

# The ME Global Chronicle

[www.let-me.be](http://www.let-me.be)

# 21 – Februari 2017



# 1. Colofon / Personalia

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Subscribe to this newsletter.

We are no association or society, just a bunch of idealists who want to give our best efforts towards recognition of this terrible disease. By trying to help connecting to each other all patients all over the world. Anyone who expresses the wish to receive the Newsletter will be added to the list: that's the only formality and thing to be done. [subscribe@let-me.be](mailto:subscribe@let-me.be) – Visit our website to subscribe to this newsletter or to download previous <http://let-me.be> –

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Picture front page: **Greg & Linda Crowhurst, Eddy Keuninckx**

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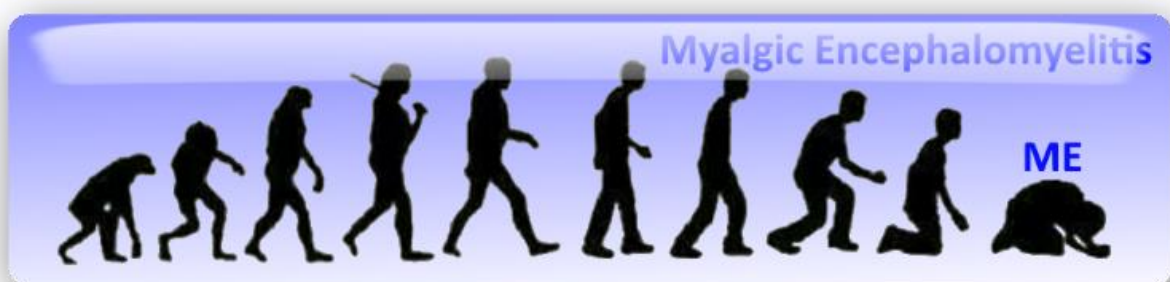
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*We as editors tried to make the magazine much more accessible by adding a link to each article as included in the Table of Contents, which gives you direct access to the article itself. Any suggestion is most welcome.*



**At all times remember Severe ME:** <https://youtu.be/BoVvJzmmVWg>

# 3. Editorial

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Sign the petition: ME isn't MUPS: <http://bit.ly/2e2Nsq7>

**Dear friends,**

We hereby present to you the 21st edition of the ME Global Chronicle, in which we hope to have collected the most significant ME-related news since our last edition, all complemented by columns, facts, current states of affairs and **Djanko's** famous cartoon.

So much is happening, and many developments seem to be flying on a tailwind, hence we probably missed some important news. If you wish to fill us in on this, please do so via mail (via [info@let-me.be](mailto:info@let-me.be)) so we can pay more attention to said subject in our next edition.

Even if the "enormous stimulus towards ME research" as promised by NIH chairman **Francis Collins** in November 2015<sup>(1)</sup> isn't making itself apparent just yet, the gap between the old and new world of approaching ME seems to be getting progressively bigger.

In Europe, the repudiation of the PACE trial only seems to have led to an even stronger chokehold of the BPS exponents and their MU(P)S-perspective on ME patients. It is an impregnable fortress that - thanks to the findings of **Mella** and **Fluge** - has only been penetrated in Norway, where prime minister **Erna Solberg** is personally committing to the terrible fate of seriously ill ME patients.

How different that is from the United Kingdom, where the overtly protested MAGENTA and MEGA studies are only receiving more credit from the government and every criticism of the PACE trial is nonchalantly being chucked into the dustbin. And the Netherlands, where the Dutch Health Council has to advise the government about the current state of ME and its culture. Where a special committee was subsequently arranged which gives BPS exponents carte blanche when it comes to propagating their MUPS-perspective and psychological interventions - subsidized by insurance and tax money. Exponents, which are narrowly connected to their British colleagues...

Hence why the time is now, now that it's still possible (until mid-March), for all ME patients worldwide to protest against this committee through the petition ME isn't MUPS: a protest against the way this committee is arranged.

Help out your fellow Dutch sufferers of ME, and in turn yourself, by signing this petition: <http://bit.ly/2e2Nsq7>

What's possible in the Netherlands, is possible anywhere. Both in a negative and positive sense.

We hope the content of this MEGC is of interest to you. Simply click on an article in the Table of Contents to instantly navigate to it.

Edition 22 will be published around April 20th. The deadline for contributions is April 10th. If you have any, please mail them to [contribute@let-me.be](mailto:contribute@let-me.be)

To everyone who contributed to this edition, we thank you wholeheartedly.

Have a lovely springtime on the northern hemisphere and a beautiful autumn on the southern. And share this fruit of hard labour as much as you can 😊

## The editors

(1) In a TV- interview with **Charlie Rose** on Nov. 25, 2015 ('so we just announced that we are going to make a big push to try to get an answer here') which since has been removed from YouTube



# 4. PACE

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# Assessment Of Individual PACE Trial Data

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Assessment of Individual PACE Trial Data: in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, Cognitive Behavioral and Graded Exercise Therapy are Ineffective, Do Not Lead to Actual Recovery and Negative Outcomes may be Higher than Reported

## **Mark Vink**

Family Physician, Soerabaja Research Center, Amsterdam, The Netherlands

The PACE trial's methodology and conclusions that CBT and GET are moderately effective, with 22% of patients recovering if they are treated with these therapies, have been questioned and criticized by patients (which the PACE trial authors have ignored thus far) and contradict the general experience of patients and the fundamental basis of ME/CFS.

## **Abstract**

The PACE trial concluded that Cognitive Behavioral Therapy (CBT) and Graded Exercise Therapy (GET) are moderately effective in managing Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and yielded a 22% recovery rate. Nonetheless, the recently released individual participant data shows that 13.3% of patients had already recovered, on one or both primary outcomes, upon entering the trial. Moreover, no one classified as recovered achieved the physical functioning, together with the fatigue scores, of the healthy sedentary controls from another trial by the PACE trial's lead principal investigator or achieved Kennedy's definition of recovery, whereby symptoms are eliminated and patients return to premorbid levels of functioning, due to CBT or GET (alone).

Therefore, CBT and GET do not lead to actual recovery.

After CBT and GET therapy, 59% and 61% of participants, respectively were labeled as improvers in the original paper, which was lowered by the PACE trial authors to 20% and 21% in the newly released papers in which they used the original protocol; nevertheless, only 3.7% and 6.3% were objective improvers in the objective 6-minute walk test as defined by the same improvement of 50% or more, as used by the trial itself, to classify someone as an improver. If the effect of Specialist Medical Care had been removed from the analysis, then 0% and 1.3% of patients improved objectively with CBT and GET, respectively.

Highlighting the fact that unblinded trials like the PACE trial, should not rely on subjective primary outcomes, but use either objective primary outcomes alone, or combined with subjective primary outcomes, as a methodological safeguard against the erroneous inference of efficacy in its absence. The objective individual participant data shows that in up to 82.2% and 79.8% of ME patients their health might have been negatively affected by CBT and GET, respectively.



The independent PACE trial review had shown that this proportion was between 46% and 96%, and found to be between 63% and 74% by surveys involving more than 3000 patients by the Norwegian, British, and the Dutch ME Associations.

These data confirm the conclusions of a number of studies that patient health was negatively affected by CBT and GET, including one that found that in 82% of patients with severe ME their symptoms were made worse by GET.

Analysis of the individual participant PACE trial data has shown that CBT and GET are ineffective and (potentially) harmful, which invalidates the assumption and opinion-based biopsychosocial model.

Consequently, we should stop using CBT and GET as (compulsory) treatments for ME/CFS to prevent further unnecessary suffering inflicted on patients by physicians, which is the worst of all harms, yet totally preventable.

**Source:** SciForschen vol.3:1 <http://bit.ly/2jTLHiK>

# 5. Dutch Citizen Initiative

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# Please Unite, From All Over, Help And Sign...

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Still possible until the middle of March <http://bit.ly/2mfJ3Bm>

Understand that this MUS (medically unexplained symptoms) thing is getting out of hand. Not many understand how influential the Wessely-school followers are throughout Europe. It is not just a Dutch problem. This MUS movement has been going on for years and is now being implemented everywhere....

This is the Dutch MUS guideline for general practitioners, citing CFS as an undifferentiated somatoform disorder! (table 5). <http://bit.ly/KxqLbQ>

This is a recent document from the UK

<http://www.jcpmh.info/wp-content/uploads/jcpmh-mus-guide.pdf>

Also see: <http://www.kcl.ac.uk/.../S.../Seminar-7/Trudie-Chalder-intro.pdf>

Margaret Williams wrote about it in a new piece

<http://www.margaretwilliams.me/2017/absence-of-evidence.pdf>

"absence of evidence"

Don't let ME (ICD G93.3) disappear (renamed as functional somatic syndrome, or other classifications that are basically part of the ICD mental and behavioral disorder group). It is insane that with all the biomedical evidence that this is a chronic complex multi-system disease these professionals are still able to have so much power, based on hypotheses and lack of evidence. Their unproven BPS hypothesis is being disseminated widely in health care at the moment, in several countries around the world. Their MUS rhetoric is gaining ground, especially with health care services and health care insurers. It means patients confronted with health care professionals will not be helped appropriately, their disease not recognized for what it is.....

This will not stop unless we speak up. We truly hope International ME experts will speak up as well

If you want to help please help; The author of the Dutch MUS guideline, and several Dutch PACE colleagues (don't forget the Dutch PACE colleagues provided the CBT protocol for PACE) are now in positions (on the Dutch Health Council Committee, writing an advisory report to parliament) that directly influence our future ... We cannot wait another decade for change....

<http://bit.ly/2dcdgWUu>

# Cartoon Djanko

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## 6. Grassroot

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# Yada, Yada, Yada

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As a 12 year old I watched doctors bend over backwards to doubt my word and dent my character. I watched them make choices based on false assumptions: I was lying because I was lazy; I was lying because there was "a problem in school"; I was lying; I was lying; I was lying... Yada, yada, yada. I dumped doctors over M.E because they were hurting me too much.

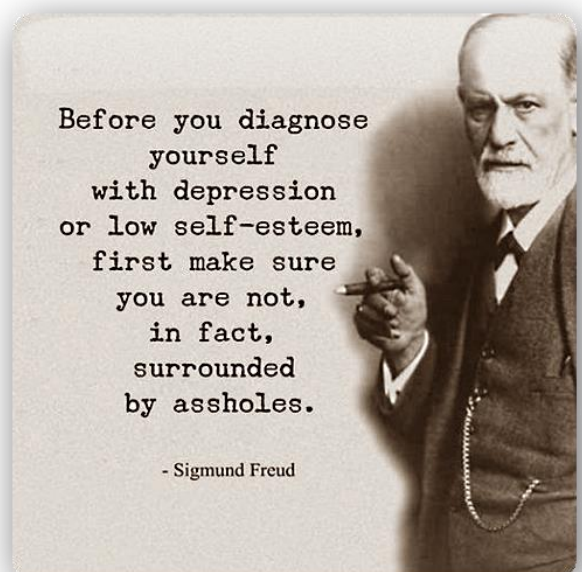


As a 42 year old I watched patients bend over backwards to doubt my word and dent my character. I watched them make choices based on false assumptions: I was lying because I was hateful, I was lying because I wanted to make trouble; I was lying; I was lying; I was lying... Yada, yada, yada. I dumped patients over M.E because they were hurting me too much.

I am not an "asshole", **Professor Coyne**; I am a pwme (patient with ME) who tried his utmost to help. I tried to freely give the fruits of 16 years of work. I tried to impress upon pwme the importance of standing together against mistreatment as opposed to tolerating it; I tried; I tried; I tried... Yada, yada, yada. I stopped trying because the hurt was creating indifference within me.

I've never, ever, lied about my illness. Why would I? Lies are weak. The truth, however, is strong: The M.E community hurt me. And so it lost me. The conclusion is I hope obvious: Don't hurt and don't lose other pwme. You are weak enough already.

**James/.**  
@batteredoldbook



# Survey On The Accessible Information Standard (AIS)

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<http://bit.ly/2jUrTHM>

*Note of the editors: this is quite an extensive survey with 25 questions to be filled in, but you can skip anything*

Six months ago, NHS England launched its Accessible Information Standard (AIS) and they are asking the public and health professionals whether they have used the AIS and if there have been any problems.

If you have a condition which affects things like speaking, following a conversation or remembering information you are told, the health professionals you come into contact with have to take this into account and make consultations and appointments easier for you in the way that you find helps you.

Whether you've made use of this policy when you've had contact with health professionals or not it is still worth telling them what you think because the survey also asks if you have felt able to ask for this sort of help. The closing date is 10th March.

NHS England will use survey responses to review:

- ✚ How organisations have implemented the AIS
- ✚ The impact of the AIS, including organisations' and service users' experiences
- ✚ Any aspects of the AIS which need updating or clarifying

I've seen references to the AIS in waiting rooms but they seemed to make the assumption that it's only people who are deaf, blind or have learning disabilities that the AIS applies to, possibly because these are examples given in the policy. It was off-putting though so I think this could do with being clarified, as AIS applies based on someone's needs rather than being limited to those with particular diagnoses.

I have found the AIS useful as a patient on a couple of occasions so I've completed the survey. I was lucky that the health professional I was going to see knew me well enough to be able to tell when my cognitive fatigue (or brain-fog) was really affecting my communication and that I would have found it difficult to remember what we were talking about later.

She made a list of the things we were discussing and explained that she was doing this because she could tell I was having a bad brain-fog day. It was really useful to have a list and also a relief that someone understood my needs without me having to explain or justify why I need help.

Taken from **Emily Beardall's** <http://bit.ly/2kKdstV>

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# MEGA

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January 31, 2017 — Letter to Mainstream Research Funders regards: <http://bit.ly/2kEFOpY>

FAO: All persons with responsibility for research grant applications



CC: Any persons with an interest in the above  
To whom it may concern,

This letter is to inform you that a majority of people reject calls by the M.E./CFS Epidemiology and Genomics Alliance (a project of the UK CFS/ME Research Collaborative) to support their forthcoming submissions for funding for their research proposals.

MEGA created a petition addressed to 'mainstream research funders' on a public petition site and this petition was publicised on internet sites of CMRC member charities representing ME patients, from 28th September 2016.

A number of valid concerns about this call for funding were not allayed by subsequent correspondence with members of the board of CMRC. Thus, a counter-petition was posted on 19th October on the same petition site as used by MEGA to provide an option to register rejection of calls for mainstream funding of their study proposals.

Supporters of the counter-petition were described by a charity representative member of the CMRC Board as 'a vocal minority' and the Chairman of the board wrote that they were 'baffled' by opposition to the MEGA proposals, in spite of having read carefully considered and in some cases, quite detailed explanations of the various concerns.

The 'MEGA' petition was open for 35 days. It closed on the evening of 2nd November and has 2,542 signatures. The counter-petition 'Opposing MEGA' had 2,912 signatures at 35 days (currently over 3,000). This shows that more people rejected the call by MEGA for mainstream research funding than supported it within the same amount of time.

It is understood that the MEGA petition was a means to demonstrate the weight of support from patients for forthcoming grant applications. In that respect, it has not succeeded as it is now a matter of public record that the majority of patients have cast a vote of no confidence in MEGA and reject calls for mainstream research funding applications by an alliance formed by the CMRC.

It will not suffice for MEGA or CMRC to reassure research funders that patients are represented on their steering and monitoring committees and advisory groups or that patient concerns will be taken on board. Such measures have not served the best interests of ME/CFS patients over decades past and there is no reason to suppose there will be any change in this position going forward. Indeed, great harm has been caused to many ME/CFS patients with the same establishment charities involved as are currently represented in the CMRC.

In addition, we are informed that the children and young persons' representation will be taken from an existing group working within the University of Bristol. We must assume that this group of young people will already be involved in other trials being conducted by MEGA applicant, **Professor Esther Crawley** - MAGENTA and FITNET-NHS - both of



which are already embroiled in controversy. These young people will, therefore, be already subjected to bias and influence.

**Dr. David Tuller**, academic coordinator of the concurrent masters degree program in public health and journalism at the University of California, Berkeley, explained:



"**Dr. Crawley** is a professor of child health at the University of Bristol. She is also currently recruiting for the MAGENTA study of graded exercise therapy for children with the illness. She is a lead player in the U.K. CFS/ME Research Collaborative, an umbrella organization that is sponsoring an ambitious Big Data effort called MEGA, now in the planning stages. While patients and advocates are desperate for the kind of top-notch biomedical and genetic research being proposed, many oppose MEGA precisely because of the involvement of **Dr. Crawley** and

**Peter White**, the lead PACE investigator. (**Dr. White** is reportedly no longer involved in MEGA; **Dr. Crawley** still definitely is.)"

The PACE trial has been debunked internationally by leading clinicians and scientists, and 42 experts signed an open letter to The Lancet, condemning its egregious flaws and noting that they "have no place in published research." The PACE trial has even been presented as a case study of bad science in graduate epidemiology seminars and at major scientific gatherings. MAGENTA relies on the PACE trial as evidence of efficacy of graded exercise therapy in adults.

