

Tweets from 6th set of 100 posts in S4ME thread:
Michael Sharpe skewered by @JohntheJack on Twitter

MS retweeted this.



Indigophoton
Senior Member
(Voting Rights)

Messages: 674
Likes Received: 7,182
Location: UK



Henrik Vogt
@HenrikVogt

Why is it that, the context of #mecfs, one talks of "psychological" disorders, which can be devastating, as something one has to be "vindicated" from? Please explain @lucybannerman @thetimes. This language is stigmatising.
thetimes.co.uk/article/me-suf...

8:24 PM - May 26, 2018



ME sufferer who was dismissed as hysterical vindicated in de...
It took a death certificate for Merryn Crofts to be vindicated. For the last six years of her life she had fought to convince people that ME,
thetimes.co.uk

Various people have responded with impressively restrained explanations. I thought this one was a particularly good summary rebuttal for those who follow Sharpe and only know ME/CFS through his posts, to be exposed to (if they read the thread),



Dr. Homeslice @8Homeslice8

27 May

Replying to @HenrikVogt and 2 others

Nobody is trying to stigmatise or belittle psychological disorders. But telling someone dying of a neuroimmune disease that they are hysterical and that it is all in their mind is extremely damaging. It prevents people like Merryn receiving adequate biomedical treatment.



Dr. Homeslice

@8Homeslice8



Psychological disorders are very serious and merit appropriate treatment and acknowledgment in their own right. ME is not a psychological disorder. There is enough biomedical research evidence of that. It needs to be acknowledged as such and merits biomedical treatment.

4:33 PM - May 27, 2018



44



See Dr. Homeslice's other Tweets



Dr. Homeslice @8Homeslice8

27 May

Replying to @8Homeslice8 and 3 others

That is not to say that psychological or biological illnesses are mutually exclusive not that one is more legitimate than the other. The point is that ME has underlying physical causes and disease processes and these need to be properly acknowledged and treated appropriately.



Dr. Homeslice

@8Homeslice8



CBT and GET are simply not enough as they don't address the underlying physiological pathology. CBT might be helpful where anxiety is exacerbating symptoms for example. But that's a treatment for the anxiety, not for the ME itself. ME is not caused by false illness beliefs.

4:41 PM - May 27, 2018



34



See Dr. Homeslice's other Tweets



[View Dr. Homeslice's profile on Twitter](#)



Dr. Homeslice @8Homeslice8

27 May

Replying to @8Homeslice8 and 3 others

It's the same as how cancer patients are likely to need counselling. But that doesn't treat their cancer. They still need surgery, radiotherapy, chemotht etc.for that. It would be very harmful to tell them they are hysterical or having false illness beliefs.



Dr. Homeslice
@8Homeslice8



Like cancer, ME also has an underlying pathophysiology. This is what researchers at Stanford, Harvard, LSHTM and in Australia and many other institutions are finding. Patients are simply trying to put to bed the outdated theory that ME is psychosomatic.

4:47 PM - May 27, 2018

♡ 32 👤 See Dr. Homeslice's other Tweets



Dr. Homeslice @8Homeslice8

27 May

Replying to @8Homeslice8 and 3 others

Like cancer, ME also has an underlying pathophysiology. This is what researchers at Stanford, Harvard, LSHTM and in Australia and many other institutions are finding. Patients are simply trying to put to bed the outdated theory that ME is psychosomatic.



Dr. Homeslice
@8Homeslice8



Nobody is trying to undermine psychological illness or psychiatry. It's just not the appropriate approach to treating ME. It could help with the psychological impact of the illness and ant psychological exacerbating factors. But not the illness itself. Does that explain it?

4:51 PM - May 27, 2018

♡ 41 👤 See Dr. Homeslice's other Tweets





Joar Øveraas Halvorsen @joarhalvorsen

24 Mar

Replying to @profmsharpe

Thank you for your response, Michael. Could you be more specific as to why the reanalysis is misleading? Given the significance - and controversy - of the #PACEtrial, wouldn't it be an idea to release the data for independent reanalysis?



michael sharpe

@profmsharpe



Thanks I am afraid that would be a very long tweet! Please read the actual papers - the trial paper and the published analysis plan as well as the 'reanalysis'. qmul.ac.uk/wolfson/resear... And google all the reanalysis authors to see how objective they are.

