The ME Global Chronicle

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 # 16 – April 2016

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

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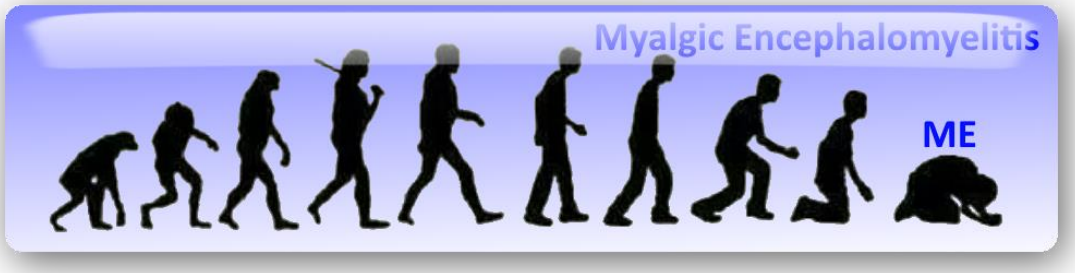
We as editors tried to make the magazine much more accessible by adding a link to each article as included in the Table of Contents, which gives you direct access to the article itself. Any suggestion is most welcome.



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

3. Introduction

Dear readers,

In this 16th issue of the ME Global Chronicle we continue following the course we announced and started in the February issue: focusing on some issues where we can throw our weight behind, all over the world. This in order to help arise global solidarity.

Currently the issues are:

- The Danish patient **Karina Hansen** who is living for over three years in psychiatric 'captivity'. In her case has came a perhaps decisive turning-point: Danish patients and the civil rights movement managed to find a very skilled advocate who is willing to defend her case. And there are sufficient keystones for. You can read everything about it in the impressive overview Valerie Eliott Smith wrote about Karina and her casus.

  This will bring along costs. Therefore, here and elsewhere in this issue we make an urgent appeal to everyone who is able to donate, even just minimal, to the fund Save4Children, of which all incomes will go to **Karinas**' casus until she is free: http://let-me.be/page.php?11

- The controversial appointment of some researchers in the study planned by the NIH. Around the time of publication, signatures of a petition initiated by **Mary Schweitzer** will be presented to **Francis Collins**, but you can try to vote against participation of **Drs Walitt**, **Gill** and **Saligan**, all three representatives of the biopsychosocial approach of the disease ME. Nonetheless, please still try to vote: http://bit.ly/1RU2Wdw

- The Dutch petition against the composition of the HC-committee that will reassess the disease ME on request of the parliament, in which four supporters of the biopsychosocial approach are represented. One of them is head of the Nijmegen Research Center Chronic Fatigue, whose executives like **Profs Van Der Meer**, **Bleijenberg**, **Prins** and **Knoop** published together with **Profs Wessely**, **Sharpe**, **Chalder** and **White**: http://bit.ly/1YtAEH8

- The increasing pressure on The Lancet to withdraw publications of the British PACE-trial and their follow-ups, and on Queen Mary University of London (QMUL) to let the publicists of the PACE-trial release the raw data of the trial and to respond substantive to the many flaws in the study as shown by fellow scientists.

In addition, as usual we pay attention to other grass-root activities, promising researches and news from several countries. We hope you can identify with the content, and are always open to constructive comments. Because you already know our motto from the very start of this magazine: This is a magazine by and for all of us.

The deadline for ME Global 17 is **June 10th**, **2016**. Your contributions can be sent to contribute@let-me.be

An as lovely as possible spring wished for all on the northern hemisphere and a wonderful autumn for those on the southern hemisphere.

The editors

4. Preface

Dear readers,

We are happy to submit the Spring issue of the ME Global Chronicle to you. Once more, many of you have expressed their appreciation and even gratitude for this initiative; your enthusiasm is the fuel that keeps our engine going.

The rites of Spring are here again. The longer evenings and blossoming flowers, crops and trees are joyful to behold. Hope anew is in the air. The NIH is continuing in its efforts to understand ME and it's biological dynamics, with its extra mural study and the extension of additional funding to ongoing ME research project is a good start. I contacted the top officials in the NIH and asked them to look at the infectious causes of ME and the complex immune, neurological and endocrine dysfunctions and mitochondria abnormalities in ME, see http://bit.ly/1oXQq0X. Much more is expected in these NIH studies and research funding.

Doctors and researchers continue to find Chronic Lyme disease and co-infections in 40 – 80% of ME patients. This is a very important finding as Chronic Lyme is identical to ME. Furthermore, there is an epidemic of Chronic Lyme worldwide, with a minimum of 300,000 people being infected every year in the USA. The real figure is believed to be higher. Many of these people are undiagnosed due to inaccurate and outdated diagnostic tests.

This is quite dangerous as Chronic Lyme is destructive to the joints, the nerves and the brain, the heart, the endocrine system, the muscles, the mitochondria and the immune system. Most people are given a vague and false diagnosis of ME, CFS, Fibromyalgia, Gout, Arthritis, Rheumatism, Depression, Multiple Sclerosis, Parkinsons, Alzheimers, Dementia. And left to rot and die, and take ineffective pain killers for years and decades. This is disgraceful neglect of ill patients. This issue is examined in some more depth at http://bit.ly/20BJqV6 and at http://bit.ly/1V1v2G7 from a treatment perspective.

The PACE trial authors still refuse to release important data from the trial, citing privacy concerns. Their concern over patient privacy is contradicted by the dozens of patient files which went missing or were stolen, due to lack of proper security procedures by the PACE trial authors. This non release of data is preventing proper analysis of the results and preventing science from moving forward. The British and European courts will need to be used to resolve this issue.

The Open Medicine Foundation (http://bit.ly/1hqgP4n) has developed an accurate set of biomarkers for the Mitochondria and related genes which is being reviewed by the prestigious scientific journal JAMA in 2016. This will be published soon. **Dr. Sonya Marshall-Gradisnik** and her research team at the National Centre for Neuroimmunology and Emerging Diseases (http://bit.ly/1UHoGsl) in Griffith University, Australia has developed a highly accurate test to identify ME and CFS, which is due to be commercialised in 2016. It is based on consistent scientific research findings (http://1.usa.gov/2609Cgh).

Genotype Frequencies of Transient Receptor Potential Melastatin M3 Ion Channels and Acetylcholine Muscarinic M3 Receptor Gene Polymorphisms in Chronic Fatigue Syndrome/Myalgic Encephalomyelitis Patients. **Marshall-Gradisnik et al**. Immunology and Immunogenetics Insights 02/2016; 8:1-2. DOI: 10.4137/III.S37042

Dr. Mady Hornig and her research team at Columbia University, New York has found that there are significant cytokine differences between patients who have the illness for 3 years or less and those who have it for 3 years or more. The p values in this research are less than 0.05 in many cases, with several less than 0.01, proving that several cytokines are playing an important role in the illness.
Hornig et al. Distinct plasma immune signatures in ME/CFS are present early in the course of illness (http://bit.ly/1qRmXYr). 27 February 2015, Sci. Adv. 1, e1400121 (2015) DOI: 10.1126/sciadv.1400121

Dr. Jonathan Kerr has found important MicroRNA's in the immune cells of ME patients which could serve as biomarkers. MicroRNAs hsa-miR-99b, hsa-miR-330, hsa-miR-126 and hsa-miR-30c: Potential Diagnostic Biomarkers in Natural Killer (NK) Cells of Patients with Chronic Fatigue Syndrome (CFS)/ Myalgic Encephalomyelitis (ME) (http://bit.ly/1oXRIZD).

We will be discussing these successes and more in this April edition. We hope you enjoy our offering.

David Egan

5. Grassroot

Cartoon Djanko

Forgotten Plague

New Blue Ribbon Foundation board member **Stephanie Land** writes about jumping in feet first and immersing herself in the ME community in a new blog post on the foundation's website! Read about her journey from discovering her friend, **Whitney Dafoe**, was severely ill to traveling to his house to meet his family.

"When I'd brought up the idea of visiting Janet a month ago, it was during our second phone conversation. I'd called her to find out how I could help raise awareness of her son **Whitney**'s disease, called myalgic encephalomyelitis, after seeing a picture of him on Facebook being loaded into an ambulance. His face was hollowed and gray. He looked gravely ill. Nothing like how I remembered him when we knew each other over a decade ago."
http://bit.ly/1S6I1Tk

It's Official. DVD Pre-Sales are now LIVE!

You can have your very own DVD copy of Forgotten Plague (http://bit.ly/1QAbuom), the film that tells the great under-reported medical story of our time.

Reserve Your FORGOTTEN PLAGUE DVD Today!
http://bit.ly/1RdQbul

PACE, Emerge Australia's letter to QMUL to release the data of the PACE study

Following numerous other patient organizations, scientists, patients and reporters who protested against QMUL's secrecy on the raw data of the PACE trial, and requests to The Lancet to withdraw its publication, also Emerge Australia has sent a poignant letter of request to QMUL, after a research study on 608 patients, 90% of which reported a relapse after GET:

Professor Simon Gaskell
President and Principal Queen Mary's University London
Mile End Road London E1 4NS
United Kingdom

20th March 2016

Call for release of PACE trial data and independent analysis of data

Dear Professor Gaskell,

Emerge Australia is a not-for-profit organisation that supports people with ME/CFS and associated conditions. We are writing as an organisation representing and supporting Australians with ME/CFS, to express our concern about Queen Mary University of London's (QMUL) refusal to comply with the UK Information Commissioner's order to release the PACE trial anonymised raw data.

As QMUL is seeking the "advice of patients" on the matter, we are writing to convey our view to you. We support the request of an 11,000-signature petition hosted by the ME patient-advocacy organisation, ME Action Network, which asked "the study authors… to give independent researchers full access to the raw data".

Currently, much of the information available to Australian medical practitioners is based on the PACE trial, (in particular, the Royal Australian College of General Practitioners' website). However, eminent scientists have identified serious flaws in the PACE trial data analyses, putting the authors' claims of patient recovery in serious doubt.

Contrary to the PACE trial authors' claims, GET can be extremely harmful to people with ME/CFS. In 2015, Federation University Australia undertook an extensive research study into the health and wellbeing of Australian's with ME/CFS.

Preliminary findings of the survey (unpub.) show that 90% of the 608 respondents said that increasing their level of exercise/activity makes them feel worse. In the UK's ME Association's 2012 patient survey, 74% of the 233 people who tried GET report that their condition worsened.3 This anecdotal evidence is supported by studies reporting abnormal physiological responses to exercise in people with ME/CFS.

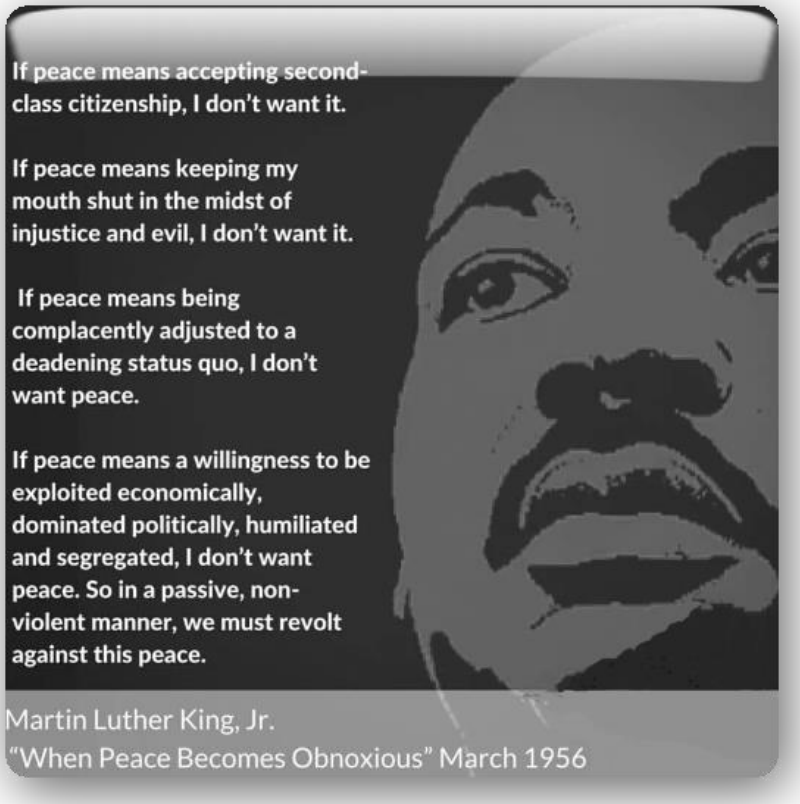
PACE-style GET and CBT are based on the underlying rationale that ME/CFS is the result of activity avoidance and deconditioning. This view is at odds with the Institute of Medicine's (IOM) determination that "ME/CFS is a serious, chronic, complex and multisystem disease that frequently and dramatically limits the activities of affected patients". It is also at odds with the findings of eminent Australian researchers on the bio-medical basis of ME/CFS (Staines, Marshall-Gradnisik).

Given these concerns with the trial, and in the interest of open and transparent science, we request that QMUL to comply with the Information Commissioner's request to release the PACE trial data to independent researchers for reanalysis.

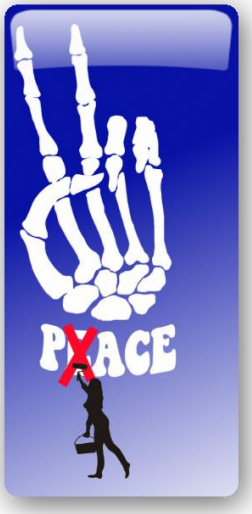
Yours sincerely,

Sally Missing, President

cc: Rachael Cragg Group Manager Information Commissioner's Office Wycliffe House Water Lane Wilmslow Cheshire SK9 5AF United Kingdom



PACE, Patient Organisations and the PACE-trial



All 13 organisations in the European ME Alliance (EMEA) and many others have answered ME/CFS patient Clark Ellis's call to request Queen Mary University of London (QMUL) to release data from the PACE trial.

QMUL are due to appeal the UK Information Commissioner's decision that they should release the data to a patient who requested it, at a tribunal to be held in late April. The data would allow calculation of the trial's main clinical effectiveness and recovery outcomes as they were originally specified in the study protocol.

The EMEA's action brings the total number of organisations who have written to QMUL to 24, from 14 countries: the UK, the US, Belgium, Denmark, Finland, Germany, Iceland, Ireland, the Netherlands, Norway, Spain, Sweden, and Switzerland. Together, the groups represent tens of thousands of patients.

The letter from the EMEA says, "The evidence from the PACE Trial… directly affects patients across Europe and therefore the data must be freely available… It is totally unacceptable for QMUL to ignore the many reasonable requests for data to be released for truly independent review. QMUL now have an opportunity to save, or even restore their reputation before it is too late."

Clark Ellis said, "*It's simply incredible. The support from patients and the organizations that represent them has far exceeded my expectations. It's unprecedented and I think it highlights how absurd QMUL's position has been*."

He added, "It's clearly untenable for them to avoid transparency and deny patients access to the data that impacts their lives. It's a very peculiar stance they've chosen and I hope this organic movement that just keeps growing will cause them to realize that and reverse their position."

The online ME/CFS forum, Phoenix Rising, which is a US-based non-profit with 14,000 members, have now also written to QMUL. In their letter, they said, "flaws [in the study], and the PACE authors' failure to adequately address them, have caused a catastrophic loss of confidence in the trial among patients worldwide…. We do not believe that patients risked their health in the PACE trial so that its authors could evade scrutiny of their questionable analyses by preventing other researchers from reanalysing the data."

The organisations who have written to QMUL include six UK charities invited by **Clark Ellis** and 18 others who have joined the campaign, which he began on 1 February.

They are the ME Association, the 25% ME Group, Action for ME, Invest in ME, the Tymes Trust, ME Research UK, the Irish ME Trust, Hope 4 ME & Fibro NI, the Welsh Association of ME & CFS Support, the Dutch Citizen's Initiative for ME, Het Alternatief (Netherlands), the Belgium ME/CFS Association, ME-Gids.net (Belgium), WUCB (Belgium), Foreningen for Myalgisk Encefalomyelitis (Denmark), Suomen CFS-Yhdistys/Finlands CFS-förbund (Finland), Fatigatio e.V. (Germany), the Icelandic ME Association, Norges ME-forening (Norway), Liga SFC (Spain), Riksföreningen för ME-patienter (Sweden), Verein ME/CFS Schweiz (Switzerland), ME Foreningen (Denmark), and Phoenix Rising (US)*.

Dr. Esther Crawley

The only organisation to reject **Clark Ellis**'s call to join the campaign is the UK charity AYME (the Association of Young People with ME), whose chief medical adviser is **Dr. Esther Crawley**, who is herself planning a trial of graded exercise therapy for children with ME/CFS. AYME now stands isolated among the international community of ME/CFS organisations in its refusal to act in support of data release.

Clark Ellis encourages patients to continue to contact organisations in their own countries to ask them to write to QMUL to urge them to release the PACE data.

Source : MEAction
http://bit.ly/1RUjHUq

*Meanwhile the Dutch consultative body MEON, in which the three main Dutch ME/cfs organizations are represented wrote to QMUL as to The Lancet as well and as reported in this issue of the MECG, Australian Emerge wrote to QMUL too.

Updates on The Self-taught Author, the blogs of **Clark Ellis**:
https://autodidactauthor.wordpress.com/about/

PACE, Trial Invalidates The Use Of CBT And GET

The PACE Trial Invalidates the Use of Cognitive Behavioral and Graded Exercise Therapy in Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome: A Review

Mark Vink*

Abstract

The main findings reported in the PACE trial were that cognitive behavioral therapy (CBT) and graded exercise therapy (GET) were moderately effective treatments for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), and fear avoidance beliefs constituted the strongest mediator of both therapies.

These findings have been challenged by patients and, more recently, a number of top scientists, after public health expert **Tuller**, highlighted methodological problems in the trial. As a doctor who has been bedridden with severe ME for a long period, I analyzed the PACE trial and its follow-up articles from the perspectives of a doctor and a patient.