The PACE trial results have been shown to have been grossly exaggerated to claim positive effects of psycho-behavioural therapies, and in any case, had shown null effect at long-term follow-up. FITNET-NHS relies on a **Dutch study**, with methodological flaws, and which showed null effect of the treatment trial at long-term follow-up. As the MEGA team have consistently refused to answer all questions about PACE, and are even relying on it for funding of current treatment trials, we submit that the MEGA applicants are attempting to build a research project on crumbling foundations and should receive no further funding under any guise.

We would draw your attention to a number of parliamentary questions raised by **Kelvin Hopkins** MP regarding matters of conduct, policy, and funding, as these relate to individuals and organisations, including patient charities, involved in the MEGA proposal and on the board of the CMRC, and reflect the central concerns raised in the Opposing MEGA petition and the conclusion that we have no confidence in MEGA.

It is imperative that research funders are aware of the majority view in response to the request by MEGA for support of their proposals and the legitimate concerns behind this majority view. This is, of course, particularly important where those funds are from the public purse and when better value for money can be gleaned by using existing resources.

As **Prof Jonathan Edwards**, Emeritus Professor of Connective Tissue Medicine, stated on the Phoenix Rising Forum:

"Of course, it would be nice to have a big study of lots of things in lots of patients but it needs to be done carefully and it will cost a vast amount of money to do that. I think it likely that the money would be better spent in other ways. We already have a Biobank resource and a method for recruiting cohorts - which could be improved but is a good start. I strongly suspect that several metabolomic and genetic and other projects are already being set up with reasonable sized samples elsewhere in the UK".

The international scientific and clinical community is on the verge of establishing biomarkers for accurate diagnosis of this complex disease, known for research purposes as ME/CFS, and it would be foolhardy to fund a fishing expedition at this stage. However, we must emphasise that our petition is not primarily concerned with the details of the protocol, but rather with the insurmountable and serious matters of research conduct and integrity.

Patients and professionals alike were misled over the PACE trial from its inception to the present day. Children are among the patients suffering daily from the consequences. We cannot afford as a civilised society to repeat nor perpetuate this mistake.

Thus, we submit this letter and Opposing MEGA petition, along with its comments, as an outright rejection of calls by CMRC/MEGA for mainstream research funding and request that you ensure this letter and content is brought to the attention of all personnel in your organisation with responsibility for research funding applications.

We are willing to provide you with further information upon request. We would strongly recommend that you take note of the comments on the petition, the various updates posted and the Opposing Mega website  
<https://opposingmega.wordpress.com/>

Yours faithfully,  
**A. Kirby**

On behalf of:

Organisers and signatories to the Opposing MEGA counter-petition -  
<http://bit.ly/2eRK5DQ>

Opposing MEGA rejects this petition by MEGA to mainstream research funders -  
<http://bit.ly/2cVfMrd>

# Forgotten Plague

In April, members of the Forgotten Plague team recorded our story for StoryCorps, making ME/CFS officially a part of the Archives at the Library of Congress. Pretty cool stuff!



Amsterdam Girls Raise Funds for Blue Ribbon Foundation



<http://bit.ly/2mbKl0a>

Please donate to further our mission here:  
<http://theblueribbonfoundation.org/donate/>



**Ryan Prior**

# An American With ME

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An American with ME had strong words for the National Institute of Health (NIH): You have stolen 40 years of my life.

**Johanna Kaiser** gave a brave testimony about the neglect of people with ME during the February 1, 2017 phone meeting with the NIH in which institute leaders answered questions about the planned ME research centers and data center:

I am alarmed by the lack of urgency and the low level of funding that's been put forth. I know you've worked hard on this, but I've been a patient for almost 40 years, and that's 40 years of my life that have been taken from me by, not the disease, but the inaction of NIH. And I don't think that I and people like me should be further punished by [NIH] plodding along at a snail's pace.

I personally know two ME patients: one who's in and out of the hospital constantly, and one who is currently fighting for his life and losing. His mother is a pediatrician, and because Kaiser Hospital doesn't have any ME expertise – I hope you all realize that there are no more than a dozen ME clinicians for 2.5 million ME patients in all of the United States – his mother has been staying with him at the hospital day and night while he's dying.

So I understand that you have a responsibility to proceed with care, but the funding level isn't enough; you have to really change this. It's barbarous; this is not a humane way to treat people like us, and I urge you to reconsider.

We have been told that you [NIH] need more investigators [to apply for grants]. We've been told by investigators how their grant applications have been turned down. These are not third-rate people. These are world-renowned researchers. So patients are caught in between what NIH says, and what these world-renowned Nobel Laureates and members of the National Academy of Sciences are telling us. You've really gotta quit this and get moving, because this is murder by neglect! I don't mean to insult you, but you've stolen 40 years of my life from me. And thank you for letting me have this opportunity to speak.

**Dr. Walter Koroshetz, Director**, National Institute of Neurological Disorders and Stroke (NINDS): Yeah, we all hear the pain there and we feel terrible that we don't have...

**Johanna Kaiser:** Well do something, please change it for God's sake. I can't go on like this and neither can most of us. You give us words, but not action. And the increase in funding is just a kick in the face. You people are not doing enough.

Most of my family died in the Holocaust. They wanted to come to America. If they saw what happened to me they wouldn't believe it. This is not what America is about. So please, enough with the words, we've heard too much; it's all hollow. You've got to up the funding and get moving and save our lives. That's it.

**Dr. Koroshetz:** Okay. Yeah, I totally agree, absolutely.

Johanna Kaiser: So will you move with urgency then? I mean, thank you for, really, from my heart, thank you for saying that. Can we expect, then, a change sooner rather than later, because we're dying? I really do appreciate what you're saying. Will that translate into urgent action in the near term? I'm desperate.

**Dr. Koroshetz:** "I'm hoping yes, that's our plan, that's what the Center program is trying to do, and..."

**Johanna Kaiser:** "But that's five years. I'm not going to make it five years. I've had this for forty years. I can't go another five years at this pace. This is my point.

**Dr. Koroshetz:** Well we need to know answers, we need more answers, absolutely.

**Johanna Kaiser:** But you've got to fund the people like **Ron Davis**, the **Lipkins**, the Solve ME/CFS Initiative that was just... their grant application was just rejected. You know, NIH says one thing and does another, and we want you to know that we're seeing it. Words aren't enough; the actions have to change. The money has to change. You know, people are committing suicide, and you guys are going at a snail's pace. I don't know how else to make it clear. But you're being stubborn and letting our lives burn to the ground.

**Dr. Koroshetz:** It's certainly not our intent here...

**Johanna Kaiser:** But that's the result. And you must acknowledge reality.

**Dr. Koroshetz:** We're very knowledgeable about reality. The question is, Where are the answers? And that's sometimes not so easy to get to.

(**Dr. Koroshetz** pivots from NIH's lack of urgency and consistently low funding to "answers." He also appears to refer to the notion of reality from NINDS' perspective but not from the perspectives of people with ME, family members and caregivers, clinicians and ME researchers.)

**Johanna Kaiser:** But you're not funding the people who want to research this. Good people.

**Dr. Koroshetz:** Let me just explain this. So the NIH – most of the funding comes in because people write grants, not RFAs, so most of our funding goes out, not in RFAs, but in people sending grants

**Johanna Kaiser:** And they're being denied.

**Dr. Koroshetz:** Let me just finish... so the competition at NIH, because of the funding situation, is such that only 12% of the grants get funded. So that means 88% get rejected. We get about 10 ME/CFS grants a year. So even with those numbers that's one grant a year. What we need to do is to get 100 times more people interested in working on ME/CFS and that's what the program that we're putting out is trying to do.

I wish that I could move things faster and I will do anything I can to do that if I can see an opportunity there.

**Johanna Kaiser:** But NIH did this for AIDS; and grant [applications] from people like **Ron Davis**... Norway is making more progress than the United States is. So grant [applications] from people like **Ron Davis** are being turned down and then we're being told that low quality grants are being submitted – we just don't buy it.

**Dr. Koroshetz:** We don't say "low quality grants"... lots of high quality grants don't get funded.

**Johanna Kaiser:** Oh, in the CFSAC meeting in [August 18] 2015, that's what we were told. I can't remember her last name – **Susan** something. She actually said that; the audience was incredulous. [Note: the speaker at CFSAC was **Cheryl Kitt** (<http://bit.ly/2kW1VoJ>), **PhD, Deputy Director** of NIH's Center for Scientific Review].

**Dr. Koroshetz:** Well we are trying to turn things around. I hope this program will get some really, really strong research going that will just kind of exponentially expand.

**Johanna Kaiser:** How do we survive these next five years, then – the patients who are so desperately ill?

**Dr. Koroshetz:** I think just like in medicine we are stuck with always trying to do the best for patients with what's known, but knowing that we need to know more, and I think that's the problem with ME/CFS and with many different diseases, unfortunately. It's quite sad.

**Johanna Kaiser:** But – our disease has a larger patient population than almost any other, so there really isn't a comparison. And what was done for AIDS is not being done for us. There was an urgency there – eventually. It didn't take thirty years – thirty plus years – like it is for us. There are things that should happen that aren't. Thank you.

**Dr. Koroshetz:** I agree with you. Thank you very much.

**Source:** MEAction

# Marathon Mike

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2017 Marathons:

**#10 - Barcelona (Spain) - Sunday 12th March**

#11 - Luxembourg (Luxembourg) - Saturday 27th May

#12 - Vilnius (Lithuania) - Sunday 10th September

#13 - Amsterdam (Netherlands) - Sunday 15th October

#14 - Ljubljana (Slovenia) - Sunday 29th October



I interviewed Maria, Gabriela and Teresa from Spain about their battles with ME there; this is what they told me.....

<http://www.mikeseumarathons.eu/spain.html>

THE 28

Austria, **Belgium**, Bulgaria, Croatia, Cyprus, **Czech Rep**, Denmark, Estonia, **Finland**, **France**, Germany, **Greece**, Hungary, **Ireland**, Italy, Latvia, Lithuania, Luxembourg, Malta, Netherlands, **Poland**, Portugal, Romania, Slovakia, Slovenia, Spain, **Sweden**, **UK**

# What a surprise...

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One of my good friends' daughter **Havana** (12) surprised me with a very beautiful video message. She did something really incredible. I was so moved by it I felt it needed to be made public.

Here's what she wrote about it:

**Havana:** *"When our teacher asked us to set up a campaign for a good cause, I thought of **Anil**. **Anil** is a friend of my mother who suffers from ME. Since there is not much I can do for him, I saw this as an opportunity to make a gesture. It is hard to see him suffer, he does not deserve this!*

*By donating the money we raised, we hope to help the scientists that are researching ME, even if it is just a little bit!*

*I asked three friends to join me to raise money for this cause. They liked the idea, and so I explained to them what ME is.*

*The next step for the four of us was to think of ways to raise money, e.g. selling products or offering services. We already decided to head to a busy spot in the city, and my mother came up with the idea to make brooches/ blue ribbons (pins) with the ME logo. We sold these. Also, one of my friends baked 40 cupcakes. We took them with us to Dam Square, Amsterdam, where we asked people and explained to them what ME is about. Many cupcakes were sold and brooches were pinned! In our best English/German/French we tried, and managed, to convince many tourists as well.*

*We had a lot of fun and what excited me the most was being able to help people suffering from ME.*

*At the end of the day I counted our revenues. We raised a total of **€ 139.60!** It had been a great day and I was very happy with all we did that day."*

Click here to watch a video Havana produced about the experience. (<http://bit.ly/2lyBnNW>)

**Anil:** For me it was the first time since I fell ill that someone was raising money for ME & me. Raising awareness without my asking for it. As a patient, I am raising awareness a lot because I'm ill. It's in my own best interest.

I see people raise money for other well known illnesses which I obviously support. But ME just doesn't have that thing yet. Though the illness really deserves it. Specially with the underfunding it's suffering from.



I admit, it saddens me. Specially for the situation I'm in. Bedbound, in the dark in a sound isolation cabine, and really not improving but rather worsening, and since 2005 no federal funding for biomedical research in the Netherlands ..... But it is what it is, but the vicious cycle needs to be broken so biomedical research can progress faster.

So to have these amazing young ladies and especially **Havana** step it up like this left me speechless and with tears in my eyes. Can't thank them enough. A humbling experience really.

It just felt like a soft warm blanket of love that covered me. Wow.

As they sold Blue Ribbons there was no doubt in my mind that the money needed to go to the Blue Ribbon Foundation. And as they are young ladies and the BRF has a program to attract young scientists it was just perfect.

I think these amazing girls set an example for the adult world. They just went out there and raised money and awareness.

Maybe it could be a thing? I ask everyone who reads this to follow in their footsteps and go out and sell a few cupcakes with blue ribbons or sing a few songs, do a little dance, make some drawings. Anything. We really need your help.

Thank you again girls and thank you, **Havana**. Heroes, that's what you guys are.

Hugs,  
**Anil**

# In Memoriam: Joan Shearman Eddis-Topolski

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Toronto, October 21, 1929  
Ottawa, January 1, 2017.

A long bout with Chronic Fatigue Syndrome in the 90s led her to be an organizer and advocate for fellow sufferers as president of MESH Ottawa. Her other volunteer work included: docent at the National Gallery of Canada, Editor, Elizabeth Fry Society, International Board of Harmony, Inc.;

Sunday School teacher; Chelsea Home and School Association; Committee to save the Wakefield Train, and Child Play International.

**Joan** studied Polish language at University of Ottawa in her eighties. She was an avid Blue Jays fan. She was a familiar face around her Sandy Hill neighborhood, friendly and active, and enjoyed theater outings and friendships with undiminished zest until only a few weeks before her unexpected death.

**Joan** made a conscious effort to always see the best in people, and she brought out their good side. She believed she had a duty to better society and help those who lacked the advantages she'd had. Always generous with her vast stores of information, she never gave a short answer when a long one would do. Her empathy and practical advice won her friends, young and old, from all walks of life.

As she wished, there will be no funeral. A celebration of life will be held for Joan this summer, details to be confirmed. For those who would like to commemorate her passing with a donation, please consider a gift to University College of University of Toronto in her name.

**Source:** <http://bit.ly/2IYW4ji>

# In Memoriam: Sun, Gary 'Cherub' Pethybridge

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## Sun, Gary 'Cherub' Pethybridge (67)

On January 17th, 2017, we unexpectedly lost our dad, **Cherub**, to a Sudden Cardiac Arrest at home in Sunshine Bay, on Kootenay Lake, in BC, Canada. He was just 67 years old. He had suffered

for many years from M.E. (Myalgic Encephalomyelitis), Fibromyalgia, and Lung Disease.

Born as **Gary Pethybridge**, in Carman, Manitoba, he came to BC as a young man and acquired the nickname **Cherub**. The name **Sun** came to him when meditating in a park one day. He officially changed his name. The beloved husband of **Shannon** for 43 years; they played music and worked together as a team and lovingly raised 6 kids and invested all they had in them, and their 6 grandkids.

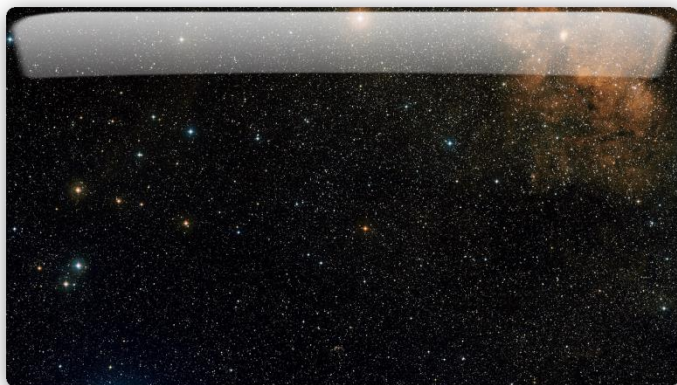
We are all in shock and so saddened. He is greatly missed already by the entire family and those who knew him. He was such a great guy, and dad, and grandpa. Compassionate and kind. A master percussionist and gardener and multitalented craftsman. He always had jokes to make people laugh, cosmic sayings, and an enthusiasm for music, and watching NBA basketball and sci-fi shows. He actively followed politics and current events, and cared for the world.

We know that our hardworking dad wouldn't have wanted to ask for help, however, with multiple disabilities in our family, multiple members with M.E. and Fibromyalgia as well as other serious health issues, (and with people asking if there is anything they can do), we're asking for support to help cover the costs for his cremation and celebration of life, and debts, and to help take care of our mom through this unexpected and difficult time. Any and all support is so greatly appreciated. Thankyou, with love from the Sun family.

gofundme accepts Credit Cards and Debit cards, but we are also accepting e-Transfers and contributions via Paypal to [sunfamilyfund@gmail.com](mailto:sunfamilyfund@gmail.com)

# In Memoriam: John Berntsen

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In Memoriam: **John Berntsen** (54)

January 4, 2017

My brother **John** died this morning. He had suffered tremendously for years with the horrific disease ME (Myalgic Encephalomyelitis), the same disease that killed our father and grandmother.

With all of his body systems malfunctioning or totally shut down, including his immune system, a simple cold that he caught on Sunday, took him out. Thankfully, he died peacefully in his sleep.

**John** was an incredibly bright and motivated person. He taught me things and he made me laugh. He had the potential to do great things in the world, but his illness kept him a tortured prisoner in his body.

I don't want condolences

I want to take a sledgehammer to the walls of the NIH and scream WAKE UP!

