

Nancy Blake's Letter to Koroshetz: publicly posted on Facebook

Nancy Blake

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For better or worse...worse, probably, I haven't made much attempt to be tactful...my letter to Koroshetz:

Dear Dr. Koroshetz

The NIH has recently professed to have a serious commitment to developing research into ME/CFS.

As I understand it, your institute is meant to be developing a consortium of interested researchers across the NIH to get funding for medical research into this disease.

Promises made by Dr. Collins to begin to take this matter seriously have been followed by a cut in the limited funding previously available, and in a year in which a trillion dollars have been spent on RFA's, no money has been made available for ME/CFS.

The NIH spent a million dollars funding the IOM report, which stated unequivocally that ME/CFS is mistakenly considered a psychiatric issue, and that it is a serious, very disabling disease (not a psychiatric disorder) of which the defining feature is that 'exertion, of any kind.....may adversely affect many organ systems'.

The psychiatric model promoted in the UK holds that patients, after a mild viral illness, develop the 'false belief' that they suffer from a medical disease, and that exertion will make them worse. Based on this model, patients are offered Cognitive Behaviour Therapy, with the specific purpose of changing the belief that they have a disease, and Graded Exercise Therapy, providing systematic increase in physical exertion. (However, even the instructions in the UK NICE Guidelines acknowledge that during the course of such a program, the patient may suffer a relapse after which they are unable to return to their previous level of function.)

The 2011 Pace Trial purported to support that these treatments were both 'safe' and 'effective'. However recent statistical analyses have shown that claims made were exaggerated, and over the long term these treatments had no different outcome from the others in the trial.

In contrast to the psychiatric model, the IOM Committee asserts that in fact we do have a serious medical disease, in which exertion can do multisystem damage.

Patient experience confirms that many who were mildly or moderately ill became severely and apparently irreversibly ill after conscientiously following a course of Graded Exercise Therapy. This would tend to support the view of many researchers that the pathogen involved is a virus, possibly similar to the polio virus, which is latent until stimulated by exertion. (The involvement of Coxsackie B was apparently dismissed because lots of us have antibodies to Coxsackie B. Lots of people also were infected with the polio virus; few got ill with a mild flu-like illness, and fewer of them...mostly the ones who exercised...went on to become paralysed. Intermittent paralyses are a common feature of

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ME, especially severe ME. But of course all of this is only based on small laboratory studies and patient experience and therefore doesn't constitute 'evidence'.)

Early researchers concluded that complete rest from the inception gave the best prognosis, and as they stated that the disease had 'an alarming tendency to become chronic', that suggests that under their treatment regime, there were patients in whom this did not occur. Today, with contemporary treatment regimes, it has become accepted that no one recovers completely, and many believe it inevitably follows a worsening path.

It has never been clear why a illness in which it is universally accepted that 'exertion exacerbates symptoms' has ever been considered one in which exercise was going to be a helpful prescription, and it is not. We don't advise diabetics to practice eating sugar, lung cancer patients to develop better tolerance to smoking, or people with life threatening allergies to practice exposing themselves to more of the allergen.

What is clear is that there is enormous cultural, medical, economic and political resistance to the idea that this disease is anything other than a fiction; a creation of the patient's imagination, a play for 'secondary gain', a feminine neurotic manifestation, or, the latest philosophical fad, a 'cultural construct'.

Adhering to this form of dismissal is undoubtedly considered a great economic benefit by medical insurers and government agencies concerned with payment of disability benefits.

All that is necessary to maintain this stance is to assume that healthy, successful, happy individuals can become completely disabled within a few days, without having suffered any particular trauma, by a psychiatric condition. Ignore the evidence that these 'lazy' people struggle to keep up their normal activities when too ill to do so, until they become completely incapacitated. Ignore that fact that there is no cohort of patients, anywhere, who have actually recovered as a result of CBT/GET. Ignore the thousands of research papers indicating measurable physiological changes. Ignore the results of your own IOM report.

It also requires ignoring the possibility that all these people who are at best economically inactive and at worst very expensive in terms of medical insurance payments might, if the proper research was funded and an effective treatment found, start being contributing workers and tax payers again...which is what they themselves want.

As a money-saving exercise, i think that pretending that it is not a medical disease, offering treatments that make us worse, and denying funding for proper medical research is likely to have been a catastrophic failure. However you may like to pretend it is a 'social construct', and blame the patients, the fact is that this disease continues to be expensive both to the patients themselves, their medical insurers, and the state, in terms of lost taxes. 'Social construct' theories do not offer any

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solution to this situation, as forcing patients into extreme poverty doesn't cure them, and only kills them slowly, in most cases.

You, and Collins, claim to be newly dedicated to the cause of research funding for ME/CFS. So you propose to offer an instructional session about ME/CFS to your agency, the ones that you are persuading to get interested in supporting ME/CFS research, presented by a man who will set out in persuasive detail the that this disease is a 'social construct', therefore doesn't actually exist.

It seems that despite saying the opposite, you are working effectively to convince the audience that actually, medical research into ME/CFS is a complete waste of time...even a patently ridiculous waste of time. I suggest that if this move doesn't effectively kill ay interest whatever in supporting medical research, you have Professor Sir Simon Wessely as your next speaker--according to a journalist who attended one of his talks to medical insurance representatives, his imitations of ME/CFS patients had them rolling in the aisles.

Yours very sincerely

Nancy Blake

I'm going to bed, now.

Sent from my iPad