During the PACE trial the eligibility criteria, both subjective primary outcomes, and most of the recovery criteria were altered, creating an overlap of the eligibility and recovery criteria; consequently, 13% of patients were considered "recovered," with respect to 1 or 2 primary outcomes, as soon as they entered the trial.

In addition, 46% of patients reported an increase in ME/CFS symptoms, 31% reported musculoskeletal and 19% reported neurological adverse events.

Therefore, the proportion negatively affected by CBT and GET would be between 46% and 96%, most likely estimated at 74%, as shown in a large survey recently conducted by the ME Association. **Medication with such high rates of adverse events would be withdrawn with immediate effect**.

There was no difference in long-term outcomes between adaptive pacing therapy, CBT, GET and specialist medical care, and none of them were effective, invalidating the biopsychosocial model and use of CBT and GET for ME/CFS.

The discovery that an increase in exercise tolerance did not lead to an increase in fitness means that an underlying physical problem prevented this; validates that ME/CFS is a physical disease and that none of the treatments studied addressed this issue.

Source: SciForschen, http://bit.ly/1SbfrNu

***Mark Vink** is a family physician who developed ME after picking up pneumonia from a patient for which he was hospitalized.*

Prior to this he was fit and well, hardly ever ill and very sporty. He doesn't smoke, hardly ever drinks alcohol, he has a brown belt in judo; he's a former Dutch national field hockey champion, captain of his team; he ran marathons (PR: 3.05), half marathons (PR: 1.19), and competed in quarter triathlons.

Graded Exercise Therapy caused a severe relapse which made him bedridden, which he still is 10 years later.

Standing Up To Coyne And Against Unfair Treatment Of ME Advocates

*Editors' note: we hesitated whether to publish this extracted blog or not. But the fact **Prof. Coyne** hasn't shown a sign of embarrassment up till now about what seemed to have been a fit of extreme anger due to causes unknown directed towards mrs. **Burmeister**, whom also we hold in high esteem as a long term most valuable patient advocate, and towards the community as a whole does classify his impertinent accusations as lack of respect and decent human behavior, to our view. We may and will differ in opinion, but respect for each other should be a fundamental guiding principle in all our communications, under all circumstances. Otherwise they're counter-productive as well.*

I am taking the liberty of posting this entry on **Jeannette**'s blog.
Many of you know that I seldom become involved in ME advocacy. My wife, **Jeannette**, is typically capable of holding her own. She has been, health permitting, a relentless advocate for ME for several years and has been effective in holding government agencies and officials accountable when their actions or inaction have damaged the ME patient community, and in particular when they have not lived up to their legal responsibilities. It is true that she has strong opinions on how to conduct effective advocacy and states her position assertively, but I can assure you that she makes it a priority to focus on the issues and to stay away from personal ad hominem attacks on other individuals advocating for ME.

On the rare occasion when she has made a mistake, she was quick to apologize and set the record straight. Far from being self-promoting, **Jeannette** has gone out of her way to support and give credit to other patient advocates for their efforts. When her health allows, **Jeannette** collaborates with other advocates, typically behind the scenes. Among other things, **Jeannette**'s advocacy efforts seem to have derailed the massive price increase for Ampligen that was scheduled for next month, which according to the Ampligen study coordinator is now not going into effect for the time being.

The recent incident starting with the Facebook posts of **Dr. James Coyne** on February 27, 2016, is so outside the realm of reasonable and civil behavior and has affected **Jeannette**'s health so directly and adversely as to render her physically unable to defend herself at the moment, that I simply cannot stand by and witness this without comment.

It is important to know that **Jeannette** had been a supporter of **Coyne**'s efforts on behalf of the ME community and has never stated, publicly or privately, anything that could possibly be viewed as attacking him in any way.

It is simply not tenable to maintain that her tweet was "abusive." You may not agree with it or with her tactic of criticizing **Walitt** or the handling of the proposed study by NIH, but the tweet was absolutely fair game and within acceptable standards of reasonable advocacy. With this background, it was shocking to her, me and most of the community that **Coyne** stepped in and demanded, in effect, that the patient community condemn **Jeannette**'s tweet, insist on an apology from the community for the tweet and ostracize advocates like **Jeannette**, calling her a "*sick crazy lawyer*," having a "*history of being abusive towards reasonable informed Americans*" and posting a "nasty and abusive tweet."

He demanded that the patient community step up and "stop the abusive crazies" or he would stop helping with attempting to obtain documents relating to the PACE trial. When many questioned him on this, he called them names (e.g., "*delusional*") and told them to "*fuck off*." All of this because **Coyne** disapproved of **Jeannette**'s reasonable approach to advocacy.

Please keep in mind that this is coming from a renowned Ph.D. in psychology with a large public following and a recent position of prominence in support of patients with ME.

Coyne is a newcomer to this community and has apparently developed a pattern of labeling long-term advocates with whom he disagrees as divisive and destructive and asking others to ostracize them for simply expressing any views that are inconsistent with his views or approach to advocacy.

Unfortunately, there are a few who have apparently harbored resentment against **Jeannette** and have taken this opportunity to add to the abuse from **Coyne**, calling her names, such as "*textbook narcissist*" with her following of "*flying monkeys*." To those few people who thought it fit to pile on in the aftermath of **Coyne**'s revolting mistreatment of **Jeannette** by egregiously defaming **Jeannette** and spreading vile lies about her (some of which are urban legends revived from years ago) and engaging in other character assassination, maybe you want to check in with your conscience because your behavior shines a bright light on your value system and, quite frankly, it's not flattering. The same goes for those hosting or "liking" such comments.

No sick person should be forced to choose between protecting her health and defending her reputation.

It is alarming that some have supported, or at least condoned or downplayed, **Coyne**'s behavior. Some have suggested that Jeannette somehow brought this on herself, which is not only untrue, but also constitutes shameless and cruel victim blaming. Some have justified it under the greater good theory, in other words, we need **Coyne**'s advocacy for obtaining the PACE data, so we have to sacrifice a sick patient advocate who has labored for years at great personal cost on behalf of this community and tolerate her abuse by **Coyne**. Others are saying that they disagree with his language, but basically agree with his sentiment about quieting advocates who don't toe the party line.

I want to be very clear that the foul language, as unacceptable and revealing as it is, is not the main issue here. Had **Coyne** done what he did—calling sick patients "*crazies*," resorting to defamation, trying to coerce a vulnerable patient population into an apology (when he is the one who should apologize) and into shunning advocates for no reason whatsoever—but done it in a more polite manner, it would still have been reprehensible. It's the substance of what he did much more so than the style in which he did it that is so objectionable. The style does reflect, however, a disturbing aspect of his approach to advocacy.

And let's not forget that this was not just one comment. It was a sustained attack that encompassed many comments and no apology has been made. To those who have suggested that **Jeannette** back off on this and, in effect, suffer in silence in order that the ME community keep its focus, i.e., the taking down the PACE trial, I respond with two points. First, it was **Coyne** who launched the unjustified attacks on the community and key advocates. It is up to him to deescalate the situation by apologizing and toning down his rhetoric.

Second, silence has facilitated **Coyne**'s attempt to shut down and ostracize other advocates—**Suzy Chapman** and **Angela Kennedy** and presumably others—without any repercussions for **Coyne**. Someone has to stand up to his bullying tactics. Otherwise, who will be next on the chopping block? Further, is it not possible that his extreme actions in this arena could backfire and give those who oppose his position on the PACE data ammunition to reject his demands?

By now, **Coyne** has had plenty of time to issue an apology to the community and the advocates he specifically targeted, including **Jeannette**. He has not done so. Instead, he stood idly by as further attacks by others, clearly incited by his initial smear campaign against **Jeannette**, took place. It is clear that he is unrepentant.

Edward Burmeister

Excerpt from a post that can be found in its entirety at http://bit.ly/1XsAPlS
Also read: Has the "**Coyne** of the Realm" been devalued? http://bit.ly/1ScWBf0

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Anyone can contribute, and everyone has something to offer, whatever your skills & experience, even if you have never edited a wiki (like Wikipedia) before. All we ask is that you read the guidelines before you edit (http://me-pedia.org/wiki/How_to_contribute).

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Jennifer Brea

NIH / CDC Keep An Eye On Your Walitt

Keep an Eye on Your Walitt: NIH Study Poses Dramatic Risk to Long-Term Disability Benefits

Many ME/CFS* sufferers are covered by employer-sponsored long-term disability ("LTD") policies. These policies almost universally limit LTD benefits to 24 months for disability caused—or even just contributed to—by a mental/nervous disorder.

The following language is taken from a current policy issued by a major LTD insurer: "*Once 24 monthly disability benefits have been paid, no further benefits will be payable for any of the following conditions:*

- *…*
- *Anxiety disorders*
- *Delusional (paranoid) disorders*
- *Depressive disorders*
- *…*
- *…*
- *Mental illness*
- ***Somatoform disorders (psychosomatic illness)**" [emphasis added]*

Another leading disability insurance company defines mental illness as:
"a mental, nervous or emotional disease or disorder of any type." [emphasis added]

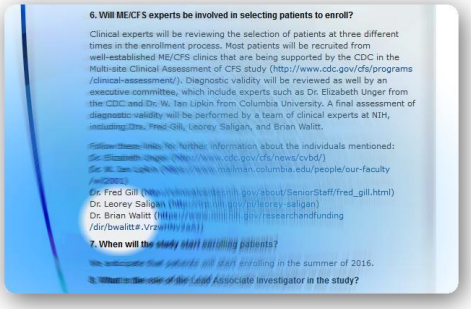
There are variations in the language, but the gist of the mental-health limitation in most LTD policies is the same: a termination of coverage for mental-health conditions after 24 months. Somatic Symptom Disorder as well as other somatoform disorders are listed in the DSM-V and regardless of whether they are expressly mentioned in a policy, any diagnosis of a somatoform disorder will, without a doubt, be classified as falling under the mental/nervous clause.

Disability insurance companies routinely claim that ME/CFS patients are suffering from a mental/nervous disorder despite the fact that the patient's physician did not diagnose such disorder. Nevertheless, LTD insurers are often successful in their effort to terminate benefits at 24 months by requiring that claimants undergo an "independent" medical exam ("IME") performed by doctors who are paid by the insurance companies and, nearly without fail—in the case of a CFS diagnosis—find a mental/nervous disorder as a primary cause or at least contributing factor for the disability.

Disabled ME/CFS patients typically suffer disability for their lifetimes, in many cases for decades. Any NIH study, finding or official reference that supports, in any way, the characterization of ME/CFS as a somatoform disorder would be a dramatic boon to disability insurance companies enabling them to limit their payments to disabled ME/CFS patients to 24 months as opposed to the age of 65 (which is the typical age at which LTD benefits terminate for disabilities not caused, or contributed to, by mental/nervous disorders).

[…] every ME/CFS patient who has been receiving disability payments beyond 24 months should expect this type of review and likely termination of their benefits should the findings or positions of any HHS agency, such as NIH, suggest a classification of ME/CFS as a somatoform (or other mental/nervous) disorder.

Enter **Dr. Brian Walitt**, lead clinical investigator for NIH's intramural study of post-infectious ME/CFS (http://1.usa.gov/1NmbV1r). **Walitt** is positioned to have a key role—probably the key role—in the study. According to the study's principal investigator, **Dr. Nath**, **Walitt** has been instrumental in the study design. As a member of the small NIH team responsible for the "final assessment of diagnostic validity" (see screen shot below taken from this link (http://1.usa.gov/1oTfYMF) to the NIH study website), **Walitt** will also be involved in the ultimate selection of the 40 ME/CFS patients, one of the most critical aspects of any study. **Walitt** is a member of that team because he is considered by NIH a "clinical expert" on ME/CFS. His influence will undoubtedly extend to the final conclusions of the study. Many patients were incredulous when **Walitt** flippantly revealed his obvious disdain during NIH's March 8, 2016 invite-only "ME Advocacy Call" about the study (http://1.usa.gov/23Abvhy) in response to concerns about his bias:
"*If chronic fatigue syndrome/myalgic encephalomyelitis is all in your head, it's only because your head is part of your body*."


6. Will ME/CFS experts be involved in selecting patients to enroll?

Clinical experts will be reviewing the selection of patients at three different times in the enrollment process. Most patients will be recruited from well-established ME/CFS clinics that are being supported by the CDC in the Multi-site Clinical Assessment of CFS study (http://www.cdc.gov/cfs/programs/clinical-assessment/). Diagnostic validity will be reviewed as well by an executive committee, which include experts such as Dr. Elizabeth Unger from the CDC and Dr. W. Ian Lipkin from Columbia University. A final assessment of diagnostic validity will be performed by a team of clinical experts at NIH, including Drs. Fred Gill, Leorey Saligan, and Brian Walitt.

Follow these links for further information about the individuals mentioned:
Dr. Elizabeth Unger (http://www.cdc.gov/cfs/news/cvbd/)
Dr. W. Ian Lipkin (http://www.mailman.columbia.edu/people/our-faculty/wil2001)
Dr. Fred Gill (http://clinicalcenter.nih.gov/about/SeniorStaff/fred_gill.html)
Dr. Leorey Saligan (http://www.nih.gov/pi/leorey-saligan)
Dr. Brian Walitt (http://www.nimh.nih.gov/researchandfunding/dir/bwalitt#.VrzaHNv1aHI)

7. When will the study start enrolling patients?

We anticipate that patients will start enrolling in the summer of 2016.

8. What is the role of the Lead Associate investigator in the study?

Given **Walitt**'s well-documented opinion on CFS as a somatoform illness, there is a high likelihood that the study design, the patient cohort selected for the NIH study, the day-to-day decisions made by the lead clinical investigator and the ultimate conclusions of the study will be affected by **Walitt**'s clear bias. The very fact that NIH appointed **Walitt** in the first place, as well as the agency's in-patients-face failure to remove him from the study after an unprecedented and ongoing outcry from the patient community, is ever so revealing in terms of NIH's objectives for the study and its recently oft-repeated assertion of a suddenly-found desire to work with patients. It is hard to imagine that NIH could have managed a more perfect middle-finger salute to ME/CFS patients than appointing **Walitt** as the lead clinical investigator.

As I have said before, this study—in its impact—has the potential of becoming PACE on steroids. In addition to the other dramatic risks posed by the design of the study (which are beyond the scope of this post), thousands of disabled ME/CFS patients could face the sudden loss of most, if not all, of their already modest lifetime income and, as a result, life-threatening poverty that would be impossible to navigate for many in the face of the debilitation caused by their disease—if **Walitt** continues to remain on the study.

Jeannette Burmeister
Abridged by herself from http://bit.ly/23qYr17
Also read **Brian Walitt**'s Radical Bias: Disorders of Subjective Perception, ME/CFS as Normal Life Experience? http://bit.ly/1S2Lika

NIH / CDC Petition

MEadvocacy sent a petition to NIH to cancel and restart the NIH Intramural Study on ME/CFS because of the many significant problems with the study's design and protocol and lack of myalgic encephalomyelitis (ME) stakeholders' input.

Since then, NIH has used various and confusing ways to communicate new and changing information about the study. As further information became available, we voiced our deep concerns about many of the significant issues with the study: multiple and ever-changing criteria, some of which are deeply flawed; biased and/or inexperienced investigators and advisors; additional problems with the study's design; mistrust of the government health agencies and the problems with the way NIH is communicating.

This is a unique opportunity to design a robust study using the comprehensive resources of the NIH Clinical Center. It is crucial that this study be done with ME experts' and stakeholders' input from start to finish. This will ensure meaningful results and scientific advancement for patients who suffer from this serious, disabling disease.

Petition Summary

The MEadvocacy petition with 725 signatures was initiated on February 9, 2016, and sent to **Dr. Francis Collins**, Director of the National Institutes of Health (NIH), on February 15, 2016.

The petition called for:

- Rejection of the Reeves' criteria and its associated questionnaires
- Restart of the NIH clinical study using a protocol pre-approved by ME experts and stakeholders
- Transparent communication to the patient community
- Use of ME criteria created by our experts to select a more homogeneous ME patient cohort such as the International Consensus Criteria (ICC) or the Canadian Consensus Criteria (CCC)

On February 23rd, we sent a follow-up reminder with additional concerns about the study:

- NIH chose a lead associate investigator, **Dr. Brian Walitt**, with a psychosomatic viewpoint of the disease
- The selection of recovered Lyme disease patient group (a disease fraught with controversy) as a comparison cohort
- The selection of functional movement disorder patient group (a disorder that falls under the mental illness classification of somatoform disorders) as a comparison cohort

At the March 8th NIH Telebriefing, we asked a question as to when we would receive a response to the petition.

On March 11th, MEadvocacy received a reply to our petition from **Dr. Koroshetz**. However, **Dr. Koroshetz**'s reply and NIH/NINDS' actions sidestepped our crucial concerns.

The Ever-Changing Criteria

Why is Research and Clinical Criteria Used for Patient Selection So Important in ME?

Many diseases have testable biomarkers for use in selection of patient cohorts in studies. This ensures that the correct group of patients are being looked at. This is not the case with ME. To date, a testable biomarker has not yet been accepted. Therefore, it is of utmost importance that the strictest criteria (ICC or CCC) be used in studying ME in order to ensure that investigators are looking at a homogeneous patient cohort.

Historically, the criteria issue has been a grave problem with research into ME because various vague criteria have been created and used. Overly broad CDC criteria, such as Reeves and Fukuda, include patients who have: chronic fatigue, idiopathic fatigue, somatoform disorders, major depressive disorders, and other unrelated conditions. CDC has created the problem of heterogeneity of the disease and caused the commingling of cohorts. For three decades, they have served to obscure the original findings of ME outbreaks which has led to the suffering of a million American men, women and children.

Timeline of Criteria Changes

From the time NIH posted the first protocol showing the Reeves' criteria on their website, it has been a fiasco of continually changing criteria and news.