I want NIH to step up to the plate and fund research that matches the disease burden,

I want the millions of marginalized people suffering from this horrendous disease to get the support they need from the world of medicine and society at large.

I want my family members to stop dying.

I want my friends in the community to stop dying.

I don't want to die.

In May 2016 I spoke about my brother and his daily fight for survival at a MillionsMissing demonstration in San Francisco. I said I was there to fight for his life. We must keep fighting. If you feel inspired to do something in his honor, please make a donation to the Open Medicine Foundation. (<http://bit.ly/1NovyZT>)

I love my brother so much. No words can express my deep sadness.

## Jennifer Isabella Berntsen



*In spite of Jenny's statement that she didn't wish any condolences, we express our deep sadness for and sympathy with her, her brother and her mother for the great loss of an obviously exceptional and utterly brave and gifted brother.*

### **The editors**

# Unrest

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## Canary in a Coal Mine is now "UNREST"

The talk I gave at last summer's TED Summit has just gone live on TED.com (<http://bit.ly/2j6zlQo>). I am so thrilled to finally be able to share it with you (with subtitles in many languages).

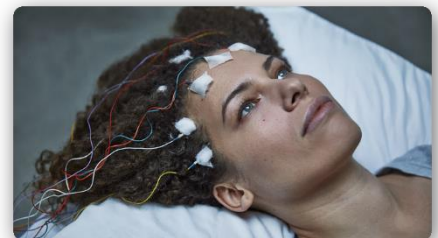


"Five years ago, TED Fellow **Jennifer Brea** became progressively ill with myalgic encephalomyelitis, commonly known as chronic fatigue syndrome, a debilitating illness that severely impairs normal activities and on bad days makes even the rustling of bed sheets unbearable.

In this poignant talk, **Brea** describes the obstacles she's encountered in seeking treatment for her condition, whose root causes and physical effects we don't fully understand, as well as her mission to document through film the lives of patients that medicine struggles to treat."



We're finally back from Park City after an amazing experience at the World Premiere of Unrest at the Sundance Film Festival. We couldn't have asked for a better reception from audiences (and critics!), and it's been deeply gratifying and profoundly moving to begin bringing this story to the public. For those of you who were with us at the festival — and to those of you who have sent your support through emails, social media, and virtual love — thank you.



Amid the tears, hugs, and standing ovations, our time at Sundance came with some exciting news. We're honored to have received the Special Jury Prize for Editing in Documentary.

A credit to our incredible editors **Kim Roberts** and **Emiliano Battista**.



We're also excited to announce that our next stop on the festival circuit will be SXSW in Austin, Texas! *Unrest* will be screening as part of the Festival Favorites section. The festival is March 10–19, 2017. Our screening dates are still to be announced, but we hope to see some of you there!

Finally, at long last, we're beyond thrilled to share that *Unrest* will be coming to public television, an outlet accessible to all. We'll have our US broadcast premiere on PBS's *Independent Lens*, a series watched by over 1.2 million viewers each week, in early 2018!



For more on our distribution timeline, read our FAQ <http://www.unrest.film/faq>

Source: <http://www.unrest.film/blog/>

**Jen**

# KissMEGoodbye

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**KissMEGoodbye: a capturing project initiated by a 9-year-old Dutch girl.**



Every December in the Netherlands, the Serious Request event takes place, in which two or three DJs confine themselves to a glass box for three days and collect money for charity.

Last December, the picked charity was the Red Cross, for which 11-year-old **Tijn** came up with varnishing everyone's nails. **Tijn** suffers from an incurable form of cancer and is in his dying phase at the moment. His idea ended up spreading like wildfire and garnered millions of Euros. A planetoid has even been named after **Tijn**.

A 9-year-old daughter of a Dutch ME sufferer, felt inspired by **Tijn's** actions and Valentine's Day and came up with KissMEGoodbye: take a selfie while wearing lipstick and call for people to donate to ME research. The donations will be going to the Open Medicine Foundation.

This Valentines #kissMEgoodbye challenge has been a success! Within one week a 1100 euro was raised and over 130 kiss(sel)files were send in. Thank you so much, if you already did participate!!

Due to circumstances the 9 yr old girl can no longer be the face for this challenge. For that reason, we have removed the video and MEMEs. We hope you can understand this decision. The family would appreciate if you would delete all images and/or videos of this girl.

Due to this success, we are now preparing for a #kissMEgoodbye follow up to continue the challenge.

Please do continue and share your kissfies on this page: <http://bit.ly/2kEIAwb>

The donation page will soon be available again.  
Stay tuned for further updates.

Thank you

## The Organizers

**Source:** <http://bit.ly/2kEIAwb>

# 7. Karina Hansen - Save4Children

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**Karina Hansen at Home**



# Karina Hansen, The Current Situation

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**Karina Hansen** is the second child the fund Save4Children is focusing on, since German **Joanne** did return home in July 2015. Inquiries with her mother didn't result into information about her present state, so we presume **Joanne's** still free. **Karina** is home as well, but her freedom is still being threatened by 'her' psychiatrist **Nils Balle Christensen** of Aarhus. As long she's not completely out of danger, she will remain our main focus, both from the aspect of information and from trying to help her and her parents with legal procedures to get her unhelpful guardian off her case.

As explained in earlier issues, it is of great importance donations will continue for obvious reasons. A proficient lawyer in such a complicated case doesn't work pro deo.

Presently there's little news about that procedure, so we publish a bird's eye view of the course of events as provided to us by Danish ME-patient **Bente Stenfalk**: **Karina Hansen** was a bright child, fond of music and local theater performances in which she participated with great joy for several years. She liked hip-hop for several years too and was very happy.

Autumn 2004: **Karina Hansen** went to an independent boarding school where she suffered from many throat- and sinus infections as sequel after mononucleosis. The following year **Karina Hansen** had a poor health.

February 2007: **Karina Hansen** was examined by psychiatrist **Ole Nielsen** from Holstebro who found no mental illness, "but just infinite fatigue". Despite these antidepressants were tested, but quickly abandoned because her health deteriorated.

April 4, 2008, psychiatrist **Nils Balle Christensen** examined **Karina Hansen** in Aarhus University Hospital, and he found no mental illness. He wrote in her medical file:

"19-year-old girl who looks age-appropriate. Awake, alert and relevant. She appears in no way to be deeply depressed. She presents neither something psychotic. She's a little quiet, but also relaxed in the interview situation and she makes good contact, both formally and emotionally. She is not affected by any severe disturbances in the structure of her character. She has only slight evasive moves. There are no anxiety problems and no depressive symptoms excepting an understandable sadness about her condition"

Mononucleosis, repeated throat infections, anesthesia, surgery and vaccinations are often conditions that precede ME. **Karina** suffered all of them in the intermediate years.

In May 2010, **Karina Hansen** was hospitalized by the family doctor in Holstebro Hospital, Department of Neurology because she had been lying in bed all day long for some time. She stayed for three days, but no diagnosis was given. She suffered a severe worsening of conditions after this hospital stay, which was arranged to get her assessed as psychiatrically disfunctioned. After this stay at a hospital **Karina Hansen** did not want to be hospitalized ever again.

In 2010, Specialist of Internal Medicine and Infectious Diseases **Henrik Isager** diagnosed **Karina Hansen** with ME (Myalgic Encephalomyelitis)

In 2011, the same diagnosis was given by the Norwegian physician **Mette John Overgaard**.

Again in 2012 practitioner **Katrine Flindt** did the same. That year **Karina Hansens'** condition was very poor and for this reason the psychiatrists tried to involuntarily institutionalize her. However, her GP did find no reason to hospitalize her.

On February 12, 2013. The National Board of Health and Health Minister **Astrid Krag**, psychiatrist **Per Fink** and psychiatrist **Nils Balle Christensen** agreed to hospitalize **Karina Hansen** by force, and she was taken away from her home by eight police officers. **Karina** was 24 years old by that time.

**Karina Hansen's** phone ran out of power at the Hammel Neuro Center, where she was brought to and held against her will. After many calls to her parents in which she requested to go home, the family did not hear from **Karina** again before the autumn of 2016.

We have no medical records from Hammel Neuro Center, but we know that without examination her mother got the diagnosis of Münchhausen by Proxy by **Nils Balle Christensen**.

We also know that **Karina Hansen's** ME-diagnosis was taken away from her during the forced hospitalization and she was given the diagnosis PAWS (Pervasive Arousal Withdrawal Syndrome, chronic withdrawal syndrome), again by psychiatrists **Per Fink** and **Nils Balle Christensen**. (PAWS is a psychiatric disorder that is only used for war traumatized children, according to a 76-page report on PAWS published by the Swedish National Board of Health which is freely available online).

**Karina's** parents were forbidden to visit their daughter because the psychiatrists believed that a visit could harm the psychiatric treatments that were forced upon her. They did not want her to be supported in the idea that her illness was physical. On January 9, 2014 **Karina Hansen** was moved to an institution for brain damaged patients in Hammel. Here she was no longer involuntarily committed. But the family was not informed until long after, so **Karina** remained isolated from her family. She had, however, a little contact a few times.

On June 20, 2016 **Karina Hansen** was hospitalized by force again, this time in Risskov Psychiatric Hospital, supposedly due to an acute psychotic state. **Karina Hansen** had an untreated urinary tract infection. She was in such a bad condition that she was put in belt fixation and medicated by force with a sedative. She was put on anti-psychotic medication. Because the infection abated she improved gradually and relatively quickly, and was discharged shortly after.

It was expected that **Karina Hansen** would gradually and rather soon be able to do without medication. In the autumn of 2016 **Karina** finally succeeded in getting in touch with her parents with the help of a stout-hearted physiotherapist. She left no doubt that she wanted to return home and she indeed got home five weeks later: 3 years and 8 months after her forced hospitalization.

After coming home, she was afraid of the slightest sound from outside, especially if a car kept standing outside the house, and when the doorbell rang.

Doctor **Stig Gerdes** did not find anything psychotic or paranoid about **Karina**, and he found that she was able to respond adequately to the questions she was asked.

After scaling down her meds a little, **Karina's** current condition has significantly improved. She shows more initiative and is able to go for a walk with a walker, usually with one of her parents, 2-3 times a day. 2 times a day **Karina Hansen** is also outside in her wheelchair with one of her parents.

She is physically more relaxed by now, her face looks more lively with a twinkle in the eye, she has humor and she smiles at people who are coming to visit and greet her. She is also laughing more often while watching funny movies or when the cats are moving in funny ways. She is more composed in her entire appearance, there is no more stiffness in her body and there are no more nervous shakes. She is participating in everyday life in her home and would like to be visited by former friends.

She does not want to talk about the time at Hammel Neuro Center and the institution for brain damages. She does not want to cooperate with the guardian. According to a doctor's assessment **Karina Hansen** is functioning so well that there is no need for a guardian because she can take care of the ordinary everyday necessities with the help of her family.

So presently all efforts are directed towards getting her relieved of the current guardianship.

Submitted by **Bente Stenfalk**

For more detailed information read **Valerie Eliot Smith's** detailed blogs about **Karina** (<https://valerieeliotsmith.com/>)

# Help Karina – Donate To Save4Children

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The charity Save4Children has been created by the editors of the ME Global Chronicle (<http://www.let-me.be>) and helps parents whose children have been forced into psychiatric wards by authorities, to try and set them free by legal procedures.

After the release in 2015 of the German girl who came to be known as **Joanna**, it was decided to focus the fund entirely on **Karina Hansen**, who was kept hostage of the Danish psychiatric system since February 2013. She returned home in October 2016 (<http://let-me.be/request.php?36>)

However, there is persisting peril she will not be able to stay home due to pressure of authorities, clinicians, the institution she left voluntarily and the guardian the state of Denmark forced upon her in 2013. Hence a most proficient lawyer has been contracted to try and get her into safer waters.

As this will involve a considerable amount on fees, please continue to donate as generously as you did this period, which has been overwhelming indeed. After **Valerie Eliot Smith's** blog on **Karina's** release <http://bit.ly/2h9dc2U> and her update and appeal in her latest blog on **Karina** of 2<sup>nd</sup> December: <http://bit.ly/2gajXQX>

Since last issue of the MEGC € 166,= has been donated, bringing the grand total to € 6.520,74. Bills of lawyers **Poblador** (DK 12.500) and **Jacobsen** (DK 6.375) have been paid (app. € 2.540,= in total). Now all your donations will start to bear fruit, as this is the final step. Sincere thanks on behalf of **Per & Kitty Hansen** and of course **Karina** to all of you.

**Link to the donation button: <http://let-me.be/page.php?11>**

The donations to this fund are exclusively for use in paying the legal expenses incurred by **Karina's** family as a result of her treatment by the state over recent years.

In case you experience any problems with your payment, please contact us at and provide us with as much as possible information: country, url, date time, error, used payment method, etc.

# 8. Science

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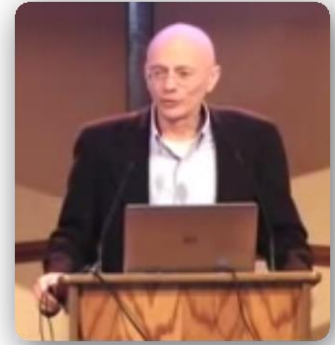


# Definition Of Inexplicable Exhaustion - From Knowledge To Action

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<https://youtu.be/CSFWTs2BbCs>

Presentation by **Professor Leonard Jason**  
of the Ethical Humanist Society of Chicago;  
January 15th, 2017 (at 2:58)



The first half of this video consists of the speech and the second half is dedicated to important questions and answers, which we hope to publish an excerpt of in the next issue of the MEGC.

To start off, **Professor Jason** brings into perspective how severe of an illness ME truly is and how large the stigma is surrounding this illness. This stigma, which primarily consists of five myths spawned by falsehoods about ME, will be addressed by the speech.

✚ The first myth encompasses the so-called “elusiveness” of ME. This has been brought into existence by a study conducted by the CDC regarding the practices of physicians in 4 urban areas in the US in the late 80s and early 90s. This study failed for 2 reasons: a. due to the stigma, many physicians didn’t believe their patients in saying they had the illness, and hence, the patients weren’t selected for the study and b. Many patients (in the US) did not have health insurance and therefore no money for a checkup; they weren’t eligible for the study either. This is how the CDC came to the conclusion of about 20,000 patients in the United States.

As a result of multiple factors, **Jason** found this amount to be greatly underestimated, and after having been applied for and received a grant from the NIH, he and his colleagues discovered that the prevalence of ME was closer to a million patients. That study from applying for the grant to disseminating its results took about 10 years. So, this type of work takes a commitment and long-time perspective to get the data to challenge myths that are still so common about this illness.

✚ The second myth was that the case definition was correct, which is a crucial aspect of monitoring illnesses. In 1988, the CDC formulated a case definition (revised in 1994) which stated that 4 symptoms specifically symptomatic of CFS would be required, out of 8 possible symptoms; however critical symptoms such as post-exertional malaise were not required of all patients. It is possible that patients with clinical depression could be diagnosed with CFS, which has negative implications as the illness is seen as a psychiatric disorder by some.

- ✚ The **third myth** was caused by a faulty measurement. The most important incorrect conclusions were created by solely the observation of the symptoms alone, and not the level of intensity thereof. If symptoms are observed merely at face value, which was the case with the case definition, the actual sufferers of CFS can be confused with normal healthy people suffering from headaches, insomnia or fatigue, which are common at low levels of severity. In addition to that, physicians do not have the means to perform advanced tests, which causes the lab results to be negative for patients. This also strengthens the image of ME being a psychogenic disorder.
- ✚ The **fourth myth** is the fact that the term CFS wouldn't have a stigmatizing effect. If you were to tell someone they had "chronic coughing syndrome", that would have a much different effect than telling them they had pulmonary emphysema or chronic bronchitis. In 1988, the CDC renamed ME to CFS. Many professionals do not think of ME patients as being seriously ill. **Jason** conducted tests with altering the names ME and CFS with a similar case that had the illness, and found that when the same illness was referred to as ME, attributions about the illness were much worse, so the name does make a difference. About 10 years ago, the CFS Advisory Committee of which Jason was a member proposed to formally call the illness ME/CFS as part of a transition to the name ME. Unfortunately, the IOM proposed in 2015 yet another different name: SEID. **Jason** introduced a large-scale survey among patients which concluded that the vast majority of them preferred the name ME over SEID. Hopefully this effort and that of others will reduce the chances that the term SEID is adopted.
- ✚ The **fifth and last myth** he discusses, is the myth of Cognitive Behavior Therapy (CBT) being effective. This idea originated among researchers in the United Kingdom especially, where it was said that patients who had an illness were subsequently overly or even phobically worried about physical limitations; so, the remedy was that patients should exercise and slowly overcome their fears of being active. The article about the PACE trial which was published in Lancet in 2011 only strengthened that view, but it's very interesting how patients have formed a strong resistance against its findings. **Jason** concisely addressed problems with the PACE trial that are now commonly discussed among patients and scientific groups. Rather than CBT, his group at DePaul university developed the energy-envelope theory which bears resemblance to pacing; considering one's available energy and how much one can spend to keep their energy balanced without relapsing. In a study, patients were allotted a buddy for one hour per week, plus a mentor with which they could talk if desired. That did have a positive effect on patients.

