Guildford ME/CFS Support Group
(& West Surrey)

Newsletter

March 2015

Future dates

The following ME meetings are open to all members and carers.

9th April 2015 (Thursday) 7.30pm The Weyside
Millbrook, Guildford, Surrey, GU1 3XJ
www.theweyside.co.uk
Over the last few years the Weyside was called the Boatman.

11th May 2015 (Monday) 11.15am The Seahorse
The Street, Shalford, Guildford, GU4 8BU
www.theseahorseguildford.co.uk

10th June 2015 (Wednesday) 7.30pm The Weyside
Millbrook, Guildford, Surrey, GU1 3XJ
www.theweyside.co.uk
Over the last few years the Weyside was called the Boatman.

Sizzling Minerals ordering information

In our last newsletter (December) we included information about trace minerals including "Sizzling Minerals".

Further information, however, may have been required for ordering Sizzling Minerals online.

Specifically, the website link for ordering should have been: www.plantminerals.eu

Further, should a distributor code be needed, the following code should be used: 111230

Major study suggests ME/CFS is hit and run disorder

Partial source: www.prohealth.com/me-cfs/library/showarticle.cfm?libid=19607
Partial source: www.cortjohnson.org/blog/2015/02/27/clock-ticking-chronic-fatigue-syndrome-hit-run-disorder

Like many thousands before it, a recent ME/CFS study offers insight into the biological reality of ME/CFS. However, this study was of such significance and scale that it broke-through even to the media.

I've used two sources. All of the first source. Which is then followed by quotes and the conclusion of the second source.

Newsletter Editor

NEW YORK (Feb. 27, 2015) — Researchers at the Centre for Infection and Immunity at 'Columbia University's Mailman School of Public Health' identified distinct immune changes in patients diagnosed with chronic fatigue syndrome, known medically as myalgic encephalomyelitis (ME/CFS) or systemic exertion intolerance disease. The findings could help improve diagnosis and identify treatment options for the disabling disorder, in which symptoms range from extreme fatigue and difficulty concentrating to headaches and muscle pain.

These immune signatures represent the first robust physical evidence that ME/CFS is a biological illness as opposed to a psychological disorder, and the first evidence that the disease has distinct stages. Results appear online in the new American Association for the Advancement of Science journal, *Science Advances*.

With funding to support studies of immune and infectious mechanisms of disease from the Chronic Fatigue Initiative of the Hutchins Family Foundation, the researchers used immunoassay testing methods to determine the levels of 51 immune biomarkers in blood plasma samples collected through two multicentre studies that represented a total of 298 ME/CFS patients and 348 healthy controls. They found specific patterns in patients who had the disease three years or less that were not present in controls or in patients who had the disease for more than three years. Short duration patients had increased amounts of many different types of immune molecules called cytokines. The association was unusually strong with a cytokine called interferon gamma that has been linked to the fatigue that follows many viral infections, including Epstein-Barr virus (the cause of infectious mononucleosis). Cytokine levels were not explained by symptom severity.

"We now have evidence confirming what millions of people with this disease already know, that ME/CFS isn't psychological," states lead author Mady Hornig, MD, director of translational research at the Centre for Infection and Immunity and associate professor of Epidemiology at Columbia's Mailman School. "Our results should accelerate the process of establishing the diagnosis after individuals first fall ill as well as discovery of new treatment strategies focusing on these early blood markers."

There are already human monoclonal antibodies on the market that can dampen levels of a cytokine called interleukin-17A that is among those the study shows were elevated in early-stage patients. Before any drugs can be tested in a clinical trial, Dr. Hornig and colleagues hope to replicate the current, cross-sectional results in a longitudinal study that follows patients for a year to see how cytokine levels, including interleukin-17A, differ within individual patients over time, depending on how long they have had the disease.

Stuck in high gear
The study supports the idea that ME/CFS may reflect an infectious "hit-and-run" event. Patients often report getting sick, sometimes from something as common as infectious mononucleosis (Epstein-Barr virus), and never fully recover. The new research suggests that these infections throw a wrench in the immune system's ability to quiet itself after the acute infection, to return to a homeostatic balance; the immune response becomes like a car stuck in high gear. "It appears that ME/CFS patients are flush with cytokines until around the three-year mark, at which point the immune system shows evidence of exhaustion and cytokine levels drop," says Dr. Hornig. "Early diagnosis may provide unique opportunities for treatment that likely differ from those that would be appropriate in later phases of the illness."