- First, the initial protocol posted on the NIH website became public with what we were later told was incomplete information. This protocol showed that Reeves' criteria would be used to select the patient cohort. Furthermore, the NIH website code reveals that changes had been made to the protocol at least two times, which makes it hard to believe that it was 'mistakenly posted' in order to achieve a study number, as stated by NIH (see details here).
- Days later, the initial protocol was removed and NIH did not post a reason why it was removed.
- Later that day, an advocate posted a notice on a website stating that NIH informed them of the following: "Enrollees will meet all definitions for ME/CFS, including Canadian Consensus Criteria, IOM, Fukuda and Reeves, in addition to post-infectious onset."
- A week later (about an hour after MEadvocacy's petition was delivered to NIH), **Dr. Koroshetz** sent an email to a select few advocates, stating that patients will: "...qualify under multiple consensus criteria including the Canadian criteria. Reeves was being used only for stratification purposes."

- The next day (after **Koroshetz** sent his email), **Dr. Nath** informed the public during his CDC Grand Rounds presentation that the NIH study would use two criteria - Fukuda and CCC - for selection of patients (see slide #53 here).
- Three weeks later, at the NIH Telebriefing, none of the four NIH presenters mentioned criteria. However, it was announced that a new website for the study went up that morning which shows one specific criteria to be used - the CCC (item #1 on FAQ page).
- The most recent letter to MEadvocacy by **Dr. Koroshetz** now states that two criteria - the CCC and IOM will be used for selecting patients (3rd paragraph).

The Need for Real ME Experts in the Study

In his March 11th letter to MEadvocacy, **Dr. Koroshetz** states: "*As you may know, the NIH study protocol is still being revised. It is being developed with guidance by experts from a number of disciplines and is intended to be the most detailed physiological analysis to date of patients who developed ME/CFS following an infection*."

Dr. Koroshetz sidesteps our request for ME experts and patient advocate involvement with the study design and protocol from the beginning. He responds with the information that experts from a number of different disciplines were involved in the guidance, but doesn't state that they were experts specifically in ME.

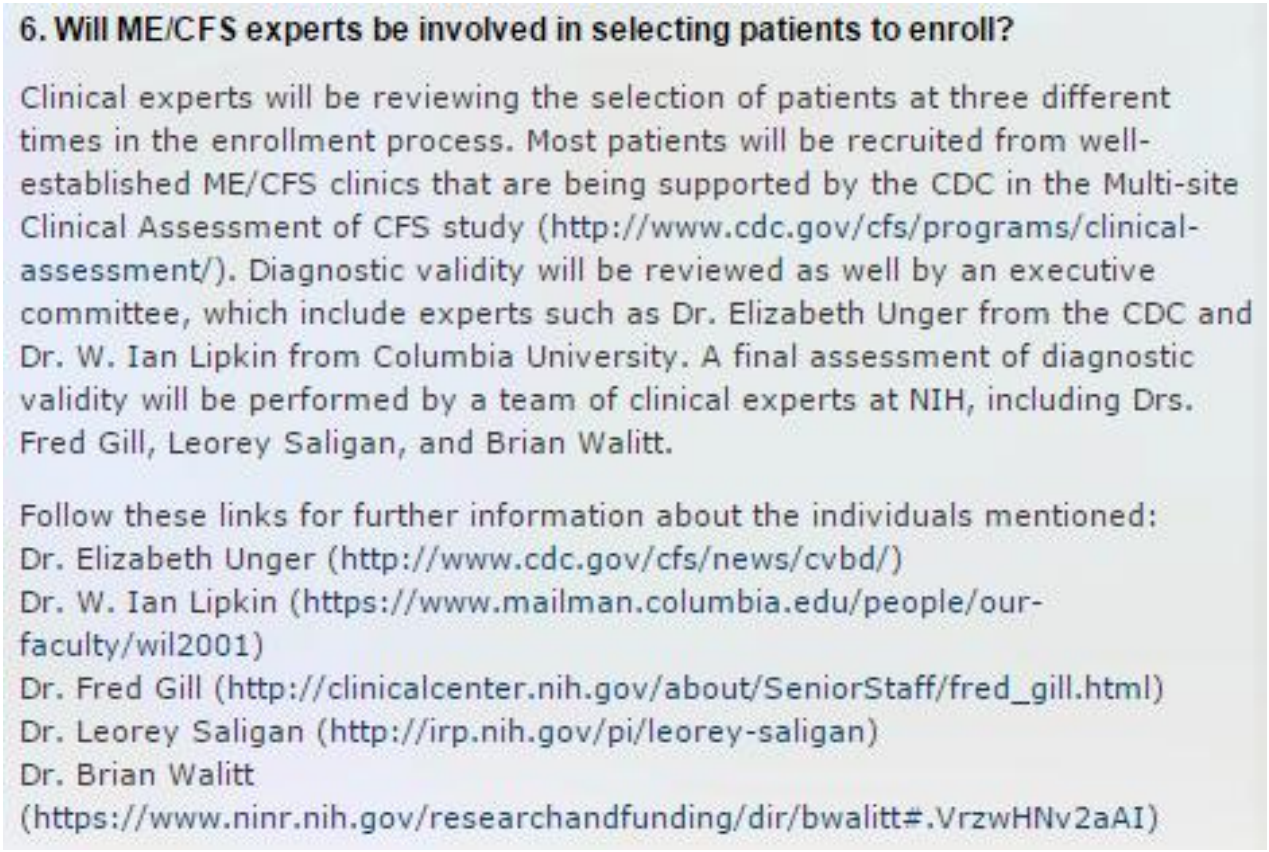
If ME advocates would have been involved from the beginning and given power of approval, **Drs. Brian Walitt**, **Fred Gill** and **Leorey Saligan** would not have been put in charge of assessing diagnostic validity for selecting and managing patients in the clinic.

The Inherent Bias of the Lead Associate Investigator and Those in Charge of Patient Selection

The FAQ section of the NIH study website states the following: "Most patients will be recruited from well-established ME/CFS clinics that are being supported by the CDC in the Multi-Site Clinical Assessment of CFS study."

It says "most" but not all. This is very troubling because we don't know what they mean by "most". For instance, does it mean 25 patients will come from the ME/CFS clinics and 15 will not? Where will those not coming from the ME/CFS clinics come from? Furthermore, the website instructions state that one can register online to become a participant in the study. Where are those patients coming from?

The final assessment will be done by "clinical experts at NIH, including **Drs. Fred Gill**, **Leorey Saligan**, and **Brian Walitt**" who have inherent and common biases about the disease. We do not believe the selection of these specific NIH researchers, who have the same inherent bias, is a coincidence, but rather an indication of the path this study was intended to take.



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Follow these links for further information about the individuals mentioned:
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Dr. W. Ian Lipkin (https://www.mailman.columbia.edu/people/our-faculty/wil2001)
Dr. Fred Gill (http://clinicalcenter.nih.gov/about/SeniorStaff/fred_gill.html)
Dr. Leorey Saligan (http://irp.nih.gov/pi/leorey-saligan)
Dr. Brian Walitt (https://www.ninr.nih.gov/researchandfunding/dir/bwalitt#.VrzwHNv2aAI)

NIH Intramural Study on ME/CFS website - FAQ section

Dr. Brian Walitt has been selected by NIH as lead associate investigator for the study, as well as part of the committee selecting the patient volunteers. Much has already been written about the concerns of having a lead associate investigator who believes fibromyalgia and chronic fatigue syndrome (CFS) are psychosomatic and somatoform disorders. In September 2015, **Dr. Walitt** gave an interview at a rheumatology conference on fibromyalgia which advocate **Jeannette Burmeister** blogged about. It is troubling that **Dr. Walitt** will be responsible for administering the subjective questions/questionnaires by phone and in person at the clinic.

Below are just a few studies **Walitt** has been involved with:

- Quantifying the influence of child abuse history on the cardinal symptoms of Fibromyalgia (http://www.ncbi.nlm.nih.gov/pubmed/26743156)
- Chemobrain: A critical review and causal hypothesis of link between cytokines and epigenetic reprogramming associated with chemotherapy (http://bit.ly/1qFnNqB)
- What Is Fibromyalgia, How Is It Diagnosed, and What Does It Really Mean? (http://onlinelibrary.wiley.com/doi/10.1002/acr.22207/full)

Dr. Fred Gill worked with the late **Stephen Straus**, NIH virologist who ignored the biological evidence of ME in favor of a psychological view which set the tone for decades to come, as noted by advocate **Dr. Mary Schweitzer** in her blog (http://bit.ly/1Q47wQH). In a letter (part 1 (http://bit.ly/1XsqMgK) and part 2 (http://bit.ly/25WpwYW)) **Dr. Straus** wrote to **Dr. Fukuda**, he laid out his plan to "evaporate CFS"; see advocate **Craig Maupin**'s blog (http://bit.ly/23A8E8m), The CFS Report.

In February 2011, **Dr. Gill** presented at NIH (presentation video here at the 54:17 minute mark) he said: "**Dr. Straus** who was much younger than me and not with us anymore but my mentor in EBV and Chronic Fatigue finally wrote a paper near the end in 2004 about pharmacotherapy. All the things I just showed you. And I agree with what he said to this day that many therapies have been tried but so far only cognitive behavioral therapy and graded exercise appear to be meaningful, to produce meaningful benefit."

Advocate **Charlotte von Salis** attended the presentation and blogged about it here. What follows is an excerpt from her blog: "**Gill**'s big on reassuring the patient, avoiding unnecessary tests, avoiding debate over whether it's psychological, and above all, getting patients to remain active and exercise no matter what."

Dr. Leorey Saligan is a family nurse practitioner/investigator who researches biobehavioral mechanisms of fatigue. He states that the reason that CFS patients report pain and fatigue is because they seek attention and are catastrophizers (http://bit.ly/1qFo7FR).

Below are just a few studies Saligan has been involved in:

- Association of catastrophizing and fatigue: a systematic review (http://1.usa.gov/1qMknTu)
- Quantifying the influence of child abuse history on the cardinal symptoms of Fibromyalgia (http://www.ncbi.nlm.nih.gov/pubmed/26743156)
- Beyond pain in Fibromyalgia: insights into the symptom of fatigue (http://bit.ly/1Wp0Zrc)

Ways to Correct Problems with the Criteria and Investigators

- Use a single criteria for the study - the ICC or the CCC.
- Declare officially that NIH will not use the Reeves' criteria and questionnaires (see references 11, 13 and 14) for any purpose in the study (see here for concerns about Reeves' questionnaires). Replacement questionnaires (aka 'instruments' per clinical investigators) must be approved by ME experts and stakeholders.
- Remove **Walitt**, **Gill**, and **Saligan** from the study and replace them with individuals with knowledge of ME as a biomedical disease who currently and historically do not ascribe to the psychosocial or psychosomatic causation of symptoms.

Problems With Executive Committee Advisors Who Are Not Experts In ME

Dr. Elizabeth Unger, CDC virologist, focused many of her studies and presentations on fatigue and the mind/body theory as she explained in this CFSAC video clip (http://bit.ly/1Q47Y1e) posted by advocate **Khaly Castle**). As co-author of the Reeves' criteria, **Dr. Unger** explained in this video (http://bit.ly/20xrBqk) how her agency applies the criteria when asked by **Eileen Holderman**, former CFSAC Member, how CDC plans to reconcile the case definition issue. In the NIH study, **Dr. Unger** has been assigned to the executive committee and charged with reviewing diagnostic validity of the patient cohort. At the February 16th CDC Grand Rounds, Unger promoted graded exercise therapy (GET) and cognitive behavioral therapy (CBT), which is also promoted by the PACE Trial, for which ME experts have warned against as causing harm to patients.

Below are just a few studies **Unger** has been involved in:

- Acute Psychosocial Stress-Mediated Changes in the Expression and Methylation of Perforin in Chronic Fatigue Syndrome (http://1.usa.gov/1ql3DSq).
- Coping styles in people with chronic fatigue syndrome identified from the general population of Wichita, KS (http://1.usa.gov/1UXI2ws).
- Early Adverse Experience and Risk for Chronic Fatigue Syndrome (http://bit.ly/1VkUKFW)

Dr. W. Ian Lipkin is a world renowned virologist. In recent years, **Dr. Lipkin** has been investigating ME/CFS and collaborating with ME experts. **Dr. Lipkin** serves as an advisor on the study and will approve patient cohort selections. While **Lipkin**'s research shows great promise, he is not an expert in diagnosing and treating ME patients.

Ways to Correct the Problem with Advisors Without ME Expertise

- NIH should seek advisors to the executive committee that have extensive experience investigating, diagnosing, and treating ME patients.
- Advisors need to be approved by ME stakeholders.

Additional Problems with the Study's Design

- The cohort size of 40 ME patients is too small.
- The study excludes patients who are the most severely affected such as the homebound and bedbound.
- The use of recovered Lyme disease comparison control groups will obfuscate the results.
- The summary of the study states they will conduct a bike exercise test twice, but does not specifically state the consecutive two-day CPET testing for post-exertional neuroimmune exhaustion.
- The specific budget for this study has not been released and published.

Ways to Correct Problems with the Study's Design

- Increase the ME/CFS patient cohort size to increase probability of producing meaningful statistical results.
- Include homebound and bedbound patients in the study. Historically, these patients have been under-researched and have the greatest potential to yield strong biomedical abnormalities.
- Remove the asymptomatic recovered Lyme disease comparison control group from the study because they are prone to developing chronic Lyme disease (refer to here (http://bit.ly/1SvhZX0) and here (http://bit.ly/1S6MeWW)). In addition, the 2-tier testing used by the CDC for Lyme disease is not accurate (http://chn.ge/23AaaY6). ME and chronic Lyme disease have overlapping symptoms and many ME patients are undiagnosed chronic Lyme disease patients due to a high level of false negative CDC test results. Therefore, this would obfuscate the comparison of these two disease groups.
- Incorporate the consecutive two-day cardiopulmonary exercise testing (CPET) protocol (http://bit.ly/1oT3owW) into the study. The current bike exercise test, mentioned in the study summary, does not confirm whether post-exertional neuroimmune exhaustion occurs by documenting reduced VO2max on the second day.
- Release and publish all budget information regarding funding for the study from its inception to conclusion.

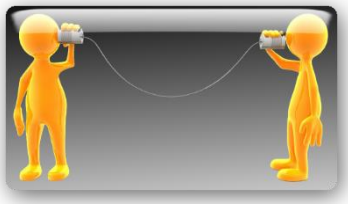
Mistrust of Government Health Agencies and Problems with the Way NIH Communicates

The government health agencies have a history of malfeasance with this disease as documented by journalist and advocate **Hillary Johnson** in her book Osler's Web (http://amzn.to/1YraHrK). In 1985, the CDC went to Lake Tahoe, Nevada to investigate an ME outbreak and dismissed what they saw. They renamed the disease with a trivial moniker, chronic fatigue syndrome (CFS), and created a vague definition - both of which have caused serious harm to patients.

Additional abuses to the ME community include: CDC diversion of $12.9 million earmarked for ME/CFS research to other diseases; NIH underfunding biomedical research; Chronic Fatigue Syndrome Advisory Committee (CFSAC) FACA violations; HHS threats of eviction made to three CFSAC members; NIH/HHS FOIA violations and unreasonable conduct during the trial of FOIA violations (refer to **Jeannette Burmeister**'s blog (http://bit.ly/1JPQsea) on violations); and HHS dissemination of erroneous information about the disease to medical professionals, the media, and the public.

As illustrated, the patient community is justified in their mistrust of the government health agencies. Therefore, the burden is on the health agencies to rebuild the lost trust. NIH's miscommunications are contributing to the mistrust.

Problems with the Way NIH is Communicating



- Causing confusion by posting the intramural clinical study summary on clinicalstudies info nih gov (http://1.usa.gov/1qFpcNU) and clinicaltrials gov (http://1.usa.gov/1SKNmgC) websites then deleting the information (study numbers 16-N-0058 (http://bit.ly/1PSECUU) is the unofficial archive of original summary from clinicalstudies info nih gov (http://1.usa.gov/1qFpcNU) and NCT02669212 (http://1.usa.gov/1Yrb2KV) is the official archive of linked study on clinicaltrials gov (http://1.usa.gov/1SKNmgC)). Removing the initial study from the websites concealed the historical changes made to the study. Creating a webpage connected to the Trans-NIH ME/CFS Research Working Group describing the study. Creating another website (http://1.usa.gov/1Nm4Gqq) for the NIH Intramural Study for ME/CFS.
- Communicating information and conducting private meetings to only a select few advocates instead of the entire ME community.
- Conveying conflicting information (by various agencies) about the study by various websites, presentations, and communications.
- Sidestepping advocates' questions and concerns (see examples below).
- In his reply to advocate **Joni Comstock**'s question during the NIH Telebriefing (http://1.usa.gov/23Abvhy), **Dr. Walter Koroshetz** stated: "*...our intent is to reach out and get input from a wide variety of folks with expertise and with experience in this illness. And we have been doing that right from the beginning at NIH through the Trans-NIH Working Group, through the CFS Advisory Committee. We've had multiple meetings with experts in the field and with advocacy groups. And I must say it has been a challenge for us because there are, well we may not have reached out to everybody*."

Does "experts in the field" mean ME experts? NIH has not officially notified the community about specific ME researchers, clinicians or advocates who have been advising about the design of the study. There have been no assurances that ME experts and their input would be part of the study's design and approval process.

- **Dr. Koroshetz** further states: "And so, I think that the major teachers at the NIH really have to be the patients who have made the sacrifice to join the protocol, to come into the Clinical Center and to work with the doctors."

By the time patient volunteers are involved, the design and protocol for phase 1 will have been set. Clearly, ME experts' and stakeholders' input and approval will not be considered.

- At The CDC Grand Rounds (http://bit.ly/1XssM8E You Tube video minute mark 53:23), **Dr. Nath** stated: "*So, careful listening to patients is absolutely critical. So, with that in mind, you know I grew up in the early AIDS epidemic, and I saw interactive with Act Up, and other patient forums whereby they had a great impact on the way disease was handled, treated and moved the Federal government to make changes at every level. And so, we understand the importance of it, and there are efforts under way to put that advisory group together*."

