing a part in some CFS cases but enteroviruses are by far the most common infection he is finding in his clinic in California[9].

References

- [1] Gelman JH, Unger ER, Mawle AC, Nisenbaum R, Reeves WC: Chronic fatigue syndrome is not associated with expression of endogenous retroviral p15E. *Molec Diagnosis* 2000, 5:155-156.
- [2] Vernon SD, Shukla S, Reeves WC: Absence of Mycoplasma species DNA in chronic fatigue syndrome. *J Med Microbiol* 2003, 52:1027-1028.
- [3] Jones JF, Kulkarni PS, Butera ST, Reeves WC: GB virus-C--a virus without a disease: we cannot give it chronic fatigue syndrome. Jones JF, Kulkarni PS, Butera ST, Reeves WC. *BMC Infect Dis* 2005, 5:78
- [4] Yousef GE, Mann GF, Smith DF, et al: Chronic enterovirus infection in patients with postviral fatigue syndrome. *Lancet* 1988;1:146-7.
- [5] Cunningham L, Bowles NE, Lane RJM, et al: Persistence of enteroviral RNA in chronic fatigue syndrome is associated with abnormal production of equal amounts of positive and negative strands of enteroviral RNA. *J Gen Virol* 1990;71:1399-402.
- [6] Galbraith DN, Nairn C, Clements GB: Phylogenetic analysis of short enteroviral sequences from patients with chronic fatigue syndrome. *J Gen Virol* 1995;76:1701-7.
- [7] Lane RJ, Soteriou BA, Zhang H, et al: Enterovirus related metabolic myopathy: a postviral fatigue syndrome. *J Neurol Neurosurg Psychiatry* 2003;74:1382-6.
- [8] Douche-Aourik F, Berlier W, Fe ´asson L, et al: Detection of enterovirus to human skeletal muscle from patients with chronic inflammatory muscle disease or fibromyalgia and healthy subjects. *J Med Virol* 2003;71:540-7.
- [9] Chia JK, Chia A: Diverse etiologies for the chronic fatigue syndrome. *Clin Infect Dis* 2003;36:671-2.

Other viruses and microbes are also worthy and studies that involve the gut may provide more information than studies that just use blood samples.

Thank you for taking the time to read this.

Tom Kindlon

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Appendix 1: Petition

http://www.ipetitions.com/petition/empirical_defn_and_CFS_research/index.html

CDC CFS research should not involve the empirical definition (2005)

The petition

We call on the Centers for Disease Control and Prevention (CDC) to stop using the "empirical" definition[1] (also known as the Reeves 2005 definition) to define Chronic Fatigue Syndrome (CFS) patients in CFS research.

The CDC claim it is simply a way of operationalizing the Fukuda (1994) definition[2]. However the prevalence rates suggest otherwise: the "empirical" definition gives a prevalence rate of 2.54% of the adult population[3] compared to 0.235% (95% confidence interval, 0.142%-0.327%) and 0.422% (95% confidence interval, 0.29%-0.56%) when the Fukuda definition was used in previous population studies in the US[4,5].

The definition lacks specificity. For example, one research study[6] found that 38% of those with a diagnosis of a Major Depressive Disorder were misclassified as having CFS using the empirical/Reeves definition.

References

[1] Reeves WC, Wagner D, Nisenbaum R, Jones JF, Gurbaxani B, Solomon L, Papanicolaou DA, Unger ER, Vernon SD, Heim C. Chronic fatigue syndrome--a clinically empirical approach to its definition and study. *BMC Med.* 2005 Dec 15;3:19.

Link: <http://www.biomedcentral.com/1...>

[2] Fukuda K, Straus SE, Hickie I, Sharpe MC, Dobbins JG, Komaroff A. The chronic fatigue syndrome; a comprehensive approach to its definition and study. *Ann Int Med* 1994, 121:953-959.

[3] Reeves WC, Jones JF, Maloney E, Heim C, Hoaglin DC, Boneva RS, Morrissey M, Devlin R. Prevalence of chronic fatigue syndrome in metropolitan, urban, and rural Georgia. *Popul Health Metr.* 2007 Jun 8;5:5.

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Wichita, Kansas. Arch Int Med 2003, 163:1530-1536.

[5] Jason LA, Richman JA, Rademaker AW, Jordan KM, Plioplys AV, Taylor RR, McCready W, Huang CF, Plioplys S. A community-based study of chronic fatigue syndrome. Arch Intern Med. 1999 Oct 11;159(18):2129-37.

[6] Jason, LA, Najar N, Porter N, Reh C. Evaluating the Centers for Disease Control's empirical chronic fatigue syndrome case definition. Journal of Disability Policy Studies 2008, doi:10.1177/1044207308325995.

Further reading:

Problems with the New CDC CFS Prevalence Estimates

Leonard Jason, Ph.D., DePaul University

tinyurl.com/2qdgu4 i.e.

<http://www.iacfsme.org/Issuesw...>

Brief comment from Tom Kindlon: I have Chronic Fatigue Syndrome (CFS) for over 20 years.

I want a lot of research progress in my lifetime and believe the empirical definition (2005) (also known as the Reeves definition (2005)) decreases the chances that this will occur: abnormalities that would show up using a more strictly defined definition won't show up using the empirical/Reeves definition; and abnormalities that might show up in the broad group covered by the empirical/Reeves definition are not necessarily representative of CFS patients.

Similarly treatments that might work on a more strictly defined group of patients might not show up using the very broad empirical/Reeves definition and treatments that might appear to work overall on the group defined using the empirical/Reeves definition might not be suitable for people who satisfy a stricter definition. This messes up the CFS literature even further.

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Technical note: I am not sure why some people have grey boxes in the comments section. Some people have told me they have sent comments that never went up. I have not idea why this is happening.

Petition sponsor

Tom Kindlon, a patient with Chronic Fatigue Syndrome (CFS) for over 20 years. I have done a lot of voluntary work in the area for over a decade. Recently I had two letters on CFS published in medical journals.

Links

The paper defining the empirical/Reeves definition can be read at:

<http://www.biomedcentral.com/1741-7015/3/19>

Some comments on the paper have been posted at:

<http://www.biomedcentral.com/1741-7015/3/19/comments>

An article by Leonard Jason PhD on the issue can be read at:

tinyurl.com/2qdgu4 i.e.

<http://www.iacfsme.org/IssueswithCDCEmpiricalCaseDefinitionandPrev/tabid/105/Default.asp>

X

<http://me-cfs.se/dok/081205-cfs-no-longer-cfs.pdf>

By Kasper Ezelius M.Sc. This includes some links to other definitions, Kasper's take on the issues and a list of some papers that have involved using the empirical definition (this list is not up-to-date; virtually all the papers from the CDC 2-day Wichita study and also from the Georgia cohort have used the empirical definition to define CFS)

http://www.ipetitions.com/petition/empirical_defn_and_CFS_research/signatures-1.html

#	Name	Comments
1	jill cooper	
2	Keith Riley	
3	Peter Ruberry	Definitions are now so broad as to include almost anyone feeling a bit off colour. WE should get back to the Melvin Ramsay definition of ME
4	Anonymous	
5	Ellen	
5	Goudsmit	
6	Jenny Wilson	
7	Irene Thorpe	20 years of being messed around. I would like some answers and treatment now . The faster the better thank you
8	Laurence Swift	The most precise definition of ME is the "Canadian Definition", which precludes many non-ME diagnoses. The present broad definition incorporates too many general cases of non-ME states to make any research valid. These non-ME cases should be called "CFS" and true ME listed separately.
9	Michele E Townsend	This is very important to those of us that carry this diagnosis.
10	Veronica Jones	It is time to get rid of the woolly definition that includes too broad a group of patients thus muddying research results
11	Anonymous	
12	Linda Wish	The 2005 definition flies in the face of calls for subgrouping CFS patients to account for possibly different etiologies and pathologies. Instead, the original CFS/ME has been dissipated in a wide far-ranging heterogeneous group with vague symptoms ignoring the specific post-exertional problems patients have and the neurological problems that need research and treatment..
13	Anonymous	
14	Dr John Greensmith	
15	Rosie Cox	I have had this illness since 1970. I too want movement in research into this illness which will not happen until reserach uses cohorts based on appropriate definitons of which the CDC Reeves 2005 is not one. I would prefer the use of the Canadian Consensus Document, or more pertinently the Ramsay selection criteria which have much greater specificity for ICD10 ME.
16	Annette Barclay	
17	Perry Townsend	

- 18 Gail R. Kansky
- 19 Elizabeth McPhillips
- 20 Penny Green
- 21 C Johnston
- 22 Marcus Doolette
- 23 Anonymous
- 24 Sarah Owens

Very good initiative! My documents on the subject: Use the Canadian criteria 2003 for CFS in the USA. <http://me-cfs.se/dok/080622-Use-Canada-criteria-in-USA.pdf> Resolution in order to make cohorts less heterogeneous. <http://me-cfs.se/dok/080901-mod-cfs.pdf> How to categorize ME and CFS. <http://me-cfs.se/dok/081023-categorize.pdf> CFS is no longer CFS, and it was never ME. <http://me-cfs.se/dok/081205-cfs-no-longer-cfs.pdf>

- 26
- 27 Rob Arnoldus
- 28 Alfchild Renbro
- 29 Rita Eckerman
- 30 Trond Aure

Go Tom Kindlon! many of us have fought the 1988 holmes lousy definition, the worse Fukuda 1994 "definition" and the overly broad reeves "chronic illness melange" as Kasper called it. us oldtimers are burned out. we need new blood to fight this terrible fight! TMH TMH

- 31 Anonymous
- 32 Hillary L. Culver
- 33 Anonymous
- 34 Anonymous
- 35 Anita Patton
- 36 Ciaran Farrell

On behalf of 225 members of CFS Facts support group

- 37 Karen M. Campbell
- 38 Catherine C Larson
- 39 Anonymous

Even though research on our disease is miserably underfunded, gene expression and other specific scientific research shows that CFS probably contains subcategories and needs to be studied in more, rather than less, specificity. Throwing the disease into a waste bin full of other fatiguing illnesses does nothing to further our research.

- 40 Elsie A. Owings
- 41 Karen Algerio
- 42 Liz Willow
- 43 christine Gow

The research following publication of the empiric defintion shows a need for this change.

- 44 Sarah LaBelle
- 45 Anonymous
- 46 patricia Fero

Thanks Tom! Much needed petition.

The Wisconsin ME/CFS Association board has discussed CDC research, and

examined specific studies including subsequent publications using Wichita and Atlanta methodology to identify CFS patients. We conclude that the study of fatiguing illnesses in people across cultures is an important epidemiological endeavor. However, to call this CFS research and to fund it under that mechanism is wrong. We believe that ultimately the pathophysiology of a specific disease entity will be revealed by investigators interested in specificity. Inclusion of challenging contributions from international Myalgic Encephalomyelitis and CFS researchers is paramount in this process.

Joan
47 Grobstein,
 M.D.
48 Frank Twisk
49 P. Simpson
 Lolly
50 McDermott

#	Name	Comments
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51 Lillie Smith
52 Wallace Provost
53 Benjamin Di
 Pasquale
54 Constance Van
 der Eb, Ph.D.

55 Steven DuPre	CDC is trying to hold up progress on the real disease by widening the criteria to include many who do not have the disease.
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Mary
56 Schweitzer,
 Ph.D.
57 K McCall
58 Gerald R.
 Campbell, Ph.D.
59 Peter Cummins
60 Alice Browne

61 Tammie Page	The Canadian definition would be a much more suitable definition, in my opinion and that of many, many others, as well.
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62 Kathy D. Patti	As far as I am concerned, use of the Reeves "definition" has resulted in the CDC studying "chronic fatigue" of any etiology rather than doing hard investigation into the unique array of symptoms dubbed -- erroneously, in my opinion -- "Chronic Fatigue Syndrome." All your past research is useless because of its wide-open definition. If you want to contribute to medical science, use the Fukada definition.
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63 Casey Pfluger	I strongly believe that the empirical definition 2005 has hindered the progress in research and treatment of this globally important disease. If the CDC is truly committed to being a world-leader in CFS research then their CFS definition needs to be updated to encompass new developments and discoveries since 2005.
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64 Joanne Shiller	I do not endorse the use of the Reeves (2005)empirical definition on CFS.
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65 Tony Foran
66 Tanya Selth

67 Thea Funk	I live in the Netherlands and have ME/CFS for nearly 20 years. As the USA, by my knowledge, always had a leading role concerning research, I really am stunned
---------------------	--

- about the recent developments in ME/CFS research in your country.
- 68** Anonymous
Alexa
- 69** McLaughlin We need reliable consistent research.
The sooner that all those severely affected by this terrible get help, the better. It
- 70** Simon Lawrence must NOT be confused with feeling tired, which affects everyone from time to time.
- 71** connie nelson
- 72** Jacqui Footman
- 73** Anonymous
Jane
- 74** Giakoumakis
- 75** harry burg
- 76** Alfhild Renbro
- 77** Hayley Klinger
- 78** Fiona Hodgkiss CFS implies a vague diagnosis or a mild diagnosis of little consequence.
- 79** Carol O. Olsen
- 80** Anonymous
- 81** Anonymous
- 82** C. Krusen Heller
- 83** Nicole Roesner
- 84** Louise Sheldo
K.B.M.
- 85** Schellekens
Millions of dollars in federal and other funding is being wasted generating totally meaningless data the "results" of which delay not advance science in this essential area of research. Julie G. Donalek, R.N. ,Ph.D., DePaul University Department of Nursing
- 86** Dr. Julie Donalek
- 87** sarah kepert
- 88** Rik Carlson
- 89** Ian McLachlan
- 90** Kathy Davis
Unn-Elin
- 91** Andreassen
- 92** jeremy bearman i fully agree with the intentions of this petition. the empirical definition of cfs/me is a step in the wrong direction and is not in the best interests of patients
I am from French Canada (Québec). Thank you for all the work you are doing.
- 93** Mona-Josée Gagnon Because in here, it is rather hopeless (no research, a very weak association). I am the mother of a 32-years old woman with ME, and those quarrels about definitions are terribly harmful and "hope destructive".
- 94** Ewan Dale We need to develop acuity not undermine it.
- 95** Anonymous
- 96** Deborah Waroff
- 97** Anonymous
- 98** Anonymous
- 99** Anonymous
Lawrence
- 100** Plumlee, M.D. An investigation of chronic fatigue, while expensive, is essential to look for any treatable causes.
- 101** Anonymous

102 Dianne Bowman

103 Cort Johnson

104 Anonymous

Fatigue is a symptom of ALL diseases and should not be used as a definition of ONE illness. The medical establishment has dismissed many ill people and thus many have gone without appropriate diagnosis and treatment; treatment that could have helped in the early stages.

105 Andy Grum

106 Evelien van den Brink

107 Willeke van der Vlist

108 C.Walker

109 Angela Kennedy

110 Suzy Chapman

111 Catherine Broughton

I gladly support your petition! The Netherlands

112 F. Wong

Specificity is critically needed in the definition of ME/CFS. Using a non-specific definition of the illness further muddies the ME/CFS waters.

113 lorraine Murray

114 genevieve gagnon

115 Diana Saba

116 Sandy Cooley

117 Kathleen Flaherty, J.D.

118 Annabel Luery

119 Dave Murry

120 Craig Maupin

121 Susan Wenger

122 Tim Gardner

123 Kerrie McCure

124 John Mitchell jr

125 Edelgard Gerstmann

126 Jess MacDonals

127 Anonymous

128 Peter Kemp

129 Carol Wong

Use the Canadian Criteria!!

130 Karen Riem

Please do not water down the thinking and the research about this devastating illness. There is little enough funding and support: lumping various illnesses and symptoms together and broadening the definition beyond useful meaning hinders research, insults those of us who are sick, and ensures that even if we learn something, we may not be able to know or effectively use what we know.

131 Ashley Hinds

The empirical definition is a step backwards, defining subgroups as per the genetic studies is the smartest way forward so that you are comparing apples with apples rather than with oranges, pears & carrots as this appallingly vague definition allows.

132 A Walsh

133 Anonymous

It disgusts me that in one of the most advanced nations in the world, CFS is merely a battle of personal agendas by those in government agencies who should instead be attempting to heal their citizens. Forget the politics and personal ambition and find a cure. I have had CFS for over 20 yrs, most of my adult life, and would like to have a good quality of life for the remaining years i have. That can only happen if a cure or at least effective

treatment for CFS is found. That will never happen if the major centers for research in the US continue to ignore the real facts about CFS, instead pushing their own biased pet theories. The continued use of the seriously flawed Reeves definition is just more of the same.

National Alliance for
134 Myalgic
Encephalomyelitis

For all unable to speak for themselves

135 Peggy Lundquist

Please include "post exertional malaise" in the definition. I have been ill since 1987 and this symptom has never left me. I am not suffering from depression, I am suffering from irritation from the lack of acceptance of a serious health condition. I now have cancer as well and still cannot find a primary care physician to care for me as I have been diagnosed with a disease few understand or take seriously. Please, focus we need better.

136 Alan Gurwitt

137 Loretta Duzan

I have had CFS for 40 Years and was diagnosed as mental case for 20 of those years. I think it is high time this disease was taken seriously. It has brought down so many people. I could only work and sleep. No personal life at all. That is no way to live.

138 Jenny Griffin

139 mia lauren

140 pauline oviden

Having had ME for over 50 years I completely concur with the statement made by Tom Kindlon

141 Anonymous

142 Anne-Marie

Woynilowicz Kemp

The Canadian Clinical Case Guidelines, which are really international, should be used around the world. CDC should adopt them.

143 Carole Sturgis

Thank you for this petition - it is crucial to get research and understanding for people with CFS.

144 jacqueline christensen

145 Anonymous

146 Laura Ingraham

147 Jan Andersson

148 Laura Dunks

I have ME/CFS and I believe that it is important to correctly define the illness to provide appropriate research. We need answers!!!!!!

149 Hillary L. Culver

150 Anonymous

151 Daniela Martins

152 Anonymous

153 Maureen Goggins

154 Barbara Berger

I have just crossed the 21 year mark as a Chronic Fatigue Syndrome patient. We all agree that research is essential, but how that research is done or interpreted is key to any progress.

155 Stephen Philip
Cox

156 Fiorella Mucci

157 Guido den
Broeder

Better still: drop CFS altogether. Myalgic Encephalomyelitis is a genuine disease, CFS is an artifact that serves only to stigmatize and confuse.

158 Shelley Lauer

159 Maartje Dijkstra

160 Charlotte von

Salis

161 Sarah Goodwin

162 Bernie Standish

163 JOAN
MCPARLAND

164 Anonymous

165 Anonymous

Dr. Reeves is using this disease for his own political gain-he is profiting personally and financially by reclassifying CFS as a psychological illness. There is overwhelming evidence that viruses are involved and the CFS definition should reflect the actual symptoms of the disease.

166 Rebecca
Cordingley

167 Christina
Omorochoe

168 Susanna Agardy

169 Lyle Allan

170 Anonymous my girlfriend has me

171 cor soeterbroek

172 A.C.van der Wel

173 gea

174 Dr. Katharine M.
Kanak

175 Anonymous

176 Diane Lewis

177 Jerrold Spinhirne

178 J McCall

179 Ray Colliton

180

181 Anonymous none

182 Truthseeker

183 Anonymous

184 Margaret
Williams

185 joy birdsey

I just want the truth, and compassion for children and adults who have ME. I will never use the initials CFS.

186 Anonymous

187 Alison Wallace

188 Marie L.
Martineau

189 Anna Wood

190 Leonard Wagner

191 Marcia Brewer

192 Anonymous

193 Cathleen Connor

194 Roger Morgan

195 Anonymous ME-patient (Belgium)

196 antoinette Christie

197 Laurence Swift

198 Paula Gilfedder

- 199** Maggie Wallace
200 Thomas Ragan
201 Denise Visscher CFS patient
202 Jan van Roijen
203 Lea Schorr
204 Jeanette Marley
205 Bernice A. Melsky
206 michael allen, ph.d.
207 Anonymous I was disabled in 1987 with chronic EBV; changed to CFS in 1988. The disease evolved into T-Cell Lymphoma in 2001
208 Christine Gow
209 Raymond Milsted Lets have some proper medical research
210 William Caroli
211 Paula Kenley
 Freeman I have had CFS since 1997, and it is way past time for the CDC to be using the obsolete empirical definition. Updating the definition would offer researchers a less vague umbrella under which to work.
212 Jules De Cuyper
213 Shan Russell
214 John Herd
215 Anonymous
216 Orla Ni Chomhraí
217 Anonymous
218 Anonymous Myalgic Encephalomyelitis is the official name for the disease - in use for over 50 years now - and the Canadian definition is superior to any of the CFS definitions.
219 Anonymous
220 Margaret Holt
 Baird, Esq. I am concerned about definitions that ignore significant additional research, and potentially stigmatize persons with this and related disabilities wrongfully.
221 katherine Bishop I am strogly opposed to the Reeves definition
222 Paul Thompson
223 Diane Grum
224 Patricia
 Blankenship The World knows what CFS (ME) is - the CDC needs to retire from the fray.
225 Anonymous
226 P.L. Bourdon
227 Sandra Cole Before my illness I was enjoying my life. First, as an advanced nurse practitioner and as a professor at a university teaching nursing. I then went back to law school and obtained a J.D. I practiced law before contracting this illness. That was 12 years ago. I believe what Mr. Kindlon has stated above. I also believe that Mr. Reeves should not be in charge of this program as he does not support logical definitions or programs concerning this population. Please get someone who cares about us to run this program. This has gotten way out of hand.
228 Catherine Foxwell
229 Guido Flobert my wife suffers from cvs me already for years and had to retire early for this by decision of a board of medicins
230 S. Young
 Vicky
231 Vandendriessche

- 232 P Angiollilo
 233 nancy Rauhofer
 234 Robin Syms It is time this illness is called what it really is. CFS
 I am very concerned that a mishmash of diseases have been incorporated under
 the umbrella of CFS. It would be premature to decide on measures to reduce
 235 Yvonne Leach CFS if there is no definitive cause. Trying to find psychological markers would
 be as wasteful of time and money as trying to find psychological markers for
 diabetes type 1, for example.
- 236 H.Patten
 237 D. de Boer
 238 RACHEL
 239 Anneco Blanson better have strict criteria for ME research - would really be more helpfull for
 Henkemans research results and ME patients.
- 240 Anonymous
 241 Anonymous
 242 sue hogben
 243 Anonymous
 244 Wil Sengers
 245 Anonymous
 246 Sarah Robinson
 247 Ingeborg
 248 gaston gingues CFIDS sufferer for 6 years and counting!
 249 Anonymous
 250 Carole Howard
 251 Rik Carlson
 252 Anonymous
 253 Jami M
 Griscom
 254 Anonymous
 255 Daniel Prince
 256 Anonymous
 257 Josette LincourtCan the Reeves definition.
 258 Anonymous
 259 jean Harrison
 260 Anonymous
 261 Liz Wenn
 262 Alpha Mason
 263 R Manning
 264 Anonymous
 kathleen
 265 Flaherty, J.D.
 266 Marie Jerales
 267 Anonymous
 Siobhan
 268 Copson
 269 Anonymous as a sufferer of m.e. for 25 yrs i need to see that this illness is taken seriously and
 classified properly and also proper bio-medical research carried out
 270 Anonymous
 271 Anne James

- 272 Rosemary Humby Incorrect selection of patients who are to be the subject of research studies renders the results of the research worthless. Every opportunity must be taken to ensure that this does not happen. The US could be leading the world in CFS research, yet it appears that it is in danger of simply following the models of bad practice which are perpetuated elsewhere.
- 273 Anonymous
- 274 Susan Marshall
- 275 Invest in ME The empirical definition identifies such a broad range of patients that it can include people who are physically able to run a marathon. Such absurdities allow the figures of prevalence of ME/CFS to be raised from 0.4% of the population to over 2.5% in a recent study. As such the empirical definition is worthless for serious scientific studies.
- 276 Sarah Labovitch
- 277 Annabel Luery
- 278 Alison Orr
- 279 Anonymous I have had Me for 7 years. It has taken away what should have been the peak years of my life - I cannot get those years back but would like to make the most of whatever years I may have left - to do this I need appropriate medical treatment - spurious arguments geared towards the selection of illness criteria which suit a particular cadre of researchers as opposed to the needs of people with this devastating illness are helping no one. Please think of the lives of people with this illness and end this now.
- 280 John Wallace
- 281 Alison Wallace
- 282 Pat Sonnett
- 283 Anonymous
- 284 Eleanor Stein MD FRCP(C) The empirical case definition (Reeves et al 2005) lacks specificity and allows the inclusion of subjects as having CFS who actually have major depression and other non CFS disorders as a primary diagnosis. This has been published by Jason et al and is clear to anyone who is familiar with the questionnaires being used and the criteria of the common psychiatric disorders. The CDC has the opportunity to set a high standard for CFS research by admitting that the Empirical Criteria were misguided and should not be used. It would be better to continue to use the Fukuda Criteria while calling together a truly representative group of experts to develop research criteria based on both epidemiological and biomedical research. I am a PWC since 1992. I have clearly defined physical abnormalities (immune dysfunction, brainwave abnormalities, seizure problems) in addition to more common symptoms. The Reeves empirical definition broadens the definition of CFS to such an extent as to make accurate diagnosis impossible. It also makes research done using the Reeves definition meaningless. Treatments effective for people with MDD are useless and possibly harmful for me. When will CFS patients receive a competent, meaningful research program from the CDC?
- 285 Anita Swann
- 286 Michelle Perkins
- 287 Carolyn Allison
- 288 Daphne Caton Anything that could help to cure or relieve the living death that ME sufferers have to endure is worth pursuing; anything that threatens to jeopardise such moves deserves total annihilation.