The investigators went to great lengths to carefully screen participants to make sure they had the disease. The researchers also recruited greater numbers of patients whose diagnosis was of relatively recent onset. Patients' stress levels were standardised; before each blood draw, patients were asked to complete standardised paperwork, in part to engender fatigue. The scientists also controlled for factors known to affect the immune system, including the time of day, season and geographic location where the samples were taken, as well as age, sex and ethnicity/race.

In 2012, W. Ian Lipkin, MD, director of the 'Center for Infection and Immunity', and colleagues reported the results of a multicentre study that definitively ruled out two viruses thought to be implicated in ME/CFS: XMRV (xenotropic murine leukemia virus [MLV]-related virus) and murine retrovirus-like sequences (designated pMLV: polytropic MLV). In the coming weeks, Drs. Hornig and Lipkin expect to report the results of a second study of cerebrospinal fluid from ME/CFS patients. In separate ongoing studies, they are looking for "molecular footprints" of the specific agents behind the disease—be they viral, bacterial, or fungal—as well as the longitudinal look at how plasma cytokine patterns change within ME/CFS patients and controls across a one-year period, as noted above.

"This study delivers what has eluded us for so long: unequivocal evidence of immunological dysfunction in ME/CFS and diagnostic biomarkers for disease," says senior author W. Ian Lipkin, MD, also the John Snow Professor of Epidemiology at Columbia's Mailman School. "The question we are trying to address in a parallel microbiome project is what triggers this dysfunction."

The following quotes and conclusion are taken from the second source for this newsletter article and is by Cort Johnson 27th February 2015. For a more in-depth technical understanding, please refer to the source article itself.

Newsletter Editor

> "This study delivers what has eluded us for so long: unequivocal evidence of immunological dysfunction in ME/CFS and diagnostic biomarkers for disease"
>
> W. Ian Lipkin

> "These immune signatures represent the first robust physical evidence that ME/CFS is a biological illness as opposed to a psychological disorder, and the first evidence that the disease has distinct stages."
>
> Columbia University Press Release

> "The immunopathology of ME/CFS is not static"
>
> the authors

> “We propose that IFN-y mediated lesions in kynurenine metabolism may culminate in the depression and psychomotor tardiness (slowed information processing) that contribute to disability in some patients with ME/CFS”.
>
> Hornig and Lipkin et. al

> “It appears that ME/CFS patients are flush with cytokines until around the three-year mark, at which point the immune system shows evidence of exhaustion and cytokine levels drop.”
>
> Dr. Hornig

Conclusion

> “We now have evidence confirming what millions of people with this disease already know, that ME/CFS isn’t psychological,”
>
> Mady Hornig, MD

This large study presents what appears to be almost novel finding in medicine: distinct before and after stages early in a chronic illness. In the early stages of ME/CFS (first 3 years) a distinct and impressive immune activation is present that is followed by modest immune deactivation.

The early immune activation is highly suggested of an infection or some other immune altering process.

The study may ultimately open up possibilities for treating patients with recent onset but provides no possible treatment options at this point for patients who have been sick longer. The more modest immune deactivation found later in the disease suggests that the core causes of the disease are either found elsewhere or were not illuminated by the study.

A major question facing researchers now is finding ways to translate this hit and run immune activation or viral infection into long lasting central nervous system problems. Microglia sensitised by chronic immune activation/kynurenine pathway activity is one possible answer.

Ian Lipkin’s statement that they hope to find important answers in their microbiome study suggests he believes a permanently altered microbiome could provide an answer to that question.

> “The question we are trying to address in a parallel microbiome project is what triggers this dysfunction.”
>
> Ian Lipkin

The authors statement that cerebral spinal fluid may provide a better medium for understanding this disease could mean we’re in for some interesting findings in a couple of weeks.

Further reading/alternative articles
http://phoenixrising.me/archives/26509
http://advances.sciencemag.org/content/advances/1/1/e1400121.full.pdf

Surprisingly good outcomes for people who get ME/CFS after Mononucleosis (Glandular Fever)

Source: http://phoenixrising.me/archives/26311
By Simon McGrath 20th January 2015

Sometimes ME/CFS emerges after mononucleosis, or glandular fever. Simon McGrath shares results from a long-term follow-up study from Haukeland University Hospital in Norway …

"When will this end?" It's a question that most ME/CFS patients have probably asked themselves and their doctor many times. I certainly have.

Yet there is astonishingly little hard data on recovery rates from this illness or on how much patients improve, and the evidence there is doesn't give too much hope.

Step forward a long-term follow-up study that shows unexpectedly good rates of improvement for younger people who developed ME/CFS after infectious mononucleosis (glandular fever) – though the results are hardly spectacular.