What is happening with ME today, also happened with MS until the end of the 60s, which had once been labeled as a psychiatric disorder. We need to overcome these myths to help reduce stigma that still makes patients who are very ill have reactions from others that produces even more trauma to their lives.

Extract edited by **Prof. Leonard Jason**

Extracted by MECentraal <http://www.facebook.com/MECentraal/>

# Ron Davis On His Research

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[https://youtu.be/-bs6\\_5Ldat4](https://youtu.be/-bs6_5Ldat4)

In this short video, Ron Davis does not only talk about which research he is doing (especially metabolites) but also how he and his group can make that cheaper ("because money seems to be the problem in research").



For example, by creating their own measurement instruments that hardly cost anything. How important teamwork is, how he got **Dr. James Watson, Medicine Nobel prize Winner**, aboard who only had two questions:

*How much money is available?* - Five million.

*How much people suffer from this disease?* - In the US alone two- to three million.

*Ok, I participate.*

How it engages **Ron**, when he's talking about those severely ill patients (among which his own son...). ME is much more severe than one can observe, because those who one sees, don't look that extremely sick.

How a call is made on private fundraising (via OMF, in particular by **Linda Tannenbaum**) because grant applications to the NIH can take just eighteen months and bring along a lot of hassle ("way too long", he sighs).

The "fast tracking" from the title of the video has also to do with the time pressure on the solution, whereby he takes for granted the errors that sneak in a study.

"We recover them in a subsequent study". We reported earlier that his by ME critically ill son told him he wanted to stay alive, so he could search for a marker and possibly an agent, after which he whispered to his son: "but that may take a considerable time".



# Stanford Takes ME Most Seriously

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A look at Stanford Medicine magazine's top stories of 2016 reveals some recurring themes: Two of the top five (based on pageviews on the magazine's website) tell stories of a father trying to save the life of his son, and two describe battles with chronic fatigue syndrome.

In 2016, the quarterly magazine published special reports on precision health, relationships, the science of well-being, and diagnostics. A story from each of these is represented among the biggest reads:

And yet, you try (<http://stan.md/2gkOZtK>): The story of a cancer diagnostics expert's quest to save his son from brain cancer.

The puzzle solver (<http://stan.md/2cZfAcu>): A renowned geneticist changes the course of his research to rescue his son from severe chronic fatigue syndrome.

Leaving frailty behind (<http://stan.md/2lCyW9a>): A Q&A with author **Laura Hillenbrand**, who wrote the best sellers *Seabiscuit* and *Unbroken* while grappling with severe chronic fatigue syndrome.

Well now (<http://stan.md/2bvn0Cj>): A quest to understand well-being.

Brain waves (<http://stan.md/21AuF9r>): On using brain imaging to customize treatment for people with anxiety, depression and other psychiatric conditions.



The Puzzle Solver is of course about **Dr. Ron Davis** whose son **Whitney Dafoe** suffers from the most severe form of ME. It is an interview in depth about his son falling ill, the increase in severity and his search for the cause and of course treatment. One quote says: "It's enormous pressure. We have to figure this out very quickly, because millions of people are suffering and my son is dying."

And about the reason **Whitney Dafoe** wants to continue and try to live, even while lying in the dark day and night and being tube-fed: "He's hoping to do this for everyone with CFS." Then he pauses. "I told him it would take a while."

In the Q&A session with **Laura** 'Leaving Frailty Behind' she tells she suffers from ME since 1987, fell in love and because of that wanted to be in Oregon with the

man she loves. A healthy environment and a coin which due to her exertions and own pacing and searching her limits stumbling and falling down seems to fall in the right direction, and cause her to live a much better life than before which of course can't be compared with a healthy person.

The physical 'experience' of ME she describes as "akin to being bound in plastic so that you can't move your arms and legs, you can't speak and be heard. You are suffocating. It closes off the world to you in a most profound way so that all that is left of you is the thoughts in your mind, because you just aren't capable of doing anything, of interacting with the world at all.

There was a period of time where I didn't leave the house for two years. I was too weak to do it. That is the physical experience of it. You become a purely intellectual thing because you are no longer a physical creature at all", to conclude with:

"A weirdly beautiful gift the disease has given me is to appreciate everything in this world, even the things that you simply take for granted if you're well."

**Source:** <http://stan.md/2im4gv4>



# Chronic Fatigue Syndrome: A Kick In The Guts

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Research suggests that chronic fatigue is linked to gut bacteria and how our bodies convert food into energy.

What if your fatigue is so severe that you have had to substantially cut down on regular work, education or social activities? This is what people with chronic fatigue syndrome (CFS), or myalgic encephalomyelitis (ME), experience.

People with ME/CFS commonly experience headaches, muscle and joint pain, unrefreshing sleep, irregular heartbeat, shortness of breath and problems in thinking and memory. They may not be able to regulate body temperature, and experience visual disturbances and extreme photosensitivity, balance problems, and irritable bowel, among other symptoms.

**Chris Armstrong**, a researcher at the University of Melbourne's Bio21 Molecular Science and Biotechnology Institute and the Department of Biochemistry and Molecular Biology, is the lead author on some recent studies that associate metabolites and microbiota in faeces, blood and urine with ME/CFS.

Together with a clinician, **Dr Donald Lewis**, he has been obtaining urine, blood and faecal samples (after overnight fasting) from 34 people diagnosed with ME and from 25 people who are not affected. All participants in the study are women, as sex significantly influences results and also because proportionally greater numbers of women are diagnosed with ME.

With the help of his University of Melbourne supervisor, Bio 21 research group director **Associate Professor Paul Gooley**, **Mr Armstrong** used magnetic resonance spectrometry to explore whether there were any differences in the energy metabolism of people with ME/CFS.

He ran his samples through magnetic resonance spectrometers to look for changes in the levels of the major metabolites in faeces, blood and urine, which include the amino acids, glucose, short chain fatty acids (SCFA) and organic acids.

At the heart of the problem is energy – how our body metabolises food and converts it to a usable form of energy. Another part of the equation is our commensals: the bacteria in our gut, which also gain energy from our food.

Building on his lab's previous work, which found altered gut bacterial populations in patients suffering from ME/CFS, **Mr Armstrong** published findings showing changes of metabolites in the blood and urine of ME/CFS patients. These changes hinted at a slight but significant shift in the body's source of energy production: from sugars to amino acids. Also, **Mr Armstrong** observed that biochemical pathways associated with cell and tissue damage as a result of oxidative stress were more active.

The complexity of ME/CFS means that by its nature, the research spans a number of disciplines, particularly metabolomics, microbiology and immunology. Both of **Mr Armstrong**'s studies have been ground-breaking across these disciplines.

The results from his most recent publication confirm differences in gut microbiota in people with ME/CFS across blood, urine and faecal biofluids, as well as elevated levels of short-chained fatty acids (SCFA) at the expense of amino acids, due to more fermentation taking place in the gut of ME/CFS patients.

How can the bacteria in the gut be making people feel tired?

It's early days, but the research is hinting that the composition of the gut bacterial populations (good gut guys vs bad gut guys) could be skewing the body's metabolism away from obtaining energy from glucose in the process of glycolysis (glucose to energy), to gaining energy from fats and proteins.

This is akin to what our body does when it is starving and it may be a possible explanation for the lack of energy people have in ME/CFS.

More research needs to be done on how the energy metabolism pathways of our body (that is, the citric acid cycle) can be affected by gut bacteria.

"ME/CFS is a complex condition and to find the answer, we need to take a whole-body approach," argues **Mr Armstrong**. "And the new knowledge gained in metabolomics and systems biology will make it possible to delve into the complexity of our body's metabolism."

**Floriene Loder,**  
University of Melbourne

**Source:** <http://bit.ly/2jtyFZd>  
Extracted by MEGC

# On ERV's

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Viruses in genome important for our brain

Over millions of years retroviruses have been incorporated into our human DNA, where they today make up almost 10 per cent of the total genome. A research group at Lund University in Sweden has now discovered a mechanism through which these retroviruses may have an impact on gene expression. This means that they may have played a significant role in the development of the human brain as well as in various neurological diseases.

Retroviruses are a special group of viruses including some which are dangerous, such as HIV, while others are believed to be harmless. The viruses studied by **Johan Jakobsson** and his colleagues in Lund are called endogenous retroviruses (ERV) as they have existed in the human genome for millions of years. They can be found in a part of DNA that was previously considered unimportant, so called junk-DNA -- a notion that researchers have now started to reconsider.

"The genes that control the production of various proteins in the body represent a smaller proportion of our DNA than endogenous retroviruses. They account for approximately 2 per cent, while retroviruses account for 8-10 per cent of the total genome. If it turns out that they are able to influence the production of proteins, this will provide us with a huge new source of information about the human brain," says **Johan Jakobsson**.



And this is precisely what the researchers discovered. They have determined that several thousands of the retroviruses that have established themselves in our genome may serve as "docking platforms" for a protein called TRIM28. This protein has the ability to "switch off" not only viruses but also the standard genes adjacent to them in the DNA helix, allowing the presence of ERV to affect gene expression.

This switching-off mechanism may behave differently in different people, since retroviruses are a type of genetic material that may end up in different places in the genome. This makes it a possible tool for evolution, and even a possible underlying cause of neurological diseases. In fact, there are studies that indicate a deviating regulation of ERV in several neurological diseases such as ALS, schizophrenia and bipolar disorder.

Two years ago, **Johan Jakobsson**'s team showed that ERV had a regulatory role in neurons specifically. However, this study was conducted on mice, whereas the new study -- published in the journal Cell Reports -- was made using human cells.

The differences between mice and humans are particularly important in this context. Many of the retroviruses that have been built into the human DNA do not exist in species other than humans and our closest relatives -- gorillas and chimpanzees. They seem to have incorporated themselves into the genome some 35-45 million years ago, when the evolutionary lineage of primates was divided between the Old and New World.

"Much of what we know about the overall development of the brain comes from the fruit fly, zebrafish and mouse. However, if endogenous retroviruses affect brain function, and we have our own set of these ERV, the mechanisms they affect may have contributed to the development of the human brain," says **Johan Jakobsson**.

**Source:** Science Daily January 17, 2017

<http://www.sciencedaily.com/releases/2017/01/170112110840.htm>

# New Study By Fluge, Mella & Tronstadt

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Metabolic profiling indicates impaired pyruvate dehydrogenase function in myalgic

New study by **Fluge, Mella & Tronstadt**, first published December 22, 2016

## **An abstract**

Myalgic encephalopathy/chronic fatigue syndrome (ME/CFS) is a debilitating disease of unknown etiology, with hallmark symptoms including postexertional malaise and poor recovery. Metabolic dysfunction is a plausible contributing factor.

We hypothesized that changes in serum amino acids may disclose specific defects in energy metabolism in ME/CFS. Analysis in 200 ME/CFS patients and 102 healthy individuals showed a specific reduction of amino acids that fuel oxidative metabolism via the TCA cycle, mainly in female ME/CFS patients. Serum 3-methylhistidine, a marker of endogenous protein catabolism, was significantly increased in male patients. The amino acid pattern suggested functional impairment of pyruvate dehydrogenase (PDH), supported by increased mRNA expression of the inhibitory PDH kinases 1, 2, and 4; sirtuin 4; and PPAR $\delta$  in peripheral blood mononuclear cells from both sexes.

Myoblasts grown in presence of serum from patients with severe ME/CFS showed metabolic adaptations, including increased mitochondrial respiration and excessive lactate secretion. The amino acid changes could not be explained by symptom severity, disease duration, age, BMI, or physical activity level among patients. These findings are in agreement with the clinical disease presentation of ME/CFS, with inadequate ATP generation by oxidative phosphorylation and excessive lactate generation upon exertion.

The main symptoms of ME/CFS are fatigue, post-exertional malaise, and lack of adequate restitution after rest or sleep, accompanied by cognitive disturbances and sensory hypersensitivity, including pain. The intensity of the symptoms is increased by exertion. Patients frequently suffer from additional symptoms ascribed to the autonomic nervous system or cardiovascular system, such as dizziness and palpitations, cold hands and feet, disturbed perceived body temperature, thirst, irritable bowel, and urinary urgency. Immune symptoms include recurrent sore throat and tender lymph nodes

Myalgic encephalopathy/chronic fatigue syndrome (ME/CFS) is a poorly understood disease of unknown etiology that affects 0.1%–0.2% of the population, according to Canadian consensus criteria. Compared with many other chronic diseases, patients with ME/CFS have a lower quality of life, with major implications for patients and their families and for society.

Recent research suggests that ME/CFS is associated with changes in fundamental processes of energy metabolism. Importantly, such metabolic changes may arise from dysregulated physiological response mechanisms that may be relevant in ME/CFS, such as immune activation, inflammation, and receptor-mediated signaling. However, there are no consistent data indicating a common metabolic defect that could explain the symptoms in these patients. Identification of responsible mechanisms is urgent in order to understand the disease pathophysiology and for the development of clinical strategies to diagnose and treat the patients.

In conclusion, this study suggests that ME/CFS is associated with PDH impairment, leading to increased consumption of amino acids that fuel alternative pathways for ATP production. ME/CFS patient serum was found to increase mitochondrial respiration in cultured muscle cells, possibly as a compensation or adaptation to an inhibition of metabolic energy pathways. The physiological consequences of such defects are likely to include energy (ATP) deficiency and excessive lactate production, in agreement with the debilitating exertion intolerance seen in ME/CFS patients.

**Source:** <http://insight.jci.org/articles/view/89376>



# Studies by Science In Service of Humanity (SISOH)

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1st metabolomics study by SisoH

<http://www.sisoh.com/metabolomics-in-chronic-fatigue-syndrome/>

Our first metabolomics study was a collaboration between **Eric Gordon, MD** of Gordon Medical Associates and SISOH, with **Robert Naviaux, MD PhD** of Naviaux Labs at UCSD. We performed targeted, broad-spectrum metabolomics to gain insights into the biology of CFS. We studied a total of 84 subjects using these methods. Forty-five subjects from the Gordon Medical practice (n = 22 men and 23 women) met diagnostic criteria for ME/CFS by Institute of Medicine, Canadian, and Fukuda criteria. Thirty-nine subjects (n = 18 men and 21 women) were age- and sex-matched normal controls.

We found that targeted, broad-spectrum metabolomics of plasma not only revealed a characteristic chemical signature but also revealed an unexpected underlying biology. Metabolomics showed that chronic fatigue syndrome is a highly concerted hypometabolic response to environmental stress that traces to mitochondria and was similar to the classically studied developmental state of dauer. This discovery opens a fresh path for the rational development of new therapeutics and identifies metabolomics as a powerful tool to identify the chemical differences that contribute to health and disease.



2nd metabolomics study by SisoH

<http://www.sisoh.com/replication-metabolomics-study-with-paul-cheney-md/>

The second study is a replication study of our first published metabolomics study, in a continuing collaboration between SISOH and **Robert Naviaux**, and bringing in **Dr. Paul Cheney** in order to look at the metabolomics of a larger group of CFS patients. The Gordon Medical Research Center (GMRC) helped with some of the funding. This North American based CFS/ME study has finished enrolling patients as of August 2016, and will be completed soon.

Update 14.12.16: We are finished with the blood collection for the 2nd study! This is the replication study of the initial "Metabolic features of chronic fatigue syndrome," (<http://bit.ly/2el83rx>) with the replication testing being done with **Dr. Paul Cheney's** patients. The blood samples are all in and have been shipped to the Naviaux-lab to be analyzed. Very exciting accomplishment since the 1st study took a great deal longer to get samples in. We are moving in an upward and onward direction. Metabolic results and a new published study should be expected in 2017.

We also have found a device that stores and holds blood for shipping so we can start collecting samples from around the world. We know that we have a growing community of individuals who would like to participate in our AIMS research from overseas. We are still in testing mode with this and will update when we have confirmation that the container safely transfers blood.

If you would like to participate in the Analyzing Individual Metabolomics Study (AIMS), sign up now to be placed on the list <http://bit.ly/2lbJ8ZA>.



3rd metabolomics study by Sisoh, entitled AIMS - Analyzing Individual Metabolomics Study

<http://www.sisoh.com/analyzing-individual-metabolomics-study-aims/>

SISOH is currently organizing AIMS, with community based funding through the non-profit Gordon Medical Research Center (GMRC), and with advice from the Naviaux Lab at UC San Diego. AIMS will be our third metabolomics study, looking at how comprehensive metabolomics analysis can be used to evaluate CFS/ME. AIMS builds on our previous studies, which have demonstrated there is a clear metabolomic profile in patients with CFS/ME. This third study will be the first to look at how individual as opposed to population based metabolomics data can be used to evaluate CFS/ME and other poorly defined illness. SISOH's research study will be a community-sponsored investigation.



Update: <http://bit.ly/2l7nu94> (21.12.16):

In research the turtle wins the race. Things always move more slowly than anticipated. The AIMS-study is simultaneously recruiting participants and collecting funding. If you have sent in a form on the website or talked to us directly then you have been put in the queue for the study. Don't worry, we won't forget you!

This third study through SISOH will be the first to look at how individual as opposed to population based metabolomics data can be used to evaluate CFS/ME and other poorly defined illness. That means that if you have something other than CFS, you can also participate in the study. Remember we are also looking for age, sex, and illness matched controls who can participate. Encourage those you know to sign up, even if they are not a match for you. Controls are essential to being sure the study results are valid.