289 Rachel
Millward
290 Caroline
Roberts

291 Catherine

292 julia warman

293 Anonymous

294 Karen
McMillan

295 Anonymous

296 Anonymous

297 Christine
Stronach

298 Pamela
Mawanda

299 J. Morton

300 Catherine
Evans

Please research the connection of ME with Wi-fi, mobile/digital phones, radio masts etc. incl. all electromagnetic effects in this so called modern/progressive world, the appalling continued use, by NHS, of mercury in amalgam fillings & the resultant detrimental health effects this practice has.

The reeves definition includes patients who have Fatigue for emotional reasons. this serves to confuse the research data. giving false results for trials of treatments. me/cfs is a devastatingly disabling neurological illness that needs bio medical research, this definition hinders this taking away funding from the true me/cfs patients. there is brilliant research being done in the usa by for eg whittlemore peterson inst, dr chia, dr learner.

Adopting the empirical definition is a waste of precious time and money as well as compounding the suffering of those with CFS/ME who continue to be failed by the NHS.

That we may help to save others from the crippling effects of misinformation

I have cfs

301	Sharon Stapleton	Get rid of Reeves and replace him with someone with a brain in their head. The CDC has done nothing for CFIDS research. Actually, CDC has thrown us backwards and kept us in the Dark Ages. We need NEW CFS leaders at the CDC - NOW.
302	Marsha Moore	After collapsing in 1989, I have lived a very limited life for 20 years, as I continue to be seriously disabled with cfids.
303	Mike Hughes	
304	Lisa Connor	
305	Anonymous	
306	Beth Beardmore	
307	Dave Holt	
308	Kathy Clifford	
309	Rose Anne Clifford	
310	Kathleen Clifford	
311	Margaret McFadden	
312	Kathy McFadden	
313	Gemma Ford	
314	Katherine Clifford	
315	Anonymous	
316	Anonymous	The new "empirical definition" of CFS/ME which is very flawed. In short, the criteria are so non specific that up to 40% of people with major depression and NO disabling fatigue would qualify as having CFS. It was after these criteria came out in 2005 that the CDC announced that the prevalence of CFS was 3X higher than previously reported. The prevalence of CFS did not jump, rather more people with other types of problems were now included under the CFS label. Leonard Jason presented his research on this issue at the November conference. The ramifications of the world researchers using these criteria are serious as it means we will continue to have inaccurate studies with misleading findings.
317	Leanne Morgan	

318	Carol McTavish	
319	Anonymous	
320	Francelia E. Poirier	
321	Steven Kusen	The criteria should include (and even quantify) the disabling fatigue that is associated with CFS.
322	Lilliana Sejjic	
323	Goran Prvulovic	
324	Mark Prvulovic	My mom has been sick for fourteen years, I wish that this illness receives the attention and funding it so desperately needs.
325	Marina Sejjic	
326	Darlene Blair	Like many modern era diseases this one is surely connected to our chemical environment and the use of chemicals to eliminate germs and decrease our natural immune system. Maybe if the CDC and the FDA were public entities then they would take more time and responsibility to find the causes of these diseases and therefore eliminate them altogether. I strongly support this action of changing the definition to more specific one.
327	Evelyn Violini	
328	Matilda Morgan	
329	Mary & Kathleen Lewin	
330	Judy Goodzeck	
331	Naomi Hooke	
332	William G Hartwell	M.E. is a real disease, with real signs and symptoms. STOP misdiagnosing it as the phony CFS!
333	Aisling	
334	Lori Hoffman	
335	trish murphy	
336	Anonymous	
337	Robin. A .Brook	
338	Vicky Stringer	
339	Anonymous	
340	Clair	
341	Anonymous	
342	Charlotte Howarth	
343	Anonymous	Please listen to CFS/ME patients
344	Warren Magrum	
345	Anonymous	
346	Susan Jasper	I speak for myself and my two adult children who are both disabled with the disease. They are 22 and 24 years old and have been disabled for 4 and 6 years respectively. They have had their lives ripped away at a young age. Using the empirical/Reeves definition muddies the research waters and delays progress towards a cure and a chance of them having any sort of meaningful life. There are many other people are out there in similar situations who do not have someone to speak for them, so please consider the possibility that for every person who has signed this petition, there are many many more who would have if they could.
347	Kristine Schaus	
348	Anonymous	
349	Anonymous	
350	Erin Donn	
351	sandra short	
352	Angela Porter	
353	marilyn bailey	
354	Carol Ann MacArthur	
355	Kathryn Edwards	
356	Monique Chantal	
357	Anonymous	
358	Chris McDowell	
359	Anne Edgington	
360	Angela	
361	Anonymous	I am grateful to the advocates who are willing to hold the CDC to task on this critical point. If we start with a poorly constructed definition, how can we have meaningful research and finally start

		making progress toward truly understanding and treating *and curing!* this disease?
362	Cheri Dennahower	
363	Teresa Craig-Morgan	A stricter definition will increase the chances of an actual treatment being discovered.
364	Angela Teliske	
365	bethany miller	
366	Pauline Orr	Without a definitive title how can there be definitive research?
367	Lindsay Kitson	
368	Alexandria Sherman	
369	Dave Holt	
370	Nikki Rush	
371	Faith Harper	
372	Nicola Creighton	
373	katie	
374	Kelly Keegan	Please hear our voices. We speak from experience and much suffering.
375	Suzen	
376	Michelle Martin	
377	Nicola Baker	
378	Bryan Wilde	Surely our voices cannot continue to be ignored, when our varied tongues all call for the one definition.
379	julian copson	
380	Briony Newbold	
381	Summer	
382	Amanda Turvey	
383	Greg White	
384	Valerie von Isenburg	
385	Anonymous	
386	Jan Donald	
387	bemi	i suffer from m.e and fibromyalgia for over 13 years
388	Eve Friday	
389	Donna Pruitt	
390	Samantha Cooper	
391	Sheila Copson	
392	Michael Copson	
393	Sarunyu Prutisart	
394	Anonymous	We call on the CDC to stop using the "empirical" definition to define Chronic Fatigue Syndrome patients in CFS research. Sallie van Merkensteijn
395	Ricky Buchanan	
396	Anonymous	
397	Deanna Mew	
398	Bob Geary	
399	sue hogben	
400	Pam Wilson	
401	Nina Bunin	sick w CFS/ME for 20 yrs. They could have been the most productive years of my life. What a waste. You have wasted so much time, and so has the CDC.

402	Anonymous	after 22 years of ME, yes you heard me, and the CDC playing with our lives for 25 years, ENOUGH is ENOUGH. 28 million people IS not a joke and with cardiomyopathy no wonder the HEART is the #1 killer... Give us a Break PLEASE... Enter the 21st Century.
403	Valerie Kiesel	
404	Jeanne	
405	Elizabeth Batty	
406	Kyle (Cokedude1324 of AYME)	After 1 and half years of M.E. i think i need to help others and to me this is important we need the world to know about M.E.
407	simon edwards	
408	Maryellen Smiley	
409	Lucy McFarlane	
410	Anna Tetlow	
411	Anonymous	
412	Rosalind Amor	The better research U do into ME, the better the results!
413	Alex Potter	
414	Anonymous	
415	MaryBeth	
416	Richard S. Christian	
417	Eirik Randsborg	
418	Anonymous	
419	Hege Renate Lochting	
420	Trude	
421	Alfhild Renbro	It's unbelievable and astounding to me!
422	Diana Lukevich	It would be unfair to receive a false positive diagnosis of chronic fatigue if depression were the real issue. Research spells hope for us with CFS and having real, relevant research may mean the difference between increased health in our lifetime or not. This depends on having actual CFS clients in studies and not depression subjects, which will skew the results.
423	Birgitte Rønning	
424	Maya VanDousen	
425	Joy Janzen	
426	Sue Oliver	
427	Anonymous	
428	Beverly Kleefeld	
429	Ola Vold	
430	Anonymous	
431	Gudny Sonnesyn	
432	Susan Magowitz	
433	J. Myers	
434	tertitta	
435	Lisa	
436	Anonymous	
437	john cobb	Good luck to your plan being submitted in May.
438	Laila G. Thongsai	
439	Gerd Marit Berge	
440	lisa brett	
441	Katie Roberts	
442	Jim Dourgarian	
443	Anonymous	
444	Smithe Celestin	

445	Joan E. Nielsen	I will also criticise the use of the definition of CFS - there is a huge difference and the problem is the treatment psychiatric and medicine don't help real ME and CFS sick people, it can do harm and instead do the sickness worse.. You need to use the Canadian criteria to make the real picture of this disease. Kind regards Joan Elisabeth Nielsen
446	Anne Örtengren	
447	Anna Fenander	
448	Thomas Lundh	
449	ragnhild rindeskog	
450	Mona Martensson	
451	Anonymous	
452	Kathleen Dunne	
453	Alfhild Renbro	
454	Karin Blomqvist	
455	Anonymous	
456	Pernilla Brandt	
457	Anonymous	
458	Katelin Hoffman	
459	Katja Landén, Sweden	
460	Josefin Dahlberg	
461	Carina Eklund	
462	Anja Klarin	
463	Anonymous	
464	Anonymous	
465	Maria Thilander	
466	annika petzäll	
467	Charlotte Kolm, Sweden	
468	Anonymous	
469	Anonymous	
470	Christina Jonk	Stop using the "empirical" definition[1] (also known as the Reeves 2005 definition) to define Chronic Fatigue Syndrome (CFS) patients in CFS research.
471	Gertie Gladnikoff	
472	Carina Sandell	
473	Rebecca Fox	
474	Anonymous	
475	inga-lill gustafsson	
476	Christina Maliqi	
477	Anonymous	
478	Anonymous	
479	Anonymous	
480	Anneli Bengtsson	
481	Johnny B. Pedersen	
482	Helena Pektas	
483	Monique Luttkhuis	It is a BIG BIG BLOODY SHAME !
484	Anonymous	
485	Anonymous	
486	Anonymous	
487	Reid & Donna Johnson	Chronic Fatigue Syndrome should be defined narrowly rather than in a wider group of other maladies so that specific research can be done in order to help those who suffer.

488	Anonymous	
489	Anonymous	
490	Anna Cotton	
491	Eva Karlsson	
492	Jan Olausson	
493	Rainer Öhman	
494	Anonymous	
495	Anonymous	
496	Hakan Lindblom	
497	Märta Hansson	
498	Heidi Jansson	
499	Aake Bjoerk	
500	Boel OLFsson	
501	Anonymous	
502	Anonymous	
503	Anonymous	
504	Anonymous	
505	SVEN HÖGBERG	
506	Anonymous	
507	Hanna Höglund	
508	Sofie Falkman	
509	Christina Nilsson Scheutz	
510	Anonymous	
511	johan bengtson	
512	Anonymous	
513	Tone Myhrer	
514	Jonte Kullersten	
515	Alfhild Renbro	
516	Saga Börrefors	
517	Peter Ahlberg	
518	Johanna Eriksson	
519	drotea pettersson	
520	Gertie Gladnikoff	
521	Anonymous	
522	Anonymous	
523	Margreth Mardby	
524	marie burlin	
525	Kristina Mårdby	
526	Anonymous	
527	Anonymous	
528	Rebecka	
529	Anonymous	
530	Anonymous	
531	Anonymous	
532	Anonymous	
533	anna håkansson	
534	Natalie	
535	Vivi Forslöw	

536	Heléne Åkerling	
537	Carina Seidegård Bengtsson	
538	Anonymous	
539	Ann-Kristin	
540	Agneta Perzon	
541	EvaLinneaTorstensson	
542	Anonymous	
543	Anonymous	
544	Sujatin	I have had ME since the beginning of 1990s and little or no treatment
545	Harry Mårdby	
546	Gunilla Valström	
547	Anonymous	
548	Anonymous	
549	Tomas Strand	Please help us with problem.
550	Anonymous	

551	Anders Fredriksson	
552	Katrin Høglund	
553	Betty Chyessler Trägårdh	
554	Annika Danielsson	
555	Anonymous	
556	Rutger Gustafsson	
557	Marjo Hänninen	
558	Ilona Walker	
559	Anonymous	
560	Anonymous	We with "CFS" suffer already enough
561	Helena Widenby	
562	Mikael Olergård	
563	Acke Schöll	
564	Christoffer Justusson	
565	Johanna Brohm	Cfs/me-life is hard enough already!
566	Anonymous	That is not a good ide!
567	Anna Söderström	
568	Anonymous	
569	Anonymous	please! This is important for so many people!
570	Anonymous	
571	Anonymous	
572	Annica Hallman	
573	Anders Collinder	
574	Anonymous	
575	Marianne Hilding	
576	Christopher Hilding	
577	Johan Hilding	
578	Anonymous	
579	Anonymous	
580	Susanne Ågren	
581	Alfhild Renbro	
582	Anders Ankarberg	
583	anne land	
584	mesut emirdag	
585	Anonymous	
586	Melanie Stromberg	
587	Lena Olsson	
588	margareta bengtson	
589	anders bengtson	
590	Anonymous	
591	Anonymous	Anything is better than "yuppie flu"

592	Ellen McKnight	
593	Anonymous	
594	Kerstin Rinman	
595	Debbie Metrustry	
596	Anonymous	
597	Anonymous	
598	Joseph Faletti	
599	Heléne Jäderberg	
600	Yvonne Cederholm	
601	Anonymous	
602	henrik simonsson	
603	Bettan N	
604	Alana Webster	
605	Fiona	
606	David	
607	Rebecca Taylor	
608	Anonymous	
609	I mansell	
610	Kathleen Hulse	
611	Georgia Stewart	
612	Christopher Smith	
613	karen harding	
614	Harriet Elson	
615	BRYAN DENNIS WILDE	
616	gaston gingues	CFIDS sufferer!!
617	Ann jacobs	I support research to help reduce and cure ME, chronic fatigue syndrome.
618	Mia Stridhfors	
619	Karolina Westerlund	
620	Elin Westerlund	
621	Isabelle Westerlund	
622	Mikael Bergvall	
623	Camilla Bergvall	
624	Janice Jones	
625	anders emmerfors	
626	Janet Thompson	I have had CFIDS for 13 years.
627	Annette Wright	
628	Anonymous	I fully agree.
629	Anonymous	I believe that a great deal of work needs doing in this field, as many Doctors still do not believe the condition exists, and those that do, have no idea how to treat someone with ME/CFS. If that is the attitude of highly trained individuals, how can we ever expect the public to accept that this is a genuine condition.
630	belinda	Our fate is in your hands
631	Anette	
632	Deborah Watson	
633	Anna-karin	
634	Unn-Elin Andreassen	
635	laura	
636	Jenny Burle	
637	Pamela Nadeau	With 3 ME/CFS children in our household we need a definition that encourages more studies not less - and we need psychiatric to be removed from the definition. Our perfectly 3 happy and previously healthy, intelligent children were fine until contracting this illness. Psychiatric problems did not play a role. Thank you for your work on this issue.

638	Simon Lawrence	This action by the CDC with have long term dragic consequences for people with Myalygic Encephalomyelitis and must be changed
639	Karin Caldenfors	
640	Marly Silverman	
641	Yvette Taylor	
642	Amy	
643	Greg Crowhurst	
644	Nicole Roesner	
645	Carole Howard	CFS sufferer since 1982, almost half my life.
646	Kathleen L. Gale	If the Reeves definition (2005) of CFS is used in research, the research that is done will be meaningless, and millions of dollars and years of time will be wasted. The research community would be spinning their wheels and getting no where, while the multitude of people who suffer from the condition are left without the hope of any real answers. Come on, CDC, lets get serious about this and quit wasting our valuble resources!
647	Lisa Markwart	
648	melanie	
649	valerie free	
650	Anonymous	

651	Robin Syms	Lets add fibromyalgia to the list.
652	Y Leach	
653	Elaine Cheshire	
654	Marry Molendijk	I am a ME mother with 2 ME kids
655	Anonymous	Please use the correct defiinition and do the study needed to help all of us who are so sick and disabled by this illness.
656	RM and N Cannon	
657	B. Isaac	
658	Anonymous	
659	James Gholston	This definition makes the infamous Fukada definition look great by comparison. If you want a new definition, how about using the Canadian Case definition as a starting point?
660	Cynthia M. Besade	
661	deb obrein	
662	Penny Green	
663	Anonymous	
664	Dan Moricoli	
665	Margot LAWRENCE	
666	Bethany Wilson	
667	Anonymous	
668	Anonymous	
669	Serena Blanchflower	
670	Iain Lee	
671	Joan Crawford	
672	lilian van Veen	
673	Jill McLaughlin	Fatigue is a symptom, not an illness. We need clinical and laboratory-based studies of homogeneous groups of patients to produce meaningful data that can be replicated and used to provide insight into the nature and pathophysiology, not questionnaires that will re-brand CFS as a somatoform mental illness.
674	Anonymous	
675	Randy Behrends	The Reeves definition has nothing to do with actual CFS/ME, and any credibility he has or had, is in serious question. I myself feel he has done the MOST HARM to people with CFS/ME than any other person in the history of this disease. He should be stripped of any licenses to practice for violating patient rights, and viloiating "to do no harm". The Canadian Consensus Definition is a much better standard to use, with more scientific standards and definitions of this multi system, neurological, chronic immune disease/illness that has affected so many.
676	E. B. Blanchard	
677	Denise Longman BSc MSc PGCE	
678	Paul Kayes	
679	Anne-Marie	

	Woynillowicz Kemp	
680	Sherry Leverett	
681	Aylwin Catchpole	
682	Rico Landman	
683	Anonymous	
684	Laurence L. Swift	I am surprised that the CDC would want to use a very broad definition for ME/CFS, since this would include many people who would not be typical of those suffering from the original disease as found in, for example, the Incline Village/Lake Tahoe outbreak or the Royal Free Outbreak of 1955, which were clear-cut examples of an identical contagious disease. The CDC could maybe research their vaguely-defined CFS, but people suffering from the very clearly defined infectious M.E. need to get answers soon, as they are suffering NOW! Using the Canadian definition would weed out many cases of glandular, allergic, and psychiatric irregularities and make proper research meaningful.
685	Anonymous	
686	Paula Kenley Freeman	
687	Claire Gittoes	
688	Lee vanderheiden	
689	Tina Beeler	I have Fibromyalgia and CFS comes along with the package. I have been given the diagnoses of "No Cure!" That is unacceptable this day and age!
690	Christine Robillard	Another attempt to push ME/CFS under the carpet. Yet our suffering is so great.
691	Bruce Roberts	
692	Bruce Roberts	
693	Patrick Hegarty	
694	Paula	
695	Clare Turner	
696	Bobbie L. Sellers	I have been ill for over 20 years and the exertional malaise, refractory fatigue, mental fog and recurrence of initial symptoms on over-exertion have persisted for all that time. I was forced to give up a lifestyle that was productive and enjoyable to learn to sit around and be passively entertained instead of going out on long distance motorcycle endurance rides which I trained for by running and use of weight training. If I get 14 to 18 hours a day of rest over an extended period (say 6 months) I become capable of a couple of hours a day of exertion.
697	Marilyn W Seskin, MD	
698	Judith Beasley	I strongly disagree with Dr. Reeves in CDC in his naming of the Chronic Fatigue Syndrome. I have had CFS for almost 20 years and I know that there are flaws in his thinking. It is infuriating to have had practically all of the symptoms of CFS that are not included in his definition of CFS.
699	Anonymous	
700	Michael Koolhaas	
701	Barbara Robinson	
702	Suellen Tritt - CFS 18 years	
703	gina reynolds	i have suffered with M.E for a number of years,more people need to be aware of this illness
704	Carol Nikolov	
705	Carolyn Richards	The name CFS developed over time from the Tahoe outbreak, then called Chronic Epstein Barre Virus. The CDC has evidently disregarded the original illness & is now studying fatigue at the patients expense. One needs to run a search on the original doctors Cheney & Peterson to see how the CDC has bastardized this illness.
706	Anonymous	
707	Sherri Hager	
708	Anthony Goggins	
709	Monte and Orvetta Conrad	
710	Maggie Wallace	
711	David J. Kemp	
712	Antonia Frigo	
713	Carrie Smith	
714	A Alexander	
715	gaston gingues	