Around 11 years on from getting sick, just over half of all ME/CFS patients were able to work part or full-time, though fatigue levels remained high:

http://bmjopen.bmj.com/content/4/11/e005798.long

The study was led by Dr Morten Nyland and comes from the Neurology department of Haukeland University Hospital in Norway, site of the famed Rituximab pilot study. In fact two of the authors of this new paper were part of that pilot study.

And although this wasn't a trial, patients were encouraged to use self-management (pacing/activity management), and the authors concluded that this probably contributed to the relatively good outcomes.

How the study worked (important)
An ideal study would take a bunch of patients and follow them at consistent time points, say the start of the illness, and then five and 10 years later. In this case, though, researchers made the most of pre-existing data to access a large group of patients who were followed up at very different times in their illness, an approach using two contact points that still yields invaluable results.

"Contact 1" was the first time the patient was seen by the specialist ME/CFS clinic at Haukeland University Hospital, any time between 1996 and 2006.

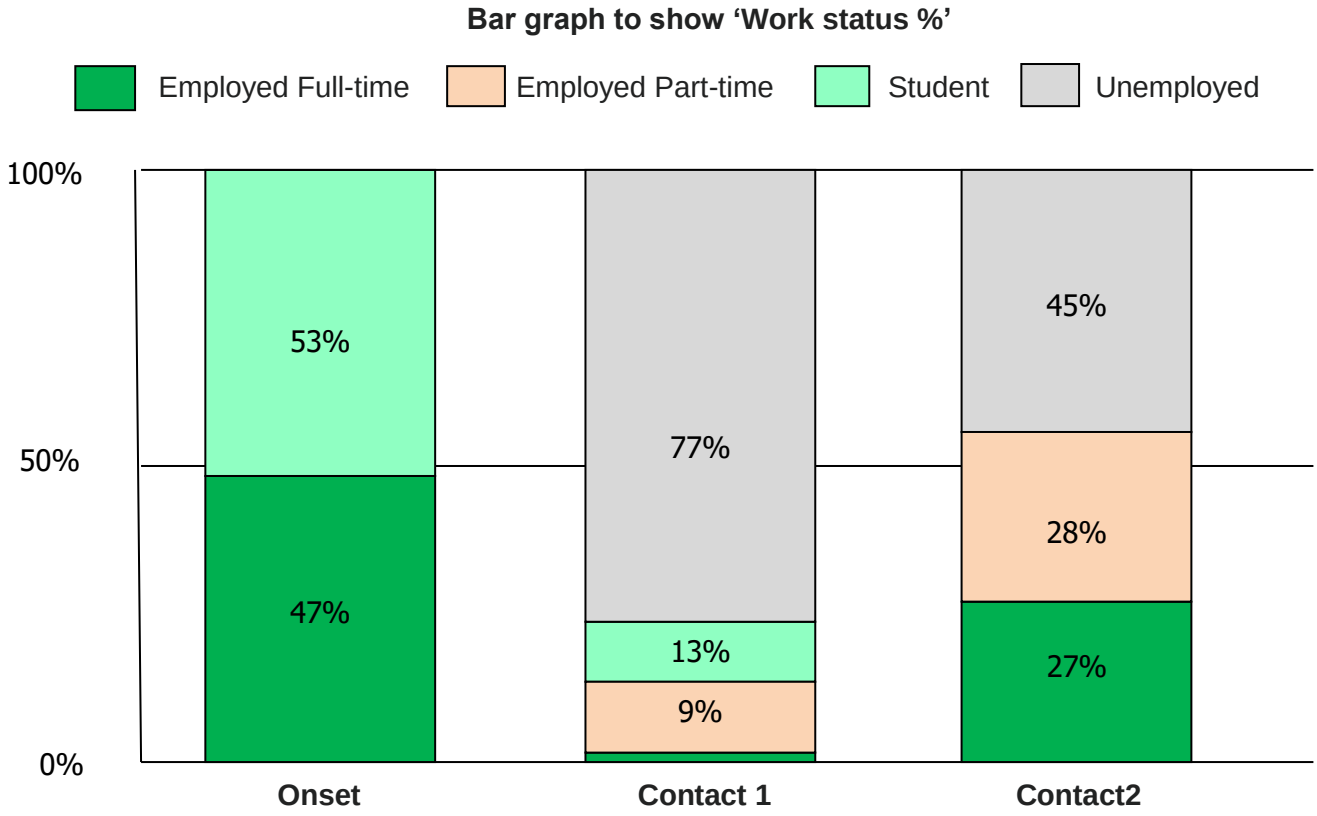
"Contact 2" was a follow-up questionnaire sent to all patients in 2009, an average of 6.5 years later. There was huge variation in follow-up time between patients, for example at the second and final contact in 2009 one patient had been ill for 24 years and another only five years. The study had data at both contact points for 92 patients, making this one of the largest follow-up studies going.