**Source:** <http://www.sisoh.com/>

# M.E. And Exercise Intolerance

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One of the critical diagnostic criteria for Myalgic Encephalomyelitis (M.E.) is intolerance of abnormally small amounts of activity or exercise.

By definition, M.E. patients experience what has been called “post-exertional relapse” (also sometimes called “post-exertional malaise” or “post-exertional neuroimmune exhaustion”), with their condition getting measurably worse following activity or exercise.

In more severe cases of the illness, relapse can occur for days or weeks following even brief mild activity.

Dozens of studies have looked at this abnormal response to exercise, uncovering numerous physiological abnormalities.

M.E. patients experience abnormally increased inflammation, oxidative stress, C4a complement levels and intramuscular acidosis after exercise. For them, exercise also results in abnormal gene and heat shock protein expression, decreased cerebral oxygenation, lowered mitochondrial ATP, and extended abnormal pH.

Most people get a variety of positive effects from exercise, including increased energy, better sleep and decreased sensitivity to pain. M.E. patients get the opposite: increased fatigue, insomnia, higher levels of pain and other negative symptoms.

Especially in the first years of the illness, M.E. patients often try to be active at a higher level than their bodies can tolerate. This generally leads to a “push-crash” pattern: a burst of activity is followed by an extended period of relapse and recovery.

Thus, a challenge for M.E. patients is how to remain even a little active without experiencing repeated “crashes.”

The issue of the role of exercise intolerance in “chronic fatigue syndrome” (a broader category that currently encompasses M.E.) has been a source of substantial confusion.

All established researchers looking at the illness (including those who suggest that very gentle “graded” exercise therapy can be better than no exercise for patients) acknowledge that exercise can be extremely harmful for individuals with M.E.

Unfortunately, many people and even some doctors are under the misconception that exercise can be substantially helpful or perhaps even curative for people with M.E.

To help sort out the confusion, following are some additional pages on the Paradigm Change site with information about this topic.

Medical Journal Articles <http://bit.ly/2IH95Ng>

More than two dozen peer-reviewed articles discuss the negative effects of exercise on patients with M.E. (studied as part of the broader condition of “chronic fatigue syndrome”).

Doctor and Researcher Quotes <http://bit.ly/1Spnfx9>

This page lists quotes from several dozen experts in M.E., discussing issues related to how exercise affects patients with the disease. Pictured: Research data on the topic provided by **Dr. Sarah Myhill**, M.D.

Problems with the PACE Study <http://bit.ly/2IH5UW3>

In 2011, a team of UK psychiatrists published a paper that has been misinterpreted by many people to suggest that exercise can be substantially helpful or even curative for M.E. patients. A discussion of issues with the paper is on this page. (Discussion: Patients in the “Graded Exercise Therapy” condition of the study used heart rate monitors to make sure that they did not go beyond a very low level of exercise, since the authors of the study acknowledged that this had the potential of making them much more sick.)

Submitted by **Els van Hoof**

**Source:** <http://paradigmchange.me/me-exercise/>

# Dr. Davis' Genetics Component update

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**Dr. Davis'** Genetics Component update:

"Our lab has received immune cells from the patient samples of **Dr. Naviaux's** metabolomics study.

We will conduct extensive DNA sequence analyses looking for alterations in the sequence that indicate decreased functioning of genes that might correlate with the variations in the metabolic results.

The goal is to determine if some of the differences in metabolites seen between patients can be explained by genetic differences. This analysis may explain some of the varied symptoms experienced by patients.

It is possible that what appear to be subtypes of this disease are caused by genetic differences interacting with a basic metabolic process. There could be a fundamental mechanism common to all ME/CFS patients.

We would like to find a treatment that impacts a fundamental mechanism."

**Ronald W. Davis, PhD**

**Source:** OMF News, February 2017

# Natural Treatments For Mild Cognitive Impairment-- Might These Also Help The "Fog" Of FM And CFS?

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Patients with ME/CFS or Fibromyalgia (FM) struggle with mental "fog". We don't understand why and there's been little research on why it happens or what to do. The Mild Cognitive Impairment or MCI of aging is a different kind of cognitive "fog". MCI confronts 5-20% of Americans, aged 65 and older. The risk is higher among people who have a high blood level of the amino acid homocysteine. High homocysteine and MCI both predicts a higher risk for developing full- fledged Alzheimer's Disease.

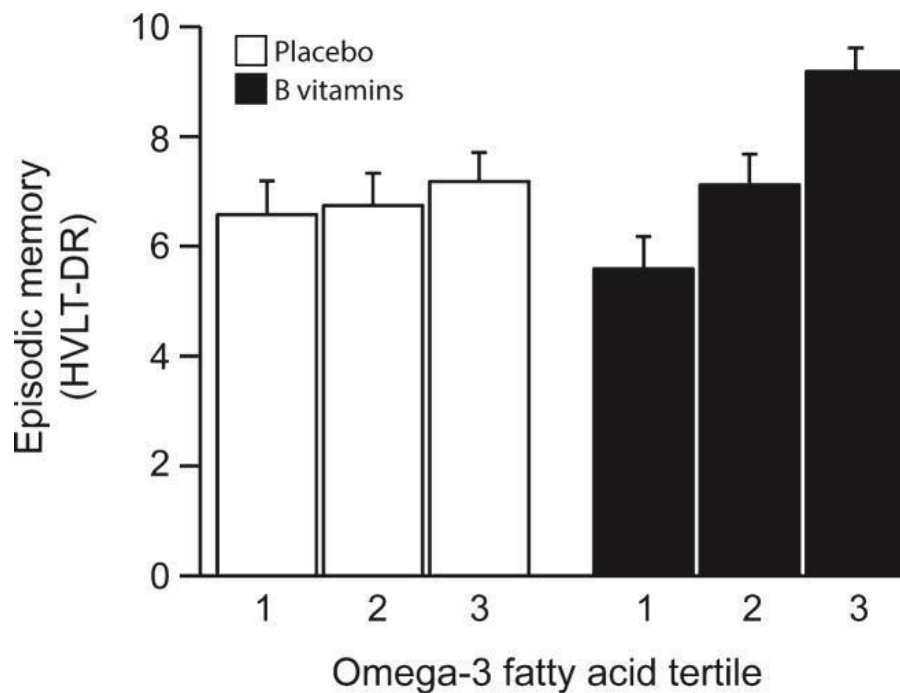
## **VITACOG Study**

We know how to reduce homocysteine with a relatively simple nutritional formula. To test whether a homocysteine lowering B vitamin complex might improve cognition for people with MCI, medical researchers in the United Kingdom recruited 266 people aged 70 and over, who had relatively mild problems with basic cognitive skills. This study of vitamins and cognition is known as the VITACOG study. Half the subjects were treated with a daily oral pill containing a moderate oral dose of vitamin B12 (500 micrograms), folic acid (800 micrograms) and vitamin B6 (20 mgs). The control group took a daily placebo. Several forms of cognitive testing were done prior to treatment and again several times during the two years of study.

## **Results**

For those taking the B vitamins, cognitive test scores improved over the two years of active treatment. Scores for the placebo group did not. The advantage for active treatment was statistically significant. The treated subjects who were most likely to improve were those who started out with high blood levels of homocysteine. Homocysteine levels fell in the treatment group, but did not fall for those who took the placebo. People with MCI also tend to have an increased rate of atrophy or loss of brain tissue over time. For those taking the B vitamins, the rate of brain atrophy was significantly slower than it was for those on placebo.

At the start of the study researchers also measured the level of omega 3 fats in the subjects' red blood cells. For those on the B vitamins cognitive improvement was much higher among those who began with relatively high levels of omega 3s. (Omega 3 fats are the kind found in fish oil.) Having enough omega 3-s on board seems to help the B vitamins do a better job. For those taking placebo, the level of omega 3s seemed not to make any difference in their scores.



The graphic shows the results of one of several cognitive tests used in the study. This one is the Hopkins Verbal Learning Test with Delayed Recall (HVL-DR). Those in the top third for their omega 3 blood levels (third tertile) did best.

### Beyond the study

Is the VITACOG study relevant to the brain fog of CFS and FM? The quick answer is we don't really know, because there's not been much study of our kind of "brain fog". However, they are relevant to us at least to this degree: If simple treatments can prevent the MCI associated with aging, there are some grounds for hope that our kind of brain fog might also improve.

**The strengths of the VITACOG:** Many studies of potential treatments for cognitive problems last only a few weeks or months. This study ran for two years. Many cognitive studies focus on lab rats. This one was done on people. Many studies lack proper control group. This study was well designed.

**Weaknesses:** Other studies using B vitamins to lower homocysteine and help cognition have had mixed results. Therefore, further controlled studies should be done to confirm the results found with VITACOG. We should also be aware that while high homocysteine also predicts increased risks for heart attacks and strokes, controlled studies using B vitamins did not succeed in improving health outcomes. All the more reason why we need more studies to further confirm VITACOG's more encouraging results.

**Thoughts to consider:** VITACOG suggests that the mild cognitive impairment associated with aging might improve if we treat with a homocysteine lowering strategy, combining B vitamins with omega 3 oils. Whether this strategy might also be useful for people with CFS or FM, we cannot yet say.

## What Patients Might Discuss With Their Physician

If you have MCI, or a family history of MCI or Alzheimer's:

- ✚ Consider measuring your fasting level of homocysteine. If homocysteine is high measure also vitamin B12, folic acid and vitamin B6.
- ✚ If homocysteine is on the high side, discuss whether or not you should add moderate doses of B12, B6 and folic acid to your supplements.
- ✚ Plasma or red blood cell levels of omega 3 oils can be measured by specialty laboratories. If on the low side consider increasing your intake of fatty fish or adding a fish oil supplement.

If your concern is with CFS or FM, understand that the VITACOG findings might or might not be relevant to our type of cognitive "fog".

**Cautions:** Although the B vitamin doses used in this study are only "moderately" high and are typically thought to be safe, there have been reports that high blood levels of folic acid might increase the risk for some cancers. The 800 ugm dose of folic acid used in the VITACOG study is only double that of the current recommended dietary allowance. However, other vitamin formulas used to treat homocysteine often contain considerably higher folate doses. Please read the labels.

Also, most nutritionally oriented physicians prefer that people take the natural methyl folate form of this vitamin, not the synthetic folic acid that most vitamin supplements use.

### Key references:

Homocysteine-Lowering by B Vitamins Slows the Rate of Accelerated Brain Atrophy in Mild Cognitive Impairment: A Randomized Controlled Trial, 2010 <http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0012244>

Preventing Alzheimer's disease-related gray matter atrophy by B-Vitamin treatment, 2013 <http://www.pnas.org/content/110/23/9523.short>

Omega-3 Fatty Acid Status Enhances the Prevention of Cognitive Decline by B Vitamins in Mild Cognitive Impairment, 2016 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4927899/>

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**Richard N. Podell, M.D., MPH**  
<http://www.DrPodell.org>



# Rich Reviews - Powerful Proof That Symptoms Of Chronic Fatigue Syndrome And Fibromyalgia Are Real And Mainly Physical

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I interviewed **Dr. Alan Light, Ph.D** by Skype in a three part video series. His research is among the very most innovative and important in the fields of chronic fatigue syndrome and Fibromyalgia.



He, along with **Lucinda Bateman, M.D.** and colleagues from the University of Utah School of Medicine, has successfully conducted one study out of a very few that identify an objective laboratory marker which closely correlates with the patients' "subjective" complaint of prolonged fatigue after modest exertion.

This proves that the patients' subjective reports of post-exertional malaise (PEM) are honest, real and based on physical events. More details on this study and its significance can be found on the following three 10-minute videos and text below.

Segment 1: Provides background on why and how this research was developed:  
<https://youtu.be/ZZyXUL7CPks>

Segment 2: Provides details about this critical study  
<https://youtu.be/oyjuWwuKmFA>

Segment 3: Reactions from the scientific study and next steps  
<https://youtu.be/S3CmUJyVBbQ>

## Details of Study

**Dr. Light, Lucinda Bateman, M.D.** and colleagues from the University of Utah School of Medicine measured output of messenger RNA output from 13 selected genes. They did this just before, shortly after, and for 48 hours following very modest exercise on a stationary bicycle. The subjects included 48 patients with CFS with or without co-occurring FM, 18 patients who had FM but not CFS, and 49 healthy controls. The 13 genes monitored related to sensory nerve signaling, cytokine and immune function and the sympathetic nervous system.

## Results

All CFS and FM patients reported increased symptoms of pain or fatigue for a full 48 hours following the exercise. In controls, there was no reported fatigue and no significant change in gene expression. All subjects showed objective changes in the RNA output from key genes which also lasted a full 48 hours.

There were two distinct patterns of response: In 71% of patients with CFS moderate exercise increased messenger RNA output from 12 of the 13 genes. This was true whether or not they also had FM. Most of these genes related to inflammation or nerve signaling. In the other 29% of CFS patients, exercise caused a decrease in output of messenger RNA from an adrenalin related gene.

Many of these patients also had a clinical history of orthostatic intolerance (low blood pressure with prolonged standing). In contrast, the FM-only patients showed no post exercise changes in gene expression. Text on the full study and results can be found at <http://bit.ly/2kZuulM>

## Significance

By showing changes in gene output this objectively proves that the fatigue and pain are real and are mainly physical. **Dr. Light's** work appears to identify two different subgroups of CFS patients—one where pro-inflammatory genes turn on, and a second type where blood pressure tends to fall and an adrenalin related gene turns down its activity. **Dr. Light's** work also suggests that Fibromyalgia can occur in two different forms—one that is closely associated with CFS and one which is not.

## Dr. Rich Podell

<http://bit.ly/2jmwEkb>



## OMF's visit to the Sundance Film Festival

OMF had the privilege of being Producer/Director **Jennifer Brea's** guest for the world premiere of her film, *Unrest*, and subsequent screenings at the Sundance Film Festival. *Unrest's* sold out audiences gave **Jennifer Brea** heartfelt standing ovations. The premiere was attended by **Dr. Ron Davis**, his daughter, **Ashley Haugen**, and CEO/President, **Linda Tannenbaum**.

Question and Answer sessions were held at the Premiere and after screening throughout the week with the crew and special guests including **Dr. Ron Davis**, **Linda Tannenbaum**, **Dr. Janet Dafoe** and **Ashley Haugen**. The film is truly beautiful and something that the public needs to see.



Maximizing their time in Utah, OMF arranged several meetings to talk about ME/CFS research.

**Dr. Ron Davis** and **Linda Tannenbaum** met with Scientific Advisory Board members **Mario Capecchi, PhD** and **Baldomero Olivera, PhD** together with University of Utah's **Kathleen Light, PhD** and **Alan Light, PhD**.

**Dr. Davis** and **Linda** also had the opportunity to meet with **Lucinda Bateman, MD** and **Suzanne Vernon, PhD** of the Bateman Horne Center.



## Webinar with **Dr. Peter Row**

SMCI is pleased to announce our first research webinar of 2017.

On Thursday, March 16, we will welcome **Dr. Peter Rowe** to discuss pediatric/adolescent ME/CFS and neuromuscular strain, among other topics. Director of the Chronic Fatigue Clinic at the Johns Hopkins Children's Center and a professor of pediatrics, **Dr. Rowe** is also a member of SMCI's Research Advisory Council. To register for this webinar, go here <http://bit.ly/2lyFHwy>

Our webinar series, which features thought leaders from academia, industry, and government agencies, is always free of charge and usually takes place once a month on Thursdays at 10:00 AM PT/1:00 PM ET (unless otherwise specified).



## National Institutes of Health Director **Dr. Francis Collins** to Stay for Now

It has just been announced that **Dr. Francis Collins** will stay on board as director of the National Institutes of Health (NIH) for the time being. It is unknown if **Trump** will formally reappoint **Collins** or if **Collins** will stay in his job only until **Trump** appoints a permanent director.



## Announcing SMCI's New ME/CFS Advocacy Webinar Series

Want to be an advocate, but you're unsure how to begin? Introducing our new advocacy webinar series, Power to the Patients! (<http://bit.ly/2mbAirM>) Led by Advocacy and Engagement Manager **Emily Taylor**, this webinar series open to all will give advocates the tools needed to flex their citizen power just in time for congressional budget season.

Whether you're a newcomer or a seasoned advocate, join us on Thursday, March 2, at 10:00 AM PT/1:00 PM ET to learn 6 Ways to Maximize Your Congressional Advocacy Impact (<http://bit.ly/2mbAirM>). We'll also provide an overview of SMCI's congressional advocacy plans for 2017 and how you can help. The goal of this series is to empower existing ME/CFS advocates and activate fresh allies in our fight. Your voice can make a difference. Join the fight to solve ME/CFS by registering for this free, one-hour webinar here (<http://bit.ly/2mbAirM>).

Submitted by **Emily Taylor**

## New publication

NCNED is excited to announce the first published paper of 2017, with the following scientific article published in the Journal of Human Nutrition and Dietetics, titled "Dietary and nutrition interventions for the therapeutic treatment of chronic fatigue syndrome/myalgic encephalomyelitis: a systematic review".