716	Anonymous	Reeves is now discredited and his ties are suspect. The CDC is under investigation for funds not used for CFS research. Real investigations and findings are being ignored by the CDC. Much as MS was considered "hysterical paralysis" ME/CFS will be validated and real progress made DESPITE the CDC by institutions such as the Whittemore Peterson Institute at the University of Reno, Nevada. The CDC will be revealed as corrupt and ideological and its leadership role in the world will end.
717	Anonymous	
718	Anonymous	
719	Lisa Baldwin	
720	Anonymous	
721	Gareth Flynn	
722	Carole Jeffries	I wish the CDC would listen to patients.
723	Nancy Dugas	
724	Anonymous	I have CFS/ME/CFIDS, and was at the first naming in Oregon in 1984 and YES YES YES, I will STILL get a LOT of pain and MANY other things within 24 hours of physical exertions. DON'T minimize this for I WILL try to stay in shape-yet I will be in MAJOR PAIN.
725	Chris Frederick	
726	diane lindeman	
727	Christine Bastian	
728	michael s. allen, ph.D	
729	Joan Grobstein, M.D.	
730	Karen Gaduyon	
731	Tatyana Burns	
732	Sally Koetsveld	
733	Michelle	I am new to this but honestly believe that it is something that should not be taken lightly. This is a very painful issue and there should be a lot more being done about it than what has all ready been done.
734	Sean Kirby	I have had the condition currently known as CFS for 25 years (though I believe that I and many patients with this formal diagnosis actually fit the Ramsay ME criteria better). I have also read through all the scientific literature related to this condition. I do not support the CDC-Reeves version of patient selection criteria. It is so dilute and vague that it is not only of no positive value, it is actual a seriously regressive step for patients and the clinical and research communities. Dump it.
735	Olive Gagnon	
736	Anonymous	
737	Rev. Kathryn J. Keener-Han	Researchers in the US and overseas are increasing the specificity of definition of Chronic Fatigue Syndrome and related diseases in order to test for clear markers and causative agents. I encourage the CDC to look into the research and redefinition work by Leonard Jason, et al. This family of diseases cripples productive, active people. My 11 year old daughter was diagnosed at Mayo Clinic after months of abdominal and head ache pain, exhaustion, dizziness and lack of coordination, brought on after a virus. I would not wish this on my worst enemy. We need our citizens to be healthy and function well for the good of society. Thank you for your attention to this request.
738	Madeline Meixner	I
739	Anonymous	I have had CFS since I was 14 or 15 years old after I nearly died in a car wreck. I have still not been diagnosed with this illness. Now, I no longer have any medical insurance and cannot work. I have no income and is struggling to survive every single day. I hope that you will use the Canadian

		definition of CFS since it is more accurate. Then, if I can get someone to take me to apply for disability I would have a chance of receiving some money to help me make ends meet. Thank you for considering this.
740	Richard Beeler	
741	Anonymous	I AGREE COMPLETELY IN THIS MANIFESTO
742	Anonymous	I AGREE COMPLETELY IN THIS MANIFESTO
743	Anonymous	pétition. ok pour des critères observables et plus de démarches scientifiques
744	bemadette bateman	THE CDC DEFINITION IS NO REFLECTION ON MYALGIC ENCEPHALOMYELITIS.
745	margaret marh	
746	Kathelijne Hugaerts	Why yet another CFS definition? The Canadian Criteria are the best to differ chronic fatigue from ME. It is about time that the CDC starts using them.
747	J. Decker	
748	Becky Darbey	
749	Chris Bullen	
750	Richard Bozanich	
751	Harry Burg	
752	simon seawright	
753	FRANCIS Dominique	
754	gunther de bock	this Reefs difinition is totally unacceptable!
755	Hugh Rout	
756	Anonymous	The definition is far too vague and does not properly represent the symptoms of people suffering from ME/CFS.
757	Anonymous	
758	Beverly Bryan	
759	Isabel Webster	
760	Anonymous	
761	P.Dacre	
762	anneco blanson henkemans	best wishes form the netherlands - and please get this louzy defenition straightened out ! Anneco
763	sarah wardle	
764	Iain Munro	
765	Anonymous	
766	Anonymous	It is time that the CDC and all researchers adopt a definition that is subgrouped, a name that is not derogatory and an attitude that this disease is serious and in need of a solution
767	Tom McGlynn	For millennia people stayed sick or died because of (excusable) medical ignorance but since the late 20th century PWMEs have witnessed a new (and inexcusable) phenomenon in medicine - internationally co-ordinated denial of laboratory evidence of a physiological condition by alleged professionals who, in labelling ME/CF as psychiatric, can only be motivated by personal gain.
768	Catherine Klatt	
769	Anonymous	
770	Nancy Henson	To attempt to trivialize this very serious illness is a travesty. It cannot be allowed to continue. This new defintion does just that. It must be stopped. Research cannot accurately address the illness I have experienced for nearly 25 years with the grossly inadequate and inaccurate defintion now presented. Stop!
771	Clare	
772	Dianne Lutes	
773	Anne Welding	I have had CFS/ME for many years & it has devastated the whole family. I want to know that my daughter will be safe from becoming affected & research is key.
774	Mrs Christine Morris	
775	Benjamin Di Pasquale	

776	Anonymous	The 1988 definition of CFS, while not ideal, more accurately reflected the real illness. The Fukuda definition was worse, and the Reeves definition is abysmal. How can the CDC even claim to care about people with CFS (which is really ME)? The more the definition is watered down, the more meaningless and useless is the research.
777	Anonymous	To classify CFS as a depressive disorder totally disregards the validation that it took 2 years of going to doctors for a diagnosis. Shame on you for falling in to the category of "its in your head."
778	Anonymous	
779	Sara	
780	Catherine Arsenault	I have been sick for 30 years, when are you going to stop playing with peoples lives? I have watched Mr. Reeves go against all written documents to further his own agenda When do you plan to be honest with yourselves, have you no integrity?
781	pam johnson	
782	John Cubbidge	I think it is shameful that in a time of global recession there are people in extremely well-paid jobs making "scientific" decisions about the health of others with total disregard for the Scientific evidence that is available to them. In other words they are taking money which they have not morally earned! Can Mr Reeves (despite his history) make a Public Statement as to why his definitions are better than the Canadian Guidelines, which empirically demonstrate true science.
783	Rosanne Averill	
784	Anonymous	
785	Claudine M Strazza	
786	Leo Curbelo	
787	Nadine Porter, RN	
788	B Chapman	
789	Carol Bass, PhD	I and many others became chronically ill with overwhelming fatigue while working in the EPA Sick Building in Washington, DC in the late 1980s. A good number of us never recovered and work-at-home because of this and other related health effects. Please listen to individuals who have this condition and the physicians who treat them. Remember, it is that community who can give you the best, real-time information.
790	Paul Clavin	
791	Michael Stephenson	
792	Carolyn Greer	
793	Loretta Duzan	We have waited 30 years for ME/CFS to be accepted as a disease and now this is being eroded more. We need help and that help will be obtained by more research into the physical aspect of this problem.
794	Anonymous	More science; less psycho-babble...
795	Lin Rout	
796	Susan Wenger	
797	Pris Campbell, Ph.D.	
798	LaRue Sloan	
799	birgitta bjorlevik	
800	Anonymous	
801	Anonymous	
802	Meghan Brasley, Psy.D.	
803	Patricia Brasley	
804	Karl Nelson	
805	Anonymous	
806	melanie schuster	
807	Patricia Snow	
808	CFS: Fatigue is just the most obvious symptom of ME/CFS.	Anonymous
809	Cindee Smolenski Rice	

810	Maria Dillon	
811		Anonymous
812	Anonymous	
813	Adewyn Le BLanc	
814	Lake	Using inaccurate definitions only further hurts those of us who truly suffer with this debilitating disease.
815	Alexander M. Constantopoulos II	
816	DF1	
817	Anonymous	
818	Onora Ni Shuilleabhain	
819	Garth Coghlan	
820	Geraldine Lavery	
821	Anonymous	
822	Megan Hodges	
823	Tara Falconer	Please do some wide scale, good quality research ... someone!
824	William Rifkin	
825	Kenneth J. Friedman	<p>The Fukuda case definition was and is a research case definition never intended for clinical diagnosis. However, it has been used as both the research and clinical case definition.</p> <p>Much research has been done using the Fukuda case definition. To abandon it, without compelling reason does a disservice to research and patient care. The definition of CFS does need to be changed but it needs to be changed to a definition that is more precise, not less precise. The Reeves, less precise definition, confounds the research of CFS; it does not help. Going back to the Fukuda case definition, until such times as a more precise definition is developed, would be a step forward!</p>
826	Shan	
827	Peggy Walk	
828	Anonymous	
829	Doreen Gugler	
830	william shawver	
831	P.L. Bourdon	
832	Aliso Deegan	
833	Paul Deegan	
834	Anonymous	I would prefer that you used the much more accurate Canadian definition of CFS for all research.
835	sigbritt Eliasson	
836	Josephine Brohoon	
837	Anonymous	I have the disease called ME?CFS I have had it for 20 years without much research being shown
838	FAYTH NEWELL	
839	Lawrence Bourg	
840	Vickie Selleck	For the science of CFS to advance, we need a scientific and accurate definition.
841	A.C.	Interviews with patients who have had to endure CFS would define CFS -
842	Jane Luft	
843	Roger Winslow	
844	Patricia Strunck	
845	Karen Fiala	
846	Trisha Fisher	
847	barbara tobias	
848	Eve Rentko	
849	billie moore	<p>This definition MUST BE CHANGED. Only the Canadian definition covers the illness with specificity and completeness of symptoms. The CDC is subverting research on CFS/ME. They are hugely biased toward having its thought of as primarily a psychological illness.</p>
850	Debbie Dietrich	

851	Judith A Walker-Riggs	The empirical definition of diabetes as "feels sleepy after a heavy meal" would not have forwarded diabetes research particularly well either.
852	Ed Emmer	
853	Anonymous	
854	Theodore B. Nilson	I have been affected by what was diagnosed as Chronic Fatigue Syndrome since 1979.
855	Karen Cassity	Please get the CFS definition right so that homogeneous groups may be studied and a cure found. Have we not suffered enough?
856	John Chmielowiec	CFS/ME is real and brutally debilitating.
857	joey tuan	
858	James Moore	
859	Sarah Owens	
860	Anonymous	
861	Anonymous	
862	Patricia Birbeck	
863	Bonita Poulin	The Canadian definition has good agreement among health professionals who treat ME/CFS so it should be used at all times!
864	Jeanne Burke	
865	Martha Reading	
866	Larry Smith	Because many are suffers of this disease I whole heartly support it. The stigma and the personal suffering should make it a priority!
867	Jeannee Waseck	
868	Larry Smith	
869	Donna Kuhn	
870	Kathleen Flaherty, J.D.	This overly broad definition strikes me as a sweet deal for the psychiatrist/Big Pharma teams hoping to claim CFS as one of their Medically Unexplained Syndromes suitable for psch drugging. Pardon my bluntless, but this is the profit motive run amok.
871	Sarah English Perry	
872	Peter Lecander	
873	Dawn Cornell	
874	Barbara Dyke	
875	Toni Marshall	Because I had PTSD due to a dramaticaly traumatic childhood, I attributed my physical, very weird symptoms to PTSD. I found an excellent, reknowned psychotherapist whom I saw for 13 years who had faith in my ability to overcome PTSD. Yet, I grew worse, physically, which led to disability retirement. I see, after studying what having CFS/OI-POTS means, I was not depressed except by my inability to keep up due to chronic fatigue and other symptoms. Research for my syndrome would be most helpful with a more specific, meaningful definition.
876	Patrick Cornell	
877	Nina Bunin	I also have had CFS for 20 yrs. This definition perpetuates a waste of resources, both financial and human. There are so many of us out here cut down at the peak of our careers. What a waste for the United States that we are so ill, and are defined like this.
878	Anonymous	
879	Barbara Bell	We need an updated definition of CFS that takes recent findings into account. The definition should be updated periodically, particularly since noone has found an etiology that causes the syndrome.
880	Kerryn Zechiel	I
881	Anthony Schifano, L.R.P.	Staten Island CFS/FIBRO Support Group of NYNY, Brooklyn and Staten Island
882	Kathy Schulik	
883	allison hurwitz	
884	James Ross, PhD	I have suffered from ME/CFS/CFIDS for more than twelve years. My decades long private practice as a licensed clinical psychologist was in partnership with multi-specialty medical and research centers. I recommend the use of the "Canadian" ME/CFS definition. Operationalizing the Fukuda definition was a very unfortunate mistake.
885	ann sautter	

886	Melinda D. McDonald	
887	ROBERT CHALMERS	
888	Rosemary Underhill	
889	Nancy Rettberg	
890	Anthony Yannotta	
891	Jane Callen	
892	Mary C Towles	
893	Marlene Wentzell	
894	Julie W	
895	Crystal Reese	
896	Leslie Little	
897	Ann Bodio	
898	Peter C. Kuiken	
899	Nancy Kuiken	
900	Anonymous	
901	Michelle Roy	
902	Anonymous	
903	Joe Sipia	
904	Lois Robinson	I suffered from Chronic Fatigue for several years. It is very debilitating to say the least. Please help.
905	Carl Rettberg	We must continue research. It is a very frustrating disease. The lifestyle for someone with this illness is very depressing.
906	Tom Iacovone	
907	Jim Lucas	
908	Stephanie Reid	
909	Rita Bagnato	
910	joyce kaye	You need a better definition of cfids! It is a neurological immune disease!
911	Christine Emmanuel	
912	George Colby	Please continue all support and research for CFS
913	Tracy Lee Bird	As a patient suffering with CFS for some thirteen-plus years with no substantial relief, I must oppose any change that would move the definition of CFS and research regarding CFS further out of view of the CDC and the medical community at large.
914	Anonymous	
915	Suzanne Straub	
916	Elizabeth Thome	Please can we move forward not backwards!!
917	Paul Thome	
918	Adrienne Dellwo	
919	Michael Nicoles	
920	Anonymous	
921	Karen shannon	
922	Anonymous	My daughter has been ill for over 20 years with CFIDS. It has taken away almost everything that she had hoped to achieve during her lifetime. This new definition does not express the illness that my daughter acquired in 1989. If current researchers use the new, empirical definition, they will not be studying the same illness. This new definition allows a much broader scope of patients to be studied, thereby, diluting the findings of the researchers. They will not find a cure or treatment for my daughter or the many others who have been sick for so long and deserve so much more respect than they are receiving by our very own CDC. Please scrap the new definition and get back to studying the original illness.
923	Maryann Dartnell	
924	Anonymous	We need to have a better defination for all to know that fatigue is not the main item for this illness. My life has been runied by this illness and with the CDC not defining it better it only alows Drs , professional and layman look at us as they have in all these year in disbelief. We need the help that you can give us... Please help Us all.

925	Deborah L Sherman	
926	Kathy Lorentz	
927	Rachel Shelton	
928	Anonymous	
929	Lars Morgan	
930	jacqui butterworth	When is Myalgic Encephalomyelitis going to be recognised as a physical illness. When are governments going to fund proper medical research?
931	Charlotte Olson	
932	Jeffrey S. Rettberg	
933	Amy L Cuzzupoli	
934	Stephen Greer	
935	Anonymous	
936	Tammy Alexaner	
937	dennis oreilly	
938	Sue B.	
939	Margaret Rumney	
940	Janis Slorance	
941	Allan Moore	
942	Alex Morgan	
943	Rich Carson	
944	Louis Reginato Jr	
945	Tim Gardner	
946	Anne Lorraine Richards	
947	Natasha	
948	Todd Monje	
949	Vera K White	
950	Emma-Louise Case	

951	Stacey	
952	Valerie Lehnert	
953	Judy G Ranney	
954	Brenda Conway	I am concerned that lumping CFS with other illnesses (such as depression) will only give ammunition to those who wish to "blame the victim" and trivialize our disease by labeling it as a psychiatric or psychological maladjustment, not the organic disease which it is.
955	Anonymous	Whatever can be done to get more research of CFS. should be.
956	Anonymous	
957	Anonymous	
958	Naomi Flanagan	
959	Cheryl Irwin	Please stop using the empirical definition of Chronic Fatigue.
960	Anonymous	
961	Mary Arispe	
962	bemadette bateman	I AGREE WITH YOUR CONCERNS ABOUT THE PROBLEMS THE PRESENT DEFINITION WILL CAUSE FOR RESEARCH IN ME.
963	Christina Omorochoe	
964	Tracy Sturgell	I too suffer from this horrible illness. I was diagnosed in 2005. I agree a more specific definition that includes the post-exertional malaise should be accepted and used. That symptom is huge for me.
965	kamala Jesrani	
966	Carolyn Siegrist	
967	Marc Cohen	
968	Annabel Luery	
969	Anonymous	
970	AJ Lee	

971	R. Simpson	
972	Lajla Mark	
973	Sheila Statlender, Ph.D.	
974	Victoria	
975	Ellen V. Piro	
976	Judith Richman, Ph.D.	Leonard Jason and I have published on the serious shortcomings of this definition in the Journal of Chronic Fatigue Syndrome. The use of this definition in empirical research produces completely flawed research as these studies are more about patients with major depression rather than CFS. I care deeply about the need to get at the root etiology of CFS, and using this definition will get us nowhere in this endeavor.
977	Jesse Lemisch	
978	robert lerman	
979	Anonymous	it is tuff enough for us without playing around with the difinition
980	Regina Clos	Also in Europe the "empirical" definition will have devastating effects for people with ME/CFS because it lumps together all kinds of "fatigue" states and people with ME/CFS will disappear in this large group as a minority. Studies on the basis of this "definition" will do more harm than good for us. Remember, still the CDC have a very good reputation in Europe - but this may change with things like this.
981	Jules De Cuyper	
982	R. Wong	
983	Karen Riem	
984	Esther N. Shelley	Please do not change the definition of CFS as it has the potential to swing the issue from physiological to phsycological, allowing for greater misdiagnosis.
985	Anonymous	
986	FRANK McBRIDE	
987	David Moor	
988	david christie	
989	Anonymous	People are dying.
990	Katrina	
991	Anonymous	
992	Anonymous	
993	john wadiak	
994	Lillian Greeley	I would like the definition of CFS to describe the clear neurological and metabolic dysfunctions that are not currently reflected in the name.
995	Vasili Romanzov	
996	barbara gershenbaum	
997	em katz	
998	Elizabeth Silver	
999	Gurli H Bagnall	Reeves proposal misrepresents the facts and cannot be tolerated.
1000	Sharon Kobrin	
1001	Edwin Overtoom	I am the husband of a woman who has lived with CFS since 1997.
1002	Anita Burgess	
1003	Erik Johnson	
1004	Donald Oas	cfs has ruined my life, we need more funding for research and a proper and meaningful name
1005	Sue Bailey	if the "empirical" definition of CFS is allowed to stand, the CDC will have succeeded in transforming the disease from a serious, progressive, multisystem, multi-causal disease into a case of incorrect thinking and incorrect emotions. Any treatment based on the "empirical" definition will be either useless or harmful for most people.
1006	Crystal Whiting	
1007	E Schuman	
1008	astrid gommers	
1009	Anonymous	Dr. Reeves definition will hurt CFS patients and I would like to ask... how many more lives will be lost as a result?
1010	Jason Johnston	
1011	Anonymous	
1012	Diane Nelson Jones	
1013	Jon Krahmer	Yes
1014	Ken Davis	
1015	Paula Carnes	
1016	brenda Brill	
1017	D. Schneider	
1018	Gregory A Stiffler	I have had CFS now for at least 10 years;perhaps,I have had it longer;its been 10 years this may since the severe fatigue took my job away
1019	Joyce Waterhouse	Dr. Jason knows more about defining this condition than anyone and thus I sign this petition.

		CBT and graded exercise are only palliative or just give temporary improvement to those with milder levels of disease.
1020	James Schinnerer	Severe post-exertional malaise is a primary symptom and should be a requirement. The CDC should adopt the Canadian Expert Consensus Panel Clinical Case Definition for ME/CFS.
1021	Anonymous	
1022	Erika Pyner	
1023	Joseph W. Lenz, PhD	Recognition of the physical, physiological nature of the disease misnamed CFS is long overdue.
1024	Jimmie Holman	
1025	Anonymous	
1026	Anonymous	
1027	Barbara W. Miller	
1028	Kristin Lindgren	
1029	Anonymous	
1030	Jane S. Millerick	
1031	Collette	
1032	Anonymous	
1033	Anonymous	
1034	Jill Lynch	
1035	Brenda	
1036	Amy Tipton	My aunt has lived with CFS for a really long time. Took a long time to get a proper diagnosis.
1037	Bernhard Liedtke	
1038	Lia Metz	
1039	Nina Otazo	Please stick with solid science and remove the empirical definition to define CFS. Thank you.
1040	Karen Morales	Please take this illness seriously!
1041	Anonymous	
1042	W. Morton Caldwell, PE	I have had "CFS" for 15 years and it has devastated my life, although I am not depressed. I resent any "CFS" definition that includes any psychological factors whatsoever, as I damn well know "CFS" is a purely physiological disease. One has to have "CFS" to realize this. "CFS" can cause depression, as can any other serious disease, but depression does NOT cause "CFS". CDC - your cause and effect reasoning is backwards! Hanging mental causes on "CFS" is a cheap way out - the real causes of "CFS" are mostly unknown and involve complex cellular biochemistry and molecular biophysics. Yeah, I know these are much more difficult to learn and apply than psychological theories, and involve a lot of knowledge of complex engineering feedback systems and higher mathematics, but doing real research requires hard learning of difficult disciplines. This commentary is from a non-depressed and non-psychotic Electrical Engineer and Cardiovascular Physiologist, who worked in both fields for 35 years, before being disabled by "CFS". The name "CFS" is inaccurate and degrading; if you want to do something constructive, change it to a meaningful and non-insulting name that uses neither fatigue or syndrome. Why not simply use its real name?
1043	Ted Shaw	
1044	Elly Kate	It would be great to change the name for CFS!
1045	Anonymous	This definition does not properly distinguish CFS from other disorders with some of the symptoms of CFS. Proper research cannot be done in CFS unless there is an established criteria used that properly defines this serious illness.
1046	J. E. Brown	
1047	Viviane Lemer, Ph. D.	GET RID OF THE NEW REEVES DEFINITION AT CDC!
1048	susan hogben	
1049	HM Sobetzko, M.D.	The use of the empirical definition in research will produce fundamental confusion about the severity and nature of CFS.
1050	James Watson	Reeves definition is a travesty of the truth.
1051	Tilla Rundhaug	
1052	Anonymous	
1053	Anonymous	
1054	vanessa vaughan	
1055	Anonymous	
1056	Darren Nesbitt	
1057	Jenny Mietzcke	
1058	A Walsh	
1059	Dan Horovitz	
1060	Susan Lucey	God help us if CFS is reduced to depression. I have been ill for 20 yrs and am in Panama as I type this. I am about to receive stem cells. After tens of thousands of dollars spent over the years looking for a cure... No depressed person would be doing what I have done to get well. Please wake up and recognize this disease.
1061	Denise Longman	

1062	Michael Attwood	I agree
1063	Jennifer McBryde	CFS is not ME. This is in the CDC guidelines for CFS. Where are the CDC guidelines for ME and why is there no research into this illness.
1064	Tanya Trick	We have three with Celiac Disease, that have been diagnosed in our family.
1065	Peter D Falconer	I have a family member severely affected by CFS, and it was difficult to have the condition recognised and acknowledged by government authorities.
1066	Reidun Gran Alkanger	
1067	Rinchen Dorje	Viral onset CFIDS/ME is a clinically and pathologically discreet disease entity. Lumping it together with every other unexplained chronic illness that has fatigue as a symptom would be a ridiculously unscientific disaster that will confound all research and completely ruin any chance to cure CFIDS/ME. Including patients with psychiatric conditions is even more unscientific, will even further confound research, and is an unacceptable outrage to all of us legitimately ill with the proven physical pathology of CFIDS/ME.
1068	Amanda Hume	I have had CFS for 5 years, only diagnosed 2 years ago. It has ruined my life and i want nothing more than to return to normality and be able to perform ordinary daily things that are a continuous struggle.
1069	Anonymous	
1070	Anonymous	
1071	Sharon Spicer	
1072	Robert Service	The effort that is being put into obscuring the nature of this disease is remarkable. Too bad the work could not have been put into actually curing it. I guess it really is effective to hide something in plain view of everyone.
1073	Marla Stice	
1074	Ms Manning	
1075	Tonette Hartmann	Not only would I like the CDC to update their "empirical" definition of CFS be changed, I also DESPERATELY wish that the name "Chronic Fatigue Syndrome" or "Chronic Fatigue & Immune Dysfunction Syndrome" be changed to reflect the severity of this illness and perhaps leave the word "fatigue" out of the name entirely, since people mis-perceive it as the same type of fatigue everyone feels at points.
1076	Judith Wisdom	
1077	Robbi Patterson	
1078	ccodella	My brother in law suffers from this as well and it is debilitating at times.
1079	Janet Knight	This disease is a complex multi-factorial condition. Using the so called "empirical" definition will decrease the validity of studies on CFID"s.
1080	Linda Ferris	Please stop using the "empirical" definition (AKA Reeves 2005 definition).
1081	Sylvia Perrine	
1082	Elizabeth Kane	
1083	GILLIAN BARCLAY	
1084	Jenny Dow	
1085	Ian Barr	
1086	Harriet Humby	
1087	Anonymous	
1088	Garry Jones	
1089	Hege Renate Lochting	
1090	Aisling Doherty	
1091	Lynn Croas	
1092	Stop spending taxpayer money on this bogus "research".	
1093	Jonathan humby	
1094	Anonymous	
1095	Elizabeth Wayne	
1096	Anonymous	
1097	Anonymous	As a one-time research scientist I am horrified at the so-called empirical definition. Widening the definition of a condition to such an extent that almost any desired "result" can be obtained is either incompetent or unethical.
1098	Jayne Waldman	
1099	Anonymous	
1100	Rebecca Bailey	