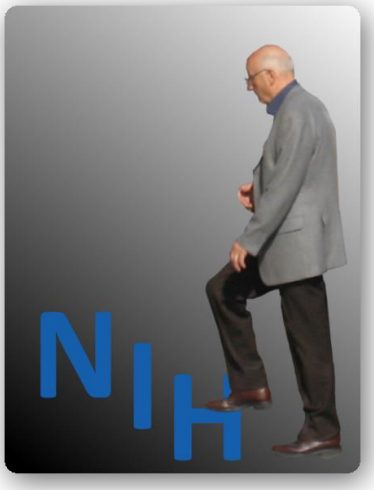
Yet, at the NIH telebriefing, **Dr. Nath** stated: "*So we looked into some of the legalities about patient advisory groups and it's a little bit complicated in the federal government.*" This implies that the assurance made by **Dr. Nath** at the CDC Grand Rounds regarding creation of a patient advisory group to provide input on the study may not occur because NIH does not want to deal with looking into an important but possibly complicated matter.

On one hand, NIH is telling the community they want patient and advocate input but on the other hand, NIH is implying that patients should just stick to telling them about their symptoms rather than advise them about the design of the study.

Ways to Correct the Problems with the Way NIH is Communicating

- Reinstate the original protocol on http://clinicalstudies.info.nih.gov/ and http://clinicaltrials.gov, showing the changes that have been made. Also, remove the now inaccurate Trans-NIH Research ME/CFS Working Group "Eligibility Requirements for ME/CFS Clinical Study at the NIH" orphan webpage (http://1.usa.gov/1Nm4Gqq) that still references functional movement disorder as a cohort. Release the history of the protocol to the public including protocol details and the Institutional Review Board (IRB) approval dates so that appropriate ME stakeholder input can be provided.
- Communicate all information in real time to the entire community by using an NIH ME/CFS listserv.
- Coordinate information across various agencies and sources so that all messaging is consistent.
- Initiate and maintain a transparent and two-way communication process between NIH and the ME community (researchers, clinicians, advocates and patients) at every step of the study.

NIH Needs to Step Up!



For over 30 years, NIH and CDC have had a history of institutional bias, malfeasance and medical abuse toward the ME community. They have accomplished this by creating a trivial name and erroneous criteria, underfunding, and the promoting of harmful treatments such as GET and CBT. The Department of Health and Human Services (HHS) has ignored our ME experts' biomedical evidence of abnormalities in the neuro-endocrine-immune systems of patients with ME - and instead used their own psychosocial and psychosomatic theories to describe a serious neuroimmune disease.

HHS needs to make concrete changes in order to affect real change in how ME is perceived and studied. Although NIH deems this study as only one piece of the puzzle, the Department has a record of turning that puzzle piece into a cornerstone of research dogma for decades to come.

Because of the opportunity for great discovery using the comprehensive resources that the NIH clinic has to offer, it is this very reason, we call for NIH to restart the study and include ME experts' and stakeholders' input throughout the entire process. The NIH study needs to use one criteria (the ICC or CCC), remove investigators and advisors without ME/CFS expertise and/or who possess a psychological bias (such as **Drs. Walitt**, **Gill**, **Saligan**, and **Unger**), eliminate comparison groups that will obscure study results, and communicate transparently to the entire ME community.

Now is the time for NIH to stop sidestepping the critical concerns ME stakeholders have about the study and step up to make the changes called for!

*Please note: MEadvocacy uses the term myalgic encephalomyelitis [ME] to describe the disease defined in the ICC or CCC. When we use the term ME/CFS or chronic fatigue syndrome [CFS], we are using the terminology due to the specific context in the blog. For information see http://www.MEadvocacy.org .

For Further Facts About ME, see MEadvocacy's
Simple ME Fact Sheet http://bit.ly/1TOkZ5V
Brief History of ME http://bit.ly/1VkWX4a
ME Science Links http://bit.ly/1qFq8Su

Just Rest Assured...

A few weeks ago I wrote a letter to the NIH ME/CFS Trans-NIH Working Group, stressing the fact that **Dr. Walitt** was not qualified to be Lead Clinical Investigator of the NIH study, or, for that matter, to be involved in the study in any capacity.

The Trans-NIH Working Group PR department has finally written me back.

It was a letter filled with reassurances designed to quell rather than to inform. I have no doubt that the person who wrote it hasn't the faintest idea what the study is about, or who **Dr. Walitt** is.

NIH has said that it is open to input from patients. But if their policy is to respond to our concerns with stock replies from their PR staff, what does that say about the value they place on our input? It is a hollow gesture to offer an open door, only to have it lead to an empty room.

This was my reply to the letter I received from NIH (scroll down to the end of this post to read it):

April 11, 2016

Dear Public Liaison staff,

Thank you for your response to my letter concerning bias among investigators involved in the NIH study on ME/CFS. You have crafted a reassuring response without actually addressing my point.

My point is not that there is potential bias, but that your lead clinical investigator **Dr. Brian Walitt** is, in fact, biased. His bias has been expressed in a number of publications, as well as in an interview last September. **Dr. Walitt** believes that patients with fibromyalgia and related illnesses, such as ME/CFS, "catastrophize," that they exaggerate their symptoms, and that their disease has psychogenic origins, specifically in child abuse.

Psychogenic theories are a remnant of Freudian psychology, in which various disease states, including MS and gall bladder disease, among others, were attributed to childhood abuse.

There is no scientific evidence to support these theories, nor will there ever be. Science demands the rigor of controlled studies, and a limitation of confounding variables. It also demands baseline measurements.

The psychogenic claims espoused by **Dr. Walitt** have not conformed to these basic tenets of science. Instead they have merely echoed an increasingly outmoded style of thinking. His inclusion in this study is not only unfathomable, it is an embarrassment.

If this were a study on the biological origins of Alzheimer's disease, ALS, or Parkinson's, would you place someone in a position of authority who believed that these diseases were caused by childhood abuse, or that the patients were "catastrophizing" or exaggerating their symptoms?

It would be absurd to include someone with such views, and equally absurd to claim that someone holding those views would not affect the study.

Dr. Walitt has no place in this study. Neither does **Dr. Gill**, who holds similar views, nor **Dr. Saligan** who has jointly published papers with **Dr. Walitt** espousing psychosomatic theories. If **Dr. Collins** is serious about studying this disease, as he has so often stated, he should show his commitment by appointing people to positions of authority who are actual experts.

Sincerely,

Erica Verrillo

Dear **Ms. Verrillo**:

Your email to the National Institutes of Health (NIH) ME/CFS Trans-NIH Working Group concerning myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) has been forwarded to this Institute for reply.

We are pleased that you were able to join us for the NIH telebriefing on ME/CFS last month. You expressed concern about potential bias among the investigators who will be involved with the new ME/CFS study at the NIH Clinical Center in Bethesda, Maryland.

Please know that the investigators have a keen interest in finding answers and life-changing treatments for people with ME/CFS. The study protocol is designed to prevent any possible bias from affecting the results, and the large group of associate investigators, combined with the collaboration and oversight of the Executive Committee, should also help to ensure this.

We have utmost confidence in the dedicated, multidisciplinary team that will conduct this study, and we sincerely believe that the combined resources and expertise of the NIH will shed light on a previously unsolved medical puzzle.

If you have not already done so, you may wish to visit the Trans-NIH ME/CFS Working Group website at http://www.nih.gov/mecfs/about-mecfs. This site will serve to keep people informed about the Working Group's activities.

The site includes FAQs about trans-NIH research on ME/CFS, reports from past ME/CFS workshops and meetings, and links to resources on ME/CFS for researchers and patients.

Thank you for your comments. We at the NIH are confident that the new clinical study and other initiatives will support the efforts of the scientific experts who are working on this very challenging disorder and will encourage rapid scientific progress and the development of new ways to diagnose and treat ME/CFS.

We hope this information is helpful.

Office of Communications and Public Liaison, National Institute of Neurological Disorders and Stroke on behalf of the Trans-NIH ME/CFS Working Group

Source: http://www.cfstreatmentguide.com/blog , **Erica Verrillo**

Mystery Of CFS Solved

April 1, 2016. Today, the Director of the National Institutes of Health, **Dr. Francis Collins**, announced that an upcoming NIH study on chronic fatigue syndrome would be cancelled, due to an unexpected breakthrough by its lead clinical investigator **Dr. Brian Walitt**.

The breakthrough came after a painstaking review of several thousand research studies in the PubMed database, which revealed the true nature of the disease.

"*It was there all along*," said **Dr. Collins**. "*But it took the eye of an experienced clinician to find it*."

Chronic fatigue syndrome, according to the NIH, is a complex, multi-system disease that affects nearly every part of the body and produces a plethora of symptoms. The wide array of symptoms, as well as the involvement of the nervous, immune and endocrine systems, have baffled scientists for decades. The question the scientific community could not answer was how one disease could produce so many effects.

"*That's just it*," said **Dr. Walitt**. "When we looked carefully, we found that not only did people with CFS have cytokines, neurochemicals, hormones, and red blood cells, but everyone else did too!"

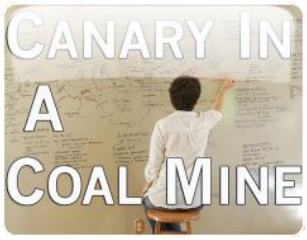
This shocking revelation led to another ground-breaking finding.
"*People with CFS have all the major organs that other people have*," said **Dr. Walitt**. "*They have arms, legs, torsos, and, in the vast majority of cases, faces, and these commonalities are found across the board. People with CFS have ALL THE THINGS. What's more, they have all these things, and these things that they have are also in their heads, which are attached to their bodies, which is true of everyone else as well. It's a narrative that encompasses all of culture and society*."

"***Dr. Walitt**'s findings will have an enormous impact on how we do science*," said **Dr. Collins**. On the heels of its cancellation of the CFS study, the NIH also announced that it would be closing down all of its Institutes, in favor of a single Institute: The Institute of Biopsychosocialculturalneuroendocrineimmune Syndromes.

"*Having only one Institute will revolutionize how we do research in the future*," said **Dr. Collins**. "*From now on we will devote all our efforts to investigating BS*."

Erica Verrillo (http://bit.ly/1oTyeWf)

Canary in a Coalmine



I'm thrilled to be working with Emmy-winning editor **Kim Roberts**.

The film is in the best of hands, and it's really starting to shape into something incredible.

Kim Roberts, A.C.E. is an Emmy-winning editor of feature documentaries. Her recent work includes The Hunting Ground, American Revolutionary: The Evolution of Grace Lee Boggs, Waiting for 'Superman' (Paramount), Food, Inc. (nominated for a 2010 Oscar®), Autism the Musical (HBO), and Inequality for All (Radius).

Kim won an Emmy for Autism the Musical, her third nomination. She was also nominated for an Eddie award for Food, Inc. and Waiting for 'Superman' from the American Cinema Editors.

Her other films include: Oscar® nominees and Sundance Grand Jury Prize winners Daughter from Danang and Long Night's Journey Into Day; Last Call at the Oasis (Participant); Two Days in October (Peabody and Emmy winner '06); Made in L.A. (Emmy winner '09); The Fall of Fujimori (Sundance '05); Lost Boys of Sudan (Independent Spirit Award '04); Daddy & Papa (Sundance), and A Hard Straight (Grand Prize, SXSW).

Kim received her Masters Degree in Documentary Film Production from Stanford University, where she won a Student Academy Award.

Learn more about our team: http://www.canaryinacoalminefilm.com/team/

Support Canary:
The film: http://www.canaryinacoalminefilm.com/donate
The impact campaign: http://j.mp/canaryimpact
Partners: http://www.canaryinacoalminefilm.com/partners/

Jen

The History Of The Disease - An Appeal

Canary in a Coal Mine (working title), my documentary film (http://canaryinacoalminefilm.com/) about myalgic encephalomyelitis, is heading toward rough cut, an early version of the finished film. Right now, we are working intensely on the historical sections to help the audience understand not only the history of the disease but a broader history of medicine. The intention is to give audiences a framework for understanding just how we arrived at where we are now with this disease.

We will be hiring an archival researcher to search for film, images, and newspaper or journal article headlines, a search that may unearth primary resources we have never seen. The collective knowledge of this community is an amazing resource, and so I am asking for your help to give our archival researcher a great start.

Specifically, I would love your help collating information and primary resources on the following topics. Actual images, news archive, etc. would be incredible, but just as important is adding what you know. Collating more detail on where and precisely when major events happened will give our researcher clues on where and when to look.

The best way to collate materials is to post them on MEpedia (http://me-pedia.org/) (I will be sharing the links directly with our researcher – just sign up for an account and click "edit" on the page and paste away. Don't worry about formatting! Others will come along and make sure links and citations work, etc.)

1) The Outbreaks

We are looking for information, archive, and visuals from all the outbreaks (http://me-pedia.org/wiki/List_of_outbreaks), but are especially interested in the 1934 Los Angeles County Hospital outbreak (http://bit.ly/1Nmum6a), the 1946 Akureryi, Iceland outbreak (http://bit.ly/23AVveY), the 1955 Royal Free Hospital outbreak (http://bit.ly/1qFWaxD), and the 1984 Incline Village, Nevada outbreak (http://bit.ly/25X0c5d).

Again, links to actual newspaper accounts and visuals would be helpful – or even uploads of materials you may have – but also useful would be just fleshing out these pages with more information to help our researcher in their search.

2) The Victorian history of the disease

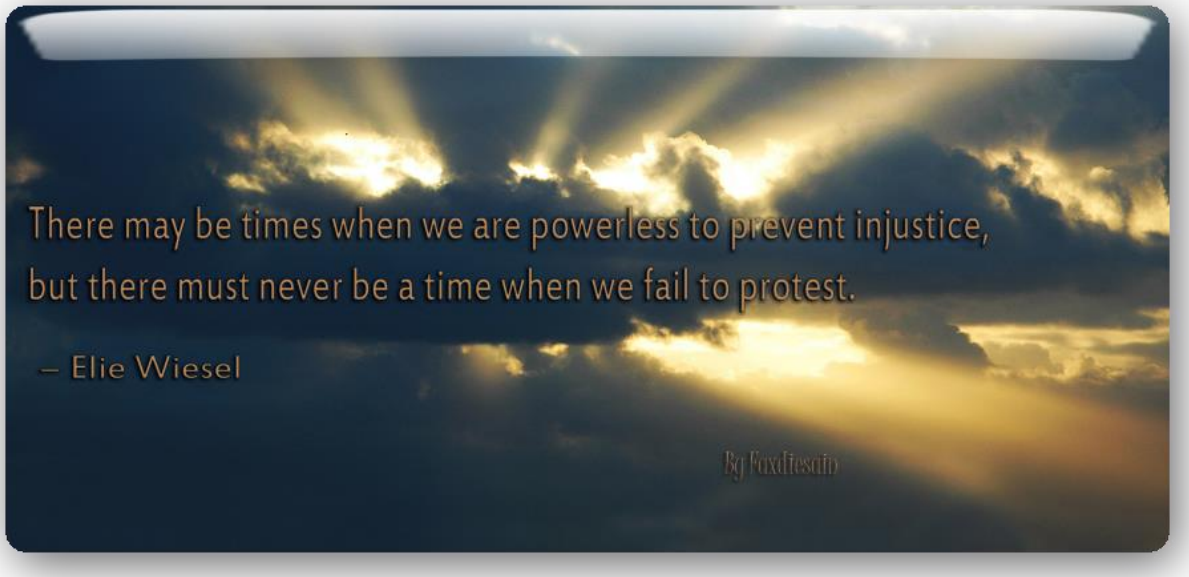
We are looking for information, archive, and visuals on Victorian understandings of the disease (http://bit.ly/1Q4yrvJ), including: hysteria (http://bit.ly/1XsX5fg), neurasthenia (http://bit.ly/1qN9oJt), Charcot (http://bit.ly/20y798A), Freud (http://bit.ly/1qN9AIB) and other contemporaries (http://bit.ly/1qFWxbG) who may have written about these two conditions – wastebasket precursors to chronic fatigue syndrome.

Edit: I do not mean to say that ME was historically diagnosed as hysteria although it was probably very close to some understanding of neurasthenia. Rather that the legacy of both illnesses influenced the whole of the history of medicine and the way that ME was later categorized and treated (http://bit.ly/23rt1ru).

But please, do correct or contest what I am getting wrong! That is part of the beauty of "crowdsourcing" this project – it helps us to learn about new sources and make sure that if we get things wrong, by the time we are picture lock, we have gotten them right.

Thanks for your help!

Jen Brea
Questions can be posted at http://bit.ly/1VjJcCb



In Memoriam - Roger Cicero

German jazz singer **Roger Cicero** dies, aged 45

Germany's best-known jazz performer has died after being diagnosed with chronic fatigue syndrome. His career spanned almost 15 years, making him one of Germany's most beloved musical celebrities.

Cicero was born into a musical family, with his father a renowned jazz pianist and his mother a professional dancer. **Cicero** started performing publicly alongside famous German acts like **Helen Vita** at the age of 11. He later studied at the Hohner conservatory, focusing on piano and voice.

He was particularly known for his interpretations on **Frank Sinatra** songs (http://bit.ly/1SPe7An), which he worked on until his death.

Cicero also featured in the movie "Hilde," a biographic film based on the life of **Hildegard Knef**, Germany's most famous post-war actress and singer. In 2012, he also recorded "Für nichts auf dieser Welt" - Germany's anthem for the 2012 UEFA European Soccer Championship.

Cicero had suffered chronic fatigue syndrome, which reportedly led to his untimely death through a sudden stroke on Thursday, March 24. His family made the news of his death public on Tuesday March 29, 2016.

Cicero was 45 years old.

Source: http://bit.ly/1Ncl16l

Appoint Lower Level Committees

One strategy often used by those in power is to appoint lower level committees that make inconsequential recommendations in order to appease dissatisfied groups.

These minor concessions do not threaten the power structure itself and represent a deflection of true challenges to power.

It is essential for change agents to recognize these types of barriers to second-order change.

Prof. Leonard Jason

From: Principles of Social Change, p33
Published January 21st 2013 by Oxford University Press, USA

ISBN 0199841853 (ISBN13: 9780199841851)

Dutch Citizen Initiative

Dutch Citizen Initiative to Recognize ME as a Biomedical Disease - Including Petition

An appeal for help from the Dutch ME-community by a single, simple action: signing its petition to show your support

This petition can be signed by anyone reading this (you don't need to be Dutch to sign).