<http://onlinelibrary.wiley.com/doi/10.1111/jhn.12435/epdf>

## NCNED describes calcium signalling disorder in CFS/ME

Our latest article (Nguyen et al., 2017) shows that certain ion channel receptors (called transient receptor potential ion channels or TRPs) responsible for calcium signalling in Natural Killer (NK) cells are defective, even when stimulated with their natural ligand.

We have used NK cells as a model to illustrate this pathology in all cells:

<http://onlinelibrary.wiley.com/doi/10.1111/cei.12882/full>

These current results indicate this ion channel is not functioning correctly and unable to modulate calcium in people with CFS/ME even when stimulated with its natural ligand, pregnenalone sulphate, under strictly controlled conditions.

As there are multiple TRP channels and autonomic receptors, we have identified these may also be implicated in this disabling illness.

We have clear evidence from at least two separate studies that these ion channels, as well as calcium and its signalling, are dysfunctional in CFS/ME.

Source: <http://bit.ly/2IVUbnd>

FB-wall of the NCNED at Griffith University, Goldcoast, Australia

# 9. News from

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# Australia

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## **Gold Coast researchers make chronic fatigue breakthrough**

In a world first, Gold Coast researchers have made an important breakthrough in understanding the cause of Chronic Fatigue Syndrome.

**Science Minister Leanne Enoch** said researchers from Griffith University's National Centre for Neuroimmunology and Emerging Diseases (NCNED) have found strong evidence that chronic fatigue syndrome was associated with a dysfunctional immune system.

"The research team, led by **Professor Sonya Marshall-Gradisnik** and **Professor Don Staines**, have identified a dysfunctional cell receptor in the immune system which seems to be at the core of the problem," **Ms Enoch** said.

"This discovery is great news for all people living with Chronic Fatigue Syndrome (CFS) and the related Myalgic Encephalomyelitis (ME), as it confirms what people with these conditions have long known - that it is a 'real' illness - not a psychological issue.

"CFS and ME are notoriously difficult to diagnose, with sufferers often going for years without getting the proper care and attention they need. Currently, there is no effective treatment.

"The Griffith University breakthrough now means we have a target for therapeutic intervention, which is welcome news to the 250,000 Australians believed to be affected by CFS and ME."

**Health Minister Cameron Dick** praised researchers for working hard to help people suffering from CFS and ME.

"According to ME/CFS Australia, the cost to the Australian community of CFS/ME diagnosis, treatment and management is estimated to reach more than \$700 million annually," **Mr Dick** said.

"But that is nothing compared to the devastating impact the conditions have on sufferers, along with their families and friends.

"I am thrilled that funding from our Government is playing a hand in changing people's lives for the better."

**Professor Marshall-Gradisnik** said Queensland Government funding had been critical in progressing the research.

“The Queensland Government has funded NCNED continuously since 2008, totalling about \$1.6 million all up, enabling the research centre to be a world leader in chronic fatigue research. This is the largest direct contribution of any government anywhere in the world to chronic fatigue syndrome research,” **Professor Marshall-Gradisnik** said. “It clearly demonstrates what can be achieved with critical government funding.”

The NCNED also received a \$4 million grant from the Stafford Fox Medical Research Foundation – the largest grant ever provided for CFS/ME research.

**Professor Don Staines** said this funding would be used to investigate the commercialisation of a diagnostic test the research team were developing as well as potential treatments.

“This is a huge boost to our research effort, enabling us to really look at how we can overcome this debilitating illness,” **Professor Staines** said.

Griffith Vice Chancellor **Professor Ian O’Connor** welcomed the ongoing support from the Queensland Government.

“The most effective research is now coming more often from powerful collaborations such as this,” **Professor O’Connor** said.

**Source:** The Queensland Government, <http://bit.ly/2IGGmMo>  
Tuesday, February 21, 2017



# Belgium

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The recently made decisions by the Minister of Public Health keep lingering. This is how the physiopathology statute got revoked for ME (CFS) patients, which now makes all medical procedures more costly for the patient.

Among these medical procedures are treatments of physical therapy. But medication itself is now also more expensive. For example, if you take many different drugs and therefore need a gastrointestinal strengthener such as Omeprazole, it's double the bad luck for you. "This medication is simply more expensive because many make excessive use of it", says the minister. An explanation that makes absolutely zero sense.

Regarding physical therapy, some time ago ME patients used to have the right to 60 yearly treatments that could be increased (albeit at a higher price), starting again each year. This will no longer be possible next year.

This year will see a transition to 18 treatments that cannot be extended no matter the circumstances. The people already possess the right knowledge to treat themselves, claims the minister. If only it wasn't the crass reality, I'd be rolling on the floor from laughter; now I'm doing that from the pain.

If you're an ME patient in Belgium, you're getting screwed over double; not only do you lose a large portion of your life, but a large portion of your income as well. We're already predicting an increasing amount of poverty among patients based merely on the increasing amount of distributed food packages.



"Prikkel" (a publication of the "Vlaamse Pijnliga") reports in their latest edition of February 2017:

"If you're suffering from ME (CFS) or fibromyalgia and are taking physical therapy, you can make notice of your complaints and shortages at the Vlaamse Pijnliga: [info@samana.be](mailto:info@samana.be) - Haachtsesteenweg 579 PB 40 - 1031 Brussel"



Petition: <http://bit.ly/2laRYXx>



The ME Association Belgium humbly invites you to be a visitor at the conference regarding the current scientific progress pertaining to Myalgic Encephalomyelitis (ME).

**Time:**

March 6, 2017

- In Dutch (primarily): 13:00-17:00pm
- In English: 18:00-22:00pm

**Where:** Thon Hotel Brussels City Centre,  
Rue des Croisades 3, 1210 Brussel - Oslo II Hall

**Registration :**

Fill in this form: (link)

Send payment via bank transfer (#IBAN: BE69 4326 3260 8178), writing down your name, last name, which conference and member ID (unless you don't have one)

**Prices:**

- members: €15
- non-members: €45
- professionals: €60 (credit provided)

**Program:**

**These are the speakers at the afternoon conference:**

Moderator **Peter Gielen**, Trefpunt Zelfhulp:

- Dr. Jo Cambridge** (UK) - What is ME/Current scientific situation
- Dr. Greta Moorkens** (België) - Endocrinology/Metabolic aspects
- Dr. Koen DeRaedt** (België) - RIZIV, current policies in Belgium
- Dr. Frank Visser** (Nederland) - Orthostatic intolerance
- Nancy Van Hoylandt**, Patiënt (België) - Quality of life
- Dr. Nigel Speight** (UK) - Children and ME

**These are the speakers at the evening conference:**

Moderator **Dr. Kenny de Meirleir**, Immunitas:

- Dr. Jo Cambridge** (UK) - What is ME/Current scientific situation
- Dr. Olli Polo** (Finland) - Physician's perspective on ME
- Dr. Simon Carding** (UK) - Mucosal Immunology/European ME Research Group
- Dr. Frans Visser** (Nederland) - Orthostatic intolerance
- Dr. Nigel Speight** (UK) - Children and ME
- Nancy Van Hoylandt**, Patiënt (België) - Living with ME
- Dr. Louise Brinth** (Denemarken) - Quality of life
- Dr. Elke Van Hoof** (België) - Burnouts vs. ME

More information can be found by following this link: <http://bit.ly/2kiTjfo>

# Canada

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Toronto: #MillionsMissing activists attended their federal health minister's "meet-and-greet" on Jan. 14th to ask the health minister to respond publicly to their request that she announce Myalgic Encephalomyelitis (ME) is a biological – and not psychological – illness.

The group brought a TV news crew with them to film (<http://bit.ly/2kBljev>) the encounter. When the health minister refused to give a satisfactory answer, one of the activists stood up on a chair and announced to the room of constituents that they should know about ME and its neglect. The health minister then agreed to set up a meeting to discuss their demands for ME. This tactic to pin down an official with a specific question in a public venue is called "bird-dogging." (<http://bit.ly/2mbJUTm>)

**Source:** MEAction <http://bit.ly/2IVA3lm>



## **ME/CFS Canadian Researcher Looking for Identical Twins**

A senior Canadian researcher has been looking for genetic factors in people with ME/CFS for several years. His studies have already yielded promising results. The next stage of his study involves looking at identical twins where both twins have ME/CFS ("concordant") or one of the twins has ME/CFS and the other does not ("discordant"). He has already found three sets of identical twins for his study but hopes to find more.

If you are identical twins with discordant or concordant ME/CFS, please contact me at [mefminfo@mefmaction.com](mailto:mefminfo@mefmaction.com) to learn more about the study and what it would involve from you.

I am interested in hearing from identical twins affected by ME/CFS anywhere in the world. There are two reasons.

- ✚ Firstly, while this researcher hopes to find enough cases in countries where he has collaborators (Canada, the US and New Zealand), he might need additional cases and might be able to work out suitable arrangements for twins in other locations to participate as well.
- ✚ Secondly, I suspect that other researchers will want to do twin studies. This will give us an indication of how easy or difficult it is to find volunteers and a list of possible volunteers. Please note that if a researcher asks me for names of twins, I will notify you about the study and ask you for permission to share your names; I will not give your names to researchers without notifying you and receiving your permission.

Please share this request widely. And if you know identical twins in this situation, please encourage them to contact me. Thank you!

**Margaret Parlor**, President, National ME/FM Action Network  
[mefminfo@mefmaction.com](mailto:mefminfo@mefmaction.com)

# France

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Millions Missing France fait partie d'une campagne mondiale pour la reconnaissance et l'avancée de la recherche pour l'encéphalomyélite myalgique.

Millions Missing France is part of a global campaign for the recognition and advancement of research for myalgic encephalomyelitis.

Event MillionsMissing 2017-We need you!

The situation of EM / CFS in the world is alarming: lack of resources, embryonic stage research, lack of treatment, non-recognition of the disease, minimal and often ineffective management of patients. However, it is difficult for us to protest against this situation and to make our voice heard.

Manifesting like AIDS activists or parents of children with autism do, is almost impossible because very few of us are able to walk long (or even very short) distances, or stand upright. Moreover, the stigmatization of this disease means that few people publicly admit to it. To combat this, a global event is organized both locally and on social networks so that patients can participate.

#MillionsMissing

Millions of broken lives...

We can't suffer anymore in silence

We need help!

Recruitment of volunteers / participants for the #MillionsMissing action day for patients with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome

Registration form: <http://bit.ly/2l1LQk4>

Avoir l'EM/SFC c'est comme,	To have ME/CFS is like
'Exister sans vivre'	To exist without living
'Laissez tourner le monde sans nous'	To let the world turn without us
'Passez sous un rouleau compresseur, chaque jour'	To pass underneath a steamroller, each day'
'Une voiture sans moteur'	A car without an engine
'Vivre dans un corps, qui ne répond plus'	To live in a body which doesn't respond anymore

Source: <http://www.em-action.fr/evenement-millionsmissing-2017/> (French)

# Japan

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Earlier this month I had an email from **Masako Mark**, the representative of "Mark House & Projects: May 12th ME/CFS Japan." (<http://www.markhouse-projects.com>) **Masako** translated the "Voices" film into Japanese and has distributed DVDs to the ME charities in Japan. They have used it very effectively to help with their fight for better recognition of the illness and better treatment for patients.

She tells me: "NPO Japan ME Association" (one of the main charities) is screening "Voices from the Shadows" again in Mitaka, in March."

I was very moved when she went on to write:

" Your film made such a huge impact and influenced the Japanese government. Still a long way, but now the research teams are studying ME/CFS as neurological and muscle related illness. NPO is making a film of their own, showing the real life of Japanese patients."

**Masako** also tells me about Spontaneous Cerebrospinal Fluid Leak Syndrome (SCSFLS) which seems to have been another of the missed diagnoses in ME patients. She says "It is a bit funny...., but more and more ME/CFS people in Japan are found to have these leaks. They don't know the relationship between ME and SCSFLS, but ME/CFS research team in Japan includes this as comorbidities." I wonder how often this is missed in patients in the UK?

According to WIKIPEDIA: "Spontaneous Cerebrospinal Fluid Leak Syndrome is a medical condition in which the cerebrospinal fluid (CSF) held in and around the human brain and spinal cord leaks out of the surrounding protective thecal or dural sac, of the dura, for no apparent reason..... A CSF leak is most often characterized by orthostatic headaches — headaches that worsen in a vertical position and improve when lying down. Other symptoms can include neck pain or stiffness, nausea, vomiting, dizziness, fatigue, and a metallic taste in the mouth (indicative of a cranial leak).

A CTM scan (a computed tomography myelogram) can identify the site of a cerebrospinal fluid leakage. Once identified, the leak can often be repaired by an epidural blood patch, an injection of the patient's own blood at the site of the leak, a fibrin glue injection or surgery.

SCSFLS afflicts 5 out of every 100,000 people. .... An alternate method of locating the site of a CSF leak is to use heavily T2-weighted MR myelography."

## Natalie Boulton

Source: Voices from the Shadows, <http://bit.ly/2lqZkCR>

# New Zealand

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## The Buddy System

New Zealand known as the 'shaky isles', is a seismically active country experiencing a record breaking 32,828 earthquakes in 2016. There were also 80,000 landslides, two tsunamis and a volcanic eruption to cap off a year described by GeoNet (the national organisation for geological hazard information for New Zealand) as a 'ground-breaker'.

Late evening in November 2016 a 7.9 earthquake struck Kaikoura on the West Coast of the South Island, devastating properties, access roads and infrastructure. Fortunately, Kaikoura is a sparsely populated so given the severity of the earthquake there were limited fatalities. The main earthquake and subsequent numerous after-shocks were followed by several days of torrential rain and flooding then a tornado struck the Kapiti Coast where I live. It was to put it mildly, an eventful time!

We kiwis are taught from an early age what to do in the event of an earthquake or natural disaster - drop, cover, hold ie drop to the floor, get under cover and hold on. Every home, organisation and enterprise is urged to have an emergency survival kit and emergency action plan. These are required by law for all government departments, commercial operations and work premises.

WellMe (the Wellington, New Zealand support group for those with ME/CFS, Fibromyalgia and related conditions) has the formalisation of an emergency action plan as part of its strategic plan. Living in New Zealand, WellMe is especially vigilant around emergency or life events and are aware when members go 'off radar', actively following up to check their wellbeing and whether support or assistance is required.

Last year, the Kapiti Support Group lost two members in quick succession - one from a medical emergency and one from suicide. Both members were reclusive and very private with the person who suffered the medical emergency refusing to give her address for our records. We were aware immediately something was amiss on the day of the medical emergency as she did not return our calls - we were extremely concerned.

Despite numerous efforts to contact, visiting where we thought she lived and at the risk of intruding on her privacy and causing offence, assistance was sought from the local Police. They advised our member had died of a medical emergency at the very time we had noted her going 'off radar'. It took several days to ascertain the fate of the member who committed suicide. Both processes were rather harrowing to the person who undertook them.

Although WellMe had done everything in its power to locate these two members and had taken immediate action, it was felt that, as well as the formal emergency action plan, a peer based support network would provide an environment where our reclusive members would feel more comfortable disclosing their physical address to their 'buddy' – hence the birth of our 'buddy system'.

WellMe has always encouraged peer to peer support within its Support Groups and to strengthen this already existing informal grass roots peer to peer support system, we introduced the 'buddy system' for the Kapiti Support Group, the Group directly affected by the two deaths. This 'buddy system' involves members teaming up with one or two others and swapping contact details.

We actively encourage those members to check in with each other between meetings and to relay any concerns about their 'buddy' to their Community Support Coordinator. Any support or assistance can then be supplied without delay. This 'buddy system' enables our members to communicate with each other, provide peer support on a one-to-one basis, strengthen their relationship providing greater social connectivity and less isolation for both parties.

Immediately following the Kaikoura earthquake (which was felt throughout WellMe's region) the buddy system was activated with global emails to all Kapiti and Levin Support Group members. We also telephoned all those without internet access. The Kapiti based Community Support Coordinator had an 'open home' and every effort was made to ensure those living alone were accounted for - no one was left unsupported.

WellMe also contacted those of it's more vulnerable members from other local Support Groups, especially those high-rise and apartment dwellers in Central Wellington City where some buildings sustained damage. No one was left unsupported.

In the Support Groups where the buddy system has been implemented, we have an open email policy where all email addresses are visible to global email recipients. We check with new members whether they have concerns around privacy - to date there have been no concerns.

Many WellMe members live alone and have minimal support systems. Often, support groups are their only social connection. WellMe is aware the stress following traumatic events can trigger flares and a stress response where feelings of fear, isolation and powerlessness can surface.

A buddy system is one way we can ensure our members are supported at every level. WellMe's focus, its prime objective, is to ensure those within the WellMe community feel supported and part of something bigger than themselves.

### **Sandra Forsyth**

Vice Chair, WellMe

Wellington, New Zealand

# Norway

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The Norwegian ME Association (ME Forening <http://www.me-foreningen.info/>) is glad about the great amount of publicity.

For more than 25 years, the Norwegian ME Association worked to improve the situation of ME patients in Norway. In this period, we have seen a growing awareness and understanding of the disease, but there are still many patients who have trouble getting proper evaluation, follow-up and care. The ME Association is doing its utmost for some of their sickest patients.

The research going on at Haukeland Hospital has attracted lots of attention for the disease.