At the initial contact, patients had been ill for an average of nearly five years, and again that hides a lot of variation. Half had been ill for 3.2 years or less, a quarter for under two years. The higher average was because some had been ill for a very long time. The patients were also relatively young (the average age was 24 years), reflecting the age profile of infectious mononucleosis, the 'kissing disease', which particularly affects young adults and teens.

Over half of all patients were employed at final contact
Pleasingly, the study used employment status as the clear-cut, objective primary outcome — and arguably the ability to earn a living is the outcome that matters most to patients. The graph below shows a lot of improvement between first and second contact, with an average gap of six years, though the gap will vary a lot between patients.

Unemployment is in red while employment (full-time or part-time) or being a student is in green. Onset is when they got ill, Contact 1 is typically five years later, and Contact 2 typically another six years on.

Clearly things have improved for many patients, but the overall situation at Contact 2 remains a great deal worse than onset.

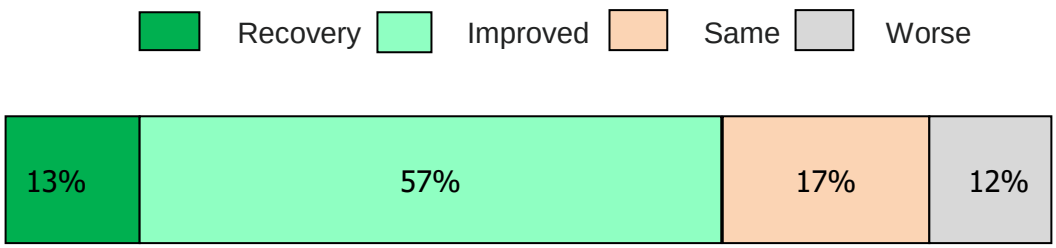


Note that half of those employed at Contact 2 were working full-time, compared with only 1 in 10 at Contact 1, so presumably there has been an increase in hours worked per person, as well as more people working.

Caution: It's possible that 11 years from onset (age 35 vs. age 24 at onset) some people would not be working anyway due to raising families so unemployment might not be zero even for a healthy group. And employment at onset wasn't split into full-time/part-time.

How patients said their overall health had changed
The study also asked patients how their overall health had changed since Contact 1 (their first visit to the clinic). Most patients said they had improved, 12% reported they had got worse.

Self-rated change after average of 6 years



Fatigue was also rated at both Contact 1 and Contact 2 using the Fatigue Severity Scale which gives an average score ranging from 1.0 (no fatigue) to 7.0 (maximum fatigue); any score of 5.0 or higher counts as severe fatigue. The average score at Contact 1 was 6.4, falling to 5.0 at Contact 2 — so even after this improvement the group as a whole was right on the threshold of severe fatigue.

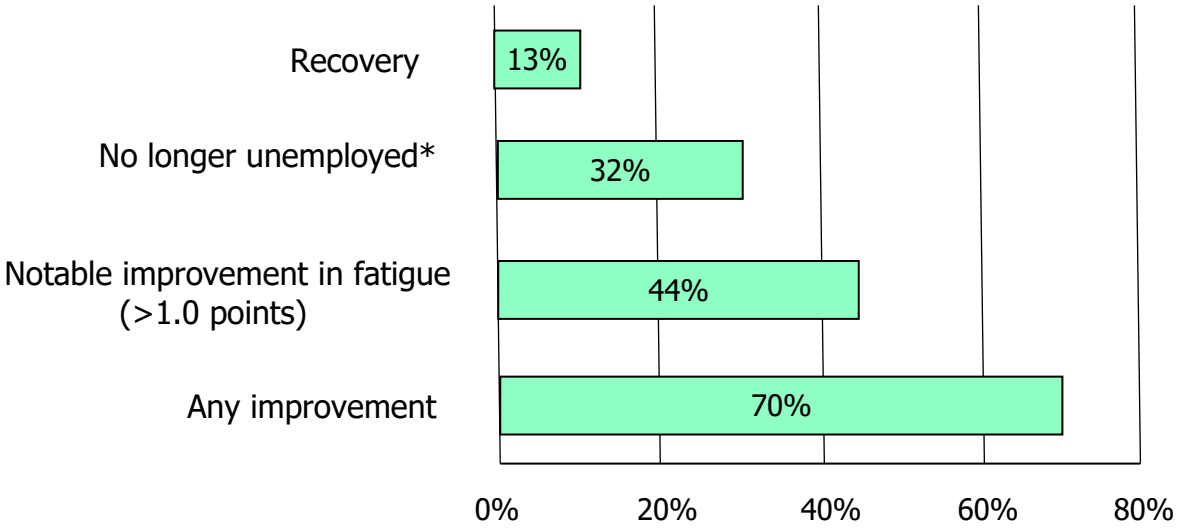
Different degrees of improvement

The study measured 'improvement' in several different ways. As well as change in employment status, they looked at self-rated improvement (including an option of 'recovered') and change in fatigue scores.