1101	Bonita Poulin	
1102	Karen R. Schoen	
1103	Carol Festejo	
1104	Anonymous	
1105	matthew smith	
1106	Rachel Porter	
1107	Janice Allen	
1108	Karen Harrell	
1109	Iain Lee	
1110	Anonymous	
1111	Emily Spivey	
1112	Jan Slama	
1113	De Wit Etienne	
1114	Julie Woodside	This definition will do unimaginable harm to current and future patients and research of this illness.
1115	Cammie Redlin	
1116	hilde maes	
1117	Stephen Spence	
1118	Jill Down	It is so important that this definition is not used. People with depressive/psychiatric illnesses need specific research and treatment programmes and people with CFS/ME deserve the same. They are not interchangeable.
1119	Alan Gurwitt	
1120	Mariska van Roijen	
1121	Carrie Presley	
1122	Nancy Hall, ATRL	
1123	Hayley Klinger	
1124	Trudie Doorduyn	
1125	pamela black	I have all of these illness and i am slowly dying so while u big wigs decide i'm dying here.
1126	Sunny Holmes	
1127	Jim McManus	
1128	Ray Lovelace	
1129	Arlene Rubb	
1130	Layla Collins	
1131	Anonymous	
1132	Anonymous	
1133	Lawrence Plumlee	The definition should include the known metabolic changes seen in CFS.
1134	Anonymous	
1135	Paulinbe Sykes	
1136	Kim Cantrell	
1137	sue smith	
1138	R. Sanderson	I have lost 20 years of my life to this illness - please give this illness the proper attention and research it deserves -- God knows I will not live long enough (at the rate federal agencies are going) to make substantial improvement (as most us who became sick during late 1980s find ourselves on steady decline / deterioration) -- but please do so for those at the prime of their lives and esp. the youth!!
1139	Anonymous	
1140	Linda Foley	
1141	Anonymous	
1142	Debbie Whittaker	I have had fibromyalgia since a car accident in 1977. Does this affect the fatigue portion of this syndrome as well?
1143	Maryka Ford	
1144	Jeannette Laframboise	
1145	Peter Ottem	CFS/ME has devastated my life. There needs to be serious ongoing clinical research into the causes and treatment of this curious and destructive illness.
1146	Ines Collins	
1147	Margaret Palmer	
1148	Emma Collins	
1149	Anonymous	
1150	phil evans	

1151	Rowena Chodorow	
1152	Carla Gardner	
1153	David Trimble	
1154	Susan Schirott	
1155	James Mather	
1156	Patricia L. Strickland	
1157	Anonymous	
1158	Deanna Brownlee	Please, if you are human, you will NOT make this illness more difficult than it already is. Living with a chronic illness can be a living hell that others refuse to acknowledge and understand. These new definitions would only serve to stomp on the broken pieces that were once complete souls. DO NOT DO THIS.
1159	Daniel Bowen	
1160	Barbara Brainard	
1161	Amy Roth	
1162	Barbara Lawson	CFS is not a psychological condition. For me it has taken away my life as I knew it and now I have constant severe pain, very tired and low immune system, just to name a few.
1163	Pat Henderson	
1164	Jeran Stephens	
1165	Rebecca Cordingley	
1166	Anonymous	
1167	Tim Hill	The only definition of CFS that governments should authorise is the 2003 Canadian Definition.
1168	Paul Doyon	
1169	Anonymous	
1170	Steve Chodorow	
1171	Bridget Gardner	
1172	Anonymous	
1173	Anne	
1174	Rebecca LFP	
1175	Anonymous	
1176	Khaly Castle	
1177	Peter Mitchell	
1178	Anonymous	
1179	K. J. Rogers	
1180	Ian Fulks	
1181	Anonymous	
1182	Virginia Thompson	
1183	RJ Kanwar	
1184	Cecile Appelmans	
1185	Patricia Carter	
1186	andrea cope	
1187	Corien	
1188	sanne peters	
1189	B. Amy Clouse	We do not have a list of lab tests or procedures that can define CFS, nor a list of effective treatments, because we have spent so much energy worldwide in blaming the victims of the disease rather than attempting to find the etiology, define the pathology, and mitigate or cure the progression. Not using the current empirical definition will allow a more precise diagnosis. This will allow researchers to focus on CFS, rather than trying to discern if the diagnosis is valid. We once considered sickle cell anemia to be a "garbage" diagnosis; we now know it is a serious illness in those of African descent worldwide. We need to learn from this error rather than repeating it.
1190	Rosie Page	The "empirical" definition would channel future research into CFS, a serious physical illness, in a psychiatric direction and result in inappropriate and possibly damaging treatment for sufferers.
1191	rhonda poole	people should understand what us sufferers of this cfs is like i would not wish this on my worst enemy as its not living
1192	Els Van Hoof	
1193	Nicola Reiss	
1194	Sue Klaus	You must, for once, consider what is best for the patients - their diagnosis, their care, and their return to some semblance of health.

1195	Suzan Jackson	I have had CFS for 7 years, and both of my sons - ages 11 and 14 - have it as well. We are desperate for solid CFS research that can lead to effective treatments. Diluting the definition of CFS to include a broader population results in research that is less focused and less useful. I would prefer that the Canadian CFS/ME definition be used in the US but would settle for sticking with the 1994 Fukuda definition.
1196	Anonymous	
1197	Barbara Riggio	
1198	Shary Kee	
1199	Robin Cupp	The Reeves definition seems like just a way to quit looking for solutions to the problem. Are their any Doctors left looking for actual solutions to real health problems?
1200	Diane J Standiford	

1201	Miriam Childs	
1202	John T. McCrea	
1203	t logan	inflammatory immune condtions are too common place today - there IS a cause
1204	Nancy Carlson	
1205	Cathy Horn	
1206	Susan Magowitz	I am one more CFS patient who has never understood the fatigue of CFS. I spent 5 years in bed unable to elevate my head, unable to sleep, and in full body pain. It took years to "recover" from what I now see as the acute part of this illness and my life with the chronic version is like walking a tightrope. If I do one too many tasks in a day I am back in bed for days. I have been sick for 15 years. The illness has moved through multiple body parts and systems - endocrine, brain and heart. Whatever CFS is, it covers it tracks which is probably not that tough since the CDC is not looking for it. My body can not supply the energy it needs - I am weak not tired so get anyone who needs more sleep out of my definition!
1207	Anonymous	
1208	Vicki Waldman	
1209	Anonymous	
1210	Omar Nunez	
1211	Anonymous	
1212	Paula Bilton	
1213	Anonymous	
1214	sally arnold	This illness is world wide and we in the US need to get on board with the others who name this ME. The Canadian defintion is a good start
1215	Anonymous	Those that are severely affected need to be recognised as such, rather than watering down this terrible disease which is so misunderstood anyway. This would just cause further confusion and misunderstanding.
1216	Nicole Roesner	
1217	Paulien van Rooij	
1218	Chloë Moíra Smith	
1219	Anonymous	
1220	Anonymous	
1221	Rhoda Freeman	
1222	Michael Larmer	
1223	Ian Johnson	
1224		
1225	Heather Falks	
1226	Anonymous	tk
1227	Ranjit Kanwar	
1228	Chris Ruhl	
1229	Patricia Ormsby	CFS is a real epidemic. People need help, not industry-favored stonewalling.
1230	Helen	I have been ill for over 10 years now and do not believe that the new (Reeves) definition accurately describes this condition. This devastating illness needs and deserves far more medical research and money to help those of us who are severely disabled. 0
1231	Christina Lucey-Ventura	
1232	Pella Schafer	
1233	Mama He Sapa	Strauss blew off the Incline Village Outbreak in 1984, and CDC has consistently been useless in meaningful work on ME/CFS since. Reeves continues to undermine any hope of taxpayer funded research. Who benefits? Not research or patients, not public health, public purse, public productivity.

Why is Reeves still employed in this position?		
1234	Donna m. Bentkowski	
1235	As a person affected by long term ME/CFS I do not support the CDC definition of the illness.	
1236	Pat Meier	
1237	Kristin Popelka	
1238	marie moore	
1239	Dan Green	
1240	Jane Wingfield	
1241	Patricia Meier	
1242	sylvie joy	
1243	Deborah Covington	
1244	Debbie Anderson	
1245	Anonymous	
1246	Alistair Mills	If the Centers for Disease Control and Prevention (CDC) use the "empirical" definition[1] (also known as the Reeves 2005 definition) to define Chronic Fatigue Syndrome (CFS) patients in CFS research, they will dilute the existing CFS data sets with ostensibly meaningless muddled and unspecific data that will hamper the research and discovery of the true causes, triggers and biological mechanisms of CFS also known as CFIDS as the Reeves 2005 definition) to define Chronic Fatigue Syndrome (CFS) definition lacks specificity. May the CDC not muddle the existing CFS definition picture by mmisguidedly adopting the Reeves 2005 definition but instead prevail with an accurate CFS definition underpined by the highest levels (worlds best practice) of the application of specificity with respect to CFS. One that is a blessing to CFS sufferers, not an obstacle.
1247	Michelle Roy	
1248	Laurel Bertrand	
1249	Brad Wiggins	This disease needs a clear definition.
1250	Wendy Beveridge	
1251	sue jorgensen	
1252	Anonymous	
1253	Toni Brown	
1254	Anonymous	
1255	Anonymous	It is an interesting situation when a disease can be defined out of existence. The implications for the future of medicine are frightening.
1256	Cynthia Bongarten, Ph.D.	
1257	Farrar Wilson	
1258	Lucy Fox	
1259	matthew stark	
1260	Ruth EJ James	
1261	Anonymous	
1262	Anonymous	This definition does not describe CFS/ME
1263	Stacie Phillips	
1264	Anne C Anderson	
1265	David Peterson	
1266	Anonymous	
1267	Anonymous	When is the CDC going to get it right?
1268	Denise Trenaman	
1269	Anonymous	
1270	Anonymous	
1271	Kerry McVeigh	

1272	Anonymous	I hope that the results of this petition would be favorable..
1273	Anonymous	Help these poor people who suffer so much. My 18 year old daughter has ME/CFS and it is ruining her life.
1274	Pamela Steinberg	I have had chronic fatigue syndrome for more than twenty years. I also have overlapping chemical intolerances.
1275	sandy reyes	
1276	Guyline Ivester	
1277	Mary Barker	I believe the hallmark of CFS is post-exertional malaise (more accurately, acute exhaustion). Although some CFS symptoms overlap with other illnesses, NO OTHER ILLNESS has the feature of post-exertional malaise. This is severe exhaustion which starts to hit several hours or more after rather minimal exertion, and which lasts for several days. Since there are so many possible causes of fatigue, the definition of CFS has to be limited to those with post-exertional malaise for any meaningful research to be done on CFS.
1278	Helen	
1279	Barbara	
1280	Karl	This disease is a theft to one's livelihood. Devastating pain, extreme suffering, relentless torture as if one has been poisoned or took in something toxic. I ask does the CDC wish this on any Human?
1281	abot bensussen	
1282	Mark Pawson	Dr Reeves should not be allowed to continue trading in other people's misery; misery which he himself has designed, produced, and sold. There are no words to describe the suffering he has caused.
1283	kathleen harper	
1284	Anonymous	We need more research!!
1285	Lori Orser	The definition of CFS/CFIDS should remain specific in order to focus research and potential treatments. The broader Reeves definition is so broad that many patients with other definable illnesses would fall into the CFS group.
1286	Anonymous	
1287	Joe Hayes	
1288	Anonymous	
1289	Greg Blair	For my buddy Gaston
1290	Anonymous	I agree with Mr. Kindlon. I have been diagnosed with Chronic Fatigue Syndrome (CFS) now for the past 2 years. I think I have had the disease for many years prior to the diagnoses but was miss diagnosed by many doctors that told me they couldn't find anything wrong with me. There needs to be a definitive test for this disabling disease and some kind of treatment that works for those of us that are in limbo suffering.
1291	Anonymous	Using the "empirical" definition will allow for a greater percentage of those with depression and other mood disorders to be misdiagnosed. It will hinder or possibly cease the research on ME/CFS that I had for past 18 years by allowing this definition as it lacks specificity.
1292	kathleen bowring	
1293	Anonymous	A blood test for CFS as mitochondrial failure has been developed and is described here: http://www.ijcem.com/files/IJCEM812001.pdf Definition of this illness should focus on etiology as well as accurate description of symptoms, including post-exertional malaise which is a key symptom. Funding should go to replication and distribution of this test and development of appropriate treatment. Why waste time and money on creating a new diagnostic criteria based on subjective data when a blood test is available?
1294	Anonymous	
1295	Evelyn Johnson	
1296	Anonymous	
1297	Michael A Murphy	As one who suffers with CFIDS/ Myalgic Encephalomyelitis I believe that It is time that this Major illness be called exactly what it is. Myalgic Encephalomyelitis. This is a devastating illness that will not be cured by talking, but by serious medical diagnosis and treatment. Bullshit talks but Myalgic Encephalomyelitis cripples. Do the right thing and keep the name M.E.
1298	Shana Dines	
1299	Lisa Bower	
1300	JFH	The empirical definition is unfit for its purpose and for the general aim of the CDC.
1301	Anonymous	My son has had this awful illness for 18yrs SOMTHING MUST BE DOWN ABOUT IT!
1302	Richard	

	Jaslovsky	
1303	A Pinto	
1304	Catherine Rowe	
1305	Anonymous	I hope that this will be of some help
1306	Kaat Deruddere	
1307	Anonymous	This is a disease that covers all ages and genders and all over the world. There is nothing being done to find a cause or cure because too many medical practitioners think it is a mental defect. Give help to those who are suffering by supporting an ME/CFS organization in your area or country today.
1308	J. Perez	
1309	Christina Gleason	
1310	john jay cooke	
1311	Anonymous	
1312	jacqui butterworth	Proper biomedical research is needed, not exercises such as CAB and GET.
1313	Dewey Ewing	
1314	Patricia Carter	
1315	David Woodcock	
1316	Andrea Pring	
1317	Gurli Bagnall	
1318	Anonymous	
1319	diane lindeman	
1320	Vickie Taylor	
1321	Victoria Storey	This group of patients are being forced to live in the dark ages, while the rest of the world lives in ignorance. There is nothing that the CDC offers in this definition that brings us any hope for treatments or a cure. It must be stopped now! and proper biological research begun.
1322	Anonymous	
1323	Christine Gow	
1324	jacqueline christensen	
1325	marie moore	
1326	MaryAnn	
1327	dirk goffin	
1328	Anonymous	
1329	James Hackett	I support this petition. Being a sufferer myself, I agree that this definition is inaccurate.
1330	Alan Gurwitt, M.D.	
1331	Catherine C Larson	
1332	Anonymous	
1333	judy chapman	
1334	Suzanne Delaney	
1335	Jamie Lalos	
1336	mike riley	
1337	Anna Biggs	
1338	Jamie Trafton	I pray they will change the name CFS to ME as CFS is doing nothing to justify what we all are living with the symptoms we have and to get the right type of help. Please take this name CFS out of the picture. Thank you for your time:O) Jamie Trafton
1339	Hilary Murphy	
1340	Myron A. Hoffman	I strongly believe that we need an updated definition of Chronic Fatigue Syndrome (CFS/ME). I am a professor of Mechanical Engineering and was forced to quit teaching almost 4 years ago when I came down with CFS. Please help us!!

1341	Rochelle Hall	
1342	Patricia Prendergast	
1343	Linda Wright	
1344	Anonymous	
1345	M. Sugarman	Definition of the disease should include all its symptoms, not just tiredness.
1346	Wendy Tubman	
1347	Linda Reed	I have suffered from this condition for nearly 10 years and finally had to quit working. Right now I do not qualify for disability due to the currently recognized definition. Believe me, fatigue is only a small part of the problem. For me, any depression is the result of not being able to carry on normal activity due to pain and the accompanying "brain fog".
1348	Kathy Rick	
1349	Jayne Roberts	
1350	Carolyn Bradford	
1351	Anonymous	
1352	michelle turner	
1353	Frances Corrow	
1354	Christine Gardner	I know several people with CFS that led active, vibrant lives before this syndrome claimed them. I would ask the CDC not to use the Reeves criteria in their study which could dilute the actual pool of people with CFS thereby making the results meaningless. This research is needed now for this difficult and debilitating disorder.
1355	Sharon Stapleton	Remove Reeves asap. HHS MUST monitor all actions of the CDC in regards to CFIDS. HHS must also fight for more funding for CFIDS generally.
1356	Dr. Richard Kugler	This is a true epidemic. The HHS, NIH, and CDC MUST get more funding for CFIDS.
1357		
1358	Karl Baty	Reeves needs to be replaced now with someone with compassion for human beings!
1359	Anonymous	I have CFS, its not fun and its NOT a psychological disorder. Give it the respect it deserves
1360	Arlene Stuart	I have now had CFS for 21 years, disabled for 10 years. It is important to correct the research definition of CFS to make sure it includes those of us who are severely ill and omits people diagnosed with depression.
1361	Anonymous	
1362	Ann U Smith	CFS/EBV for 20 years - continual recurring episodes despite following a strong nutritional program for 19 years
1363	Anonymous	
1364	Anonymous	Having my late daughter suffer endless mistreatment due to mis-attribution of her CFS illness, this is an importasnt issue to resolve
1365	Anonymous	
1366	Denise Benson	
1367	Anonymous	It is important to find the cause and cure of this disease. I have had it for over 20yrs and I am coming close to the end of my "useful" life. I regret all that I have missed and wish this not to happen to future generations.
1368	Anna Murphy	I have had fibromyalgia for 15 years and I know well the pain of post-exertional maoaise. There is a fear that FMS is going to be renamed CFIDS so anything that affects CFS, I am going to be watchful for.
1369	Karen Sterling	
1370	J. Vivanco	
1371	Anonymous	Whilst I think is great that some research is being done into ME, I think it will be completely wasted time, energy and money, if you base it on the empirical definition. People will continue to suffer and even die, unless drs start being more specific.
1372	Ariel Lansberg	Most so-called research & treatment of this horrible scourge is to date--nothing but another layer of biopsychosocioeconomic warfare against truly physically ill & vulnerable people. DOWN WITH REEVES, WHITE & ALL OTHERS LIKE THEM! They are merely moronic, self aggrandziing lackeys of an insidious

		agenda to further marginalize & destroy human lives which their collective believe to be too burdensome & expensive. Actions by members of this collective serve only to promote their own very special form of social Darwinism. While power brokers of this ilk are at the helm--nothing will occur but yet more obfuscation & strangulation of true knowledge regarding the nature of this devastating illness & how best to treat it.
1373	Alexandra	
1374	Gail Laraia	
1375	Keir Farnum	The 2003 Canadian Case Definition is the only true clinical definition that should be used and we need further research on all of the subsets of pathogenically caused ME (enteroviral, herpes related, etc.) and "Chronic Fatigue Syndrome" (organophosphate poisonings, rickettsial/Lyme related illness, bacterial toxicities [whether produced by pathogens in vitro or accumulated from the environment] such as ciguatera or estuary related syndrome.) These are serious illnesses and should have more funding than AIDS, MS, etc. since they cause more mortality and morbidity than all of these other illnesses combined. A definition of illness based on the lack of findings (such as the case with "Somatoform Disorder) is not a true definition and is not valid (in the case of somatoform disorder, I believe that it should be PROVED that there are no physical correlates rather than the other way around.) Have these folks never heard of epistemology?
1376	Anonymous	
1377	G Cowley	
1378	Natasha Vidan	
1379	Jason Johnston	
1380	marie moore	
1381	Anonymous	
1382	Angela	
1383	Anonymous	
1384	luke	
1385	White Deer Williamson	I have a very dear friend who has this and because of her, that is why I am adding my signature . This is very improtant document and others need to be made aware of this. So those you have this can and will be able to recieve the help they so much need.
1386	Honey McKinley	This redefinition is ridiculous and is likely to hinder any chance of getting proper treatments (rather than useless/dangerous CBT and GET) of this illness.
1387	Anthony Simmons	
1388	Anonymous	Please address this issue, it is paramount that research and treatment are congruant with the pathology of the illness and best practices world wide.
1389	Martha Evins	
1390	Owen Beith	Focused research is essential to achieving progress in determining the factors causing or contributing to Chronic Fatigue Syndrome / M.E. Any loss of focus is counterproductive and a retrograde step.
1391	glenna padley	
1392	Anonymous	
1393	Joe Krug	Nothing is worse than mis-diagnosis based on bad wording. Please fix.
1394	adesterke	ik wil dat alles eens goed nagekeken word
1395	Anonymous	Stop using the Empirical Definition and replace it with the Canadian Consensus Definition. Stop psychologizing the illness.
1396	Pat Askert	
1397	Joseph Shelton	Something must be done immediately to help people with Chronic Fatigue. This is a disabling disease.
1398	Jasmine Walton	
1399	Marly Silverman	Good Job Tom! We need to speak up on these important issues.
1400	kelly spencer	
1401	Anonymous	
1402	Andrew	

1403	York Gorzolla	
1404	Greg Field	The CDC is clearly muddying the waters to cover over its incompetence and avoid being brought to justice. Meanwhile patients around the world go on having ruined lives. Stop listening to your lawyers and for Gods sake, do the right thing, not just with the definition, but pushing research into a physiological causes and cure. Dont you know your names will be linked to the greatest medical scandal of modern time, unless you (the CDC) do the right thing ... now !
1405	maureen gunn	
1406	Anonymous	
1407	Jacqueline Vivanco	HHS said they would essentially remove and replace Reeves with someone else. HHS MUST do as they said they would do and soon. Everyone should email the HHS Commissioner and insist that he be removed from any CFIDS research.
1408	Ruth Darling	
1409	Maureen Mooney	
1410	Carole Hannon	
1411	Pamela G. Edelson	
1412	Anonymous	ME/CFS since 2000
1413	Clare	
1414	Anonymous	Please do not use the flawed Reeves definition of CFS. (CFS/ME). The definition does not separate out those that truly have CFS/ME. The new definition is meaningless and will dilute further meaningful research into this seriously disabling illness. It is already highly unlikely that much meaningful research will be done in my lifetime. The Reeves definition will only make things worse. It is unconscionable that the CDC has done so little to help those who suffer from this very disabling illness.
1415	Virginia Tierney	
1416	Michael Murphy	
1417	Lynne Andrews	
1418	Anonymous	
1419	Natalie Dunks	My Sister Laura Dunks and one of my friends has M.E and it has to be recognised not ignored.
1420	fietje	
1421	Sara Burton	
1422	Veronica Souza	
1423	Anonymous	
1424	kATIE G	

1425	Sharon Babbitt	We need research to continue.
1426	Sister Sandra Duma	I have no confidence in research being done by the CDC using the empirical definition. This group is too insular and needs to open up to other highly qualified ME/CFS researchers that are making greater progress with less money than that of the CDC. Too many of us have been too greatly ill for too long. It is time for a change in direction at the CDC.
1427	Sara McGroarty	
1428	Arlene Rubb	
1429	Teia Hassey	Depression and CFS have a major difference. I have chronic fatigue from Fibromyalgia, but I am NOT depressed. I wish to do things, but feel overwhelmingly "fatigued" that I can not. And when I do involve in ANY activity, it takes three days for me to recover. This is CFS and FMS. Not depression. Otherwise why am I using the energy I do not have to type this?? Thank you
1430	Judy	CFS is not to be trivialized
1431	Anonymous	
1432	Ross Voorhees	I support this petition.
1433	susan best	The definition of cfs for myalgic encephalitis is ridiculous
1434	Anonymous	I hope the CDC will change their research plan for CFS. My sister has had CFS for a number of years. I hope a cure is in the near future.
1435	joy birdsey	Over the last 20 years the UK and the USA have failed in their duty of care for ME/CFS towards children and adults, by taking on board the UK NICE guidelines. All governments have ignored the good robust scientific data of ME/CFS being a neurological disease. To offer CBT and GET to this patient group is an insult and an abuse of their human rights. Sick children and parents have been stigmatized with mental health labels, when this is purely not the case, as these children are extremely ill. The adult population with ME/CFS are also being stigmatized with having mental health probs, Is this the way a government controls the medical profession to continue. How much longer will the UK and the USA continue with this charade. Joy birdsey
1436	Anonymous	
1437	Jill Peters	
1438	Darlene Blair	I have friends who have suffered from this devastating and life threatening condition for years and need to have support from the medical professionals around the world to bring about a centralized and consistent definition and treatment.
1439	Debra	
1440	Debbie Anderson	The Chronic Fatigue Syndrome involved so much more than fatigue. Changing the name is a must so that sufferers will be taken seriously.