It also looks like the awareness about ME as a physical sickness is increasing in Norway, although we still have a long way to go.

Besides of that, we are busy starting to implement the new strategic document approved at the national Congress last November.

As the Parliamentary elections are bound for this year, we are also planning to push the political parties to do more in respect to ME.

Besides of that, these days all the regional teams are preparing for their annual meetings this spring. So the activity is speeding up as days go by.

Submitted by **Olav Osland**



Norwegian Prime Minister concerned about young ME-patients

Norwegian media have reported the **Prime Minister Erna Solberg's** concern for young ME-patients.

Last year she asked Ministry of Health and Care Services to find out how many young people have ME. On Monday February 6, 2017, the report was given to her, and showed that about 270 pupils were absent from school last year for more than three months due to ME.

The prime minister is worried the number might be even higher.



She says to the newspaper Aftenposten:

- These are conditions that may not have received enough priority because they do not fit into obvious categories. It's not like when a child has cancer. Then the hospitals and communities know what they should line up with.

From the article:

- ✚ 27 percent of the municipalities/districts and 44 percent of the counties have indicated that the figures are incomplete, but according to the Government, this are the best numbers you can expect to get now.
- ✚ Overall 1877 pupils were absent for more than three months in the previous school year. 735 had another known diagnosis than ME, and 873 had unknown diagnoses. 14 percent of the long absence is explained by ME.

More articles on this:

Adresseavisa: "This strikes a lot of families" <http://bit.ly/2knEaEN>

NRK: "Erna wants to help young people with ME" <http://bit.ly/2IHv5IT>

Google translate version of the first link - <http://bit.ly/2IfvL7r>

Google translate version of the second link - <http://bit.ly/2jUewHs>

Google translate version of the third link - <http://bit.ly/2kyPO1y>

**Source:** Health Rising & **Tom Kindlon's** ME CFS related

**Page:** <http://bit.ly/2kRE9ga>

# Northern Ireland

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On January 11 Joan Mcparland, **Martina Marks**, and **Sally Burch** attended a Patient and Client Council Steering Group meeting on ME.

The top news from the day, is that **Dr. Christine McMaster**, Specialist Registrar, Department of Public Health Northern Ireland, has been tasked with moving the ME clinic situation forwards, and with appointing a new medical consultant lead for ME services in Northern Ireland.

**Dr. McMaster** is keen to work with patient groups, and has asked a small focus group to help her re-draft the documentation for the new position. She was also willing to discuss how patients might be involved in the selection process for this clinical lead.

On top of this she said she would be talking to **Professor Julia Newton** of Newcastle University to find out about problems related to ME such as POTS.

Further **Dr. McMaster** suggested that the re-advertisement of this post could be at national level, perhaps in the British Medical Journal. She wants this to happen as soon as possible. When patients expressed concerns about the need to find the right person (i.e. somebody who regarded the illness as having a physiological aetiology), she was quick to declare that - we simply wouldn't employ the wrong person!

This was backed up by **Iain Deboys** who assured us that a psychiatric lead was out of the question.

Tempering this good news, was an awareness that the service will still be understaffed compared to what we want, and that paediatric services will unfortunately have to come after the main adult service is established.

However, our general feeling after this meeting was one of optimism and hope for the future.



Additional good news includes:

Agreement, within the steering group, to call the illness Myalgic Encephalomyelitis (ME) and to remove references to CFS.

Assurance that the NI GP Intranet will still advertise the offer made by Hope 4 ME & Fibro NI to distribute information packs, including a copy of the Canadian Consensus Criteria, to GPs. (Available since 2012)

An agreement that the Health and Social Care Board would support our May conference by advertising it to healthcare providers, medical professionals and GPs.

**Lorraine Henry**, the lead on the Condition Management Programme, was present. She totally understands the problems of ME and assured us that GET was not part of her CMP programme.

She was very concerned that there is no specialist help available for the most severe patients, as some of the mild/moderate patients on her list are now severe. The plight of the most severe was something the whole room felt strongly about, and it was agreed this would be an issue that the new lead would need to address.

2017 is certainly looking hopeful!

Submitted by **Joan McParland & Sally K. Burch**

# South Africa

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ME/CFS Foundation South Africa just applied for Public Benefit Organization Status, part of which was the following description. As this is a memorable step, we publish the entire text as it has been submitted to us:

As the Foundation was in its infancy and had no defined projects, there was a wide range of activities undertaken in line with its general goal of alleviating the suffering caused by ME/CFS and the misunderstanding thereof.

These included the following:

- ✚ Poor and needy ME/CFS patients were identified in their communities to start making a business plan regarding the establishment of care facilities.
- ✚ The Foundation used social media extensively for raising awareness and advocating the rights of patients with ME/CFS.
- ✚ Media coverage:
  - ✚ Up to now, the Foundation has done seven radio interviews with small radio stations and secured an insert on a national TV program in early 2017.
  - ✚ The Foundation conducted eight interviews together with ME/CFS sufferers for municipal newspapers and one online magazine.
  - ✚ The feedback received (i.e. almost all contact with patients) was a result of the radio interviews, newspaper articles, the Foundation's Facebook page and website.
- ✚ Compiled and distributed pamphlets with valuable information regarding the illness.
- ✚ Registered with local business forums and attended networking sessions to build awareness and draw in potential partners going forward.
- ✚ Wrote/composed a song for the Foundation.
- ✚ Distributed pamphlets to pharmacies and doctors regarding the illness and these initiatives.
- ✚ Contributed to International ME awareness month (which is in May) and participated in the first round of the Global #MillionsMissing initiative to spread awareness of ME/CFS worldwide.
- ✚ Liaised and formed networks with overseas ME/CFS communities and organisations and participated actively in the second round of the Global #MillionsMissing on 27 September 2016.
- ✚ Organised for the provision of counselling to certain severely ill patients.
- ✚ Played a role in the growth of the closed support group for ME/CFS sufferers in South Africa which also provides counselling to severely affected patients.
- ✚ Made initial contact the MEC for Health in Gauteng regarding their stance on ME/CFS. We received a formal reply from the Gauteng Department of Health on their take on ME/CFS as well as their indication that they would be willing to work "with" the Foundation thus opening the door for future projects.
- ✚ Initiated communication with a prominent University Professor in the Health Department and created a channel through which the latest research and information on ME/CFS can be shared.
- ✚ Launched a crowdfunding account.

- ✚ Shared various fundraising campaigns via social media.
- ✚ Most importantly, we have initiated the provision of medical care to certain patients and have organised for carers to attend to certain patients. This has formed the basis for the facilities mentioned above.
- ✚ Secured an insert on a national investigative journalism TV program.
- ✚ Applied for Public Benefit Organisation Status and Section 18A status"

Herewith our core activities as per the PBO application:

- ✚ The provision of health care services to poor and needy persons; and
- ✚ The care or counselling of terminally ill persons or persons with severe physical or mental disability, and the counselling of their families in this regard.

These objectives will generally be achieved through the following core activities:

- ✚ To provide healthcare and counselling services for those patients who cannot afford them;
- ✚ To raise awareness of ME/CFS; and
- ✚ To advocate for the rights and interests of persons living with ME/CFS.

Generally, the day-to-day activities of the Foundation will include:

- ✚ Securing and providing needed healthcare and other services to patients unable to afford them;
- ✚ Establishing care facilities for patients who are unable to afford their own medical care;
- ✚ Running public awareness campaigns and projects to educate people about ME/CFS and the challenges faced by ME/CFS patients, both diagnosed and undiagnosed, and their families;
- ✚ Engaging the media to raise the profile of ME/CFS as a serious medical condition;
- ✚ Creating a network of experts and supporters to assist with the provision of healthcare and counselling;
- ✚ Being a repository of knowledge and resources for the benefit of patients, their families and carers, the medical profession and other interested parties;
- ✚ Lobbying the medical profession to see ME/CFS as the chronic medical condition it is, to treat patients with dignity and respect and ensure they receive appropriate medical treatment;
- ✚ Engaging the Department of Health to advocate for appropriate accommodation of patients in the public healthcare system;
- ✚ Developing, and keeping updated, training materials based on cutting-edge scientific research on ME/CFS for use in the public and private healthcare sectors for the benefit of patients;
- ✚ Participating in, and contributing to, relevant research; and
- ✚ Conducting any other activities that may be necessary, useful, or desirable for the furtherance or accomplishment of the Objectives.

The ME CFS Foundation South Africa NPO has just heard its application for Public Benefit Organisation Status and Section 18 A status has been approved by SARS. This will open doors for it donation-wise and it can now issue tax receipts for donations.



Submitted by ME-patient and initiator of the foundation  
**Retha Viviers**

# Sweden

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## Expressen tells of severe ME

On 25th of January the Swedish newspaper Expressen shed light on how it is to live with the severe variant of ME in a couple of items and a feature of Expressen TV. Seriously ill **Karin Eriksson** told about the agonizing pain, the burning and weakness in the muscles, the almost total lack of energy, impact sensitivity and severe disability. <http://bit.ly/2IrlPuU>

In a small bedroom in the green house in Upplands-Bro outside Stockholm lies **Karin Eriksson**, 32. She is often blindfolded and has headphones on to block out impressions. She lives like that almost around the clock. She and her partner **Henrik Fransson**, 36, dreamed of getting married, having children, and make more ski trips and mountain hikes. The dreams of the future were crushed when **Karin** was affected by the neurological disease ME.

'I feel crap as always. This is a terribly debilitating disease. When you feel at your worst you're not capable to say a word or move a finger. There is no energy in the body', says **Karin**. **Karin** suffers from the neurological disease ME since seven years. Already for five years, she lies in bed virtually around the clock, isolated behind her blindfold and earmuffs. 'I have no life at all. It is ruined on just about everything', says **Karin**.

The construction of the couple's dream home has stopped. The staircase to the upper floor is located in parts of the kitchen floor. **Karin** is too ill to leave her room for a whole day, therefore the staircase cannot be done. 'It is so with ME. You can't continue to decide anything because **Karin** is able to discuss something only for a minute at a time. To choose the color of the house took a whole month.

**Karin** has still not been in the garage or seen the front of the house. She has not been able to go out. It feels more like it's my house and my life than her, even though this is something we could do together', says **Henrik**.



## ME-Training for GPs in Sweden

On February 6, 2017 doctors specializing as general practitioners in the county of Södermanland, Sweden, were given education on ME.

The all-day training included a two-hour lecture on ME, including diagnostic criteria (Canadian Consensus Criteria), medical examination and the importance of differential diagnostics; current research and theories on disease mechanisms; available treatment and symptom management. The international guidelines for diagnostics and treatments were handed out (IACFS/ME Primer).

The training was given by **Johan Edsberg**, Consultant Physician, Internal Medicine.

# The Netherlands

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In this edition, we will be paying attention to four teens who organized a collection/sale program for a prominent Dutch patient suffering from ME, **Anil van de Zee**.

And, for the last time, attention to the petition "ME isn't MUPS" which is still up and running until March 15th. Please sign it to help out your fellow Dutch patients!  
<http://bit.ly/2e2Nsq7>

At the behest of the Dutch Parliament and in response to a civil initiative to recognize ME as a bio-medical illness, the Dutch Health Council is digging into the current state of affairs surrounding ME, which they persistently label as ME/CFS. The Health Council has appointed a special committee comprised of ten members—four of which serve as paragons for the MUPS or BPS view of ME. One member has also been elected through the petition group and one of the three largest patient associations in the Netherlands.

This has already been part of the formula intended to handwave what was being requested by the bi. Even if the committee has been operational for almost a year and even if the final advice is expected to be delivered before the summer of 2017, it is and always will be important for patients to be vocal, for them to let it be known they desire a different setup of the committee.



## Half a year of ME Central

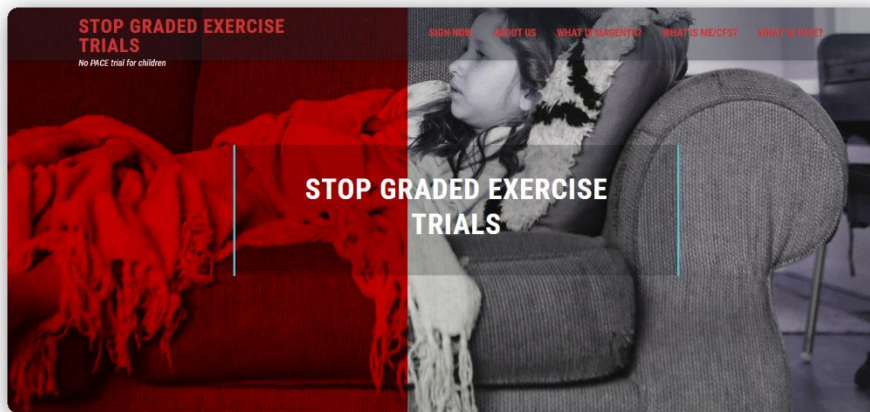
Since half a year, an ME Facebook page exists which brings forth a new item every day, e.g. columns, discussion of scientific articles, grassroots news and quotes. Even if the lion's share is published in Dutch, the page still provides the sufficiency given the interest regarding the subject matter. We hope we'll be able to post more English language-articles over the course of the year.

<https://www.facebook.com/MECentraal/>

Have a gander, and don't forget to leave a like. That also morally supports your fellow ME patients in the Netherlands.

If you have articles and news stories you'd like to bring to the attention of the Dutch ME community, send them to: [MECentraal@gmail.com](mailto:MECentraal@gmail.com)





STOP Graded Exercise Trials (<http://www.stopget.org/>)

## **No PACE trial for children**

This is a relatively new but most professional site which is worth our attention from all over the world. It is hard to believe but after the debunk of the PACE-trial the BPS-school in Great-Britain only seems to have gained in power and brutality. Let us try and stand up from all over against this form of terrorism against the ME-community, as these guys exercise their influence in all countries, not only in the UK. So have a look and sign what you're able to sign:

<http://www.stopget.org/sign-now/about-us/>

## **About Us**

We are a group of patients who have serious concerns about the use of graded exercise therapy for the treatment of people with ME.

Patient surveys report serious harm from graded exercise therapy in ME. We have also heard from friends that they have been permanently harmed by graded exercise therapy: that they have not recovered even years later.

We feel that graded exercise therapy is a risky treatment option for ME. We are further concerned that trials for this therapy are ongoing, and that the therapy is now being trialed on children. This site and the petitions linked on it are a result of our concerns about the inappropriate use of graded exercise therapy as a treatment option for ME.

One of the testimonies on the home pages goes:

“7th July 2016, my partner and I are drinking our morning coffee and reading our devices in bed. I come across the ME Association’s tweet that a “Bristol group publish protocol for study of Graded Exercise Therapy in children and young people with ME/CFS”. I feel shocked, almost winded when I read about it. It is widely reported that graded exercise causes relapses. My sister had ME as a child and I imagine the horror of her being pushed to increase exercise to a schedule, without the agency we have as adults to fully consent.

My partner and I are Bristol graduates, fairly recently my partner worked there. For this to be coming out of the University of Bristol feels more personal. My partner says “You have to do something to stop it. You can’t just moan and let it go on”. All day I can’t get the Manic Street Preachers’ song ‘If you tolerate this, then your children will be next’ out of my head.

Graded exercise is not a treatment for ME. It is an anti-treatment. It must be stopped.”

—**Jenny**

The MAGENTA study looking at Graded Exercise Therapy for children seems to be a disaster in the making. How many children will be harmed when they are encouraged to exercise with a condition that is made worse with any exertion? “

—**Sally**

# Wales

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## Blaenau Gwent well-being assessment

The well-being assessment will be used to inform the development of priorities upon which the well-being plan for the area will be based. This draft has been influenced by feedback from the consultation held in the summer of 2016.

The Blaenau Gwent Public Service Board invites you to give your views until the 28th February 2017 in the survey (<http://bit.ly/2IG3uXM>)



Do you look after a relative, friend, or neighbour who has a disability or is unable to manage on their own?

Dewis Centre for Independent Living is running events for adult and young carers in Gwent to find out how much people know about Advocacy and what support is available.

Advocacy is a process of supporting and enabling people to:

- Express their views and concerns
- Access information and services.
- Defend and promote their rights and responsibilities.
- Explore choices and options

Young carers: already took place on Tuesday 14th February 2017

Adult carers:

- Abertillery Sports Centre, Alma Street, Abertillery NP13 1QD
- 10am – 12pm on Monday 27th February 2017

**Cake will be provided!**

Transport and respite will be available on request.

If you'd like to attend, please contact **Laura Lees** 01633 288440 07375 510713  
[laura.lees@dewiscil.org.uk](mailto:laura.lees@dewiscil.org.uk)

**Source:** WAMES <http://bit.ly/2kdnAaM>

# 10. Events

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# 12th Invest In ME Conference

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News of the 12th Invest in ME Conference in London, June 2, 2017

Pre-conference dinner speaker

Our pre-conference dinner takes place on the evening before the [#IIMEC12](#) Conference.

This year we are proud to announce that **David Tuller DrPh**, - academic coordinator of University of California Berkeley's joint masters program in public health and journalism - will be giving the pre-conference dinner presentation.

**David** has performed a magnificent piece of journalism by analysing the PACE Trial.

We will not give away details of **David's** presentation at the dinner - but the working title is Tear It Up!