You can see that 'improvement' ranged from 70% reporting any improvement, to 32% moving into employment, and 13% who rated themselves as recovered.

Percentage of patients improving at Contact 2 (six years on)

*Primary outcome. All others self-rated



Most people improved, even those who hadn't improved at Contact 1.

Another encouraging point was that of the 26 people who said they had already improved at Contact 1, 25 improved again by Contact 2. And of the 38 who reported they hadn't improved before, 25 (66%) improved by Contact 2.

Fatigue improved much less than employment status

One slightly strange finding, which the authors didn't comment on, is that average fatigue levels fall rather modestly compared with the percentage improving in employment status. While 32% of patients were able to start working, fatigue scores only fell from 6.4 to 5.0.

It seems likely that this in part is down to people getting back to work but still struggling, so that their level of fatigue doesn't improve as much as it might.

Interestingly, although 28% were working full-time only 13% rated themselves as 'recovered', which supports the view that some people are improving and choosing to work full-time despite not being completely well, and may still be struggling quite a lot.

What 'predicts' return to work/improvement over time? (not a lot)
Overall, this important new study shows that outcomes for younger people who develop ME/CFS after mono are not great, but are probably better than expected. Around half were in work 11 years after onset, though fatigue remains high for most.

What might be driving this improvement? The authors ran some fancy analysis to see what features (such as symptoms and age) predicted being in employment or an improved fatigue score at the final contact. It turned out that only lower joint pain at Contact 1 was associated with later employment, but the effect was small.

Similarly, low joint pain and depression at Contact 1, and better education, were predictors of less fatigue at Contact 2 — but again the effect was small.

Surprisingly, length of illness was not an important predictor of employment or fatigue. Generally those with shorter illnesses are seen as having a better chance of recovery, but that doesn't appear to have been the case here.

It's possible that outcomes for ME/CFS after mono are better than after other triggers. I'll give the last word to the authors themselves, who suggest that both pacing/activity management and financial support through sickness benefits were likely to have played an important role to improvements:

"Self-management strategies, long-term sickness absence benefits providing a stable financial support, in addition to occupational interventions aimed at return to work were likely contributors to the generally positive, prolonged outcome."

US Neuroscientist says exercise is a noxious stimulus that worsens symptoms of ME/CFS

Source: http://theargusreport.com/us-neuroscientist-says-exercise-is-a-noxious-stimulus-that-worsens-symptoms-of-mecfs

By Penny Swift 18th January 2015

A highly regarded American neuroscientist who has researched CFS for more than a decade, has decried media reports based on The Lancet Psychiatry's recent scientific article that claims graded exercise therapy (GET) is an effective treatment for Chronic Fatigue Syndrome (CFS).

The Lancet Psychiatry report, published earlier this week, is the sixth based on the now dated PACE Trials that have been widely discredited by the international ME/CFS community.

Prof. J. Mark VanNess from the Californian University of the Pacific, referred specifically to The Lancet Psychiatry report's claim that CFS patients have "fear avoidance beliefs" when it comes to exercise, and that this plays a role in "perpetuating fatigue and disability" in CFS.

In a letter published online in the popular Myalgic Encephalomyelitis blog, Just ME yesterday, Prof. VanNess said he was "saddened" by press reports that had appeared in leading newspapers including The Guardian, The Independent, the BBC, the Mail Online, The Telegraph, and The Irish Independent. "It seems to me they've once again missed important nuances of the disease."

Prof. VanNess, who received his neuroscience doctorate from Florida State University in 1997, teaches biology, nutrition and exercise science at Pacific University. He is also committed to research on "the role of the autonomic nervous system in immune dysfunction," and is particularly interested in "post-exertional malaise in women with CFS."

Most people with ME/CFS avoid exercise

Most patients suffering from symptoms of ME/CFS avoid exercise, as Prof. VanNess points out in his letter that is addressed to Joan McParland, founder and coordinator of the Irish-based Newry and Mourne ME Fibromyalgia Support Group. But unlike the authors of The Lancet Psychiatry's latest PACE article, he states that fear and avoidance of exercise is "an understandable response in ME/CFS." They are afraid of exercise because they know that it will worsen their symptoms.