===== Appendix 2: Submission made at the end of April, 2008 =====

I spoke twice over the phone at the meeting on Monday and was asked to put what I said in writing as the note-takers had some difficulty hearing everything I said.

Unfortunately, I did not use a script so what I am sending is not verbatim.

The second part is probably pretty close to what I said as had a page full of header notes.

I wrote both up soon after the meeting so even the first one is likely not to be that different from what I said.

(If the note takers have anything that does not come up below, feel free to contact me if you are sufficiently interested).

Although this E-mail may look very long, the two main contributions are not really that long (1594 words between the two of them).

I am sending this also an attachment in case the format goes awry with this E-mail.

Thanking you,

Tom Kindlon (tomkindlon@oceanfree.net tomkindlon@gmail.com)

=====1st Contribution=====

I should first apologise and say that I didn't think I was going to be speaking today so I don't have anything prepared.

I have been ill for 20 years since the age of 16. I got 1460 in my SATs, top percentile in both of the subjects so had a promising future ahead of me, but I have now been housebound for over a decade.

I have read the CDC's research plan and am concerned that Graded Exercise Therapy and CBT based on Graded Exercise Therapy are going to be recommended. I am concerned that the CDC has been taken in by the hype of these treatments. Lots of people have been made worse by these treatments. Unfortunately, because they are not drugs, there is no easy way for patients or doctors to report adverse reactions the way there is with drug treatments. So no one is recording that many people are being made worse by these treatments. About the only place this shows up is in patient surveys: patient survey after patient survey shows a high percentage of people have been made worse by Graded Exercise Therapy and CBT based on Graded Exercise Therapy.

The draft plan uses the word "evidence based" three times. I think it is premature to use this term. There have only been a relatively small number of Randomised Controlled Trials and Controlled trials in the area. I fear what it means is that the CDC is going to be supporting and recommending GET and CBT based on GET.

The draft plan refers to arriving at an "international consensus on management". But again, I think it is premature to be talking about an "international consensus". There are lots of views. I fear that what the CDC is referring to is GET and CBT based on GET especially after the publication of the NICE Guidelines.

I am concerned by the phrase "prevention of CFS". This phrase isn't used much. One prominent person believes that one can prevent CFS by getting people moving and exercise soon after an infection. Many other people would think this is dangerous and what people actually need to do is rest. I am concerned that what the CDC is referring to is getting people to exercise after an infection which could be risky.

When the CDC refers "intervention studies" I fear what the CDC is referring to is GET and CBT and GET. In other countries, these strategies have gobbled up a lot of the governmental money. Another study just gives these treatments an unfair advantage - other treatments have barely been tested at all.

The whole idea of GET and CBT based on GET is to get people to do more. But where is the evidence that it actually achieves this? There is none. There is no actometer data. All they have is questionnaire data which could be due to factors such as placebo or time spent with a therapist. It isn't solid evidence. Indeed one CBT study by Friedberg[1] this year reported that people improved on the SF-36 physical functioning scale and on a fatigue scale but actually were doing less as measured by actometer data. This intervention involved encouraging patients to go out walking. And yet at the end people weren't walking more. So there's a lot of hype about GET and CBT based on GET but the evidence isn't there.

I think the empirical definition is flawed. It selects 2.54% of the population or 1 in 40 of the population[2]. I don't think they all have what is commonly understood to be CFS. Who knows what some of the people have. A study found that 38% of those who had major depression but didn't have CFS satisfied the empirical definition[3]. This definition messes everything up.

The thresholds for the empirical definition such as the 25th percentile for the SF-36 subscales weren't picked statistically, they were picked out of the air[4]. There is no particular reason why that should be the threshold. The role emotional subscale isn't a suitable way to pick way to find people who are functionally impaired on its own - Leonard Jason and lots of others also don't think it is suitable[5,6]. It shouldn't be used to decide that people are functionally impaired (and hence satisfy the impairment criteria in the Fukuda definition).

At this time, when we don't know who might be harmed by GET and CBT based on GET, I think it is dangerous to be recommending them.

Thank you.

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References:

[1] Friedberg F, Sohl S. Cognitive-behavior therapy in chronic fatigue syndrome: is improvement related to increased physical activity? *J Clin Psychol.* 2009 Apr;65(4):423-42.

[2] Reeves WC, Jones JF, Maloney E, Heim C, Hoaglin DC, Boneva RS, Morrissey M, Devlin R. Prevalence of chronic fatigue syndrome in metropolitan, urban, and rural Georgia. *Popul Health Metr.* 2007 Jun 8;5:5.

[3] Jason, L.A., Najar, N., Porter, N., Reh, C. Evaluating the Centers for Disease Control's empirical chronic fatigue syndrome case definition. *Journal of Disability Policy Studies* 2008, doi:10.1177/1044207308325995.

[4] Reeves WC, Wagner D, Nisenbaum R, Jones JF, Gurbaxani B, Solomon L, Papanicolaou DA, Unger ER, Vernon SD, Heim C. Chronic fatigue syndrome--a clinically empirical approach to its definition and study. *BMC Med.* 2005 Dec 15;3:19.

[5] Jason L, Richman J. How science can stigmatize: the case of chronic fatigue syndrome. *Journal of Chronic Fatigue Syndrome.* 2007;14(4):85-103.

[6] White PD. Reviewer comments on: Reeves WC, Jones JF, Maloney E, Heim C, Hoaglin DC, Boneva RS, Morrissey M, Devlin R. Prevalence of chronic fatigue syndrome in metropolitan, urban, and rural Georgia. *Popul Health Metr.* 2007 Jun 8;5:5.

Available at:

http://www.biomedcentral.com/imedia/1083914155124266_comment.pdf (and <http://tinyurl.com/dakhlz>)

=====Second contribution on the phone=====

I just thought I'd add something as my first piece wasn't pre-planned and I left some information out.

- The draft plan refers to "international consensus on management", "intervention studies" and "evidence based .. management of CFS". I fear that these will not include strategies such as pacing and the "envelope theory".

Leonard Jason in 2007 published a study, "non-pharmaceutical interventions for CFS"[1], from money from an NIH Grant. It found that pacing came out better than CBT, an exercise program and a relaxation intervention.

There is also some evidence that a similar strategy, the "envelope theory", is useful.

These strategies have excellent safety records.

These strategies involve listening to your body. This is very different from the rationale of Graded Exercise Therapy and CBT based on Graded Exercise Therapy.

So I am not sure how there can be any consensus at this time. It is premature to have consensus at this time. However I fear what is being talked about is to recommend Graded Exercise Therapy and CBT based on Graded Exercise Therapy.

- There is a lot of hype about GET and CBT based on GET. I fear that the CDC may have been taken in by this hype. Often the words "evidence based" and "effective" for example are used with regard to these treatments. However, reviews of the treatments do not show them to be that effective.

Malouff in 2008 published a meta-analysis of cognitive behavioural therapy Trials[2] (this included some studies on Graded Exercise Therapy). They calculated a Cohen's d effect size to be an average of 0.48 for the outcome measures. For those who don't know, an effect size is a measure of how effective a treatment is - some treatments can help a little, some

treatments can help a lot. 0.48 is below the threshold for a treatment to be seen as having a moderate effect size.

So the hype of cognitive behavioural therapeutic interventions isn't justified.

A Cochrane Review of CBT studies[3] found that at the end of treatment, 40% of people in the CBT group showed clinical improvement in contrast to only 26% in the control group (usual care) but at follow-up, 1-7 months after the treatment end, when drop-outs were included, there was no difference.

In Belgium[4], they set up five rehabilitation clinics that used GET and CBT. If you look at the questionnaire data, yes, it looks like the patients were helped like with other published literature.

However, on the exercise studies, there was no difference. And on the hours worked, patients were actually working less hours than before they did the CBT and GET.

So as I say, many questions remain about GET and CBT based on GET.

- With regard to the empirical definition, I forgot to say in my first submission that I set up a petition on the issue on the 15th of April. Already 250* people have signed it. It calls for the CDC to stop using the empirical definition, also called the Reeves definition, for its research. It's on ipetitions.com [5] - if people go there they can see the many points people have made on the issue [I am copying it below. I did not get a chance to say that other people also added comments but for some reason they did not show up]

- I forgot to say that I have a personal reason that I am so concerned about exercise programs. My own health was ruined by an exercise program. Before I did the exercise program I was only mildly affected but now I have been housebound for over a decade.

- A final point is to say that there are many problems with the philosophy surrounding GET and CBT based on GET. Many of the proponents say patients with CFS shouldn't be entitled to disability benefits. They also say that people shouldn't get home help as this can get in the way of the rehabilitation. Also that family and relatives should not be helpful for the

same reason. They can also recommend against people getting disability aids and parking badges.

And this is for an illness where at the very least we don't know what is causing it. But there is plenty of evidence to suggest it's "physical". As one person said to me once, the attitude (of those promoting the CBT/GET model) is medieval.

*Addendum: This has increased by nearly 100 to 347 in the 3 or so days since the meeting. I am appending the list below (Appendix 1). A lot of people told me that they put comments but for some reason the comments did not show. I intend leaving the petition up for the moment. It shows up (or articles talking about it) on various searches which use search words such as: cfs OR "chronic fatigue syndrome" reeves cdc OR "Centers for Disease Control and Prevention" etc.

Appendix 2: I am enclosing some comments I have made that have been accepted and have been placed beside articles that use the empirical/Reeves definition. Some of the team of course may be aware of them.

=====

References:

[1] Jason LA, Torres-Harding S, Friedberg F, Corradi K, Njoku MG, Donalek J, et al. Non-pharmacologic interventions for CFS: A randomized trial. *Journal of Clinical Psychology in Medical Settings* 2007; 14:275-96.

[2] Malouff JM, Thorsteinsson EB, Rooke SE, Bhullar N, Schutte NS. Efficacy of cognitive behavioral therapy for chronic fatigue syndrome: a meta-analysis. *Clin Psychol Rev.* 2008 Jun;28(5):736-45.

[3] Price JR, Mitchell E, Tidy E, Hunot V. Cognitive behaviour therapy for chronic fatigue syndrome in adults. *Cochrane Database Syst Rev.* 2008 Jul 16;(3):CD001027.

[4] Rapport d'évaluation (2002-2004) portant sur l'exécution des conventions de re-éducation entre le Comité de l'assurance soins de santé (INAMI) et les Centres de référence pour le Syndrome de fatigue chronique (SFC). 2006.
<http://tinyurl.com/d48t7u> i.e.
<http://www.inami.fgov.be/care/FR/revalidatie/general-information/studies/study-sfc-cvs/index.htm>