The Dutch myalgic encephalomyelitis (ME) community has started a petition (http://bit.ly/22r5cKN) to the Dutch Health Council to change the current composition of its Health Council of the Netherlands panel reviewing the state of science resulting in an advisory report on ME.

The reason for the petition is the concern from the patient community that some of the current panel members are biased toward the psychogenic view of the disease. This, they say, is incompatible with the state of the scientific knowledge of the neuroimmune disease, ME (WHO recognition ME 1969, ICD G93.3).

ME is not Medically Unexplained Physical Symptoms (MUPS), as some of the panel members propose. The petition calls for the adjustment of the composition of the Dutch Health Council Committee with the guidance of the patients. They want the inclusion of international ME experts and are calling for the Council to heed its advisory report assignment.

History of events

The Dutch Ministry of Health has been and is currently using a chronic fatigue syndrome (CFS) guideline (http://bit.ly/22r84XU) for practitioners which was issued in 2013. This guideline recommends Cognitive Behavior Therapy (CBT) and Graded Exercise Therapy (GET) as the only effective treatments for the disease.

In the Fall of 2011, a group of ten independent patients, calling themselves the Groep ME Den Haag (Group ME The Hague http://bit.ly/1N60PTs), started a petition (http://bit.ly/1WpjKL6) requesting the Dutch Ministry of Health to: recognize ME as a biomedical neuroimmune disease (separate from CFS); disseminate information about ME to medical practitioners and in medical education; use the ME ICC criteria for diagnostic purposes; increase ME biomedical research. They successfully collected 56,000 signatures and delivered the petition to the Dutch Ministry of Health. (They only needed 40,000 for a responsive action)

In 2014, in response to the successfully completed and delivered petition, the Dutch parliament commissioned the Health Council of the Netherlands to evaluate the current state of knowledge about ME with special attention to:

- definition and criteria for diagnosis
- origin, progress and prevalence
- ability for prevention and treatment
- impact on the quality of life; environment and social
- organization of treatment and support
- current scientific developments and perspectives

The Groep ME Den Haag wrote to the Health Council, before the start of the commission to review the state of science on ME, requesting that they should be extra critical regarding the subject of CBT and GET, taking published criticisms into account. In addition, because of the lack of local ME experts (due to the long decades of stigma), the group urged the Health Council to include foreign ME experts.

The following International ME experts wrote to the Groep ME-Den Haag pledging their support:

Prof. Alan Light, the late **Dr. M. Lerner**, **Dr. A. Kogelnik**, **Prof. Mady Hornig**, **Dr. Nigel Speight**, **Prof. Leonard A. Jason**, **Prof. P. Powles**, **Dr. Spurr**, **Dr. Lucinda Bateman**, **Dr. Byron Hyde**, **Dr. Ellie Stein**, **Dr. Dan Peterson**, **Dr. John Chia**, **Prof. Gordon Broderick**, **Prof. Patrick McGowan**, **Prof. Kenny de Meirleir**, **Prof. Jarred Younger**, and others.

Yet, in March 2016, the Health Council appointed a highly biased panel, with three out of the ten members favoring the MUPS theory of the disease and the promotion of CBT and GET. The Council dismissed the Groep ME-Den Haag's warning against panel members who are proponents of the psychosomatic beliefs of the disease and cautions about the dangers of CBT and GET.

Panel Members (http://bit.ly/1VQiuQC)

The following three members of the panel are proponents of the Medically Unexplained Physical Symptoms (MUPS) belief of the disease:

Dr. Hans Knoop - the present head of the Nijmeegs Kenniscentrum Chronische Vermoeidheid (NKCV, CFS knowledge center in Nijmegen). He and his predecessor **Prof. Gijs Bleijenberg** and others from the NKCV published extensively together with **Profs. Simon Wessely**, **Peter White**, **Trudy Chalder**, **Michael Sharpe** and others.

Prof. Rosmalen - head of a project Grip op Klachten (Grip on Complaints http://www.gripopklachten.nl, only Dutch) which has been subsidized for 1,5 million euro by the Innovatiefonds Zorgverzekeraars (Innovation Fund Health Care Insurance Companies) to disseminate the benefits of CBT in ME (which is explained to be the same as CFS or MUPS, Medically Unexplained Physical Symptoms) and to train as many health practitioners as possible in applying CBT with people with ME. The NKCV plays a crucial part in this project. **Dr. Olde Hartman** - publishes and disseminates CBT as being the preferred therapy to be given by GPs for people with ME who he proposes suffer from MUPS.

In addition, the panel includes four specialists with very little ME research experience and two patients' representatives. The Health Council dismissed the Groep ME Den Haag's and the parliament's insistence that this investigation is about the disease ME - not CFS, CF or MUPS, and named the panel ME/CVS(ME/CFS) instead. Dutch ME patients are concerned that this doomed course will result in the conclusion that it's best to leave things as they are - meaning that the present CFS-guidelines (which are almost a copy of the British NICE-guidelines) are the be-all and end-all of the present state of knowledge of ME. The day after the publication of the names of the panel, Dutch patients started the current petition against the choice of problematic panel members and urging the Health Council to replace them with experts on different aspects of the disease, instead of representatives of the MUPS-school of thought.

Petition

The petition to protest against MUPS-members of the panel of the Health Council of the Netherlands in support of the Dutch ME community can be signed by anyone reading this. (You don't need to be Dutch to sign) http://bit.ly/22r5cKN

We

Myalgic Encephalomyelitis (ME) patients and all those who recognize the severity and nature of this biomedical disease

Observe

That the Dutch Health Council Committee composition is incompatible with the state of the scientific knowledge, of which the Dutch Health Council is aware (WHO recognition ME 1969, ICD G93.3, the Institute of Medicine refers to a chronic, complex, multisystem disease with symptoms that can be explained by objectifiable physical abnormalities as described in thousands of scientific publications),

- nor does it fit the advisory report assignment given by Parliament (an advisory report about ME),
- ME is not MUPS! The Dutch Health Council should select the best available expertise, relevant to this disease, but fails to do so.

And request

To adjust the composition of the Dutch Health Council Committee. Input of patients should be taken as the guiding principle. After all, the Citizen's Initiative "Recognize ME" was the direct reason for the advisory report assignment. They together with the patient organizations have submitted, at the request of the Dutch Health Council, names of (international) ME experts, who are willing to participate (none of them from the MUPS/Mental Health Care field!). The fact that the Dutch Health Council nonetheless prefers irrelevant MUPS and Mental Health Care professionals, that were not suggested to them, over international ME expertise, is unacceptable. The Dutch Health Council must adhere to its advisory report assignment!

Thanks to **MEAdvocacy** for editing

Karina Hansen, BREAKING NEWS

Editorial note: although we try and keep articles shorter than at most 600 words, we decided to make exceptions on the 4 items we're focusing on since Febr. 2016, the start of the third year of the MEGC; being **Karina**, NIH/CDC, NICE/PACE and the Dutch citizen initiative.

It was confirmed yesterday (Aoril 3, 2016 ed.) that Danish High Court Attorney **Cristina Poblador** (http://bit.ly/1PTHZK3) from Homann law firm in Copenhagen has agreed to take this case. This is wonderful news and hopefully will begin to change the narrative of this tragic story.

This post follows on from my previous posts Karina Hansen 3 (http://bit.ly/1SbqDto): Update March 2016 (KH3) and Karina Hansen 2 (http://bit.ly/1oj5Ey5): The Ghost in the Room (KH2). For the full background to this story, please refer to KH2.

A brief re-cap

Karina lives in Denmark. In 2008, she was diagnosed with severe Myalgic Encephalomyelitis (ME) (http://bit.ly/1Wc37CC). The diagnosis was disputed and in February 2013, then aged 24, she was forcibly removed from home, where her family had been caring for her. She was taken to Hammel Neurocenter (http://bit.ly/1RFDNTT)(part of "The Research Clinic for Functional Disorders" at Aarhus University Hospital).

Several doctors have been involved in her case but psychiatrists **Nils Balle Christensen** (http://bit.ly/1oDtIeX) and **Per Fink** (http://bit.ly/1RFE7lB) have dictated the overall course of her treatment at Hammel. Since shortly after her initial detention, she has been classed as a "voluntary" patient; she was found by a court subsequently to lack capacity to make her own decisions. As a result of that finding, the court appointed a legal guardian to take responsibility for her welfare.

Three years on, **Karina** remains a de facto prisoner of the state. She has been moved to a nearby "rehabilitation centre" but allowed very little contact with her family. Her father was allowed to visit her in December 2015. Whilst she was physically clean and cared-for, she was nevertheless in a wheelchair and unable to speak except for incomprehensible mumbling and grimaces. She did not recognise her own father.

Timeline of events

In an attempt to make sense of what has happened to **Karina**, I have constructed a Timeline. It is followed by some important explanatory points.

THE TIMELINE

- 2005 **Karina** first becomes ill but there is disagreement about the diagnosis
- 2008 **Karina** diagnosed with severe ME
- 2009 ME is re-classified by the Danish Board of Health as Bodily Distress Syndrome (http://bit.ly/1V951UU), a somatoform, quasi-psychiatric construct. Two specialist clinics are designated in due course to research/treat BDS patients, one in Copenhagen and one at Hammel Neurocenter in Jutland.
- 2012 First attempt at removing **Karina** from home fails. She becomes increasingly concerned and arranges for her parents to have power of attorney so they can act on her behalf.
- January 2013 The Danish Board of Health (BOH) produces a report which discusses at length how to justify removing **Karina** from her home by force and restricting contact with her family. They conclude that they could achieve this under **Articles 3*** and **8**** of the European Convention on Human Rights.
- February 2013 **Karina** is forcibly removed from home under the emergency doctrine of "nødret" (necessity) by a team of police, doctors and social workers. This is clearly against her express wishes and those of her parents. She is incarcerated at Hammel Neurocenter.
- April 2013 **Karina**'s sister (a nurse) visits her at Hammel. **Karina** is already too incapacitated to communicate with her sister.
- May 2013 First court hearing: **Karina** is found to lack capacity so **Kaj Stendorf** (**KS**) is appointed as her temporary guardian, despite his apparent conflict of interest as former police chief of **Karina**'s district at the time of her removal from home.
- May 2013 An international symposium is held in Aarhus to celebrate 15 years of The Research Clinic for Functional Disorders and **Per Fink**'s 60th birthday. **Ole Thomsen** (director of health for **Karina**'s region) publicly congratulates **Dr Fink** and the team on having "dared to take a risk...[and] saved a young woman's life" - with the aid of the Minister for Health (then **Astrid Krag** http://bit.ly/1RNXsxf). British psychiatrists **Peter White**, **Michael Sharpe** and **John Weinman** are scheduled to attend and address the event.
- September 2013 Court hearing at which **KS** is confirmed as **Karina**'s permanent guardian, despite the family's continuing opposition.
- October 2014 **Karina** is moved to the "rehabilitation centre". The psychiatrists continue to claim that she is a "voluntary" patient and can leave whenever she wants (but she is physically and mentally incapacitated and cannot do anything without the guardian's consent).
- October 2015 The District Court reaffirms **KS** as **Karina**'s guardian.
- December 2015 **Karina**'s father visits her at the rehabilitation centre. She is in a wheelchair, unable to speak, communicate or recognise him. She mumbles and grimaces incomprehensibly
- February 2016 Following another challenge by Karina's parents, the High Court upholds the District Court's ruling; **KS** continues as **Karina**'s guardian. **Karina** remains at Hammel, completely physically and mentally incapacitated. Not only has the treatment failed but she is considerably worse than when she was involuntarily admitted, three years earlier.

* **Article 3** is the right not to be subjected to torture, inhuman or degrading treatment. Apparently, the BOH decided that **Karina**'s situation in being cared for at home by her family was equivalent to (for example) the treatment which might have been experienced by an inmate at the US military prison at Guantanamo Bay.

Article 8 is the right to respect for private and family life; this is taken to include healthcare. The BOH concluded that **Karina**'s right to a private and family life was best enforced by removing her from her chosen place of safety in her home, being cared for by her parents. It is also important to note that, following lengthy investigation, no further action was taken against her parents for any supposed harm to **Karina**.

Explanatory notes

1. ME (http://bit.ly/1Wc37CC) is a complex, multi-systemic neuro-immune disease. The first documented outbreak was in Los Angeles, California in the US in 1934. The first similar outbreak in the UK was in 1955 at the Royal Free Hospital in London. The pattern has been much the same in many other countries. ME may have previously been mis-identified as "neurasthenia". Historically, ME has been difficult to diagnose with the inevitable result that patients have been largely abandoned and even abused for decades (there is still no effective treatment and no universally-accepted diagnostic approach/biomarkers).

2. The cyclical involvement of the psychiatric profession has complicated things further by constantly shifting research and treatment towards the psychosocial treatment approach (http://bit.ly/25KNqXe) which is, at best, ineffective and at worst, harmful. In many countries, (including Denmark, at Hammel where **Karina** was taken) recommended treatments consist of Cognitive Behavioural Therapy (CBT), Graded Exercise Therapy (GET), occupational therapy and psychotropic medications (eg. antidepressants).

3. ME (as defined in the 2011 International Consensus Criteria http://bit.ly/1q68lDl) has been burdened with a variety of different names and around 20 different case definitions. Since 1988, the term "chronic fatigue syndrome" (as "CFS" or "CFS/ME" or "ME/CFS") has been widely exported from the US to many other countries. This has caused great distress to patients with classic ME and widespread confusion generally. Patients with CFS may benefit from the treatments mentioned above, as distinct from genuine ME patients who will mostly become worse with such treatment (particularly GET).

How - but not why...

The Timeline tells us how this chain of events came about but it cannot answer the vital question of why. As I explained in KH2, I asked an academic colleague to contact both the Ministers for Health and Justice and Hammel Neurocenter. **Per Fink** replied on behalf of Hammel that all patients are there on a voluntary basis and that the clinic is very popular (see KH2 for fuller details).

Despite repeated requests, the Minister for Health has refused to comment on the basis of patient confidentiality (although the request was worded as a general inquiry rather than for specific information about **Karina**). The Minister for Justice has sent standard acknowledgments but no substantive answer.

Professional reputations are key to personal and financial success in any sphere of life. The psychiatric profession is no exception to this; despite a wealth of evidence (mostly privately-funded) that ME is an organic disease (http://bit.ly/1V95vKX), it has been singled out as an easy target by psychiatric healthcare professionals in many countries as a way of displaying professional skills and bolstering reputations. For this to succeed, a ready supply of suitable patients is needed on which the psychosocial treatments can be shown to work.

In the UK, the controversial PACE Trial (http://bit.ly/1SAcC92) fulfilled that obligation admirably, thanks to unquestioning endorsement (http://ind.pn/1qremvk) by many media organisations. In Denmark, the same process has presumably been in action with patients like **Karina**. However, despite several requests by Borgerretsbevægelsen (Civil Rights Movement group http://borgerretsbevægelsen.dk/) for details of successful treatments, none has been forthcoming as yet.

Follow the money

The unholy alliance of insurance companies, healthcare professionals and the pharmaceutical industry is frequently the subject of comment and debate in relation to many medical conditions. Given its nebulous nature and largely disempowered patient population, ME as a disease entity is particularly susceptible to manipulation by this dubious triad.

Keeping an illness defined as either "psychiatric" or "chronic" reduces or eliminates the need for payouts by insurers; pharmaceutical companies are only interested in investing in research and development which looks likely to generate a healthy (sic) income (such as the lucrative antidepressant market). The input of healthcare professionals is vital in maintaining the status quo for all parties; however, in this scenario, patients are no more than a cog in the investment machine.

The Danish clinics which carry out research on BDS (also known as MUS - medically unexplained symptoms - and FSS - functional somatic syndromes) receive funding from a number of different sources. These include:

- Substantial regular donations from TrygFonden (http://bit.ly/1MS5PLq), a charitable foundation owned by the Scandinavian conglomerate TryghedsGruppen. TryghedsGruppen (http://bit.ly/2076U4n) also owns Tryg (http://bit.ly/1TBJfbl), second largest insurance company in the Nordic region.
- Generous donations from the Lundbeck pharmaceutical company (http://bit.ly/1YePQrA) via the Lundbeck Foundation (http://bit.ly/1RXHt27) (see P 17 of link). Lundbeck's home page proudly declares: "*Progress in Mind is Lundbeck's dedication to addressing the global burden of psychiatry and neurology*".

CSR (Corporate Social Responsibility) or COI (Conflict Of Interest)? Or both?

The role of the state

The "follow the money" approach also benefits state finances; maintaining an ill-defined disease status is instrumental in keeping the lid on increasingly stretched welfare budgets. The sick and disabled are merely collateral damage along the way. But does that justification really hold water in the case of the disease ME?

In 2015, the US Institute of Medicine (http://bit.ly/23gNZWI) produced a lengthy report called "Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness" (http://bit.ly/1PTKhc0).

The report states: Between 836,000 and 2.5 million Americans suffer from myalgic encephalomyelitis/chronic fatigue syndrome—commonly referred to as ME/ CFS... ME/CFS can severely impair patients' ability to conduct their normal lives (at p 31)... The direct and indirect economic costs of ME/CFS to society [in the US] are estimated to be approximately over $18 to $24 billion annually (at p 33) [my emphasis].

These "direct and indirect economic costs" consist mainly of healthcare costs, welfare payments and lost productivity. In recent years, the US's average annual spending on "ME/CFS" research has been less than $5million (£3.54m/€4.47m). It doesn't take a genius to work out that these figures don't stack up. In the UK, government spending on ME research has been far less than that.

The economic costs of this disease burden are enormous; it therefore seems the height of fiscal irresponsibility not to have invested far more into funding ME research - with the focus on biomedical, not psychosocial, investigation.

Legal issues

In legal terms, **Karina**'s case is highly complex and encompasses a number of different areas of law (of which human rights law is only one strand). The issues involved present matters of significant public importance, both in Denmark and internationally. It also presents some serious challenges, not least in that there appear to have been anomalies in both the legal and executive processes right from the start.