> "Our studies clearly show that dynamic exercise like walking or jogging exacerbates symptoms associated with ME/CFS".
>
> Dr. J. Mark VanNess

Not only is fear and avoidance of exercise "a natural defence mechanism against a harmful stimulus," but US researchers use graded aerobic exercise to amplify and worsen the symptoms of ME/CFS, says Prof. VanNess. This is not done as a treatment that will be beneficial to patients, but rather as a therapeutic intervention that is intended to "improve quality of life for ME/CFS patients." The therapy is very specific and focuses mainly on "strengthening muscles and improving range of motion."

> "We even provide tools like heart rate monitors to help patients avoid significant aerobic exertion," he says.

As Prof. VanNess explains, fear of exercise and exertion is more than just an understandable response for those with ME/CFS. It is "a reasonable, knowledgeable, and learned response to a noxious stimulus. If ME/CFS patients could exercise away their symptoms they most certainly would, regardless of the pain. But that is not the case."

Knowing that aerobic exercise will worsen the pathologies of ME/CFS, the exercise physiologists he works with focus rather on utilising "intact metabolic pathways with strength training and recumbent stretching (that help alleviate symptoms). These exercise recommendations are consistent with our understanding of ME/CFS pathology."

> "We would all hope that ME/CFS was viewed with attention given to immunological, metabolic, cardiovascular and neuroendocrinological dysfunction that has been demonstrated with previous research."
>
> Dr. J. Mark VanNess

This is the saddest part, because there is valid research that tells the story of ME/CFS the way it really is – but mainstream media does not appear to be listening.

Prof. J Mark VanNess and exercise

Exercise physiology is all about how the body responds and adapts to exercise. Dr. J. Mark VanNess

In the classes that Prof. VanNess teaches, students learn how the body's major organ systems become involved in a response to exercise, specifically the metabolic, muscular and cardiovascular systems.

As he states on the University of the Pacific website, it is important to have a good, thorough background in chemistry, physics and biology to understand exercise physiology. This is because when we exercise, all the major organ systems in our bodies change, particularly our nervous and immune systems.

Students also learn why and how exercise is good for the body. But then there are CFS patients, and at the Pacific Fatigue Lab, the prof and his students test patients with CFS using stress of exercise. They are committed to making a difference and only last year, five of his students presented their research findings at an international conference on fatigue.

Prof. J Mark VanNess and CFS
Dr. VanNess and his colleagues recognise the huge physical problems that CFS patients face. This is why they continue to research the subject constantly.

In a research paper entitled 'A Realistic Approach to Exercise for CFS Patients', co-authors VanNess, Dr Christopher Snell and exercise physiologist Staci R. Stevens of the Workwell Foundation state: "Since chronic fatigue syndrome is characterised by debilitating malaise and the inability to perform physical activity, it is often assumed that patients should begin an exercise training regime to increase their ability to function. However, the ability to generate energy through aerobic energy pathways appears to be dramatically impaired in CFS patients and post-exertional malaise can extend for days. Because of this, aerobic-type exercise may be inadvisable for the CFS patient."

This is, of course a Catch 22, since an inability to exercise will lead to "further deconditioning."

Furthermore, even seasoned researchers, like Prof. VanNess, don't know why CFS patients are often not able to perform even simple tasks without becoming "fatigued." But it might have something to do with oxygen consumption.

> "Any reduction in aerobic function due to impaired oxidative function may lead to an abnormal reliance on anaerobic energy pathways during exercise."
>
> VanEss, Snell and Stevens

What this means is that a positive aerobic exercise regime for healthy people could be an anaerobic activity for those suffering from CFS. This would explain why activities as supposedly simple as vacuuming the house might result in the "rapid onset of fatigue" and an often inexplicably long recovery period.

This research paper shows "significantly impaired oxygen consumption levels" in CFS patients doing treadmill exercise tests. They seem to take in a normal amount of oxygen, but can't use it all.

The three co-authors suggest that a solution might be to avoid extended period of aerobic exercise and to rely rather on short periods of stretching or resistance exercise with frequent breaks. They suggest that this would improve flexibility and increase strength instead of trying to recondition the aerobic body system. Additionally, it should reduce muscle pain, improve cognition, and provide a sense of achievement.

> "If exercise is to prove beneficial for CFS patients, it is important that the exercise prescription is one they can accomplish."
>
> VanEss, Snell and Stevens

For this reason, any CFS patient exercising should start slowly and increase gradually. But, the researchers warn, this will only be suitable for people who don't have other health problems, and they should work with a qualified exercise physiologist or physical therapist with experience of CFS.