[5] "CDC CFS research should not involve the empirical definition (2005)"
http://www.ipetitions.com/petition/empirical_defn_and_CFS_research/

~~~~~

[http://www.ipetitions.com/petition/empirical\\_defn\\_and\\_CFS\\_research/index.html](http://www.ipetitions.com/petition/empirical_defn_and_CFS_research/index.html)

## **CDC CFS research should not involve the empirical definition (2005)**

### **The petition**

We call on the Centers for Disease Control and Prevention (CDC) to stop using the "empirical" definition[1] (also known as the Reeves 2005 definition) to define Chronic Fatigue Syndrome (CFS) patients in CFS research.

The CDC claim it is simply a way of operationalizing the Fukuda (1994) definition[2]. However the prevalence rates suggest otherwise: the "empirical" definition gives a prevalence rate of 2.54% of the adult population[3] compared to 0.235% (95% confidence interval, 0.142%-0.327%) and 0.422% (95% confidence interval, 0.29%-0.56%) when the Fukuda definition was used in previous population studies in the US[4,5].

The definition lacks specificity. For example, one research study[6] found that 38% of those with a diagnosis of a Major Depressive Disorder were misclassified as having CFS using the empirical/Reeves definition.

### References

[1] Reeves WC, Wagner D, Nisenbaum R, Jones JF, Gurbaxani B, Solomon L, Papanicolaou DA, Unger ER, Vernon SD, Heim C. Chronic fatigue syndrome--a clinically empirical approach to its definition and study. *BMC Med.* 2005 Dec 15;3:19.

Link: <http://www.biomedcentral.com/1...>

[2] Fukuda K, Straus SE, Hickie I, Sharpe MC, Dobbins JG, Komaroff A. The chronic fatigue syndrome; a comprehensive approach to its definition and study. *Ann Int Med* 1994, 121:953-959.

[3] Reeves WC, Jones JF, Maloney E, Heim C, Hoaglin DC, Boneva RS, Morrissey M, Devlin R. Prevalence of chronic fatigue syndrome in metropolitan, urban, and rural Georgia. *Popul Health Metr.* 2007 Jun 8;5:5.

[4] Reyes M, Nisenbaum R, Hoaglin DC, Unger ER, Emmons C, Randall B, Stewart JA, Abbey S, Jones JF, Gantz N, Minden S, Reeves WC: Prevalence and incidence of chronic fatigue syndrome in Wichita, Kansas. *Arch Int Med* 2003, 163:1530-1536.

[5] Jason LA, Richman JA, Rademaker AW, Jordan KM, Plioplys AV, Taylor RR, McCready W, Huang CF, Plioplys S. A community-based study of chronic fatigue syndrome. *Arch Intern Med.* 1999 Oct 11;159(18):2129-37.

[6] Jason, LA, Najar N, Porter N, Reh C. Evaluating the Centers for Disease Control's empirical chronic fatigue syndrome case definition. Journal of Disability Policy Studies 2008, doi:10.1177/1044207308325995.

Further reading:

Problems with the New CDC CFS Prevalence Estimates

Leonard Jason, Ph.D., DePaul University

[tinyurl.com/2qdgu4](http://tinyurl.com/2qdgu4) i.e.

<http://www.iacfsme.org/Issuesw...>

Brief comment from Tom Kindlon: I have Chronic Fatigue Syndrome (CFS) for over 20 years.

I want a lot of research progress in my lifetime and believe the empirical definition (2005) (also known as the Reeves definition (2005)) decreases the chances that this will occur: abnormalities that would show up using a more strictly defined definition won't show up using the empirical/Reeves definition; and abnormalities that might show up in the broad group covered by the empirical/Reeves definition are not necessarily representative of CFS patients.

Similarly treatments that might work on a more strictly defined group of patients might not show up using the very broad empirical/Reeves definition and treatments that might appear to work overall on the group defined using the empirical/Reeves definition might not be suitable for people who satisfy a stricter definition. This messes up the CFS literature even further.

--

Technical note: I am not sure why some people have grey boxes in the comments section. Some people have told me they have sent comments that never went up. I have not idea why this is happening.

## Petition sponsor

Tom Kindlon, a patient with Chronic Fatigue Syndrome (CFS) for over 20 years. I have done a lot of voluntary work in the area for over a decade. Recently I had two letters on CFS published in medical journals.

## Links

The paper defining the empirical/Reeves definition can be read at:

<http://www.biomedcentral.com/1741-7015/3/19>

Some comments on the paper have been posted at:

<http://www.biomedcentral.com/1741-7015/3/19/comments>

An article by Leonard Jason PhD on the issue can be read at:

[tinyurl.com/2qdgu4](http://tinyurl.com/2qdgu4) i.e.

<http://www.iacfsme.org/IssueswithCDCEmpiricalCaseDefinitionandPrev/tabid/105/Default.aspx>

<http://me-cfs.se/dok/081205-cfs-no-longer-cfs.pdf>

By Kasper Ezelius M.Sc. This includes some links to other definitions, Kasper's take on the issues and a list of some papers that have involved using the empirical definition (this list is not up-to-date; virtually all the papers

from the CDC 2-day Wichita study and also from the Georgia cohort have used the empirical definition to define CFS)

[http://www.ipetitions.com/petition/empirical\\_defn\\_and\\_CFS\\_research/signatures-1.html](http://www.ipetitions.com/petition/empirical_defn_and_CFS_research/signatures-1.html)

| #  | Name                 | Comments                                                                                                                                                                                                                                                                                                                                                                               |
|----|----------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1  | jill cooper          |                                                                                                                                                                                                                                                                                                                                                                                        |
| 2  | Keith Riley          |                                                                                                                                                                                                                                                                                                                                                                                        |
| 3  | Peter Ruberry        | Definitions are now so broad as to include almost anyone feeling a bit off colour. WE should get back to the Melvin Ramsay definition of ME                                                                                                                                                                                                                                            |
| 4  | Anonymous            |                                                                                                                                                                                                                                                                                                                                                                                        |
| 5  | Ellen                |                                                                                                                                                                                                                                                                                                                                                                                        |
| 5  | Goudsmit             |                                                                                                                                                                                                                                                                                                                                                                                        |
| 6  | Jenny Wilson         |                                                                                                                                                                                                                                                                                                                                                                                        |
| 7  | Irene Thorpe         | 20 years of being messed around. I would like some answers and treatment now . The faster the better thank you                                                                                                                                                                                                                                                                         |
| 8  | Laurence Swift       | The most precise definition of ME is the "Canadian Definition", which precludes many non-ME diagnoses. The present broad definition incorporates too many general cases of non-ME states to make any research valid. These non-ME cases should be called "CFS" and true ME listed separately.                                                                                          |
| 9  | Michele E Townsend   | This is very important to those of us that carry this diagnosis.                                                                                                                                                                                                                                                                                                                       |
| 10 | Veronica Jones       | It is time to get rid of the woolly definition that includes too broad a group of patients thus muddying research results                                                                                                                                                                                                                                                              |
| 11 | Anonymous            | The 2005 definition flies in the face of calls for subgrouping CFS patients to account for possibly different etiologies and pathologies. Instead, the original CFS/ME has been dissipated in a wide far-ranging heterogeneous group with vague symptoms ignoring the specific post-exertional problems patients have and the neurological problems that need research and treatment.. |
| 12 | Linda Wish           |                                                                                                                                                                                                                                                                                                                                                                                        |
| 13 | Anonymous            |                                                                                                                                                                                                                                                                                                                                                                                        |
| 14 | Dr John Greensmith   |                                                                                                                                                                                                                                                                                                                                                                                        |
| 15 | Rosie Cox            | I have had this illness since 1970. I too want movement in research into this illness which will not happen until reserach uses cohorts based on appropriate definitons of which the CDC Reeves 2005 is not one. I would prefer the use of the Canadian Consensus Document, or more pertinently the Ramsay selection criteria which have much greater specificity for ICD10 ME.        |
| 16 | Annette Barclay      |                                                                                                                                                                                                                                                                                                                                                                                        |
| 17 | Perry Townsend       |                                                                                                                                                                                                                                                                                                                                                                                        |
| 18 | Gail R. Kansky       |                                                                                                                                                                                                                                                                                                                                                                                        |
| 19 | Elizabeth McPhillips |                                                                                                                                                                                                                                                                                                                                                                                        |
| 20 | Penny Green          |                                                                                                                                                                                                                                                                                                                                                                                        |
| 21 | C Johnston           |                                                                                                                                                                                                                                                                                                                                                                                        |
| 22 | Marcus               |                                                                                                                                                                                                                                                                                                                                                                                        |

- Doolette
- 23** Anonymous
- 24** Sarah Owens
- 25** Kasper Ezelius
- 26**
- 27** Rob Arnoldus
- 28** Alfhild Renbro
- 29** Rita Eckerman
- 30** Trond Aure
- 31** Anonymous
- 32** Hillary L. Culver
- 33** Anonymous
- 34** Anonymous
- 35** Anita Patton
- 36** Ciaran Farrell
- 37** Karen M. Campbell
- 38** Catherine C Larson
- 39** Anonymous
- 40** Elsie A. Owings
- 41** Karen Algerio
- 42** Liz Willow
- 43** christine Gow
- 44** Sarah LaBelle
- 45** Anonymous
- 46** patricia Fero
- Very good initiative! My documents on the subject: Use the Canadian criteria 2003 for CFS in the USA. <http://me-cfs.se/dok/080622-Use-Canada-criteria-in-USA.pdf>
- Resolution in order to make cohorts less heterogeneous. <http://me-cfs.se/dok/080901-mod-cfs.pdf>
- How to categorize ME and CFS. <http://me-cfs.se/dok/081023-categorize.pdf>
- CFS is no longer CFS, and it was never ME. <http://me-cfs.se/dok/081205-cfs-no-longer-cfs.pdf>
- Go Tom Kindlon! many of us have fought the 1988 holmes lousy definition, the worse Fukuda 1994 "definition" and the overly broad reeves "chronic illness melange" as Kasper called it. us oldtimers are burned out. we need new blood to fight this terrible fight! TMH TMH
- On behalf of 225 members of CFS Facts support group
- Even though research on our disease is miserably underfunded, gene expression and other specific scientific research shows that CFS probably contains subcategories and needs to be studied in more, rather than less, specificity. Throwing the disease into a waste bin full of other fatiguing illnesses does nothing to further our research.
- The research following publication of the empiric definition shows a need for this change.
- Thanks Tom! Much needed petition.
- The Wisconsin ME/CFS Association board has discussed CDC research, and examined specific studies including subsequent publications using Wichita and Atlanta methodology to identify CFS patients. We conclude that the study of fatiguing illnesses in people across cultures is an important epidemiological endeavor. However, to call this CFS research and to fund it under that mechanism is wrong. We believe that ultimately the pathophysiology of a specific disease entity will be revealed by investigators interested in specificity. Inclusion of challenging contributions from international Myalgic Encephalomyelitis and CFS researchers is



paramount in this process.

Joan  
47 Grobstein,  
M.D.  
48 Frank Twisk  
49 P. Simpson  
Lolly  
50 McDermott

# Name  
51 Lillie Smith  
52 Wallace Provost  
53 Benjamin Di  
Pasquale  
54 Constance Van  
der Eb, Ph.D.  
55 Steven DuPre  
Mary  
56 Schweitzer,  
Ph.D.  
57 K McCall  
58 Gerald R.  
Campbell, Ph.D.  
59 Peter Cummins  
60 Alice Browne

### Comments

61 Tammie Page CDC is trying to hold up progress on the real disease by widening the criteria to include many who do not have the disease.

62 Kathy D. Patti The Canadian definition would be a much more suitable definition, in my opinion and that of many, many others, as well. As far as I am concerned, use of the Reeves "definition" has resulted in the CDC studying "chronic fatigue" of any etiology rather than doing hard investigation into the unique array of symptoms dubbed -- erroneously, in my opinion -- "Chronic Fatigue Syndrome." All your past research is useless because of its wide-open definition. If you want to contribute to medical science, use the Fukada definition.

63 Casey Pfluger I strongly believe that the empirical definition 2005 has hindered the progress in research and treatment of this globally important disease. If the CDC is truly committed to being a world-leader in CFS research then their CFS definition needs to be updated to encompass new developments and discoveries since 2005.

64 Joanne Shiller I do not endorse the use of the Reeves (2005)empirical definition on CFS.  
65 Tony Foran  
66 Tanya Selth

67 Thea Funk I live in the Netherlands and have ME/CFS for nearly 20 years. As the USA, by my knowledge, always had a leading role concerning research, I really am stunned about the recent developments in ME/CFS research in your country.

68 Anonymous  
69 Alexa McLaughlin We need reliable consistent research.

70 Simon Lawrence The sooner that all those severely affected by this terrible get help, the better. It must NOT be confused with feeling tired, which affects everyone from time to time.

- 71 connie nelson
- 72 Jacqui Footman
- 73 Anonymous
- 74 Jane  
Giakoumakis
- 75 harry burg
- 76 Alfhild Renbro
- 77 Hayley Klinger
- 78 Fiona Hodgkiss CFS implies a vague diagnosis or a mild diagnosis of little consequence.
- 79 Carol O. Olsen
- 80 Anonymous
- 81 Anonymous
- 82 C. Krusen Heller
- 83 Nicole Roesner
- 84 Louise Sheldo  
K.B.M.
- 85 Schellekens
- 86 Dr. Julie Donalek Millions of dollars in federal and other funding is being wasted generating totallly meaningless data the "results" of which delay not advance science in this essentail area of research. Julie G. Donalek, R.N. ,Ph.D., DePaul University Department of Nursing
- 87 sarah kepert
- 88 Rik Carlson
- 89 Ian McLachlan
- 90 Kathy Davis  
Unn-Elin
- 91 Andreassen
- 92 jeremy bearman i fully agree with the intentions of this petition. the empirical definition of cfs/me is a step in the wrong direction and is not in the best interests of patients  
I am from French Canada (Québec). Thank you for all the work you are doing.
- 93 Mona-Josée Gagnon Because in here, it is rather hopeless (no research, a very weak association). I am the mother of a 32-years old woman with ME, and those quarrels about definitions are terribly harmful and "hope destructive".
- 94 Ewan Dale We need to develop acuity not undermine it.
- 95 Anonymous
- 96 Deborah Waroff
- 97 Anonymous
- 98 Anonymous
- 99 Anonymous
- 100 Lawrence Plumlee, M.D. An investigation of chronic fatigue, while expensive, is essential to look for any treatable causes.
- 101 Anonymous
- 102 Dianne Bowman
- 103 Cort Johnson
- 104 Anonymous Fatigue is a symptom of ALL diseases and should not be used as a definition of ONE illness. The medical establishment has dismissed many ill people and thus many have gone without appropriate diagnosis and treatment; treatment that could have helped in the early stages.
- 105 Andy Grum

- 106** Evelien van den Brink I gladly support your petition! The Netherlands
- 107** Willeke van der Vlist
- 108** C.Walker
- 109** Angela Kennedy
- 110** Suzy Chapman
- 111** Catherine Broughton
- 112** F. Wong Specificity is critically needed in the definition of ME/CFS. Using a non-specific definition of the illness further muddies the ME/CFS waters.
- 113** lorraine Murray
- 114** genevieve gagnon
- 115** Diana Saba
- 116** Sandy Cooley
- 117** Kathleen Flaherty, J.D.
- 118** Annabel Luery
- 119** Dave Murry Use the Canadian Criteria!!
- 120** Craig Maupin
- 121** Susan Wenger
- 122** Tim Gardner
- 123** Kerrie McCure
- 124** John Mitchell jr
- 125** Edelgard Gerstmann
- 126** Jess MacDonals
- 127** Anonymous
- 128** Peter Kemp
- 129** Carol Wong
- 130** Karen Riem Please do not water down the thinking and the research about this devastating illness. There is little enough funding and support: lumping various illnesses and symptoms together and broadening the definition beyond useful meaning hinders research, insults those of us who are sick, and ensures that even if we learn something, we may not be able to know or effectively use what we know.  
The empirical definition is a step backwards, defining subgroups as per the genetic studies is the smartest way forward so that you are comparing apples with apples rather than with oranges, pears & carrots as this appallingly vague definition allows.
- 131** Ashley Hinds
- 132** A Walsh It disgusts me that in one of the most advanced nations in the world, CFS is merely a battle of personal agendas by those in government agencies who should instead be attempting to heal their citizens. Forget the politics and personal ambition and find a cure. I have had CFS for over 20 yrs, most of my adult life, and would like to have a good quality of life for the remaining years i have. That can only happen if a cure or at least effective treatment for CFS is found. That will never happen if the major centers for research in the US continue to ignore the real facts about CFS, instead pushing their own biased pet theories. The continued use of the seriously flawed Reeves definition is just more of the same.
- 133** Anonymous
- National Alliance for
- 134** Myalgic Encephalomyelitis For all unable to speak for themselves

- 135 Peggy Lundquist Please include "post exertional malaise" in the definition. I have been ill since 1987 and this symptom has never left me. I am not suffering from depression, I am suffering from irritation from the lack of acceptance of a serious health condition. I now have cancer as well and still cannot find a primary care physician to care for me as I have been diagnosed with a disease few understand or take seriously. Please, focus we need better.
- 136 Alan Gurwitt
- 137 Loretta Duzan I have had CFS for 40 Years and was diagnosed as mental case for 20 of those years. I think it is high time this disease was taken seriously. It has brought down so many people. I could only work and sleep. No personal life at all. That is no way to live.
- 138 Jenny Griffin
- 139 mia lauren
- 140 pauline oviden Having had ME for over 50 years I completely concur with the statement made by Tom Kindlon
- 141 Anonymous
- 142 Anne-Marie Woynillowicz Kemp The Canadian Clinical Case Guidelines, which are really international, should be used around the world. CDC should adopt them.
- 143 Carole Sturgis Thank you for this petition - it is crucial to get research and understanding for people with CFS.
- 144 jacqueline christensen
- 145 Anonymous
- 146 Laura Ingraham
- 147 Jan Andersson
- 148 Laura Dunks I have ME/CFS and I believe that it is important to correctly define the illness to provide appropriate research. We needs answers!!!!!!
- 149 Hillary L. Culver
- 150 Anonymous
- 151 Daniela Martins
- 152 Anonymous
- 153 Maureen Goggins
- 154 Barbara Berger I have just crossed the 21 year mark as a Chronic Fatigue Syndrome patient. We all agree that research is essential, but how that research is done or interpreted is key to any progress.
- 155 Stephen Philip Cox
- 156 Fiorella Mucci
- 157 Guido den Broeder Better still: drop CFS altogether. Myalgic Encephalomyelitis is a genuine disease, CFS is an artifact that serves only to stigmatize and confuse.
- 158 Shelley Lauer
- 159 Maartje Dijkstra
- 160 Charlotte von Salis
- 161 Sarah Goodwin
- 162 Bernie Standish
- 163 JOAN MCPARLAND
- 164 Anonymous
- 165 Anonymous Dr. Reeves is using this disease for his own political gain-he is profiting

personally and financially by reclassifying CFS as a psychological illness. There is overwhelming evidence that viruses are involved and the CFS definition should reflect the actual symptoms of the disease.

- 166** Rebecca Cordingley
- 167** Christina Omorochoe
- 168** Susanna Agardy
- 169** Lyle Allan
- 170** Anonymous        my girlfriend has me
- 171** cor soeterbroek
- 172** A.C.van der Wel
- 173** gea
- 174** Dr. Katharine M. Kanak
- 175** Anonymous
- 176** Diane Lewis
- 177** Jerrold Spinhirne
- 178** J McCall
- 179** Ray Colliton
- 180**
- 181** Anonymous        none
- 182** Truthseeker
- 183** Anonymous
- 184** Margaret Williams
- 185** joy birdsey        I just want the truth, and compassion for children and adults who have ME. I will never use the initials CFS.
- 186** Anonymous
- 187** Alison Wallace
- 188** Marie L. Martineau
- 189** Anna Wood
- 190** Leonard Wagner
- 191** Marcia Brewer
- 192** Anonymous
- 193** Cathleen Connor
- 194** Roger Morgan
- 195** Anonymous        ME-patient (Belgium)
- 196** antoinette Christie
- 197** Laurence Swift
- 198** Paula Gilfedder
- 199** Maggie Wallace
- 200** Thomas Ragan
- 201** Denise Visscher    CFS patient
- 202** Jan van Roijen
- 203** Lea Schorr
- 204** Jeanette Marley
- 205** Bernice A. Melsky

- 206** michael allen, ph.d.
- 207** Anonymous I was disabled in 1987 with chronic EBV; changed to CFS in 1988. The disease evolved into T-Cell Lymphoma in 2001
- 208** Christine Gow
- 209** Raymond Milsted Lets have some proper medical research
- 210** William Caroli
- 211** Paula Kenley  
Freeman I have had CFS since 1997, and it is way past time for the CDC to be using the obsolete empirical definition. Updating the definition would offer researchers a less vague umbrella under which to work.
- 212** Jules De Cuyper
- 213** Shan Russell
- 214** John Herd
- 215** Anonymous
- 216** Orla Ni Chomhraí
- 217** Anonymous
- 218** Anonymous Myalgic Encephalomyelitis is the official name for the disease - in use for over 50 years now - and the Canadian definition is superior to any of the CFS definitions.
- 219** Anonymous
- 220** Margaret Holt  
Baird, Esq. I am concerned about definitions that ignore significant additional research, and potentially stigmatize persons with this and related disabilities wrongfully.
- 221** katherine Bishop I am strogly opposed to the Reeves definition
- 222** Paul Thompson
- 223** Diane Grum
- 224** Patricia  
Blankenship The World knows what CFS (ME) is - the CDC needs to retire from the fray.
- 225** Anonymous
- 226** P.L. Bourdon
- 227** Sandra Cole Before my illness I was enjoying my life. First, as an advanced nurse practitioner and as a professor at a university teaching nursing. I then went back to law school and obtained a J.D. I practiced law before contracting this illness. That was 12 years ago. I believe what Mr. Kindlon has stated above. I also believe that Mr. Reeves should not be in charge of this program as he does not support logical definitions or programs concerning this population. Please get someone who cares about us to run this program. This has gotten way out of hand.
- 228** Catherine Foxwell
- 229** Guido Flobert my wife suffers from cvs me already for years and had to retire early for this by decision of a board of medicins
- 230** S. Young
- 231** Vicky  
Vandendriessche
- 232** P Angiollilo
- 233** nancy Rauhofer
- 234** Robin Syms It is time this illness is called what it really is. CFS  
I am very concerned that a mishmash of diseases have been incorporated under the umbrella of CFS. It would be premature to decide on measures to reduce CFS if there is no definitive cause. Trying to find psychological markers would be as wasteful of time and money as trying to find psychological markers for
- 235** Yvonne Leach

diabetes type 1, for example.

- 236 H.Patten  
237 D. de Boer  
238 RACHEL  
239 Anneco Blanson      better have strict criteria for ME research - would really be more helpfull for  
Henkemans              research results and ME patients.  
240 Anonymous  
241 Anonymous  
242 sue hogben  
243 Anonymous  
244 Wil Sengers  
245 Anonymous  
246 Sarah Robinson  
247 Ingeborg  
248 gaston gingués      CFIDS sufferer for 6 years and counting!  
249 Anonymous  
250 Carole Howard  
251 Rik Carlson  
252 Anonymous  
253 Jami M  
Griscom  
254 Anonymous  
255 Daniel Prince  
256 Anonymous  
257 Josette Lincourt      Can the Reeves definition.  
258 Anonymous  
259 jean Harrison  
260 Anonymous  
261 Liz Wenn  
262 Alpha Mason  
263 R Manning  
264 Anonymous  
kathleen  
265 Flaherty, J.D.  
266 Marie Jerales  
267 Anonymous  
Siobhan  
268 Copson  
269 Anonymous      as a sufferer of m.e. for 25 yrs i need to see that this illness is taken seriously and  
classified properly and also proper bio-medical research carried out  
270 Anonymous  
271 Anne James  
272 Rosemary      Incorrect selection of patients who are to be the subject of research studies renders  
Humby              the results of the research worthless. Every opportunity must be taken to ensure that  
this does not happen. The US could be leading the world in CFS research, yet it  
appears that it is in danger of simply following the models of bad practice which  
are perpuated elsewhere.  
273 Anonymous  
274 Susan Marshall

- 275 Invest in ME The empirical definition identifies such a broad range of patients that it can include people who are physically able to run a marathon. Such absurdities allow the figures of prevalence of ME/CFS to be raised from 0.4% of the population to over 2.5% in a recent study. As such the empirical definition is worthless for serious scientific studies.
- 276 Sarah Labovitch
- 277 Annabel Luery
- 278 Alison Orr
- 279 Anonymous I have had Me for 7 years. It has taken away what should have been the peak years of my life - I cannot get those years back but would like to make the most of whatever years I may have left - to do this I need appropriate medical treatment - spurious arguments geared towards the selection of illness criteria which suit a particular cadre of researchers as opposed to the needs of people with this devastating illness are helping no one. Please think of the lives of people with this illness and end this now.
- 280 John Wallace
- 281 Alison Wallace
- 282 Pat Sonnett
- 283 Anonymous
- 284 Eleanor Stein MD FRCP(C) The empirical case definition (Reeves et al 2005) lacks specificity and allows the inclusion of subjects as having CFS who actually have major depression and other non CFS disorders as a primary diagnosis. This has been published by Jason et al and is clear to anyone who is familiar with the questionnaires being used and the criteria of the common psychiatric disorders. The CDC has the opportunity to set a high standard for CFS research by admitting that the Empirical Criteria were misguided and should not be used. It would be better to continue to use the Fukuda Criteria while calling together a truly representative group of experts to develop research criteria based on both epidemiological and biomedical research. I am a PWC since 1992. I have clearly defined physical abnormalities (immune dysfunction, brainwave abnormalities, seizure problems) in addition to more common symptoms. The Reeves empirical definition broadens the definition of CFS to such an extent as to make accurate diagnosis impossible. It also makes research done using the Reeves definition meaningless. Treatments effective for people with MDD are useless and possibly harmful for me. When will CFS patients receive a competent, meaningful research program from the CDC?