10:08 AM - Mar 26, 2018



4



See michael sharpe's other Tweets



Indigophoton

Senior Member
(Voting Rights)

Messages: 674

Likes Received: 7,183

Location: UK

Referring to PACE,



Gabby Klein @GabbyKlein1

25 Apr

Replying to @profmsharpe and 2 others

So, you are stating that PACE was a study on #CFS, not #MyalgicEncephalomyelitis? #CFS being the fatigue syndrome as opposed to #ME the acquired neuroimmune disease?



analogue

@analoguefade



They claim it was both given that they applied both Oxford CFS and modified London ME criteria. They claim the results apply to both, but only if fatigue is the main symptom. Fatigue of course is not a main symptom of ME. pic.twitter.com/cB2uKfqLbu

1:02 AM - Apr 26, 2018

Our findings were strengthened by the small numbers of dropouts, high rates of acceptance of the treatments, use of manual-defined treatments provided by competent clinicians, high rates of participant satisfaction, adherence to manuals, and therapeutic alliance. The PACE findings can be generalised to patients who also meet alternative diagnostic criteria for chronic fatigue syndrome¹² and myalgic encephalomyelitis¹³ but only if fatigue is their main symptom.¹¹



21



See analogue's other Tweets





michael sharpe @profmsharpe

26 Apr

Replying to @analoguefade and 3 others

That is right - all participants met criteria for CFS and a subset also for (one set of) criteria for ME. All had to have fatigue as the principal complaint. I hope clear in the paper.



Kelly Morris

@KellyMorris1969



I'm confused! A subset of ME patients but their principal complaint was fatigue. If the principal complaint is fatigue, a patient gets a diagnosis of CFS? So the patients were misdiagnosed ME? But were labelled a subset of CFS as they met ME criteria also?

8:35 AM - Apr 28, 2018



See Kelly Morris's other Tweets



Kelly Morris @KellyMorris1969

28 Apr

Replying to @profmsharpe and 4 others

I'm confused! A subset of ME patients but their principal complaint was fatigue. If the principal complaint is fatigue, a patient gets a diagnosis of CFS? So the patients were misdiagnosed ME? But were labelled a subset of CFS as they met ME criteria also?



michael sharpe

@profmsharpe



You are right. A limitation.

9:11 PM - May 27, 2018



See michael sharpe's other Tweets



If I'm reading this correctly, MS is now stating that the PACE patients did not have ME, but were misdiagnosed - some just happened to meet one set of ME criteria as well as having chronic fatigue.

Indigophoton, May 28, 2018 [Report](#) [Bookmark](#)

#559 [Like](#) [+ Multiquote](#) [Reply](#)

JohSenior Member
(Voting Rights)

Messages: 544

Likes Received: 3,905

Location: Germany

German. He wasn't tagged and reacted on the same day, so he apparently searches twitter for the hashtag #pacetrial. Makes him look a little desperate.

**MillionsMissing Deutschland** @MMissingGermany

28 May

»Sobald alle Fakten der #PaceTrial Studie bekannt sind, wird diese sich als einer der größten Medizinskandale des 21. Jh. herausstellen.«bit.ly/2qJUwOj #ME #MEcfs #MillionsMissing @jensspahn @DHAEV_Sprecher @BMG_Bund @BAEKaktuell @BMBF_Bund @rki_de @LutzStroppe pic.twitter.com/M5wlr1PL0V

**michael sharpe**

@profmsharpe



Really ? Have you read the paper? or just copying with others have said?
kind regards

8:10 AM - May 29, 2018



See michael sharpe's other Tweets



Joh, May 29, 2018 Report Bookmark

#572 Like + Multiquote Reply



Indigophoton
Senior Member
(Voting Rights)

Messages: 674
Likes Received: 7,183
Location: UK

Sharpe follows an account called CFS research, which claims to belong to a recovered patient whose tweets are very pro CBT, GET, and PACE. Happily, that means that MS saw this tweet from physicist Sten Helmfrid,



GET has no rationale—never did have. It is purely a manifestation of the familiar problem for the onlooker of being faced with someone disabled—needing to have it 'put right', regardless of whether or not it helps the person who is disabled.



Sten Helmfrid
@StenHelmfrid
Sten Helmfrid



Comment by Jonathan Edwards, Emeritus Professor of Connective Tissue Medicine at University College London, on graded exercise therapy (GET) for #MECFS.