More details at <http://bit.ly/2kocUWI>

We are delighted that **Professor Ian Charles** - Director of the Institute of Food Research and lead for the new Quadram Institute in Norwich Research Park - will be opening the conference.

**Professor Charles** spoke at our 2015 Conference.

The UK Centre of Excellence for ME hub at Norwich Research Park provides a unique opportunity to share the future of research into ME for UK and Europe for the next decade.

Also opening will be **Dr. Vicky Whittemore** from NIH in USA. We are very pleased to see **Dr. Whittemore** return to the conference and Colloquium as a great deal of dynamism occurred in last year's events and the events benefited enormously from her presence and input.

Other speakers announced for the conference / Colloquium include **Professor Simon Carding** from IFR/UEA, **Professor Ron Davis** from Stanford, **Professor Mady Hornig** from Columbia University, New York, and **Professor Maureen Hanson** from Cornell University in Ithaca, USA.

We also welcome back **Professor Olav Mella** and **Dr. Øystein Fluge** from Haukeland University Hospital in Bergen.

We hope to have other announcements shortly. Early-bird registration fees are in effect currently. The conference web site contains more information.



Register here

<http://www.investinme.eu/IIMEC12.shtml#register>

Agenda here - <http://www.investinme.eu/IIMEC12.shtml#agenda>

Venue Details here - <http://www.investinme.eu/IIMEC12.shtml#venue>

News of the conference can be found here –

<http://www.investinme.eu/IIMEC12-news.shtml>

“The #BRMEC7 Colloquium and #IIMEC12 Conference provide unique opportunities in Europe for sharing of knowledge, experience, ideas and collaboration for sound biomedical research into ME.

For our 2017 events we have representatives from most of the major institutes around the world, as well as participation from NIH and CDC.

To help our friends in other countries we have extended invitations - to the Canadian Minister for Health Jane Philpott and the Canadian National Research Council – and to the Dutch Health Council.

We continue to work for improvement in education and awareness of ME around the world.” Registration: <http://investinme.eu/IIMEC12.shtml#register>

Agenda as per February 19, 2017

Conference Schedule for IIMEC12 -- 2nd June 2017

- ✚ 08:55 Chair - **Dr Ian Gibson**: Welcome to #IIMEC12
- ✚ **Professor Ian Charles**, Opening Keynote Speech: A Centre of Excellence for ME
- ✚ **Dr Vicky Whittemore**, Keynote Speech: NIH Research into ME
- ✚ **Professor Sonya Marshall-Gradisnik** and **Professor Donald Staines**: Dysregulation of Transient Receptor Potential (TRP) ion channels and calcium in natural killer cells in CFS/ME patients
- ✚ **Dr Jo Cambridge**: Immunoregulation in patients with ME
- ✚ **Professor Simon Carding**: Gut Microbiota in ME
- ✚ **Jakob Theorell**: ME Research at Karolinska Institutet
- ✚ **Student Panel**: Q & A for Students Researching ME
- ✚ **Associate Professor Mady Hornig**

- ✚ **Professor Olav Mella**
- ✚ **Dr Øystein Fluge**
- ✚ **Professor Warren Tate**
- ✚ **Professor Ron Davis**
- ✚ Plenary Session - **Dr Ian Gibson**

About the speakers till so far:

**Dr Ian Gibson**, former Labour MP for Norwich North, worked at University of East Anglia for 32 years, became Dean of the school of biological sciences in 1991 and was head of a cancer research team and set up the Francesca Gunn Leukaemia Laboratory at UEA. In 2011 Dr Gibson received an honorary doctorate of civil law from UEA.

**Professor Ian Charles** joined the Institute of Food Research in May 2015 to lead the programme to develop the UK's new Centre for Food & Health to be based at the Norwich Research Park. **Professor Charles** has over 30 years' experience in academic and commercial research. His academic career has included being a founding member of The Wolfson Institute for Biomedical Research at University College London, one the UK's first institutes of translational medicine. His current research interests include infectious diseases as well as the microbiome and its impact on health and wellbeing.

**Dr Vicky Whittemore** is Program Director in the National Institute of Neurological Disorders and Stroke at the National Institutes of Health in the United States.

**Professor Marshall-Gradisnik** is one of Australia's foremost researchers in the area of neuroimmunology. Much of her work relates specifically to autoimmunity in Chronic Fatigue Syndrome sufferers. Her research in the area of exercise immunology has also contributed to the body of knowledge relating to the effect of doping in sport and she serves as Sports Medicine Australia's national spokesperson in this area.

**Professor Staines** has been a public health physician at Gold Coast Population Health Unit. He has worked in health services management and public health practice in Australia and overseas. His interests include collaborative health initiatives with other countries as well as cross-disciplinary initiatives within health. Communicable diseases as well as post infectious fatigue syndromes are his main research interests.

**Dr. Jo Cambridge** is Principal Research Fellow Inflammation, Div of Medicine Faculty of Medical Sciences, UCL. Her group focuses its interests on B cell depletion (an idea which they introduced (with the Professor Jo Edwards) approximately 10 years ago, for the treatment of rheumatoid arthritis), exploring more precisely how the technique works and trying to explain the marked variation in response between different patients.

**Professor Simon Carding** is Professor of Mucosal Immunology at University of East Anglia and Institute of Food Research. His scientific interests are in understanding how the immune response in the gut functions and in particular, is able to distinguish between the commensal microbes that reside in the gut and environmental microbes that cause disease, and in the mechanisms by which the body's immune system no longer ignores or tolerates commensal gut bacteria and how this leads to immune system activation and inflammatory bowel disease.

**Jakob Theorell** is **M.D./Ph.D. student**, Center for Infectious Medicine, Department of Medicine, Karolinska Institutet, Stockholm, Sweden. His work focuses on understanding the mechanisms of disease in patients suffering from chronic immunodeficiency syndromes

**Ass.Prof. Mady Hornig**, MA, MD is a physician-scientist in the Center for Infection and Immunity (CII) at the Columbia University Mailman School of Public Health where she serves as Director of Translational Research and is an associate professor of epidemiology. Her research focuses on the role of microbial, immune, and toxic stimuli in the development of neuropsychiatric conditions, including autism, PANDAS (Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal infection), mood disorders and myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS).

**Professor Mella** has performed clinical trials to test the benefit of B-cell depletion therapy using Rituximab in ME/CFS patients. He began his investigation of Rituximab's effects on CFS after treating several Hodgkin's Lymphoma patients who had long standing cases of CFS prior to developing cancer. Together with **Dr Fluge** he has published a paper "Benefit from B-Lymphocyte Depletion Using the Anti-CD20 Antibody Rituximab in Chronic Fatigue Syndrome. A Double-Blind and Placebo-Controlled Study"

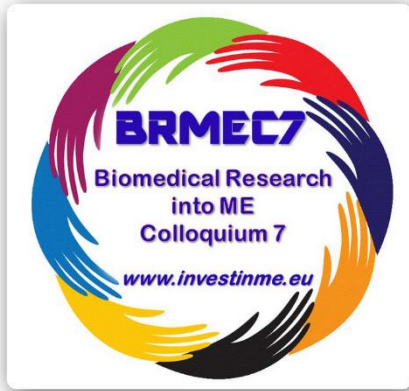
**Dr Øystein Fluge** is a specialist in oncology since 2004. He has worked as a Research Fellow with support from the Norwegian Cancer Society and is now chief physician at the Cancer Department, Haukeland University Hospital. Doctoral work emanates from the Surgical Institute and Department of Molecular Biology, University of Bergen.

**Prof. Warren Tate** from New Zealand is an internationally respected biochemist and molecular biologist, whose research has revolutionized understanding of how proteins are synthesized in living cells and contribute to memory formation and neurological disease, which has important implications for Alzheimer's disease, HIV and ME.

**Prof. Ron Davis**, a professor of biochemistry and genetics at Stanford School of Medicine, is a world leader in the development of biotechnology, especially the development of recombinant DNA and genomic methodologies and their application to biological systems. He and his research team also develop novel technologies for the genetic, genomic and molecular analysis of a wide range of model organisms as well as humans.

**Source:** <http://bit.ly/2lvzrW8>



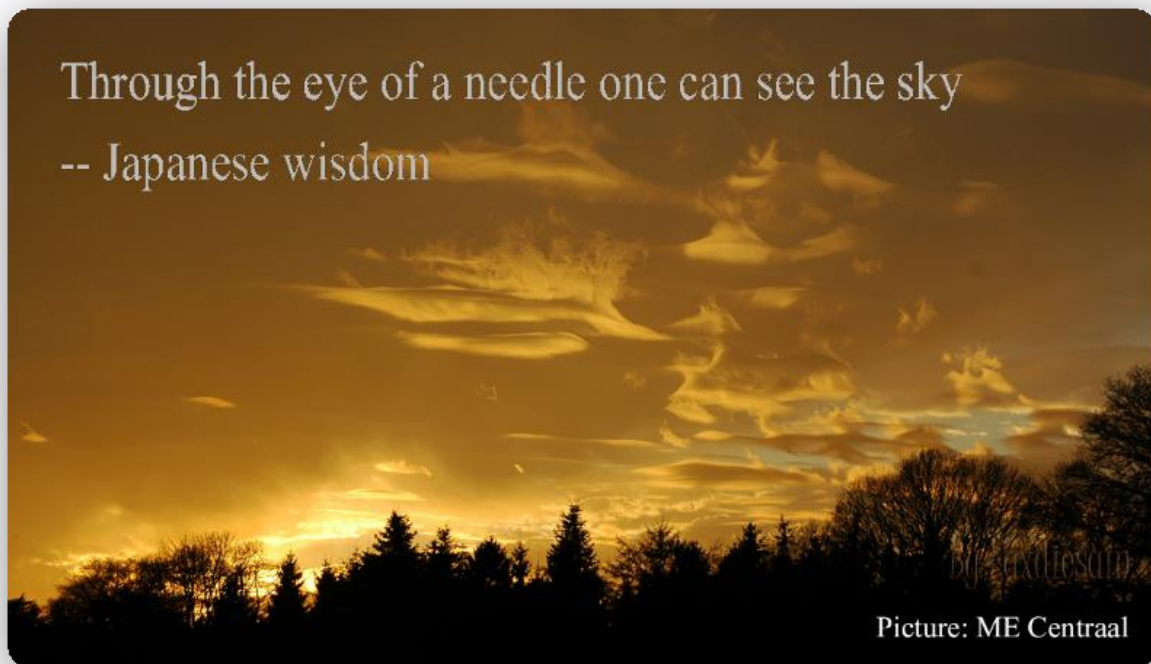


Our seventh Biomedical Research into ME Colloquium - #BRMEC7 - is taking shape and we are pleased to have some very interesting presentations planned from some researchers outside the field of ME as well as some who are at the forefront of research into the disease.

We have invited researchers from eleven countries so far.

More details at:

<http://www.investinme.eu/BRMEC%20Colloquiums.shtml#brmec7>



# Belgian ME Conference

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The ME Association Belgium humbly invites you to be a visitor at the conference regarding the current scientific progress pertaining to Myalgic Encephalomyelitis (ME).

**Time:**

March 6, 2017

- In Dutch (primarily): 13:00-17:00pm
- In English: 18:00-22:00pm

**Where:** Thon Hotel Brussels City Centre, Rue des Croisades 3, 1210 Brussel - Oslo II Hall

**Registration:**

Fill in this form: <http://bit.ly/2kBTQhu>

Send payment via bank transfer (#IBAN: BE69 4326 3260 8178), writing down your name, last name, which conference and member ID (if you have one)

**Prices:**

- members: €15
- non-members: €45
- professionals: €60 (credit provided)

**Program:**

These are the speakers at the afternoon conference:

Moderator **Peter Gielen**, Trefpunt Zelfhulp:

**Dr. Jo Cambridge** (UK) - What is ME/Current scientific situation

**Dr. Greta Moorkens** (België) - Endocrinology/Metabolic aspects

**Dr. Koen DeRaedt** (België) - RIZIV, current policies in Belgium

**Dr. Frank Visser** (Nederland) - Orthostatic intolerance

**Nancy Van Hoylandt**, Patiënt (België) - Quality of life

**Dr. Nigel Speight** (UK) - Children and ME

These are the speakers at the evening conference:

Moderator **Dr. Kenny de Meirleir**, Immunitas:

**Dr. Jo Cambridge** (UK) - What is ME/Current scientific situation

**Dr. Olli Polo** (Finland) - Physician's perspective on ME

**Dr. Simon Carding** (UK) - Mucosal Immunology/European ME Research Group

**Dr. Frans Visser** (Nederland) - Orthostatic intolerance

**Dr. Nigel Speight** (UK) - Children and ME

**Nancy Van Hoylandt**, Patiënt (België) - Living with ME

**Dr. Louise Brinth** (Denemarken) - Quality of life

**Dr. Elke Van Hoof** (België) - Burnouts vs. ME

More information can be found by following this link: <http://bit.ly/2kiTjfo>

# 11. Poem – The Terrace As High As It Was

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The terrace as high as it was,  
carried me and so did the wind

I had forgotten, that company is  
more than spoken words or human  
faces

The wind the water the earth and all  
that lives in between that, igniting  
fire, had promised to carry me, so  
they did.

As I fell on the concrete, sobbing my heart out, I found a song again.

And I sing it.

For those who can no longer sing.  
For those who never learned to sing.  
For those who died too soon to know their own tunes but the rythm of their heart.

For those who are forgotten, dismissed, unheard, unseen and all situations in  
between.

For those whose hopes were raised for a better future and then were crushed all  
over again.

For those whose smiles are frozen and no longer real.  
For those whose tears became solid in a broken heart.  
For those who can sing and smile.  
For all of us - for we make it worthwhile

I sing. I sing. And I'll sing some more.

For I need to believe that dancing in my head, when in bed, not carried by my  
feet, is just as real, as those days when I stood on a party floor.

I need to believe.

So I will.

**Maja Marianne Hendrickx**

# 12. Column – The Story Behind Ostensible Disinterest In ME Patients

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Bent over forward with my head in my arms. A pillar shielded me from the sight of my employer on the day I came to re-integrate. My dream job. A dream shattered into a million pieces the day I fell ill.

It must have looked like disinterest. Reluctance. As if I had no desire to be there. Everything inside me was crying at that moment. I didn't have the strength to sit upright during that one hour. The strength, both physical and mental, to put in that little effort. The exhausted spots on my body, the pain, the muscle balance disorder, dizziness and fatigue went to great lengths to warn me of the fact that I was grossly crossing my own limits.

I persisted in trying it. It remained unseen. Wrongly explained. Aside from being seriously ill, I also lost my job. One I worked at from the bottom of my heart for years. It wasn't just my job. It was so much more.

Friendships faded away. There was a lack of energy to have a happy conversation over the phone. Within five minutes, I was lying on the couch, exhausted, my cheeks tomato-red from the exhaustion. No longer able to move or do anything at all. Having to refuse invitations to various trips. Even long-lasting friendships proved to be vulnerable to this illness. The fact that I couldn't go anywhere became a literal truth. One that kept being misunderstood.

Someone once said before passing away: "now I get what you mean". Yeah, that's what I think now too. The feeling of being on the verge of dying during an ME relapse remains all too known to me. A relapse in which you feel all of your energy being siphoned out.

Where you don't know if you'll ever snap out of it, still hearing everything but unable to respond. The relief that washed over me after I thought this had been it, and accepted I would most likely die, just before shifting out of it a moment later. The tears that kept flowing after that, without even crying. How does one explain that? To the normal sight, I was delightfully fast asleep.

Now I know that this is part of it all. The fact that my body seems to "shut off", figuratively speaking, but that it will eventually turn itself on again after a while.

Carrying conversations is something a person with ME proves to be nearly impossible at. To protect myself, I usually listen with half my ears. Disinterest? No, it's just that this way I can stay with you longer.



With those I hold dear. Those that make me willing to soon enough lay down on my bed again, completely fatigued. Those that make me willing to rest my head in my arms behind a pillar to give you the impression I'm still there for you. I'm sorry if it looks like disinterest if I give an incomplete answer, or find a way to conveniently end the conversation.

I'm sorry that I have to regularly ask you to talk more slowly because I cannot catch up. It's a survival strategy. One that's hurtful to me as well, but there is simply no other alternative.

Fortunately, life is still a big invitation for me. One I wish to accept with all my heart. Live and enjoy.

Even if every little bit of effort sickens me to the core.

To me, it is the love and desire for life itself, the adrenaline of the moment and a dose of happiness which makes occasional contact possible.

My truth and the story behind the ostensible disinterest in ME patients.

### **Rosa**

(**Rosa** is the penname of a Dutch ME-patient known by the editors)

# 13. Connecting You To M.E.

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**Leonard A. Jason, Ph.D.** DePaul University - Chicago, USA

"The future of the field is in connecting the many patient and scientific groups into one larger body that is united for change. Any events that bring people together across countries and organizations should be promoted."

*"The message is simple, we have more impact with numbers, and when we flex our collective muscles, then we become a movement like the civil rights, women's and disability revolutions of the 60s, 70s and 80s."*

The HIV/AIDS groups changed policy throughout the world, but they did it by keeping their focus on critical issues and demanding change, and although the voices in that movement were also divided, for a few things like increased funding and provision of services, they were all together."