- 285 Anita Swann
- 286 Michelle Perkins
- 287 Carolyn Allison
- 288 Daphne Caton Anything that could help to cure or relieve the living death that ME sufferers have to endure is worth pursuing; anything that threatens to jeopardise such moves deserves total annihilation.
- 289 Rachel Millward
- 290 Caroline Roberts
- 291 Catherine Please research the connection of ME with Wi-fi, mobile/digital phones, radio masts etc. incl. all electromagnetic effects in this so called modern/progressive world, the appalling continued use, by NHS, of mercury in amalgam fillings & the



- resultant detrimental health effects this practice has.  
The reeves definition includes patients who have Fatigue for emotional reasons. this serves to confuse the research data. giving false results for trials of treatments. me/cfs is a devastatingly disabling neurological illness that needs bio medical research, this definition hinders this taking away funding from the true me/cfs patients. there is brilliant research being done in the usa by for eg whittlemore peterson inst, dr chia, dr learner.
- 292** julia warman
- 293** Anonymous
- 294** Karen McMillan
- 295** Anonymous
- 296** Anonymous
- 297** Christine Stronach
- 298** Pamela Mawanda
- 299** J. Morton
- 300** Catherine Evans
- 301** Jo Gurney
- 302** Susannah Johnson
- 303** Katy Wimhurst
- 304** paula gilfedder
- 305** Sharon Stapleton
- 306** Marsha Moore
- 307** Mike Hughes
- 308** Lisa Connor
- 309** Anonymous
- 310** Beth Beardmore
- 311** Dave Holt
- 312** Kathy Clifford
- 313** Rose Anne Clifford
- 314** Kathleen Clifford
- 315** Margaret McFadden
- 316** Kathy McFadden
- Adopting the empirical definition is a waste of precious time and money as well as compounding the suffering of those with CFS/ME who continue to be failed by the NHS.
- That we may help to save others from the crippling effects of misinformation
- I have cfs
- I have been a carer for 15 years and have seen my daughter lose what should have been the best years of her life, going from "young and upcoming" to almost middle aged, bedridden, pretty helpless and still getting worse. We, her elderly parents, remain terrified for her future wellbeing.
- Get rid of Reeves and replace him with someone with a brain in their head. The CDC has done nothing for CFIDS research. Actually, CDC has thrown us backwards and kept us in the Dark Ages. We need NEW CFS leaders at the CDC - NOW.
- After collapsing in 1989, I have lived a very limited life for 20 years, as I continue to be seriously disabled with cfids.

317 Gemma Ford

318 Katherine  
Clifford

319 Anonymous

The new "empirical definition" of CFS/ME which is very flawed. In short, the criteria are so non specific that up to 40% of people with major depression and NO disabling fatigue would qualify as having CFS. It was after these criteria came out in 2005 that the CDC announced that the prevalence of CFS was 3X higher than previously reported. The prevalence of CFS did not jump, rather more people with other types of problems were now included under the CFS label. Leonard Jason presented his research on this issue at the November conference. The ramifications of the world researchers using these criteria are serious as it means we will continue to have inaccurate studies with misleading findings.

320 Anonymous

321 Leanne  
Morgan

322 Carol  
McTavish

323 Anonymous

324 Francelia E.  
Poirier

325 Steven Kusen The criteria should include (and even quantify) the disabling fatigue that is associated with CFS.

326 Lilliana Sejc

327 Goran  
Prvulovic

328 Mark My mom has been sick for fourteen years, I wish that this illness receives the attention and funding it so desperately needs.

329 Marina Sejc

Like many modern era diseases this one is surely connected to our chemical environment and the use of chemicals to eliminate germs and decrease our natural immune system. Maybe if the CDC and the FDA were public entities then they would take more time and responsibility to find the causes of these diseases and therefore eliminate them altogether. I strongly support this action of changing the definition to more specific one.

330 Darlene Blair

331 Evelyn Violini

332 Matilda  
Morgan  
Mary &

333 Kathleen  
Lewin

334 Judy Goodzeck

335 Naomi Hooke

336 William G M.E. is a real disease, with real signs and symptoms. STOP misdiagnosing it as the phony CFS!  
Hartwell

337 Aisling

338 Lori Hoffman

339 trish murphy

340 Anonymous

341 Robin. A

- .Brook  
342 Vicky Stringer  
343 Anonymous  
344 Clair  
345 Anonymous  
Charlotte  
346 Howarth  
347 Anonymous Please listen to CFS/ME patients

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Appendix 2: Some comments I (mainly) and some others have made on the empirical/Reeves definition and related papers:

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<http://www.pophealthmetrics.com/content/3/1/8/comments>

## **Psychometric properties of the CDC Symptom Inventory for assessment of Chronic Fatigue Syndrome**

**Dieter Wagner** ✉, **Rosane Nisenbaum** ✉, **Christine Heim** ✉, **James F Jones** ✉, **Elizabeth R Unger** ✉ and **William C Reeves** ✉

*Population Health Metrics* 2005, **3**:8doi:10.1186/1478-7954-3-8

### **More symptoms could be added to a CFS Symptom Inventory**

**Tom Kindlon** (21 June 2007) Irish ME/CFS Support Group ✉

Many would feel that the 8 symptoms used in the CDC '94 definition [1] were chosen in a somewhat arbitrary fashion; so it is to be welcomed that the CDC itself has started to look beyond these symptoms with the CDC CFS Symptom Inventory. The idea of a Short Form of the CDC Symptom Inventory is also interesting.

However, it is not clear to me where the extra symptoms that are on the CDC CFS Symptom Inventory came from. For example, I didn't see some of the symptoms listed in Reeves et al [2].

In 2001, De Becker et al [3] published data on the symptoms found in over 2500 patients. They tried to improve on the 1988 [4] and 1994 CDC criteria. They suggested a list of symptoms that could be used to strengthen the ability to select ME/CFS patients. Many of the symptoms they mentioned are not in

the CDC CFS Symptom Inventory. So to claim that the "CDC Symptom Inventory assesses the full range of CFS associated symptoms" seems questionable.

It would be interesting if in future these symptoms (that De Becker et al were suggesting) were added before statistical analyses are performed.

The fatigue criteria and functional impairment criteria have become much less restrictive [5]. For example, to satisfy the fatigue criteria, the fatigue is required to be greater than or equal to the medians of the MFI general fatigue ( $\geq 13$ ) or reduced activity ( $\geq 10$ ) scales. So it now seems particularly important that the symptom criteria have good sensitivity and specificity or one is going to end up with a definition that leads to very heterogeneous samples.

Tom Kindlon

[1] Fukuda K, Straus SE, Hickie I, Sharpe MC, Dobbins JG, Komaroff A: The chronic fatigue syndrome; a comprehensive approach to its definition and study.

Ann Int Med 1994, 121:953-959.

[2] Reeves WC, Lloyd A, Vernon SD, Klimas N, Jason LA, Bleijenberg G, Evengard B, White PD, Nisenbaum R, Unger ER, International Chronic Fatigue Syndrome Study Group: Identification of ambiguities in the 1994 chronic fatigue syndrome research case definition and recommendations for resolution.

BMC Health Services Research 2003, 3:25.

<http://dx.doi.org/10.1186/1472-6963-3-25>

[3] A definition-based analysis of symptoms in a large cohort of patients with

chronic fatigue syndrome, P. De Becker, N. McGregor, and K. De Meirleir.

Journal of Internal Medicine 2001;250:234-240

[4] Holmes GP, Kaplan JE, Gantz NM, Komaroff AL, Schonberger LB, Straus SE, et al.: Chronic fatigue syndrome: a working case definition. Ann Intern Med 1988, 108:387-389.

[5] Reeves WC, Wagner D, Nisenbaum R, Jones JF, Gurbaxani B, Solomon L, Papanicolaou DA,

Unger ER, Vernon SD, Heim C: Chronic fatigue syndrome — a clinically empirical approach

to its definition and study. BMC Medicine 2005, 3:16.

### **Competing interests**

No competing interests

[top](#)

### **Observations on apparent changes in methods of assessing symptoms**

**Tom Kindlon** (06 July 2007) Irish ME/CFS Support Group 

I notice that the *"Symptom Inventory collects information about the presence, frequency, and intensity of.. symptoms during the month preceding the interview"*.

However the Fukuda et al '94 definition [1] is supposed to look for *"the concurrent occurrence of four or more of the following symptoms, all of which must have persisted or recurred during 6 or more consecutive months of illness and must not have predated the fatigue"*.

Was there a particular reason why a time frame of one month was chosen? This would suggest that relatively short-lived symptoms would be counted. If the reasoning was that asking people detailed questions about symptom severity and frequency over a longer period would might not be as accurate, perhaps a two-stage question could be asked: firstly asking whether symptoms "have persisted or recurred during 6 or more consecutive months of illness" and then asking a more detailed question about frequency and intensity.

I also see no mention of the requirement, that was in the initial definition [1], that the symptoms didn't predate the fatigue. Again, if this is a change, it would seem to risk reducing the specificity of the symptom criteria (i.e. increasing the chences that symptoms from other causes are counted) so perhaps again a yes/no question would be good.

Tom Kindlon

[1] Fukuda K, Straus SE, Hickie I, Sharpe MC, Dobbins JG, Komaroff A: The chronic fatigue syndrome; a comprehensive approach to its definition and study. *Ann Int Med* 1994, 121:953-959.

### Competing interests

No Competing Interests

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<http://www.biomedcentral.com/1741-7015/3/19/comments/comments>

Chronic Fatigue Syndrome – A clinically empirical approach to its definition and study

William C Reeves , Dieter Wagner , Rosane Nisenbaum , James F Jones , Brian Gurbaxani , Laura Solomon , Dimitris A Papanicolaou , Elizabeth R Unger , Suzanne D Vernon  and Christine Heim 

BMC Medicine 2005, **3**:19doi:10.1186/1741-7015-3-19

How many SF-36 subscales were used for the "standardized clinically empirical criteria"?

Tom Kindlon (26 June 2007) Irish ME/CFS Support Group 

I wonder whether the authors would confirm in a quick comment how many of the 8 subscales of the SF-36 they used?

In the "empirical definition", they appear to me to use four: Role-Physical, Role-Emotional, Physical Functioning and Social Functioning:

[Reference: "We defined substantial reduction in occupational, educational, social, or recreational activities as scores lower than the 25th percentile of published US population [11] on the physical function (≤ 70), or role physical (≤ 50), or social function (≤ 75), or role emotional (≤ 66.7) subscales of the SF-36."]

However, in the pre-publication history they say:

".. We used only 3 of the 8 SF-36 and 2 of the 5 MFI scales in the empirical definition."

- see http://www.biomedcentral.com/imedia/7804319382956733_comment.pdf

I was just hoping that 3 is actually the number of subscales they used and that they didn't use the Role-Emotional subscale, as I question the value of using that subscale to satisfy functional impairment criteria.

Tom Kindlon

Competing interests

No Competing Interests

[top](#)

MDDm should be resolved for more than 5 years before a CFS diagnosis can be given

Tom Kindlon (26 June 2007) Irish ME/CFS Support Group 

In this paper, it says:

"Following recommendations of the International CFS Study Group, only current MDDm was considered exclusionary for CFS."

However, part of the specific recommendations of the International CFS Study Group [1] was that MDDm had to have been resolved for more than 5 years:

"The 1994 case definition stated that any past or current diagnosis of major depressive disorder with psychotic or melancholic features, anorexia nervosa, or bulimia permanently excluded a subject from the classification of CFS ... we now recommend that if these conditions have been resolved for more than 5 years before the onset of the current chronically fatiguing illness, they should not be considered exclusionary."

It might not be important to point this out for definitions for some illnesses: however if one looks at table 2, 6 of the 16 who are said to have CFS using the "current classification" of CFS, had been diagnosed with MDDm at a previous assessment which suggests it is important in this context.

Tom Kindlon

[1] Reeves WC, Lloyd A, Vernon SD, Klimas N, Jason LA, Bleijenberg G, Evengard B, White PD, Nisenbaum R, Unger ER, International Chronic Fatigue Syndrome Study Group: Identification of ambiguities in the 1994 chronic fatigue syndrome research case definition and recommendations for resolution.

BMC Health Services Research 2003, 3:25.

<http://dx.doi.org/10.1186/1472-6963-3-25>

Competing interests

No Competing Interests

[top](#)

Data from another population study found scores on the RE subscale are similar in CFS patients to those found in healthy controls

Tom Kindlon (09 July 2007) Irish ME/CFS Support Group 

In a previous comment I said that I questioned the value of using the Role Emotional (RE) subscale to satisfy functional impairment criteria.

Researchers deciding whether to follow the method of operationalizing the Fukuda [1] used in this study, might be interested at looking at Table 2 in Jason et al [2]. The subjects were also obtained from a random-digit population study.

Here is what the authors said in the text on this part of the results:

"A MANCOVA for the Medical Outcomes Study SF-36 Health Survey (controlling for the effects of work status) revealed significant differences in gradations of disability across the diagnostic categories of CFS only, MCS only, FM only, more than one diagnosis, and no diagnosis on seven of the eight subscales ($F(4,208) = 1.82, p < .05$). The role-emotional scale was the only scale that did not reveal significant differences between the groups (see Table 2). Significant post hoc tests revealed that individuals with CFS demonstrated greater disability than those with no diagnosis on the role-physical; bodily pain; vitality; and social functioning scales. Individuals with MCS demonstrated greater disability than the no diagnosis group on the physical functioning; role-physical; bodily pain; general health; vitality; social functioning; and mental health scales. Individuals with FM demonstrated greater disability than the no diagnosis group on the physical functioning; role-physical; bodily pain; and social functioning scales. In addition, individuals with more than one diagnosis demonstrated greater disability than those in the no diagnosis group on the physical functioning; role-physical; bodily pain; vitality; and social functioning scales. Means for each of the Medical Outcomes Study subscales are reported in Table 2."

This issue of how the Fukuda criteria [1] are operationalized is not a trivial matter. Using the previous method of operationalizing the criteria, a CDC team found a prevalence for CFS of 235 per 100,000 [3]. Using the method of operationalizing the criteria outlined in this study, the prevalence rate for CFS was found to be 2.54% or 2540 per 100,000 [4] or 10.81 times the previous prevalence rate!

Tom Kindlon

[1] Fukuda, K., Straus, S.E., Hickie, I., Sharpe, M.C., Dobbins, J.G., & Komaroff, A. (1994). The chronic fatigue syndrome: A comprehensive approach to its definition and study. *Annals of Internal Medicine*, 121 (12):953-959. <http://www.annals.org/cgi/content/full/121/12/953>

[2] Jason, L.E., Taylor, R.R., & Kennedy, C.L. "Chronic Fatigue Syndrome, Fibromyalgia, and Multiple Chemical Sensitivities in a Community-Based Sample of Persons With Chronic Fatigue Syndrome-Like Symptoms." *Psychosomatic Medicine* 62:655-663 (2000).

<http://www.psychosomaticmedicine.org/cgi/reprint/62/5/655>

[3] Reyes M, Nisenbaum R, Hoaglin DC, Unger ER, Emmons C, Randall B, Stewart JA, Abbey S, Jones JF, Gantz N. Prevalence and incidence of chronic fatigue syndrome in Wichita, Kansas. Arch Intern Med. 2003;163:1530–1536. doi: 10.1001/archinte.163.13.1530.

[4] Reeves WC, Jones JF, Maloney E, Heim C, Hoaglin DC, Boneva RS, Morrissey M, Devlin R. Prevalence of chronic fatigue syndrome in metropolitan, urban, and rural Georgia. Population Health Metrics 2007, 5:5 doi:10.1186/1478-7954-5-5

Competing interests

No Competing Interests

[top](#)

This may not be a representative group of those who would be diagnosed in a random sample using the "standardized clinically empirical criteria"

Tom Kindlon (02 January 2008) Irish ME/CFS Association - for Information, Support & Research



This "empirical" method of operationalizing the CDC 1994 CFS criteria[1] has subsequently been used in a population study[2]. It found a prevalence rate for CFS of 2540 per 100,000 persons 18 to 59 years of age[2].

This is considerably higher than the prevalence rates found in earlier studies. For example, a previous study using this cohort using a "previous" method of operationalizing the CDC 1994 CFS criteria[1] found a prevalence rate of 235 per 100,000[3].

Given the way the cohort in this current study was drawn up, using 58 people who had previously been diagnosed using a "previous" method of operationalizing the CDC 1994 CFS criteria, the group satisfying the new method of operationalizing the CDC 1994 CFS criteria, the "empirical" criteria, in this study may well not be the same sort of people that would show up if the method was used on a random sample of the population. So for example the results in Table 6 may not be similar to the results one can get in a random sample.

Unfortunately the paper giving the prevalence rate for Georgia[2] does not give the same pieces of information as is in Table 6 in this study. However we do have a paper which uses a group from the Georgia cohort[4]. Table 1 of this study[4] includes similar data. Some of the numbers are somewhat

similar. However one that particularly stands out is the Role Emotional score. It was 35.6 (95% CI: 26.3-44.8). That compares to the value in this paper of 55.8+/-42.2.

Perhaps other data will be published in time. The main point of this comment is to point out or remind people that the data presented in this paper may not be representative of those that would be diagnosed using the empirical criteria.

Tom Kindlon

[1] Fukuda K, Straus SE, Hickie I, Sharpe MC, Dobbins JG, & Komaroff A. (1994). The chronic fatigue syndrome: A comprehensive approach to its definition and study. *Annals of Internal Medicine*, 121 (12):953-959. <http://www.annals.org/cgi/content/full/121/12/953>

[2] Reeves WC, Jones JF, Maloney E, Heim C, Hoaglin DC, Boneva RS, Morrissey M, Devlin R. Prevalence of chronic fatigue syndrome in metropolitan, urban, and rural Georgia. *Population Health Metrics* 2007, 5:5 doi:10.1186/1478-7954-5-5

<http://www.pophealthmetrics.com/content/5/1/5>

[3] Reyes M, Nisenbaum R, Hoaglin DC, Unger ER, Emmons C, Randall B, Stewart JA, Abbey S, Jones JF, Gantz N, Minden S, Reeves WC: Prevalence and incidence of chronic fatigue syndrome in Wichita, Kansas. *Arch Int Med* 2003, 163:1530-1536.

[4] Nater UM, Maloney E, Boneva RS, Gurbaxani BM, Lin JM, Jones JF, Reeves WC, Heim C. Attenuated Morning Salivary Cortisol Concentrations in a Population-based Study of Persons with Chronic Fatigue Syndrome and Well Controls. *J Clin Endocrinol Metab*. 2007 Dec 26

Competing interests

No competing interests

[top](#)

Why is this definition being referred to as an "empirical definition"?

Tom Kindlon (18 June 2008) Irish ME/CFS Association - for Information, Support & Research 

I believe most people's understanding of "empirical criteria" or an "empirical definition" would be that the data would speak for itself; it "would decide" the cut-off points through methods such as cluster analysis (for example).

Indeed this would seem to have been William Reeves' understanding of an empirical definition. For example, in a presentation on the CDC's CFS research program (to a Task Force Meeting on the Epidemiology of Interstitial Cystitis)[1], he said:

"The problem with the CFS criteria was that they were not specific enough and not empiric-based. For example, one of the criteria stated that the research subject must have at least four of eight symptoms, among them, impaired concentration or memory and postexertional worsening of physical or mental fatigue. "The accompanying symptoms need to be defined in and of themselves," Dr. Reeves said. The 1994 International Study Group also hypothesized that fatigue led to patients' symptoms rather than the reverse. The CDC is currently conducting population studies to develop an empiric definition of CFS that is based on statistical modeling."

At the inaugural meeting of the US Department of Health and Human Services' Chronic Fatigue Syndrome Advisory Committee (CFSAC), Dr Reeves said the CDC team of research would *"derive an empirical case definition based on data"*. [2]

The definition presented here does not seem to have been based either on "statistical modeling" or "data". It seems to involve relatively arbitrary cut-off points; for example, of the 8 subscales of the SF-36, four are chosen and, for each of these, the 25th percentile of the published US population is chosen as a cut-off point. A patient is required to be in the bottom quartile for just one of these subscales to satisfy the criteria. Where did this cut-off point come from? There is no mention of it in the paper that suggested the use of the SF-36[3]; nor is there any mention that these particular subscales should be chosen or that one would be sufficient. One of the authors of the paper[3] has confirmed that cut-off points were never chosen nor was it decided which sub-scales would be used. Given that the CDC's definition of CFS tends to go on to be used in numerous studies, would it not be better to investigate which thresholds give a "better" definition e.g. with a higher specificity and sensitivity - for example, for some of the SF-36 subscales, perhaps (say) the 13th, 15th, 20th or even 30th percentiles may be more appropriate.

The cut-off points suggested in this paper may or may not be useful. But is it really accurate to suggest that they are "empirically" derived?

[1] Epidemiology of Interstitial Cystitis - Executive Committee Summary and Task Force Meeting Report October 29th, 2003. http://www.niddk.nih.gov/fund/reports/ic/task_force_summary.pdf

[2] US Department of Health and Human Services - Chronic Fatigue Syndrome Advisory Committee (CFSAC). Inaugural Meeting. September 29th, 2003

Meeting Summary. http://www.hhs.gov/advcomcfs/CSFAC_mins_2003.09.29R.pdf

[3] Reeves WC, Lloyd A, Vernon SD, Klimas N, Jason LA, Bleijenberg G, Evengard B, White PD, Nisenbaum R, Unger ER, International Chronic Fatigue Syndrome Study Group: Identification of ambiguities in the 1994 chronic fatigue syndrome research case definition and recommendations for resolution. BMC Health Services Research 2003, 3:25

Competing interests

No competing interests

[top](#)

Using two MFI scales ("General Fatigue" or "Reduced Activity") to ensure patients satisfying the definition have "severe fatigue"

Tom Kindlon (30 June 2008) Irish ME/CFS Association - for Information, Support & Research 

Initially when I read this paper, where it says "we defined severe fatigue as \geq medians of the MFI general fatigue (≥ 13) or reduced activity (≥ 10) scales", I thought this referred to medians of the general population.

Hearing other people commenting on it, that's how some other people have been interpreting it also. It is probably somewhat natural to do this as the sentence before reads: "We defined substantial reduction in occupational, educational, social, or recreational activities as scores lower than the 25th percentile of published US population [11] on the physical function (≤ 70), or role physical (≤ 50), or social function (≤ 75), or role emotional (≤ 66.7) subscales of the SF-36."

However from looking at the scores for controls in other papers, these MFI scores do not look like medians for the whole US population but in fact are medians for this particular group of patients. This seems a strange way to set cut-off points for a CFS definition that is used for numerous studies into the illness, given the cohort that is being used as a basis:

"This population-based case control study enrolled 227 adults identified from the population of Wichita with: (1) CFS (n = 58); (2) non-fatigued controls matched to CFS on sex, race, age and body mass index (n = 55); (3) persons with medically unexplained fatigue not CFS, which we term ISF (n = 59); (4) CFS accompanied by melancholic depression (n = 27); and (5) ISF plus melancholic depression (n = 28)." i.e. this is not a random sample of the US population but a group of people selected for a specific purpose (or purposes) (not necessarily to design a definition, but as a follow-up study of people

previously diagnosed with CFS or given some other label). Some of the groups are of different sizes - if the relative size of these groups had been changed, with relatively more people taken from some classification groups and less people taken from other groups, the median scores would likely have been different.

It should also be remembered that in this context the categories listed in the last paragraph refer to their classification when they evaluated years before (from 1997 to 2000), and not necessarily at the time when they were evaluated in this study (December 2002 to July 2003) (as is clear from the tables in this paper).

I thought it would be interesting to look at MFI scores in some other papers on CFS that did not use the "empirical definition".

I don't claim this is a definitive list but, at the same time, mean MFI scores with standard deviations only seem to be listed in a small percentage of papers.

The papers use cohorts from a variety of locations: England [3], The Netherlands [4], Germany [5] and the USA (New Jersey) [6].

I did not see any ranges given which would be useful given the task at hand (selecting cut-off points for a definition).

Unfortunately not all of the papers I found used the Fukuda [1] definition for CFS; some also used the Sharpe [2] definition for CFS. I indicate which definition is used in each case.

MFI: General Fatigue

Sample Sample Size Mean SD (Mean - 13)/SD Definition

Weatherley-Jones [3] 53 18.4 1.7 3.176470588 Sharpe (1991)

Vermeulen (Group 1) [4] 30 18.6 1.9 2.947368421 Fukuda (1994)

Vermeulen (Group 2) [4] 30 18.4 1.8 3 Fukuda (1994)

Vermeulen (Group 3) [4] 30 19.1 1.4 4.357142857 Fukuda (1994)

Gaab [5] 21 17.7 0.5 9.4 Sharpe (1991) and Fukuda (1994)

Brimacombe [6] 65 18.41 2.02 2.678217822 Fukuda (1994)

Combining these give a sample of 229 patients with a mean "General Fatigue" score of 18.45655022.

This data suggests that a threshold of ≥ 13 will have a very very high sensitivity. This would suggest that another measure would not be necessary (unless it was being used as an extra criterion to increase the specificity, which isn't done with this definition).

However for completeness, I'm including the "Reduced Activity" data from the same papers:

Reduced activity (MFI)

Sample Sample Size Mean Score SE (Mean-10)/SD Definition

Weatherley-Jones [3] 53 16.1 3.1 1.967741935 Sharpe(1991)

Gaab [5] 21 15 0.7 8.714285714 Sharpe (1991) and Fukuda(1994)

Brimacombe [6] 65 15.93 4.55 1.340659341 Fukuda 1994

Combining these give a sample of 139 patients with a mean Reduced Activity score of 15.85431655.

Note: the Vermeulen paper[4] did not collect the MFI scores for Reduced Activity, just "the fatigue axes of the Multidimensional Fatigue Inventory" (which they defined as the MFI scores for General fatigue, Physical fatigue, Mental fatigue). It seems strange in the definition of Chronic Fatigue Syndrome defined in this paper (i.e. Reeves et al) that the "severe fatigue" criterion can be satisfied by a patient having a low score on a subscale of the MFI testing activity levels (as opposed to one of the 3 subscales measuring fatigue), especially when the function of the SF-36 is to "measure functional impairment". Just because someone is inactive doesn't mean they have severe fatigue. Allowing patients to be included if they simply have a "Reduced Activity" score of 10 or more (without necessarily having a low score on one of the fatigue axes of the MFI) risks reducing the specificity of the definition.

[1] Fukuda K, Straus SE, Hickie I, Sharpe MC, Dobbins JG, Komaroff A. The chronic fatigue syndrome; a comprehensive approach to its definition and study. *Ann Int Med* 1994, 121:953-959.

[2] Sharpe MC, Archard LC, Banatvala JE, Borysiewicz LK, Clare AW, David A, Edwards RH, Hawton KE, Lambert HP, Lane RJ, et al. A report--chronic fatigue syndrome: guidelines for research. *J R Soc Med.* 1991 Feb;84(2):118-21.

[3] Weatherley-Jones, E., Nicholl, JP., Thomas, KJ., Parry, GJ., McKendrick, MW., Green, ST., Stanley, PJ and Lynch, SPJ. A randomised, controlled, triple-blind trial of the efficacy of homeopathic treatment for chronic fatigue syndrome. *Journal of Psychosomatic Research*, 2004, 56, 2, 189-197.

[4] Vermeulen, RCW and Scholte, HR. Exploratory open label, randomized study of acetyl- and propionylcarnitine in chronic fatigue syndrome. *Psychosomatic Medicine*, 2004, 66, 276-282.

[5] Gaab J, Hüster D, Peisen R, Engert V, Heitz V, Schad T, Schürmeyer TH, Ehlert U. Hypothalamic-pituitary-adrenal axis reactivity in chronic fatigue syndrome and health under psychological, physiological, and pharmacological stimulation.

Psychosom Med. 2002 Nov-Dec;64(6):951-62.

[6] Brimacombe, Michael; Lange, Gudrun; Bisuchio, Kim; Ciccone, Donald S.; Natelson, Benjamin. Cognitive Function Index for Patients with Chronic Fatigue Syndrome *Journal of Chronic Fatigue Syndrome*, 2004, vol 12; number 4, pages 3-24

Competing interests

No competing interests

[top](#)

Analyses of 2 separate CFS cohorts found 6 of the 8 SF-36 subscales group together - two that don't are MH and RE (the latter is being used in this definition)

Tom Kindlon (30 September 2008) Irish ME/CFS Association - for Information, Support & Research ✉

This paper is supposed to operationalize the recommendations in the consensus paper by Reeves et al[1]. That paper suggested that the SF-36 could be useful as a measure of functional impairment but did not specify which subscales should be used.

The authors of the current paper chose to define "substantial reduction in occupational, educational, social, or recreational activities" as "scores lower than the 25th percentile of published US population [11] on the physical function (less than or equal to 70), or role physical (less than or equal to 50), or social function (less than or equal to 75), or role emotional (less than or equal to 66.7) subscales of the SF-36."

Priebe et al[2] have just published an analysis of a cohort of CFS patients from the UK. "Principal-component analysis of all scale scores revealed 2 distinct components, explaining 53% of the total variance."

"Component 1 comprised 14 variables and had an eigenvalue of 7.9 (32.9% of the variance). It had positive loadings of the SCL-90-R subscales depression, anxiety, obsessive-compulsive symptoms, psychoticism, hostility, phobic anxiety, interpersonal sensitivity, paranoid ideation, the Spielberger Trait Anxiety Questionnaire, Health Anxiety Questionnaire and Beck Hopelessness Scale, and negative loadings of the SF-36 subscales of mental health and emotional role fulfilling." (Remember that lower the scores on the SF-36, the lower the reported functioning in that domain).

The other component involved the other 6 SF-36 subscales, The Fatigue Visual Analogue Scale, SCL-90-R subscale somatization and the Somatic Discomfort Questionnaire (SDQ) (the authors say "the majority of physical symptoms that were assessed was measured on only 2 scales, the somatization subscale of the SF-36* and the SDQ")

(*This is presumably a typo and what they are referring to is the SCL-90-R subscale somatization).