While improvement, they believe, is possible, "A return to pre-morbid fitness levels may not be possible for CFS patients."

> "Determining whether a CFS patient has benefited from exercise requires a different assessment approach than with individuals suffering from other illnesses."
>
> VanEss, Snell and Stevens

Clearly this is something that the researchers involved in the PACE Trial Studies have failed to take into account. And the media reporting on their research studies don't know any better!

SEID – Systemic Exertion Intolerance Disease

Sources: Please refer to the end of the article

The following article is USA centric, however, the potential for global consequences are high.

Between 836,000 and 2.5 million Americans suffer from myalgic encephalomyelitis/chronic fatigue syndrome—commonly referred to as ME/CFS.

The Institute of Medicine (IOM) was approached by a number of organisations[1] to convene an expert committee to examine the evidence base for ME/CFS.

In a report called "Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness", the committee proposes:

- using new diagnostic criteria focused on three core symptom sets including post-exertional malaise;
- replacing the name ME/CFS with the name Systemic Exertion Intolerance Disease (SEID);
- using a new code for the condition in the International Classification of Diseases (ICD-10), not linked with chronic fatigue or neurasthenia; and
- developing a standardised toolkit for screening and diagnosing patients.

INSTITUTE OF MEDICINE
OF THE NATIONAL ACADEMIES

The Institute of Medicine (IOM) is an independent, non-profit organization in the USA that works outside of government to provide unbiased and authoritative advice to decision makers and the public.

Established in 1970, the IOM is the health arm of the National Academy of Sciences, which was chartered under President Abraham Lincoln in 1863.

Our aim is to help those in government and the private sector make informed health decisions by providing evidence upon which they can rely.

Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness
Peter Rowe, who heads the Chronic Fatigue Clinic at the Johns Hopkins Children's Center in Baltimore, Maryland, and was one of 15 committee members, had high praise for the process and the product. "This is a phenomenal report," Rowe said, noting that it had unanimous support. "It has the best summary of the evidence that I've ever read." The U.S. Department of Health and Human Services and the Social Security Administration sponsored the IOM study and report.

A copy of the 248 page report can be viewed online using the following link:
http://books.nap.edu/openbook.php?record_id=19012

Certain key information, such as a report brief, can be accessed using the following link:
www.iom.edu/Reports/2015/ME-CFS.aspx

A "ME/CFS Clinicians' Guide" is due to be released soon.

New name
After reviewing more than 9000 scientific studies, hearing testimony from experts, and soliciting input from the public, the committee concluded that "the name 'chronic fatigue syndrome' has done a disservice to many patients," calling it "stigmatising and trivialising." Myalgic encephalomyelitis (ME), they noted, "does not accurately describe the major features of the disease."

[1] The Department of Health and Human Services;
The National Institutes of Health;
The Agency for Healthcare Research and Quality, The Centers for Disease Control and Prevention;
The Food and Drug Administration; and
The Social Security Administration.

Systemic exertion intolerance disease (SEID) does not exactly roll off the tongue. IOM committee member Ronald Davis[2] says the group considered about 100 options.

“Boy, did we struggle with that,” he said. “It’s hard to come up with a good name, and I don’t think this is a perfect name.”

Davis hopes the report will convince all clinicians that they can diagnose the disease and that it is real. “I hope it will get rid of those who may not believe it,” Davis said. “They’ll have to keep it to themselves. It’s incompetence and it’s malpractice.”

From the report brief:

> SEID “captures a central characteristic of the disease: the fact that exertion of any sort — physical, cognitive, or emotional — can adversely affect patients in many organ systems and in many aspects of their lives. The committee believes systemic exertion intolerance disease appropriately captures the complexity and severity of the illness.”

Proposed Diagnostic Criteria
The new diagnostic criteria build on what are known as the Canadian Consensus Criteria, first put forward in 2003. But the report offers a distinct, simpler definition that focuses on “the central element of this disorder,” said committee chair Ellen Wright Clayton at “public release event” held at IOM on the 10 Feb 2015.

“The essence of this disorder is that if patients with this disorder engage in exertion—cognitive, emotional, physical, whatever—that their symptoms are made much worse and often for a prolonged period of time,” said Clayton, a law professor at Vanderbilt University in Nashville. The name, she said, reflects this. “We want to name it for what it is,” she said. “This is what the patients experience.”

The report recommends that a multidisciplinary committee review the diagnostic criteria for SEID within 5 years. Rowe says they may want to review the name, too. “We don’t believe it’s going to be the name forever, but it’s a step forward,” he says.