Because of the now exceptional nature of this case, legal representation of the highest calibre is needed, ideally on a pro bono or reduced rate basis. There is a fund for donations towards legal costs (see end of post for details) but further funding is still required. Karina's family have now exhausted all their own resources.

The method by which **Karina** was placed and retained at Hammel appears to have been artificially constructed and has resulted in a total impasse. The direct and indirect costs to the state of maintaining **Karina**'s constant care will be considerable. The amount it has already cost private donors and/or Danish taxpayers will be excessive; for this, the Minister for Health should be held accountable.

Clearly there is an urgent need for a senior Danish lawyer to carry out an in-depth review of the case on behalf of **Karina**'s family (**Karina** herself cannot instruct a lawyer except through her legal guardian). Borgerretsbevægelsen has for some time been conducting a search for an experienced lawyer who is willing to take the case. As I mentioned at the top of this post, it has now been confirmed that **Cristina Poblador** (http://bit.ly/1PTHZK3) is taking the case which is excellent news.

THE TRAGEDY

As I said in KH3: "is her condition the direct result of a state-orchestrated plan which went horribly wrong?" If so, can the state not take responsibility for this error of judgment and return **Karina** to her home with appropriate compensation to her and/or her family in the hope that she might then be able to begin recovery from this traumatic episode? (see the case of American teenager **Justina Pelletier** (http://bit.ly/1SAdx9z) - a structurally simpler case, legally speaking, but one which involves similar issues).

There are two separate answers to that question: the first is that the state is unlikely to agree to such a course because it could be construed as accepting liability thereby opening the floodgates to further claims. However, although **Karina**'s case is by no means unique, her circumstances must now be classed as exceptional and critical; her case could therefore be viewed as distinguishable from any opportunistic claims which might arise later on.

The second answer is this: in the case of ME patients, collective responsibility by the psychiatric profession for its mistakes - and the resulting injury to patients - is not deemed necessary. A broad coalition of psychiatrists and related groups appears to enjoy worldwide state-sanctioned immunity from the consequences of their actions; most ME patients, on the other hand, continue to carry the burden of a stigmatised and untreatable illness for the rest of their lives. **Karina**'s situation is an extreme example of how badly wrong the process can go. In the continuing absence of a global political will to change this, her story will continue to be repeated throughout future generations. That is the tragedy.

Acknowledgements

Unless something unexpected happens, this article will be the last in my series about **Karina** for the time being. I would like to thank the following people for their assistance with compiling the information on which this series is based:

- **Bente Stenfalk** of Borgerretsbevægelsen
- **Rebecca Hansen**, Chairman of ME Foreningen - ME Association, Denmark
- The Justice for Karina Hansen group
- **Katharina Voss**, ME advocate/writer

Donations

Borgerretsbevægelsen and Save4Children are collecting donations for the legal fund. You can visit their home pages to make a donation.

Valerie Eliott Smith (Disclosure: I have lived with the illness ME since 1981. For more information about my background see About.

Karina Hansen, A Lawyer For A Ruined Lady

Denmark, April 3, 2016

"Today I have the pleasure to tell you that the Civil Rights Movement has managed to find a lawyer who will take the **Karina**-case.

It has been difficult. Many lawyers have been contacted, and many have read and read and ALMOST taken the case and then 'ran away'.

But now the case is finally under preparation, and this courageous lawyer has taken the case:
Christina Poblador http://homannlaw.dk/da/advokat/cristina-poblador/

We have also informed the Dutch association **Save4Children** which has been so kind to gather a large sum of money to support the case financially, and we have informed **Valerie Eliot Smith**, an English lawyer, who has followed the case closely. A lot of people have followed her blog about **Karina**.

I sincerely hope that this will be the beginning of the end of **Karina Hansen**'s completely unfair and unfortunate fate in psychiatric 'care'.

If you have got more trust in us now, there is still an opportunity for donations to the **Karina**-case:

You can donate a sum of money, small or big, on this account:
5352 0243262 / Workers' Land Bank, or
via MobilPay or Swipp on mobile: **53314832** –

Remember to mention " Donation for **Karina**"

As also to the fund **Save4Children**: http://let-me.be/page.php?11

Bente Stenfalk

Karina Hansen, Save4Children

Help Karina – donate to Save4Children

The charity Save4Children has been created by the editors of the ME Global Chronicle (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 is kept hostage of the Danish psychiatric system since February 2013.

Donations made to this fund will presently solely be used to provide financial support for expenses, needed to try and set free **Karina Hansen**, a young ME-patient who was taken from her home against her will in February 2013 and placed under psychiatric care

Donations will be collected at the S4C site: http://let-me.be/page.php?11

Information about **Karina** and the case can be found in this and future issues of the ME Global Chronicle and at these sites:

Justice for Karina Hansen - find info under notes.
https://www.facebook.com/JusticeForKarinaHansen

Two videos about Karina from 2013:
http://www.youtube.com/watch?v=Dk3e8IWj7M0
http://www.youtube.com/watch?v=JTkkcvlvYf8

The ME Global Chronicle Special Karina Hansen 20151025:
http://let-me.be/download.php?view.24

The Citizen's Rights Group of Denmark-documents in the case in Danish:
http://xn--borgerretsbevgelsen-xxb.dk/

Since the February 2016-issue of the MEGC **€ 1.045** has been donated, which brings the current credit balance to **€ 2.534,59**.

Thanks to all those who donated so generously. You are making it possible that finally a most proficient lawyer takes up Karina's case.


Yes, I donate to Karina Hansen
(https://www.geef.nl/donatiemodule/taal:en/doel:save4children)


Yes, I donate to Karina Hansen
(https://www.geef.nl/donatiemodule/taal:en/doel:save4children)


Ja, ik doneer aan Karina Hansen
(https://www.geef.nl/donatiemodule/taal:nl/doel:save4children)


Oui, je soutiens Karina Hansen
(https://www.geef.nl/donatiemodule/taal:fr/doel:save4children)


Ja, ich unterstütze Karina Hansen
(https://www.geef.nl/donatiemodule/taal:de/doel:save4children)


Sí, apoyo Karina Hansen
(https://www.geef.nl/donatiemodule/taal:es/doel:save4children)


Ja, jeg donerer til Karina
(https://www.geef.nl/donatiemodule/taal:en/doel:save4children)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Latest status: http://save4children.geef.nl/doel/save4children/donaties
In case you experience any problems with your payment, please contact us at donate@letme.be and provide us with as much as possible information: country, url, date time, error, used payment method, etc.

6. Science

Rich' Reviews: Psychological Treatment for ME/CFS DOES NOT HELP FATIGUE

Most of my essays focus on potential treatments for chronic fatigue syndrome and fibromyalgia. Instead, this report is about an ME/CFS treatment that failed--and why that's important. In the U.S. few physicians or scientists still believe that ME/CFS is mostly "all in your mind". At last, the National Institutes of Health is coming on board. NIH has charged the National Institute of Neurological Disorders and Stroke with the (not yet budgeted) task of advancing research on ME/CFS.

But, in Europe, influential elements remain committed to the view that ME/CFS is mainly a problem of psychological distress. This stress, they argue, makes people to become inactive. Inactivity causes physical deconditioning—much like the astronaut who can barely stand up when she first returns from space. This "psychosomatic" theory tends to block research institutions, aspiring scientists, drug companies and philanthropies from committing themselves toward research on ME/CFS. The PACE study (http://www.ncbi.nlm.nih.gov/pubmed/21334061), done in England, is the most cited report used to justify the "all in your mind" hypothesis. The PACE study created 3 groups of patients with a chronic fatigue-like illness. One group received cognitive behavioral psychotherapy; another did a gradually graded exercise program. The third group—the control—visited physicians who specialize in CFS but did not receive psychotherapy or graded exercise.

The PACE study has flaws, some of which may be fatal. It's far from certain that all their subjects really had ME/CFS. There's suspicion of mischief in the author's method of deciding which patients did and which did not meet criteria. Nor is the degree of improvement reported anywhere close to what one might view as a "cure". (http://www.virology.ws/2016/02/10/open-letter-lancet-again/). But, more troublesome is the false extrapolation from this data that people who should know better have made—even assuming that the study's data and findings were perfectly correct.

Cognitive behavioral therapy is a useful technique to help train people into the habit of positive thinking—seeing the glass half full instead of half empty. Cognitive therapy has been shown to help people cope better with many different forms of indisputably physical health problems. Similarly, carefully monitored exercise reconditioning—if done within a patient's limits—can modestly help how people feel and function. What's mischievous or misinformed about how the PACE study has been used is to imply that better coping through psychological support or modest improvement through reconditioning— implies that the illness is substantially psychosomatic. No one would claim that for a patient with angina, emphysema, rheumatoid arthritis or cancer.

Why assign that blame to patients with ME/CFS? But, since this debate continues it might be refreshing to review a study—also from England—where a psychological intervention for chronic fatigue indisputably FAILED. (http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2859122/) 298 patients with long term chronic fatigue (not clearly defined as ME/CFS) received either one of two forms of psychological counseling—"pragmatic rehabilitation" or "supportive listening". The "control group" had routine treatment with their general practitioner. The "pragmatic rehabilitation" counseling taught patients about physical deconditioning, coping with anxiety, improving sleep and "overcoming impediments to change". "Supportive listening" focused on "creating an emotional and physical environment conducive to helping relationship". Each patient's fatigue and related symptoms was scored at entry, again after 20 weeks and then again about a year later.

Using the Chalder fatigue scale (an 11 questions survey asking about people's symptoms and activities), after 20 weeks the average score in all three groups improved but only modestly. Scores in the pragmatic rehabilitation group were modestly better than either "supportive listening" or general practitioner care. At 20 weeks this advantage to pragmatic rehabilitation was statistically significant. BUT, by 70 weeks no further improvement had occurred in any of the 3 groups. And the difference between pragmatic rehabilitation treatment and the general practitioner group was no longer statistically significant. Basically, the two different forms of behavioral/psychological counseling had at best a very modest short term impact on the severity of illness. Over the long run the psychological component had no meaningful impact.

Why is this important? So long those who matter believe ME/CFS is mainly "all in your mind", everyone suffers—patients, their families, scientists, health care budgets and society in general. (Well maybe not disability insurance companies.) But our battle is far from won—even in the USA. NIH has committed itself to look seriously at ME/CFS. But, no increase in budget has yet been set. Please recall, for 2015 and 2016 NIH has budgeted only about $5 million a year, while the Centers for Disease Control estimates that more than one million Americans may suffer from chronic fatigue syndrome. In contrast, an estimated 400,000 Americans have Multiple Sclerosis. NIH's budget for MS? About $98 million a year. This isn't a knock against MS research; just a comparison.

NIH has not yet committed to a new and presumably higher budget for ME/CFS research. As all such decisions reflect a mix of political and scientific issues, those among us who have some credibility with federal legislators or bureaucrats—this might be a good time to employ some of our clout.

Richard N. Podell, M.D., MPH
Clinical Professor
Department of Family Medicine
Rutgers-Robert Wood Johnson Medical School
Podell2@gmail.com

Genetic Database For Individuals With ME/CFS

NSU is currently recruiting ME/CFS patients AND Healthy Controls for their completely web based study to create a one of a kind genetic database for individuals with ME/CFS:

Participation for this study requires you to have a computer with internet access, an email account and your agreement to map your genes through the use of a publicly available genetic testing websites. If you agree to participate, you will provide us with your raw genetic data for us to compile in a one of a kind, ME/CFS Genetic Database. Participating in this study is purely web based, meaning communication will be completed via email.

Besides providing us with your genetic data, participants will be completing online surveys at your own pace. As all communication is done via secure email server, NO travel is necessary and participation can be done in the comfort of your home! Interested individuals must email MECFSGenes@Nova.edu. Please state whether you have ME/CFS or are a Healthy Control. You will receive a personalized link, within 24-48 hours, to a secure web based platform, RedCap, which is how the study is conducted.

Below, please find all the information you will need to better understand the purpose of this completely web based study including how to participate, and how you will be receiving information regarding this study.

Click here (http://bit.ly/22rcxdk) for a video message from **Dr. Nancy Klimas**, Director of the INIM!

This research study is simply to collect genetic data for future analysis. Information is de-identified prior to analysis so no interpretation can be made for individuals.

For FAQ, e.g. about participation and informed consent and other info: http://www.nova.edu/nim/research/mecfs-genes.html

Open Medicine Foundation

Open Medicine Foundation welcomes **Dr. David S. Bell**, newest Scientific Advisory Board member

We've got lots of researchers, many of them leaders in their fields. But seeing the disease close up adds an important understanding that can be attained by no other way. This is why we are excited to announce another experienced and world-famous doctor to our ME/CFS Scientific Advisory Board, **David Bell**, MD.

Not only does the retired **Dr. Bell** know the disease, he has done his own research on his ME/CFS patients and collaborated with others in their research. His long history (since an outbreak in Lyndonville in the mid-1980s) also allowed him to make clinical observations that even newer experts may not have, yet.

"I am thrilled to become part of the open medicine foundation for several reasons," said **Dr. Bell**. "First and foremost is that in the many years I have been studying the illness, there has not been the commitment to it by the state of the art science, and that has been mainly because of scientific apathy and/or lack of funds. But the Open Medicine Foundation is starting with the understanding that ME/CFS is not going to reveal its mysteries without real science. It is my hope that I can add to the overall effort with my clinical perspective."

In the mid-1980s, Lyndonville, a small town in Upstate New York, was the site of an outbreak of ME/CFS, about half of them being pediatric cases. Lost with no direction from the existing medical paradigms, **Dr. Bell** took to trying to figure out the cause by doing his own research. This journey continues for him, despite his retirement from practice. **Dr. Bell** is often asked to give presentations to share what he has learned is true and not true about the disease.

We believe the other scientists on our board will benefit from the extensive and intimate experience he has. Want to know some of what he has learned? We invite you to watch and listen to his latest presentation at an event in late 2015 that was sponsored by our organization HERE (http://bit.ly/1SL1aaN).

WELCOME **DR. BELL**!

With hope,

Linda Tannenbaum
Executive Director, Open Medicine Foundation http://bit.ly/1qFOtHZ
Source: http://www.prohealth.com/library/showarticle.cfm?libid=28748

Illness Progression In Chronic Fatigue Syndrome

Illness progression in chronic fatigue syndrome: a shifting immune baseline
Lindsey Russell, **Gordon Broderick**, **Renee Taylor**, **Henrique Fernandes**, **Jeanna Harvey**, **Zachary Barnes**, **AnneLiese Smylie**, **Fanny Collado**, **Elizabeth G. Balbin**, **Ben Z. Katz**, **Nancy G. Klimas** and **Mary Ann Fletcher**

Abstract

Background
Validation of biomarkers for myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) across data sets has proven disappointing. As immune signature may be affected by many factors, our objective was to explore the shift in discriminatory cytokines across ME/CFS subjects separated by duration of illness. Methods

Cytokine expression collected at rest across multiple studies for female ME/CFS subjects (i) 18 years or younger, ill for 2 years or less (n = 18), (ii) 18–50 years of age, ill for 7 years (n = 22), and (iii) age 50 years or older (n = 28), ill for 11 years on average.

Control subjects were matched for age and body mass index (BMI). Data describing the levels of 16 cytokines using a chemiluminescent assay was used to support the identification of separate linear classification models for each subgroup. In order to isolate the effects of duration of illness alone, cytokines that changed significantly with age in the healthy control subjects were excluded a priori.

Results
Optimal selection of cytokines in each group resulted in subsets of IL-1α, 6, 8, 15 and TNFα. Common to any 2 of 3 groups were IL-1α, 6 and 8. Setting these 3 markers as a triple screen and adjusting their contribution according to illness duration sub-groups produced ME/CFS classification accuracies of 75–88 %.

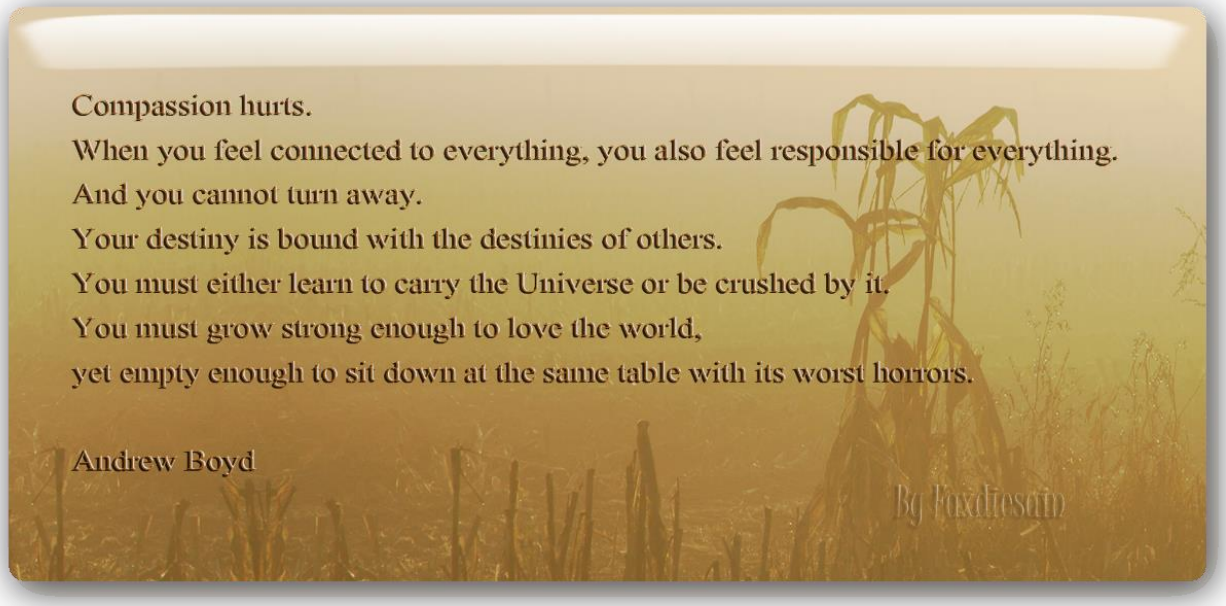
The contribution of IL-1α, higher in recently ill adolescent ME/CFS subjects was progressively less important with duration. While high levels of IL-8 screened positive for ME/CFS in the recently afflicted, the opposite was true for subjects ill for more than 2 years. Similarly, while low levels of IL-6 suggested early ME/CFS, the reverse was true in subjects over 18 years of age ill for more than 2 years.