Hardt et al [3] have previously performed factor analyses on a large cohort of patients (740 CFS patients from the US, 82 from the UK, and 65 from Germany). They said: "Overall, there was a remarkable similarity in HRQoL among all CFS patients, regardless of location. Patients scored two to three standard deviations below normal on six subscales and one standard deviation below normal on the other two subscales. Factor analysis suggested a two-factor model where the same six subscales (i.e. Bodily pain, General health perception, Limitations due to physical problems, Physical functioning, Social functioning and Vitality) constitute the first factor and the two others (i.e. limitations due to emotional problems (RE) and Mental health) the second factor."

These result bring into question the use of the role emotional subscale alongside the other three subscales (physical function, role physical and social functioning) being used in this so-called "empirical definition".

[1] Reeves WC, Lloyd A, Vernon SD, Klimas N, Jason LA, Bleijenberg G, Evengard B, White PD, Nisenbaum R, Unger ER: International Chronic Fatigue Syndrome Study Group: Identification of ambiguities in the 1994 chronic fatigue syndrome research case definition and recommendations for resolution.

[2] Priebe S, Fakhoury WK, Henningsen P: Functional Incapacity and Physical and Psychological Symptoms: How They Interconnect in Chronic Fatigue Syndrome. Psychopathology. 2008 Sep 3;41(6):339-345.

[3] Hardt J, Buchwald D, Wilks D, Sharpe M, Nix WA, Egle UT: Health-related quality of life in patients with chronic fatigue syndrome: an international study. J Psychosom Res 2001; 51: 431-434.

Competing interests

No competing interests

[top](#)

Exclusionary conditions or essential pathology?

John Mitchell jr (23 January 2009) Patient Support Advocate 

One important criticism of the CDC CFS case definition as it stands is based on the following sentences- "CFS is defined as persistent or relapsing fatigue of at least 6-months' duration, that is not alleviated by rest, and that causes substantial reduction in activities. The fatigue cannot be explained by medical or psychiatric conditions and must be accompanied by at least 4 of 8 case defining symptoms (unusual post exertional fatigue, impaired memory or concentration, unrefreshing sleep, headaches, muscle pain, joint pain, sore throat and tender cervical nodes)."

By including the misleading and out of context 'cannot be explained by medical or psychiatric conditions', the authors set up a damaging catch-22 in regards to pathophysiology in CFS, being that if any underlying pathophysiology is found then that patient is then excluded from further study. This makes sense if one understands that fatigue is a common symptom of many illnesses and should not immediately be ascribed to CFS, however in the context the author's use it, it ends up being as if pneumonia or Kaposi Sarcoma were exclusionary conditions when studying AIDS, instead of correctly being considered co-morbid conditions that are results of the underlying disease process.

So although pneumonia and Kaposi Sarcoma do happen in the population without a person having AIDS, to exclude them from being co-morbid conditions would be absolutely disastrous to AIDS

patients; as many CFS patients argue that excluding any thyroid involvement, elevated c-reactive protein, inflammatory disease, etc. is to them, especially when you consider that these are some of the very areas in which progress is being made by other groups studying CFS.[1,2]

1.Evidence of inflammatory immune signaling in chronic fatigue syndrome: A pilot study of gene expression in peripheral blood. Aspler AL, Bolshin C, Vernon SD, Broderick G. Behav Brain Funct. 2008

2.Neuroendocrine and immune network re-modeling in chronic fatigue syndrome: An exploratory analysis. Fuite J, Vernon SD, Broderick G. Genomics. 2008 Sep 30.

Competing interests

none

[top](#)

Another CFS study raises questions about the use of the RE subscale in a definition of CFS

Tom Kindlon (23 January 2009) Irish ME/CFS Association - for Information, Support & Research



Firstly, apologies for sounding like a broken record but the definition the CDC proposes for CFS is an important issue - it tends to be the one adopted by researchers around the world. The definition laid out in this paper continues to be used in papers involving cohorts the CDC has gathered for CFS population studies such as the papers using this cohort (which has been analysed in numerous papers) as well as a later study in Georgia[1].

Fulcher (2000)[2] is another study which raises questions about the use of the Role Emotional (RE) subscale of the SF-36 to select patients with CFS. The study involved 66 patients with CFS without a current psychiatric disorder, 30 healthy but sedentary controls, and 15 patients with a current major depressive disorder. It found, amongst other things, that *"the two patient groups were significantly more incapacitated than the sedentary controls on all SF-36 measures ($p < 0.001$), except that the patients with CFS were not significantly different in emotional or mental function."* Also, *"the depressed subjects were significantly more incapacitated in emotional and mental functioning than the patients with CFS $p < 0.001$."* These results suggest that low scores on the emotional and mental functioning subscales of the SF-36 do not seem to be an intrinsic part of CFS (if they're found, they could be related to comorbid psychiatric issues). They also points out the risks of using the RE subscale alone [especially given CFS shares some characteristics with depression and so some people with

depression (but not CFS) could potentially score the required 25 points on the Symptom Inventory] i.e. one could inadvertently include some people who have depression but not CFS, as CFS patients.

[1] Reeves WC, Jones JF, Maloney E, Heim C, Hoaglin DC, Boneva RS, Morrissey M, Devlin R. Prevalence of chronic fatigue syndrome in metropolitan, urban, and rural Georgia. *Popul Health Metr.* 2007 Jun 8;5:5.

[2] Fulcher KY, White PD. Strength and physiological response to exercise in patients with chronic fatigue syndrome. *J Neurol Neurosurg Psychiatry.* 2000 Sep;69(3):302-7.

Competing interests

No competing interests

[top](#)

Research Study finds 38% of those with a Major Depressive Disorder satisfied these criteria for CFS (i.e. they lack specificity)

Tom Kindlon (17 March 2009) rish ME/CFS Support Group 

An interesting study [1] has recently been published on this issue: It investigated 37 participants with a diagnosis of a Major Depressive Disorder and 27 participants with a diagnosis of CFS. It found that 38% of those with a diagnosis of a Major Depressive Disorder were misclassified as having CFS using this new CFS definition [2]. That is to say these criteria lack specificity.

The authors gave some background to the study pointing out that there are several CFS symptoms that are not commonly found in depression and that there has been previous research which has distinguished between CFS and depressed patients.

The authors screened participants from the MDD group to ensure that they did not have CFS as defined by the Fukuda et al. (1994) criteria [3].

For the data, the authors subdivided the MDD group into two groups: those that satisfied the new definition [2], called "MDD/CFS" and those that did not, called "MDD".

There were large differences between the "pure" CFS patients and the other two groups across some of the measures that make up the Reeves (2005) definition [2]. There were also not surprisingly differences in the percentage scores satisfying the criteria from the Reeves (2005) definition.

For example, on the **Role Physical subscale of the SF-36**, the means scores (SDs) across the CFS,

MDD/CFS and MDD groups were: 5.56 (16.01); 51.79 (40.98); 58.7 (45.61). (The data showed that there were the following statistically significant differences at the $p \leq .001$ level: CFS<MDD/CFS and CFS<MDD). The percentages satisfying the criteria (RP less than or equal to 50) were, respectively, 96%, 50% and 44% (The data showed that there were the following statistically significant differences for the percentages at the $p \leq .001$ level: CFS>MDD/CFS and CFS>MDD).

For the **SF-36 Physical Functioning subscale** the respective scores across the CFS, MDD/CFS and MDD groups were 37.41 (23.43); 70.36 (32.90); 76.74 (21.25). (The data showed that there were the following statistically significant differences at the $p \leq .001$ level.: CFS<MDD/CFS and CFS<MDD). The percentages satisfying the criteria (PF less than or equal to 70) were, respectively, 93%, 43% and 35% (The data showed that there were the following statistically significant differences for the percentages at the $p \leq .001$ level: CFS>MDD/CFS and CFS>MDD).

For the **CDC Symptom Inventory CDC scores** (i.e. for the 8 case-defining symptoms) the respective scores across the CFS, MDD/CFS and MDD groups were 43.97 (14.28); 37.56 (10.54); 17.05 (8.62). (The data showed that there were the following statistically significant differences at the $p \leq .001$ level: CFS>MDD and MDD/CFS>MDD). The percentages satisfying the criteria (CDC Symptom Inventory greater than or equal to 25) were, respectively, 100%, 100% and 9% - this part of the definition should naturally the first two groups would be 100% (The data showed that there were the following statistically significant differences for the percentages at the $p \leq .001$ level: CFS>MDD and MDD/CFS>MDD).

However the differences were the opposite (or "backwards") for the **Role Emotional subscale of the SF-36** i.e. rather than the CFS group having the worst score, they actually had the best score - the scores across the CFS, MDD/CFS and MDD groups were: 69.14 (40.22); 19.05 (31.25); 30.43 (40.09) (The data showed that there were the following statistically significant differences at the $p \leq .001$ level: CFS>MDD/CFS and CFS>MDD). The percentages satisfying the criteria (RE less than or equal to 67) were, respectively, 44%, 93% and 78% (The data showed that there were the following statistically significant differences for the percentages at the $p \leq .001$ level: CFS<MDD/CFS and CFS<MDD).

For some subscales, there were no differences across the groups, which also brings about questions about their use in a CFS definition
e.g.

(i) for the **Social Functioning subscale of the SF-36**, the mean scores (SDs) across the CFS, MDD/CFS and MDD groups were: 30.09 (28.43); 41.96 (23.31); 40.22 (25.27). The percentages satisfying the criteria (SF less than or equal to 75) were, respectively, 96%, 100% and 91% (The data showed that there were also no statistically significant differences for the percentages).

(ii) for the **Reduced Activity scale of the Multidimensional Fatigue Inventory** the scores were: 14.44 (3.79); 13.64 (3.95); 13.17 (4.77). The percentages satisfying the criteria (Reduced Activity score greater than or equal to 10) were, respectively, 85%, 86% and 78% (The data showed that there were also no statistically significant differences for the percentages).

The authors also calculated the **total from each group that would satisfy each of the three criteria in the Reeves Definition[2]**. This showed how poor the SF-36 and MFI criteria are for differentiating between CFS and MDD.

Using the **SF-36 criteria**, every one of the 37 patients with a Major Depressive Disorder satisfied the

criteria used in the Reeves (2005) definition.

With the **Multidimensional Fatigue Inventory criteria**, 34 of the 37 patients (92%) with a Major Depressive Disorder satisfied the Reeves criteria.

The only measure that had any power to distinguish between the two groups was the CDC Symptom Inventory where 16 of the 37 patients (43%) with a Major Depressive Disorder satisfied the criteria. Of course, this is still not a particularly good percentage.

The authors make many of the points that have been made already in these comments. They point out that to score 25 on the CDC Symptom Inventory, somebody doesn't have to be that severely affected by more classic CFS symptoms. They could endorse symptoms such as unrefreshing sleep, impaired memory, headaches and muscle pain and score 25 without too much difficulty (one can score 16 from any one symptom).

This study clearly demonstrates that there is plenty of potential for a CFS definition to be "better" than the Reeves (2005) definition[2].

[1] Jason, L.A., Najar, N., Porter, N., Reh, C. Evaluating the Centers for Disease Control's empirical chronic fatigue syndrome case definition. *Journal of Disability Policy Studies* 2008, doi:10.1177/1044207308325995.

[2] Reeves WC, Wagner D, Nisenbaum R, Jones JF, Gurbaxani B, Solomon L, Papanicolaou DA, Unger ER, Vernon SD, Heim C. Chronic fatigue syndrome--a clinically empirical approach to its definition and study. *BMC Med.* 2005 Dec 15;3:19.

[3] Fukuda K, Straus SE, Hickie I, Sharpe MC, Dobbins JG, Komaroff A. The chronic fatigue syndrome; a comprehensive approach to its definition and study. *Ann Int Med* 1994, 121:953-959.

Competing interests

No competing interests

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<http://www.biomedcentral.com/1471-2377/6/41/comments/comments>

## Sleep characteristics of persons with chronic fatigue syndrome and non-fatigued controls: results from a population-based study

William C Reeves ✉, Christine Heim ✉, Elizabeth M Maloney ✉, Laura Solomon Youngblood ✉, Elizabeth R Unger ✉, Michael J Decker ✉, James F Jones ✉ and David B Rye ✉

*BMC Neurology* 2006, **6**:41doi:10.1186/1471-2377-6-41

### New or "Unusual" definition for CFS used in this study

Tom Kindlon (27 October 2008) Irish ME/CFS Association - for Information, Support & Research ✉

People reading this study need to be aware that it uses a new or "unusual" definition of Chronic Fatigue Syndrome (CFS)[1] so the results may not apply to CFS cohorts as usually defined[2].

This definition selects a group covering 2.54% of the adult population[3].

This is much higher than previous estimates of the prevalence of CFS. For example, members of the team in this study have previously estimated the prevalence as 0.235%[4] i.e. the prevalence rate using this definition is 10.8 times the rate found using the more usual CFS definition[2].

There has been some criticism of this new definition[5].

Unlike previous times when the CDC produced definitions for CFS[2,6], the definition used in this study is generally only being used by the CDC-funded CFS research team.

[1] Reeves WC, Wagner D, Nisenbaum R, Jones JF, Gurbaxani B, Solomon L, Papanicolaou DA, Unger ER, Vernon SD, Heim C: Chronic Fatigue Syndrome – A clinically empirical approach to its definition and study. *BMC Medicine* 2005, **3**:19 (15 December 2005)

[2] Fukuda, K., Straus, S.E., Hickie, I., Sharpe, M.C., Dobbins, J.G., & Komaroff, A. (1994). The chronic fatigue syndrome: A comprehensive approach to its definition and study. *Annals of Internal Medicine*, **121** (12):953-959. <http://www.annals.org/cgi/content/full/121/12/953>

[3] Reeves WC, Jones JF, Maloney E, Heim C, Hoaglin DC, Boneva RS, Morrissey M, Devlin R

Prevalence of chronic fatigue syndrome in metropolitan, urban, and rural Georgia. *Population Health Metrics* 2007, **5**:5 (8 June 2007)

[4] Reyes M, Nisenbaum R, Hoaglin DC, Unger ER, Emmons C, Randall B, Stewart JA, Abbey S, Jones JF, Gantz N, Minden S, Reeves WC: Prevalence and incidence of chronic fatigue syndrome in Wichita, Kansas. Arch Int Med 2003, 163:1530-1536.

[5] Jason Leonard: Issues with CDC Empirical Case Definition and Prevalence of CFS. IACFS website

<http://tinyurl.com/2qdgu4> i.e.

<http://www.iacfsme.org/IssueswithCDCEmpiricalCaseDefinitionandPrev/tabid/105/Default.aspx>

[6] Holmes GP, Kaplan JE, Gantz NM, Komaroff AL, Schonberger LB, Straus SE, et al. Chronic fatigue syndrome: a working case definition. Ann Intern Med. 1988; 108:387-9.

### Competing interests

No competing interests

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<http://www.pophealthmetrics.com/content/5/1/5/comments>

Comments(5)

Prevalence of chronic fatigue syndrome in metropolitan, urban, and rural Georgia

William C Reeves ✉, James F Jones ✉, Elizabeth Maloney ✉, Christine Heim ✉, David C Hoaglin ✉, Roumiana S Boneva ✉, Marjorie Morrissey ✉ and Rebecca Devlin ✉

Population Health Metrics 2007, **5**:5doi:10.1186/1478-7954-5-5

Does the use of the "Role emotional" subscale of the SF-36 help with sensitivity and specificity rates? Can we find out the prevalence rate if this subscale hadn't been used?

Tom Kindlon (15 June 2007) Irish ME/CFS Support Group ✉

It is to be welcomed that attempts are being made to operationalize the CDC (94) CFS criteria [1], enabling easier comparisons between studies and making it easier for researchers to try to replicate findings.

So for example, having some sort of numerical value on a symptom so that one can say whether a symptom is present or not in a patient seems to be a good idea.

However if one is aiming to do this, it would seem preferable to choose methods that have good sensitivity and specificity rates for the condition in question. And it's questionable whether the methods used in this study have good sensitivity and specificity.

The authors claim that they "*used stringent (i.e., \leq 25th percentile population norms on any of the 4 SF-36 scales) to define severe functional impairment*". One of the SF-36 subscales in question is the "role emotional" subscale. This involves questions such as: "During the past 4 weeks, have you accomplished less than you would like as a result of any emotional problems?"

Does this really capture whether there has been a "substantial reduction in previous levels of .. personal activities"? [Full quote from paper[1]: *1) clinically evaluated, unexplained, persistent or relapsing chronic fatigue that is of new or definite onset [has not been lifelong]; is not the result of ongoing exertion; is not substantially alleviated by rest; and results in substantial reduction in previous levels of occupational, educational, social, or personal activities*]

Perhaps the other three sub-scales cover this? For example, a better measure of whether the condition is having an effect on somebody's "personal activities" might be got from using the physical functioning subscales which asks about ability to walk distances, bath or dress oneself, etc. If this score is low, it's likely one's ability to do "personal activities" has been impaired.

Baraniuk[2] used the CDC '94 not operationalized in the same way as this study and found that CFS patients scores did have lower scores on some of the SF-36 subscales - but role emotional was one of the ones that weren't different (the others that weren't different were mental health and general health change).

Would it be possible for the authors to calculate the all important overall prevalence rate if those people who only satisfied this part of the "functional impairment" criteria are excluded? This data would be useful not just in the US but around the world - countries around the world have been depending on the US to undertake such large scale (and expensive) studies on CFS.

Even before the recent broadening of the criteria, it had been felt by some that the CDC '94 criteria lacked specificity.

For example, Kennedy[3] investigated *"patients with self-reported symptoms which developed sporadically (sCFS, n=48); after Gulf War service (GW, n=24); and following exposure to organophosphate insecticides (OP, n=25)"* all of whom fulfilled the CDC '94 criteria[1]. Based on their findings, they concluded that *"differences in simple, easily performed clinical outcome measurements can be observed between groups of patients, all of whom fulfill*

the CDC-1994 criteria for CFS. It is likely that their response to treatment may also vary. The specificity of the CFS case definition should be improved to define more homogeneous groups of patients for the purposes of treatment and research."

Perhaps what is required is a totally new set of criteria?

Tom Kindlon

[1] Fukuda, K., Straus, S.E., Hickie, I., Sharpe, M.C., Dobbins, J.G., & Komaroff, A. (1994). The chronic fatigue syndrome: A comprehensive approach to its definition and study. *Annals of Internal Medicine*, 121 (12):953-959. <http://www.annals.org/cgi/content/full/121/12/953>

[2] James N Baraniuk, Begona Casado, Hilda Maibach, Daniel J Clauw, Lewis K Pannell and Sonja Hess S. A chronic fatigue syndrome - related proteome in human cerebrospinal fluid

BMC Neurology 2005, 5:22 doi:10.1186/1471-2377-5-22

<http://www.biomedcentral.com/1471-2377/5/22>

[3] Kennedy G, Abbot NC, Spence V.A, Underwood C, Belch JF. The specificity of the CDC-1994 criteria for chronic fatigue syndrome: comparison of health status in three groups of patients who fulfil the criteria. *Ann Epidemiol* 2004; 14: 95–100.

Competing interests

No competing interests

[top](#)

Does the use of the 'role emotional' subscale of the SF-36 help with sensitivity and specificity rates? Can we find out the prevalence rate if this subscale had not been used?

Sarah LaBelle (18 June 2007) Chicago area CFIDS support group 

This paper presents results long awaited, prevalence of CFS beyond metropolitan areas. The huge difference in the metropolitan area rate of the Georgia study as compared to prior rates based on studies in other metropolitan areas is not well explained. The pre-publication discussion includes comment by the authors that this difference is not important, rather it is important that CFS is not diagnosed by simple physical test measurements.

The prevalence rate of this study is its single most important result. Huge variation needs more exploration of reasons why they occurred, and whether the result is reliable. Inclusion of the 'role emotional' subscale constitutes a substantial change in diagnostic method from prior work by the same lead author. The authors state they are using diagnostic approaches meant to improve the specificity of who is included as CFS, per the CDC 1994 criteria for CFS (1), which intention is applauded. However, 'role emotional' does not relate to any symptom in the listed criteria, directly or indirectly.

This has the effect of straying from the definition, perhaps broadening it, to include many who may be ill, but not with CFS.

The authors are correct in pointing out the difficulty in diagnosis for the purpose of research. The similarity in rate in two studies by different groups of researchers suggest the difficulty can be overcome by stringent application of the best tools at hand to include a person in the group with CFS. As the methods of this study are meant to be used in future studies of CFS, to standardize the study populations among various researchers, it is of great importance that the authors fully explore the effect of the new methods, and alter the methods if shown to decrease specificity.

Computing the prevalence rate without those changes to the criteria may reveal substantial differences in the prevalence rate for this specific disease, and explain the apparent change in rate of CFS. Can this further analysis be conducted, before other papers are published? These data should prove to be a rich vein of valuable information on CFS and the people who suffer from it. Those papers will not be of much value on this shaky starting ground.

In short, I agree with the comments by Tom Kindlon, in calling for re-analysis of the rate based on these data, with changes to cling more rigidly to the published criteria. A ten-fold difference in prevalence is too large to ignore.

[1] Fukuda, K., Straus, S.E., Hickie, I., Sharpe, M.C., Dobbins, J.G., & Komaroff, A. (1994). The chronic fatigue syndrome: A comprehensive approach to its definition and study. *Annals of Internal Medicine*, 121 (12):953-959. <http://www.annals.org/cgi/content/full/121/12/953>

Competing interests

no competing interests

[top](#)

Questioning the use of the Role Emotional (RE) subscale of the SF-36 questionnaire in the diagnosis of CFS

Tom Kindlon (19 June 2007) Irish ME/CFS Support Group 

As background to the previous two comments, I thought I'd point out that if people would like to see what makes up the Role Emotional (RE) subscale of the SF-36, a copy of a sample SF-36 questionnaire can be seen at: <http://www.nhlbi.nih.gov/resources/deca/wave/w11.pdf> .

It is question 6 i.e. 3 questions with only yes or no as possible answers.

The cut off point used in the current study is less than or equal to a score of 66 [1], so two "yes" answers (out of the three questions) is the cut off point for functional impairment.

[Tom: 30th April, 2009: I know now it is actually only one "yes" answer]

Tom Kindlon

[1] Chronic Fatigue Syndrome – A clinically empirical approach to its definition and study.

William C Reeves, Dieter Wagner, Rosane Nisenbaum, James F Jones, Brian Gurbaxani, Laura Solomon, Dimitris A Papanicolaou, Elizabeth R Unger, Suzanne D Vernon and Christine Heim

BMC Medicine 2005, 3:19 doi:10.1186/1741-7015-3-19

<<http://www.biomedcentral.com/1741-7015/3/19>>

Competing interests

No competing interests

[top](#)

Whither Post-exertional Fatigue?

cort johnson (21 June 2007) CFS Phoenix 

The Empirical Definition has many positive aspects; better characterization of CFS patients, a way to track treatment efficacy and perhaps identify symptom based subsets and it does appear to identify a very ill population. But does it single out the peculiar condition called CFS. Some aspects of it suggest to me that it does not.

Some researchers have proposed that post-exertional fatigue is a hallmark symptom in CFS. The Canadian Consensus and 1990 Australian definition require post-exertional fatigue to be present for a CFS diagnosis. The Fukuda definition does not; although it is one of eight major symptoms it is not required for a CFS diagnosis. The empirical definition appears to dilute the importance of this symptom further. Some evidence produced by CDC studies and others, however, suggests it is a central component of CFS.

A CDC study examining the symptoms in a wide variety of fatigued groups (prolonged fatigue, chronic fatigue, CFS-like, CFS) found that as the levels of fatigue increased the percentage of people reporting 'unusual fatigue after exercise' did as well (Nisenbaum 2006). That only 1.6% of people with no fatigue reported this symptom indicated it is rarely found in healthy people. (Problems with sleep, muscle and joint pain on the other hand were fairly common (10-20% of healthy people)). About 14% of people with prolonged fatigue and 33% with chronic fatigue reported unusual fatigue after exercise but from there the percentages jumped up markedly; 77 and 74% of CFS-like and CFS patients reported this symptom. This suggests there is a big difference between chronic fatigue patients (fatigued but don't meet 1994 criteria for CFS) on the one hand and CFS-like (met the criteria but didn't undergo the clinical evaluation) and CFS patients (meet the criteria, visited the clinic) with regard to this symptom.

Similarly CDC studies exploring the question of subsets in CFS (Conna et. al. 2006, Aslakson et. al. 2006) found that post-exertional fatigue – was the first and third most important differentiating variable in the PCA and Latent Class Analyses. Its discriminatory prowess was highlighted by the fact that it and concentration difficulties were the only variables not found at all in the Well Group. The very high

levels of post exertional fatigue (78-91%) in the three classes dominated by CFS patients and the low to moderate levels of it (33-41%) in the classes dominated by idiopathic fatigue patients again indicated that this symptom plays a special role in CFS. CFS is often described as being an amalgam of very common symptoms but these studies indicate that post-exertional fatigue is only rarely found even a subset of the population one might expect it to; the BMI matched overweight, obese and even morbidly obese healthy controls in this study who presumably don't exercise much.

Since the 'chronic fatigue' group in the Nisenbaum was the largest fatigued group studied in the Nisenbaum study (PF=575, CF=1085, CFS-like=263, CFS=43) this group will surely account for most of the increase in the prevalence rates under the empirical definition. This indicates that most CFS patients under the empirical definition will not be characterized by 'unusual fatigue after exercise'. This is not in some ways surprising; Dr. White and Jason have pointed out patients can meet the new criteria for CFS simply by reporting they have low activity levels.

A Personal Response: For the first ten years after I got CFS I, who was formerly an avid exerciser, didn't try to do anything more than walk. My symptoms at that point, while very disturbing, were nevertheless mostly not that unusual overall; I was very tired, I couldn't concentrate well, my muscles hurt, I had constant sore throats, I felt out of it, I wasn't strong. Basically I felt like I was shadow of my former self but I was able to get around, I was able to go to school. It probably could have been argued that I had some strange mental condition. Given the lack of information on CFS around that time – mid-1980's, in the back of my mind I wondered if something like that had indeed occurred.

About 10 years into the disease I did something very unusual - I began an exercise program and have tried to do so several times since then. Each time my response was to it has been bizarre. The symptom exacerbation has been immense, not just at the beginning of the exercise program but throughout. Over time I was able to increase my strength and duration. In fact I usually felt good while I was exercising – but the aftermath was always devastating. Starting anywhere from ½ hour to several hours later I could feel that peculiar package of symptoms set in; the stiff, painful muscles, the heart yammering, the uncoordination, the need to lie down, the difficulty thinking or talking, the feelings of irritation. These symptoms would typically peak a day or so later and then slowly subside. It is an utterly strange response to exercise and it is the hallmark symptom of my CFS – it's what convinced me that there was a physiological basis to my problems.

The idea that this vital part of CFS is being subsumed under this new definition suggests that while researchers may uncover important aspects of unwellness by studying this population they may very well have a very difficult time understanding the condition known as CFS.

Aslakson, E., Wollmer-Connar, U. and P. White. 2006. The validity of heterogeneity in chronic unexplained fatigue. *Pharmacogenomics* 7, 365-373

Conna, U., Aslakson, E. and P. White. 2006. An empirical delineation of the heterogeneity of chronic unexplained fatigue in women. *Pharmacogenomics* 7, 355-364.

Jason, Leonard. 2007. Problems with the new CDC CFS Prevalence Estimates. IACFS Website.

White, P. 2007. How common is chronic fatigue syndrome; how long is a piece of string? Population Health Metrics 5:6 doi:10.1186/1478-7954-5-6

Competing interests

none

[top](#)

Many possibilities to consider for metropolitan, urban, and rural differences in sex ratio.

Claire C. (15 August 2007) N/A

One of the most interesting and potentially informative findings from this study is the finding that the gender ratio of CFS was strikingly different among metropolitan, urban, and rural populations.

The only suggestion that the authors make regarding this finding is that "The striking differences between female and male rates in the 3 strata may indicate risk effects of gender (a social construct) in distinction to sex (a biologic attribute)."

This is a very interesting suggestion, in light of all the research demonstrating that CFS is a physical disorder with biological markers. We should not fall under the line of thinking that medical observations whose causes are not yet explained are psychological or social constructs, or psychosomatic. This suggestion also assumes that gender constructs are different among metropolitan, urban, and rural populations.

There are many more obvious factors that are different among metropolitan, urban, and rural populations that should be investigated. Namely environmental factors including pollution, exposure to sunlight, microbes, and other things that may be different among metropolitan, urban, and rural populations.

There are many interesting studies which show that other illnesses such as multiple sclerosis have different prevalence rates by geography (latitude), and that asthma and allergies have different prevalence rates between urban and rural children. Could it be possible that the sexes have different levels of biological susceptibility to environmental triggers of some illnesses such as CFS?

Competing interests

None