Proposed Diagnostic Criteria for ME/CFS (new name SEID)

Diagnosis requires that the patient have the following three symptoms:

1. A substantial reduction or impairment in the ability to engage in pre-illness levels of occupational, educational, social, or personal activities, that persists for more than 6 months and is accompanied by fatigue, which is often profound, is of new or definite onset (not lifelong), is not the result of ongoing excessive exertion, and is not substantially alleviated by rest, and
2. Post-exertional malaise,* and
3. Unrefreshing sleep*

At least one of the two following manifestations is also required:

1. Cognitive impairment,* or
2. Orthostatic intolerance

- Frequency and severity of symptoms should be assessed. The diagnosis of ME/CFS should be questioned if patients do not have these symptoms at least half of the time with moderate, substantial, or severe intensity.

[2] A biochemist who heads the genome centre at Stanford University in Palo Alto, California

Feedback from Dr Charles Sheppard
(Medical Adviser, ME Association)

Like any report produced by a committee, some of whom may have very differing views, this one has its strengths and weaknesses.

Overall, the strengths far outweigh the weaknesses, in particular the way the report is sending a number of very clear messages to health professionals.

ME/CFS – as currently named and defined:

- is a serious, chronic, complex, systemic disease (the use of the latter term being very important) that severely impairs a person's ability to conduct any form of normal life with around 25% being house-bound or bed-bound at some point
- occurs in children and adolescents as well
- is a physical disease
- often remains undiagnosed and untreated but it can and should be diagnosed from the characteristic complex of symptoms (which form their proposed diagnostic criteria) as a distinct clinical entity
- is often absent from key components of medical education: tuition at medical schools, information in medical textbooks, postgraduate education etc, So many health professionals misunderstand the disease, regard it as a mental health problem, and lack the knowledge on how to diagnose and treat it
- urgently requires high quality research into the underlying disease processes/cause
- has no magic answers when it comes to treatment, and although a review and recommendations on management were not part of the remit, CBT and GET are not the solutions

So I would like to thank the IOM committee for all the time and effort that they have put into producing a very detailed report which, certainly in America, should help to improve the recognition, diagnosis and management of people with what is currently called ME or CFS.

I will now comment in a bit more detail on the recommendation that ME and CFS should be replaced by a new definition and a new name: systemic exertion intolerance disease/SEID, which the committee believe will more accurately capture the central characteristic of the illness

Whilst it is encouraging to note that the proposed new definition includes post exertional malaise and orthostatic intolerance (something the MEA has been trying to persuade NICE to accept) I think most doctors here in the UK will continue to take a pragmatic approach when it comes to making a diagnosis and not rigidly adhere to one particular set of diagnostic criteria. So I do not think this recommendation is going to have any real effect on UK medical practice.

Regarding nomenclature:
CFS/chronic fatigue syndrome is an absolutely dreadful name for a serious and debilitating neurological illness. It is the equivalent of saying someone with dementia has a chronic forgetfulness syndrome. CFS needs to be placed in the medical dustbin of obsolete names as soon as possible.

But I'm not feeling very excited about what is being proposed – systemic exertion intolerance disease or acronym SEID – by the IOM.

If the international medical community really wants to put a thick red line through the name ME/myalgic encephalomyelitis (due to the probable pathological inaccuracy of the E in ME) I would suggest that we once again consider the term ME/myalgic encephalopathy – which is consistent with the structural and functional neurological abnormalities that have been reported in the medical literature and cannot be seriously challenged from the position of pathological inaccuracy.

If the medical community won't accept ME in either format, I would far prefer a name new that emphasises the neurological and immunological components of ME/CFS – perhaps something along the lines of a chronic postural neuroimmune dysfunction disease.

My gut feeling is that the IOM proposal is not going to gain sufficient support from either the international patient community, or the international medical community.

SEID is not therefore the simple solution we need.

A far better way of dealing with the issues of definition and nomenclature would have been for the IOM to say that CFS is dead (which would have been widely welcomed by the ME patient community and many doctors) and that we must now to start a process of consultation which involves the international medical community and patient community on a new name and a new definition.

Because without this type of international consultation and agreement, we are not going to resolve the major problem of what we should call this disease and how we should define it.

Sources for this newsletter article:

www.iom.edu/Reports/2015/ME-CFS.aspx

http://news.sciencemag.org/health/2015/02/goodbye-chronic-fatigue-syndrome-hello-seid

www.meassociation.org.uk/2013/06/me-medical-or-mystery-dr-charles-shepherd-writes-for-public-services-europe-magazine-june-2013