10:24 AM - May 29, 2018

♡ 142 💬 85 people are talking about this

Indigophoton, May 29, 2018 Report Bookmark #574 Like + Multiquote Reply



Indigophoton
Senior Member
(Voting Rights)

Messages: 674
Likes Received: 7,183
Location: UK

Looks like it:



Rosybel Drury @Rosybel69

29 May

Esther Crawley talking in #ESPID2018 about the strength of societies and the voices from groups, to be supported and be able to raise your voice and defend science and true facts.



Animal
@Animal783



Esther Crawley from Bristol? She falsely claimed her SMILE trial was prospectively registered on ISRCTN, misrepresented results from notorious #PACEtrial, and TEDx made her talk 'unlisted' on youtube after her misrepresentations were pointed out. #ESPID2018

5:59 PM - May 29, 2018

♡ 3 👤 See Animal's other Tweets





michael sharpe @profmsharpe

29 May

Replying to @Animal783 @Rosybel69

Nice to see notorious instead of discredited. We all need variety. How about well conducted- but a bit boring?



Animal

@Animal783



Certainly not boring. The failure to correct errors and the fight against releasing results for protocol outcomes are serious black marks, even ignoring other problems. Did you get TSC approval for recovery deviation? It's worrying that so far you've not said.

7:33 PM - May 29, 2018



2



See Animal's other Tweets



Animal @Animal783

29 May

Replying to @profmsharpe @Rosybel69

Certainly not boring. The failure to correct errors and the fight against releasing results for protocol outcomes are serious black marks, even ignoring other problems. Did you get TSC approval for recovery deviation? It's worrying that so far you've not said.



michael sharpe

@profmsharpe



Do you really think the difference between treatments found in the trial is not real ?

7:37 PM - May 29, 2018



0



See michael sharpe's other Tweets





Animal @Animal783

29 May

Replying to @profmsharpe @Rosybel69

Certainly not boring. The failure to correct errors and the fight against releasing results for protocol outcomes are serious black marks, even ignoring other problems. Did you get TSC approval for recovery deviation? It's worrying that so far you've not said.



michael sharpe

@profmsharpe



That is the real point. Not hundreds of loaded questions about details of scales and approvals. Please look at the graphs in the main paper and let me know. Thanks.

7:39 PM - May 29, 2018



See michael sharpe's other Tweets



Never mind the ethics and the details of the measures used - our figures look good to us, do you like the ~~pictures~~ graphs too? 🍌

Indigophoton, May 29, 2018 [Report](#) [Bookmark](#)

#583 [Like](#) [+ Multiquote](#) [Reply](#)

TiredSam

Moderator

Staff Member

Messages: 3,512

Likes Received: 15,646



michael sharpe

@profmsharpe

Folgen

Antwort an @MMissingGermany @jensspahn und 6 weitere

Really ? Have you read the paper? or just copying with others have said?
kind regards

00:10 - 29. Mai 2018



1



MillionsMissing Deutschland @MMissingGermany · 8 Std.

Antwort an @profmsharpe @jensspahn und 6 weitere

Yes, we did & one of our member is a scientist.

Yes, we've copied a quote "I think that when the full details of the trial become known, it will be considered one of the biggest medical scandals of the 21st century"@CMonaghanSNP

Some of our members are bedridden, cause of GET.



1



kd @Kdcfsme · 3 Std.

Unfortunately @CMonaghanSNP seems to be under some misapprehensions about the PACE trial and that quote and her speech is a reflection of her lack of grasp of the issues rather than a statement of reality, although she may be well-intentioned in trying to help people with CFS/ME



1



1



michael sharpe @profmsharpe · 2 Std.

A bit disappointing for a science teacher in my view. I was lucky enough to have some great science teachers.



Henrik Vogt
@HenrikVogt



Amazingly @BBCHealth uncritically blurbs this analysis from a - for some reason - extremely biased group hellbent on proving #mecfs is not "psychological" as the truth about the #PACEtrial. This is patient activism in guise of scholarshipbbc.com/news/health-43... @KristianGunder

9:37 PM - Mar 23, 2018



Chronic fatigue trial results 'not robust'

A new analysis of the controversial PACE trial suggests the effects of exercise therapy have been exaggerated.

bbc.com

♡ 3 💬 27 people are talking about this