Conclusions

These preliminary results suggest that IL-1α, 6 and 8 adjusted for illness duration may serve as robust biomarkers, independent of age, in screening for ME/CFS.

Source: http://bit.ly/1V95vKX

Submitted by
Prof. Gordon Broderick



Autonomic Correlations With MRI Are Abnormal In The Brainstem Vasomotor Centre In Chronic Fatigue Syndrome

Leighton R. Barnden, **Richard Kwiatek**, **Benjamin Crouch**, **Richard Burnet**, **Peter Del Fante**

Abstract

Autonomic changes are often associated with the chronic fatigue syndrome (CFS), but their pathogenetic role is unclear and brain imaging investigations are lacking. The vasomotor centre and, through it, nuclei in the midbrain and hypothalamus play a key role in autonomic nervous system regulation of steady state blood pressure (BP) and heart rate (HR).

In this exploratory cross-sectional study, BP and HR, as indicators of autonomic function, were correlated with volumetric and T1- and T2-weighted spin-echo (T1w and T2w) brain MRI in 25 CFS subjects and 25 normal controls (NC). Steady state BP (systolic, diastolic and pulse pressure) and HR in two postures were extracted from 24 h blood pressure monitoring.

We performed (1) MRI versus autonomic score interaction-with-group regressions to detect locations where regression slopes differed in the CFS and NC groups (collectively indicating abnormality in CFS), and (2) MRI regressions in the CFS and NC groups alone to detect additional locations with abnormal correlations in CFS. Significant CFS regressions were repeated controlling for anxiety and depression (A&D).

Abnormal regressions were detected in nuclei of the brainstem vasomotor centre, midbrain reticular formation and hypothalamus, but also in limbic nuclei involved in stress responses and in prefrontal white matter. Group comparisons of CFS and NC did not find MRI differences in these locations.

We propose therefore that these regulatory nuclei are functioning correctly, but that two-way communication between them is impaired in CFS and this affects signalling to/from peripheral effectors/sensors, culminating in inverted or magnified correlations.

This single explanation for the diverse abnormal correlations detected here consolidates the conclusion for a brainstem/midbrain nerve conduction deficit inferred earlier (**Barnden** et al., 2015, http://bit.ly/1Mruxm7).

Strong correlations were also detected in isolated NC regressions
http://bit.ly/1YrwbVv

Acute Changes In Striatal Microstructure Predict The Development Of Interferon-Alpha Induced Fatigue

An abstract

Dowell NG, **Cooper EA**, **Tibble J**, **Voon V**, **Critchley HD**, **Cercignani M**, **Harrison NA**. *(More from and about **Dr. Neil Harrison** in the Science to Patients-article in this issue. **The editors**)*

BACKGROUND:
Interferon-alpha (IFN-α) is a key mediator of antiviral immune responses used clinically for hepatitis C treatment. Though effective, IFN-α induces marked behavioral changes that, when severe, can appear indistinguishable from major depression. Curiously, fatigue and motivational impairment evolve rapidly, suggesting acute engagement of immune-brain communicatory pathways, yet mood impairments typically emerge later, after weeks of treatment. Whether this reflects prolonged modulation of motivational processes underpinning fatigue or separate neurobiological mechanisms is currently unclear.

RESULTS:
IFN-α injection stimulated an acute inflammatory cytokine response and evoked fatigue that peaked between 4 and 12 weeks, preceding mood change by 4 weeks. In the brain, IFN-α induced an acute change in striatal microstructure that additionally predicted development of fatigue but not mood symptoms.

CONCLUSIONS:
Our findings highlight qMT as an in vivo biomarker of central effects of peripheral inflammation. We demonstrate exquisite sensitivity of the striatum to IFN-α, implicate striatal perturbation in IFN-α-induced fatigue, and dissociate this from mechanisms underlying IFN-α-induced mood symptoms, providing empirical support for distinct neural substrates mediating actions on motivation and mood.
Source : http://www.ncbi.nlm.nih.gov/pubmed/26169252

Science to Patients

Science to Patients
An international project of the Dutch ME/cvs Vereniging
http://www.me-cvsvereniging.nl/welkom-bij-de-me-cvs-vereniging

To date three of seven webinars of the British Neuropsychiatrist **Dr. Neil Harrison** from the UK have been broadcast:
Webinar 75:
https://youtu.be/BdgUMip5Cys
Me and ME, in which he briefly introduces himself and talks about the type of researches he does, about inflammation-models, and about the connection of ME with inflammation.

Webinar 76:
https://youtu.be/g7TDSNejoEk
ME & Fatigue, about measuring fatigue, the different components of fatigue, the (non-)consensus on fatigue in psychoneuro-immunology, the over-emphasis of fatigue in ME-research, and the difference between fatigue and PEM.

Webinar 77:
https://youtu.be/pnWinDtPurY
ME & the brain, part 1, about the general effects of inflammation on the brain, more specific effects, and the insula & the basal ganglia.

Webinars to be broadcast: (all will be announced and posted on http://www.facebook.com/pages/MECVS-Vereniging/146572212103103)
78, April 19, 2016: ME & the brain, part II: parts of the brain associated with ME, connection brain-immunesystem, connection brain- gastrointestinal track, cognitions & priming and strongest arguments that ME is not a psychic condition.

79, May 3, 2016: ME & inflammation, part I: general effects of inflammation on the body, general effects of inflammation on the brain & relation to feelings of fatigue, different responses to an inflammation in ME, different effects of inflammation, and interferon.

80, May 17, 2016: ME & inflammation, part II: ME-patients & inflammation: the differences, evidence of inflammation in the blood after the infection is gone, evidence of effect of inflammation in the brain after an infection, evidence of brain-inflammation in ME, and microglia and their function.

81, May 31, 2016: ME & diagnosis: present and future possibilities and technologies, what is an MRI and what is an fMRI, SPECT- & PET-scans, other hopeful possibilities, and if he expects a breakthrough in research on ME.

On Friday 1st April for an hour questions could be asked to **Dr. Harrison**, out of which we selected the following answers:

We are about to start a new study here trying to tease apart how inflammation relates to post-exertional malaise in ME. We are aiming for quite a small cohort to begin with 20-25 people with ME and a similar sized group of controls. We are working with some colleagues in the sport science department as they have lots of experience in carefully measuring physiological responses. It's in collaboration with other people at Sussex, a colleague in London and the local ME group. We were planning to just use a single exercise challenge as the study is already quite complicated - though appreciate double challenge could be a very good way to go also.

Fatigue is a poorly defined word, we all think we know what we mean by the word - yet all probably use it slightly differently. I think we're still struggling to 'dissect' the concept of fatigue.

The way that I am currently approaching 'fatigue' is similar to the way the emotional neuroscience community has defined emotion - i.e. to try and break it down into its different parts. For example, we know that emotions aren't just feelings states - they also include changes in motivation, behavior and physiology. Until now we have only looked at the acute effects of inflammation on fatigue - though in the next study we will look at how mild exercise impacts performance a day later.

We are looking at associated changes in physiology e.g. heart rate variability, and a range of blood markers of inflammation, will also look at how fatigue relates to attention and cognitive function. This will be done with fMRI.

We don't have a genetic component to this study - though we are also currently involved in a separate study where we are trying to see if we can find a gene expression profile associated with depression. Gene expression analyses are very expensive - and we don't have funding for this for the ME study. One approach that we could take would be to store a small blood sample that could be used in future gene expression studies - we are currently in the process of writing the ethics - so could include this.

Q: You give young healthy persons a mild infection. Isn't that risky, as they might have a predisposition for ME?
A: We don't give people 'real' infections - just mild stimulation of their immune system - on average people get 3 colds per year - what we give them is a lot less severe than an average cold.

Though I think it's fascinating that even tough Australian sheep farmers experience often very prolonged fatigue and cognitive problems after infections - suggests to me that we don't know enough about the long term effects of infections on the body's response.

Q: Is inflammation also a possible explanation of pain (headaches and muscle pain)?

A: There is very definitely a relationship between inflammation and pain processing. A couple of groups have been looking at this recently, using brain imaging (Manfred Schedlowski and Mats Lekander). They have shown that inflammation (induced experimentally) increases the sensitivity to some types of pain - i.e. deep visceral and muscular pain but not cutaneous pain i.e. sharp type pain.

Inflammation readily induces fatigue - and quite quickly. We found that people who experienced the most fatigue showed the greatest activation of an immune-brain communication pathway to a brain region called the insula. The insula is closely connected to the anterior cingulate and together they play a role in regulating the autonomic nervous system.

Q: What according to your present knowledge about the disease shows that ME is much more than being fatigued?

A: There are lots of pieces of accumulating evidence - changes in brain function (Andrew Millers recent paper), the TSPO data (Japan) work on physiological responses to exercise etc.

The field of emotional neuroscience had terrible problems moving forward until they stopped focusing on subjective experiences of emotion (feelings) and started focusing on all of the accompanying behavioral, motivation and physiological changes.

On Diagnostic Driteria – A New Study By Leonard Jason Et Al

Case definitions integrating empiric and consensus perspectives

Leonard A. Jason, **Stephanie McManimen**, **Madison Sunnquist**, **Abigail Brown**, **Jacob Furst**, **Julia L. Newton** & **Elin Bolle Strand**

An abstract

Background: There has been considerable controversy regarding how to name and define the illnesses known as myalgic encephalomyelitis (ME) and chronic fatigue syndrome (CFS).

The Institute of Medicine (IOM) report has proposed new clinical criteria and a new name for this illness, but aspects of these recommendations have been scrutinized by patients and scientists.

Purpose: It is possible that both empiric and consensus approaches could be used to help settle some of these diagnostic challenges. Using patient samples collected in the USA, Great Britain, and Norway (N = 556), the current study attempted to categorize patients using more general as well as more restricted case definitions.

Results: Overall, the outcomes suggest that there might be four groupings of patients, with the broadest category involving those with chronic fatigue (N = 62), defined by six or more months of fatigue which cannot be explained by medical or psychiatric conditions.

A second category involves those patients who have chronic fatigue that can be explained by a medical or psychiatric condition (N = 47).

A third category involves more specific criteria that have been posited both by the IOM report, Canadian Clinical Case criteria, ME-ICC criteria and a more empiric approach. These efforts have specified domains of substantial reductions of activity, post-exertional malaise, neurocognitive impairment, and sleep dysfunction (N = 346). Patients with these characteristics were more functionally impaired than those meeting just chronic fatigue criteria, $p < .05$.

Finally, those meeting even more restrictive ME criteria proposed by Ramsay, identified a smaller and even more impaired group, $p < .05$.

Conclusion: It is important that scientists world-wide develop consensus on how to identify and classify patients using clinical and research criteria, and ultimately develop subtypes within such categories.

Source : http://bit.ly/1SL5xmr

Solve ME/CFS Initiative Receives Award to Create Global Patient Registry

The Solve ME/CFS Initiative has received an award through the Robert Wood Johnson Foundation White Label PEER (Platform for Engaging Everyone Responsibly) program. The competitive grants program is managed by Genetic Alliance, the world's largest nonprofit health advocacy organization network which includes 10,000 organizations, 1,200 of which are disease organizations.

The Solve ME/CFS Initiative was one of only six disease-related organizations selected to participate in the program and utilize PEER to engage the ME community in participant-centric research.

SMCI will use the award to boost the Solve CFS BioBank and Patient Registry, which has received growing interest from patients and researchers alike in the past year. Specifically, the Solve ME/CFS Initiative will undertake a dramatic expansion of the BioBank and Registry, which will allow the organization to: collect more comprehensive and useful data on patients and their experience with ME/CFS; inform study design; and support clinical, translational and epidemiological studies.

"This award will enable us to launch an international state-of-the-art patient registry for ME—an unmet and urgent need in the community—and include built-in options for data sharing and collaboration among patients, researchers and other disease organizations worldwide," said **Dr. Zaher Nahle**, Vice President for Research and Scientific Programs at the Solve ME/CFS Initiative.

Submitted by **Jeryldine Saville**

7. ME & Children

Justina Pelletier – The Aftermath

In 2013/2014 **Justina Pelletier** spent 16 months and two birthdays in state custody as the central but largely off-stage player in an explosive drama involving parents' rights and the controversial new field of medical child abuse.

While she was incarcerated, the psychiatrists refused to accept a second opinion from doctors, and deprived the child of her treatments for her physical, biological illness, thus depriving her of her legal and human rights. She deteriorated while being imprisoned in the mental hospital, as her physical illness was completely neglected. It took a number of court cases in the USA and several public protests to get her released from this mental hospital and back to her family, on Wednesday June 18, 2014.

On February 25, 2016 the Boston Globe published an article, written by **Michael Levenson** on **Justina** and her parents right now. Here are some extracts:
Nearly two years after she returned home in the arms of her father, **Justina Pelletier** was back in the spotlight Thursday, speaking in a small, slightly shaky voice about the 16 months she spent in state custody, much of it in a locked psychiatric ward.

Justina, whose case drew national attention to the power of medical professionals to override parental rights, said she remains outraged that she was placed in state custody in 2013 after Boston Children's Hospital accused her parents of interfering with her care.

"I'm very angry, and I just don't understand how this happened, and I just really don't want this to happen again to another family," said **Justina**, who was with her parents, two of their attorneys, and a family spokesman from the Christian Defense Coalition.

She was taken into state custody three years ago after Children's determined that her many health problems were the result of psychiatric issues and that her parents were pushing for her to undergo unnecessary treatment. The **Pelletiers** vehemently disagreed, pointing to the opinion of doctors at Tufts Medical Center, who said **Justina** suffers from mitochondrial disease, a rare genetic disorder that affects how cells produce energy.

Justina's parents, **Lou** and **Linda Pelletier**, sued Children's Hospital in Suffolk Superior Court this month, accusing the renowned institution and four of its doctors of gross negligence and civil rights violations. The lawsuit seeks unspecified monetary damages.

Lou Pelletier said he is suing Children's Hospital because he doesn't want other parents of children with complex medical problems to fear losing custody if they have to seek emergency medical care at a hospital.

"This is not about revenge," **Lou Pelletier** said. "This is about making people accountable and making the medical community think twice before they take actions that can do damage to a child and a family that can be irreversible."

*Photo: **John Tlumacki**/globe staff*

Justina was being treated at Tufts Medical Center for mitochondrial disease when her parents brought her to Children's Hospital with gastrointestinal problems in 2013.

Justina's case became a rallying point for Christian conservatives and parent activists, who accused the hospital and state officials of violating the Pelletiers' rights to make medical decisions for their daughter.

Under mounting pressure, the same judge who had placed **Justina** in state custody returned her to her parents' care in June 2014, saying there was "credible evidence that circumstances have changed" and that her parents "have been cooperative and engaged in services," including individual therapy for the teen and family therapy.

Michael Levenson can be reached at mlevenson@globe.com.
Follow him on Twitter @mlevenson (http://twitter.com/mlevenson).

Source interview: http://bit.ly/1SAdx9z
More on **Justina** in the MEGC 5, June 2014, p. 50 http://let-me.be/request.php?7

ME – The Truth About Exercise And Therapy

*Editorial: as the British PACE-trial of 2011 is one of the present focuses of the MEGC, we're publishing an already 'ancient' letter by **Jane Colby**, chairperson of the Tymes-trust, as published in the Guardian of February 24, 2011 (http://bit.ly/1qlRZ9O). It proves once more that the controversy against trial isn't just a recent topic.*

*

Reporting on the PACE trial of treatments for ME/CFS by **Professor White** and colleagues, **Sarah Boseley** (Report (http://bit.ly/23B4hda), 18 February) writes that patient groups "insist it is a physical disease, which probably has a viral cause".

Research co-funded by The Young ME Sufferers Trust and published by Dundee University last year revealed abnormalities in children's blood consistent with persistent viral infection.

The trust deals with childhood cases so severe that sufferers cannot swallow and have to be tube-fed. Too weak to walk, they need to be carried and suffer unbearable neuropathic pain.

Professor Malcolm Hooper points out that the World Health Organisation (http://bit.ly/1SLaA6j) classifies ME as a neurological disorder but that the PACE researchers selected patients on criteria that exclude neurological disorders. They claim that graded exercise therapy (GET) and cognitive behaviour therapy (CBT) promote recovery.

However, in the latest study of GET and CBT for people with chronic fatigue syndrome, researchers concluded that the treatment resulted in worse physical function and bodily pain scores (Clinical Rheumatology, 15 January 2011).

In the practical experience of the families we help, we found children's symptoms are exacerbated with GET, and a period of extended convalescence is needed to enable their strength to return.

In 2010, we were honoured to receive the Queen's Award for Voluntary Service (the MBE for volunteer groups) and we feel it important that we distance ourselves from comments in the article by the Association of Young People with ME, calling for the PACE trial to be replicated in children.

Such misguided views have already caused too much distress to patients and families.

Jane Colby FRSA

Executive director, The Young ME Sufferers Trust (http://bit.ly/1UYsys8)

8. Events

IMEC 11

11th Invest in ME International ME Conference 2016
Friday, June 3, 2016
Venue: 1, Great George Street,
London SW1P 3AA, England

Conference Schedule

Times & presentations are subject to change: http://bit.ly/1Wpsxg8

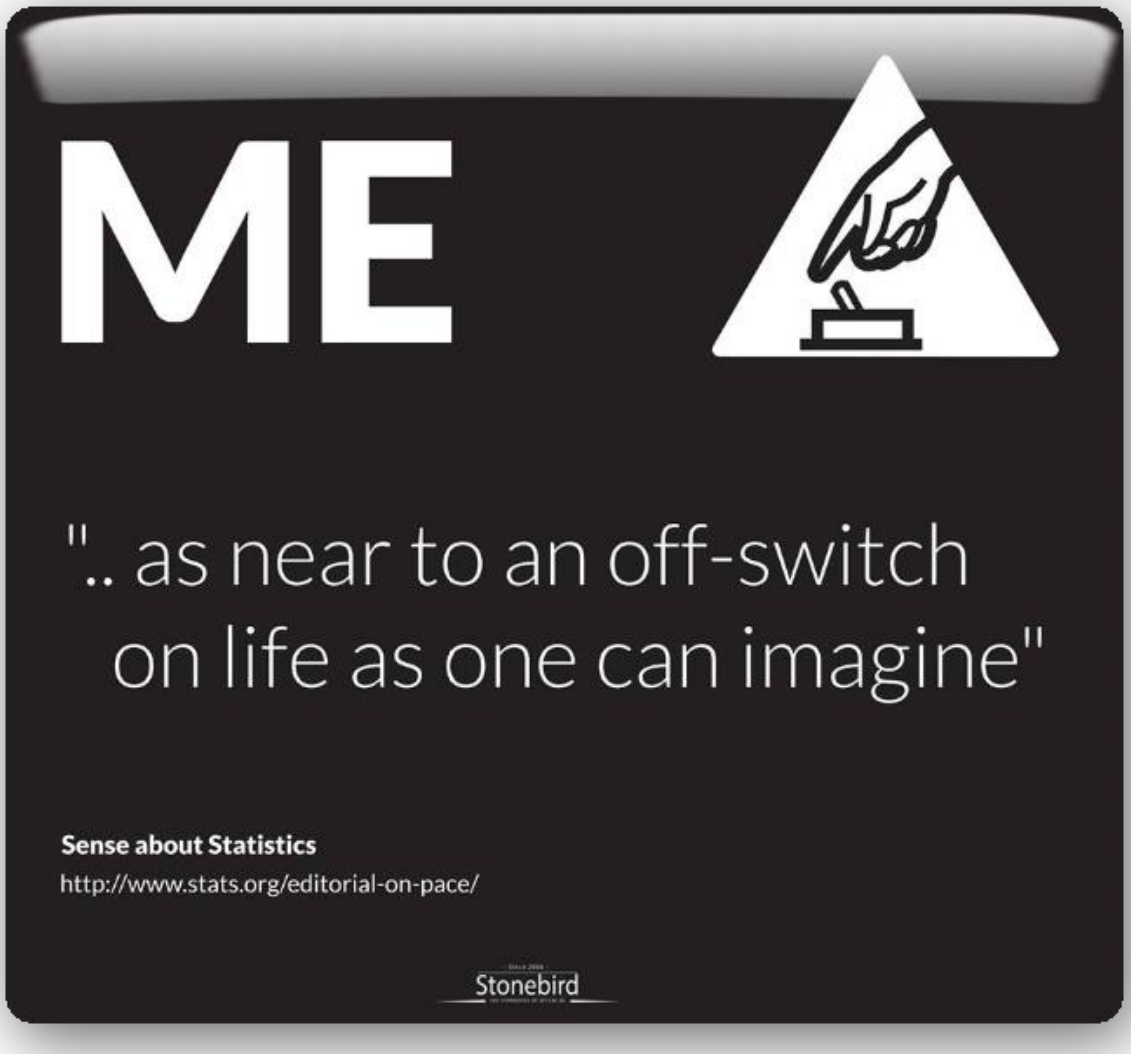
Registration possible from 7:30 onward
09:00 Chair - **Dr Ian Gibson**
09:10 Keynote Speech - tbc
09:25 **Professor Olli Polo**-Clinical Diagnosis of Myalgic Encephalomyelitis
09:50 **Professor Carmen Scheibenbogen** -Autoantibodies to adrenergic and acetylcholine receptors in CFS/ME
10:20 Refreshment Break
10:50 **Dr Jo Cambridge** -Immunoregulation in patients with ME
11:20 **Professor Tom Wileman** -Gut Virome in ME
11:50 **Dr Don Staines** -Update from NCNED: Receptor identification and intracellular signalling

12:30 Tbc
12:45 Lunch

13:45 Associate **Professor Mady Hornig** -Pathogen Discovery in ME
14:25 **Professor Maureen Hanson** -The Search for Biomarkers for Myalgic Encephalomyelitis
14:55 **Professor Elisa Oltra** -Molecular Biomarkers of Myalgic Encephalomyelitis
15:25 Refreshment Break
15:55 **Professor James Baraniuk** -Exercise testing and Orthostatic Tachycardia
16:20 **Professor Ron Davis** -Big Data Approach: Severely Ill ME Patient Cohort
17:00 Plenary Session - **Dr Ian Gibson**
17:30 Adjourn

Registration: http://bit.ly/1Nmo8TZ
All info: http://www.investinme.eu/index.shtml

The 4DVD conference-video of all presentations of the 10th international conference on May 29, 2015 can be ordered here:
http://www.investinme.eu/IIMEC10-DVD-Order.shtml


ME
".. as near to an off-switch
on life as one can imagine"
Sense about Statistics
http://www.stats.org/editorial-on-pace/
Stonebird

Help Karina – Donate To Save4Children

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, if the parents have proven to be incapable of affording needed legal assistance.

They helped in **Joanne**'s case – the German teenager who has been held under psychiatric care for 18 months, and **Joanne** has been allowed to go home last July. Now they would like to help **Karina Hansen**.

Karina is a severely-ill ME patient who has been held in a hospital against her will for 2 ½ years. Her parents are still not allowed to see her. Her condition is worse now than when she was forcibly removed in 2013.

She can no longer speak in full sentences. She sits in a wheelchair and mumbles to herself. She is allowed to wear her earplugs as she becomes very distressed when they have tried to take them from her.

When she was first taken, she actively resisted treatment and was therefore given the diagnosis of Pervasive Refusal Syndrome.

This is the same diagnosis as **Joanne** was given. Now **Karina** no longer resists treatment and the psychiatrists claim that this is improvement. **Karina** has never resisted eating, which is a core symptom of PRS, so of course this diagnosis is completely ridiculous.

Also, **Karina** is a young adult and PRS is exclusively a pediatric diagnosis.

Although it does not look good for **Karina** at the moment, the fact that "**Joanne**" has been released gives us hope.

If you would like to help, please donate to **Save4Children** at:
http://let-me.be/page.php?11

The money that will be donated will be transferred in mutual deliberation to a volunteer non-profit civil rights group called The Citizens Right's Group (Borgeretsbevægelse) that has taken up **Karina**'s case.

CRG fights for cases that are examples of principle human rights violations and they are finding many violations in **Karina**'s case.
Donations will be collected at the S4C site here:
http://let-me.be/page.php?11

Information about the **Karina** and the case can be found in this and future issues of the ME Global Chronicle and at these sites:
Justice for **Karina Hansen** - find info under notes.
https://www.facebook.com/JusticeForKarinaHansen

Two videos about **Karina** from 2013:
http://www.youtube.com/watch?v=Dk3e8IWj7M0
http://www.youtube.com/watch?v=JTkkcvlvYf8

The Citizen's Rights Group – documents in the case in Danish
http://xn--borgerretsbevgelsen-xxb.dk/

The ME Global Chronicle Special Karina Hansen 20151025:
http://let-me.be/download.php?view.24

New documents will be added as they become available.


Yes, I donate to Karina Hansen
(https://www.geef.nl/donatiemodule/taal:en/doel:save4children)


Yes, I donate to Karina Hansen
(https://www.geef.nl/donatiemodule/taal:en/doel:save4children)


Ja, ik doneer aan Karina Hansen
(https://www.geef.nl/donatiemodule/taal:nl/doel:save4children)


Oui, je soutiens Karina Hansen
(https://www.geef.nl/donatiemodule/taal:fr/doel:save4children)


Ja, ich unterstütze Karina Hansen
(https://www.geef.nl/donatiemodule/taal:de/doel:save4children)


Sí, apoyo Karina Hansen
(https://www.geef.nl/donatiemodule/taal:es/doel:save4children)


Ja, jeg donerer til Karina
(https://www.geef.nl/donatiemodule/taal:en/doel:save4children)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(https://www.geef.nl/donatiemodule/taal:en/doel:save4children)

Latest status: http://save4children.geef.nl/doel/save4children/donaties
In case you experience any problems with your payment, please contact us at donate@letme.be and provide us with as much as possible information: country, url, date time, error, used payment method, etc.

9. News from

Australia

ME Australia's appeal

Write to the UNSW and Mason Foundation (http://bit.ly/1UI4glW), and urge your representatives at the state and territory societies to endorse the International Consensus Criteria and commend the ICC Medical Primer to the National Medical Health Research Council (NHMRC), the AMA and the RACGP

How the UNSW chronic fatigue syndrome studies use 'potentially harmful' guidelines

Interviewing **Prof Andrew Lloyd** last year for this story (http://bit.ly/1UVv82g), he explained he was working on an online program of graded exercise therapy (GET) and cognitive behavior therapy (CBT) program at the University of NSW's Fatigue Clinic.

Prof Lloyd described the PACE trial, which evaluated these therapies, as having "reasonably solid data".

The University of NSW has now registered a trial (http://bit.ly/1N8nWHI) to 'investigate the efficacy of online continuing education for health professionals to improve the management of chronic fatigue syndrome'.

The study is designed to educate medical professionals. **Prof Lloyd** said it would 'protocolise the intervention' and that he had a grant to turn into an online module and evaluate it.

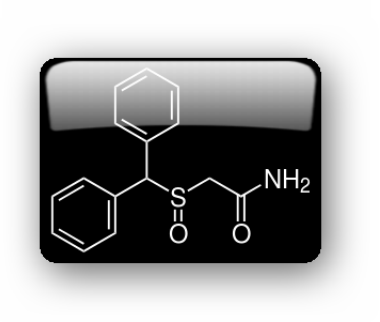
The study isn't evaluating CBT and GET, it already accepts those as "widely acknowledged as best-practice interventions for CFS", it is training health professionals in:

1. Psychoeducation;
2. Activity pacing and graded exercise therapy;
3. Interventions for sleep-wake cycle disturbance;
4. Interventions of neurocognitive functioning in CFS;
5. Interventions for mood disturbance;
6. Interventions for anxiety;
7. Interventions for coping.

This study is funded by the Mason Foundation (http://bit.ly/1MdkYad).

Modifinil study

The second study he mentioned was the trial for a brain stimulant called Modafinil. **Prof Lloyd** received a grant for this work and is accessing the drug directly from the manufacturer, he said. "*It changes the perception of fatigue and lengthens time to exhaustion*", **Prof Lloyd** said.



Modafinil is used to treat idiopathic somnolence (excessive sleepiness) and the US National Library of Medicine (http://1.usa.gov/1XgGdsj) warns "*Modafinil may be habit-forming. Modafinil may decrease your sleepiness, but it will not cure your sleep disorder. Modafinil should not be used in place of getting enough sleep*."

What needs to be done

Prof Lloyd is one of the authors of the 2002 Australian criteria (http://bit.ly/1UI4R7c) and also sits on NHMRC grant review committees. The Australian set of criteria states chronic fatigue syndrome overlaps with the psychiatric condition, neurasthenia, that it is on the spectrum of fatigue so it is not its own 'entity' and apart from minor, non-specific signs of illness, the physical examination in people with CFS is normal. **Prof Lloyd** doesn't believe these criteria need updating.

Australia needs to adopt the International Consensus Criteria for Myalgic Encephalomyelitis, which does not recommend these therapies and has a much higher standard, providing much more evidence of the biological processes of a disease.

As well as writing to the UNSW and Mason Foundation (http://bit.ly/1UI4glW), we should urge our representatives at the state and territory societies to endorse the International Consensus Criteria and commend the ICC Medical Primer to the National Medical Health Research Council (NHMRC), the AMA and the RACGP. Write to them, call them and let them know this is the time to act.

As authors of the Canadian and International Consensus Criteria, the National Centre for Neuroimmunology (NCNED) at Griffith University should also be commending these criteria to the NHMRC, ask NCNED (http://bit.ly/1PTB6Z3) to recommend it formally.

Taken from a much larger article
by **Sasha Nimmo** http://bit.ly/206UqcM

Belgium

The WUCB (Wake Up Call-movement Belgium) will organize an Info-show in the context of the campaign 'Stop the Diagnosis CFS', with live performances of singer/songwriter **Mira** on Wednesday May 18th.

Address:
Cultuurcentrum 'De Bogaard'
Capucienessenstraat 8
3800 Sint-Truiden

Start: 19:30 pm
Guest speaker **Prof. Dr Frank De Comheire** (internist-endocrinologist)

Booking is possible via the number +32 485 91 79 57 or by sending an email to wucb.limburg@yahoo.com

Entrance € 6,-

All information on
http://www.wakeupcallbeweging.be

There is a newsletter published by the WUCB, which you can download here:
http://www.wakeupcallbeweging.be/pdf/nieuwsbrief01WUCB2016.pdf

- In this there is i.a. attention to the discussion of the WUCB with a delegate of the cabinet of minister **Maggie De Block**.
- One also asks for filling in a survey launched by the Vlaams Patienten Platform. Participation is possible due to the end of May 2016.
- Volunteers are asked for participating in a study in the context of people with CFS and logopaedic problems in the province East-Flanders.

Next info-show 'Stop the diagnosis CFS' will take place in Antwerp on October 15th.

Much more news from Belgium:
http://www.wakeupcallbeweging.be/pdf/nieuwsbrief01WUCB2016.pdf

Become member of the WUCB now, because numbers counts:
http://www.wakeupcallbeweging.be/wucb/word-lid

Membership is for free.

Greece

ME in Greece (Source: http://bit.ly/1NdlOhX)
From an interview **Mike Harley** (the Marathon Man) while in Greece to run his fifth marathon to raise awareness of ME and funds for Invest in ME, took from **Lefteris**, an ME patient for over 20 years who lives in Athens. About what it's like to have the illness in Greece. Here's a summary of what **Lefteris** told **Mike**: "As far as I know, there aren't any ME charities or support groups in Greece - if any do exist, they must be very few.

Unfortunately, as a result, there aren't any reliably registered figures in regards to how many people in the country suffer from ME. If you were to apply a similar ratio to other European countries, it could be suggested that as many as 50,000 of the 12 million population suffer with the illness. As far as the Government is concerned, it doesn't have a clue about ME/CFS (and even if it did know, the economic crisis is deep and the possibility to devote funds to research is limited). I don't know if there is a general treatment in Greece as doctors may not be really familiar even with the diagnosis.

I was lucky enough to find **Dr. Naoum**, for whom ME/CFS belongs to his research interests. The treatment he prescribed is the usual one for stomach ulcers (zantac, riopan antacid, drinking soda throughout the day in amounts someone can easily bear in order to neutralize gastric acid) as he believes that one of the main causes of the illness exists in the digestive system. As far as I know, Greece does not have a specialist clinic for the diagnosis and treatment of ME/CFS. I'm not sure if the government are currently funding biomedical research projects, it is possible that research programs at an academic level occur but if they do they are not publicized.

I don't believe that the state gives any special benefits to patients who are unable to work. Unfortunately, people here in Greece are not organized in groups, forums etc. Therefore, I think that the knowledge background of Greek patients on the illness, depends upon the effort each of us can individually (or with the help of friends/family) consume via internet surfing, international forums, etc. I personally was not aware about the ongoing Rituximab Trial in Norway or the controversy surrounding PACE in the UK, so it would surprise me if others were too.

My improvement in the last 1.5 years after being treated by **Dr Naoum** has been really impressive. I would really like to see other people that share the same ME/CFS root cause to get better as soon as possible. I would like doctors at least instead of diagnosing psychological problems, to be able to diagnose the illness properly. I don't feel optimistic about the current situation over here. However, sometimes one spark is enough to make a fire. Therefore, the effort of fundraisers and charities is really important."

Lefteris

Northern Ireland

Update on Campaign for ME & Fibro services in Northern Ireland

When Hope 4 ME & Fibro Northern Ireland was founded in 2011, the group joined a decades long campaign attempting to persuade the Health and Social Care commissioning board (HSCB) that Northern Ireland needed a consultant physician led clinic, where ME and fibromyalgia patients could be properly diagnosed and given best care based on the latest biomedical knowledge.

In the last two years, at the request of our charity, the Patient & Client Council and the Pain Alliance have also joined this campaign. Unfortunately, **Iain Deboys**, the lead commissioner of the HSCB, has concluded that a Condition Management Programme (CMP), currently being delivered by occupational therapists in the Northern Trust would be suitable to roll out across the region.

Patient charities regard this programme as unfit for purpose. A management programme led by occupational therapists should never be an acceptable alternative to proper bio-medically based services, with a specialist consultant physician in the lead position. It is vitally important that doctors in general practice are supported by a consultant capable of diagnosing and appropriately treating these complex conditions.

Independent campaigners and patient charities have consistently explained this problem to **Iain Deboys** and the HSCB since consultations began in 2009. Yet their voices are repeatedly ignored. For a while, last year it seemed as if some small progress had been made when **Iain Deboys** agreed to fund copies of the Canadian Consensus Criteria (CCC), for distribution when Hope 4 ME & Fibro NI gave awareness events. Sadly, the HSCB has now decided that the CCC does not meet NICE guidelines and has rescinded this offer.

Meanwhile professionals from hospitals, pharmacies, and GP surgeries continue to contact our charity requesting information packs and details of support group meetings. Obviously the staff on the ground are very aware of the lack of specialist services, and the desperate need of these patient groups.

The proposed roll-out of the Condition Management Programme has not yet occurred due to lack of funding. Perhaps this is fortunate given its unpopularity with patient groups. Iain Deboys explained that it was now on the "escapable" list, and he suggested that funding was only available for projects deemed "inescapable". He gave no indication of how we could make our need "inescapable"!

Louise Skelly, Head of Operations for the Patient and Client Council has voiced serious concerns on the total lack of progress for ME and fibromyalgia patients when compared to other patient group campaigns. She has assured us that the Patient and Client Council will be exploring other avenues, and will continue to offer full support to these badly neglected patient populations in Northern Ireland.

So, it now seems that we must start our campaign again: new changes to the structure of NHS provisions mean that commissioning of services will leave HSCB and become the responsibility of regional trusts. Meanwhile, there is still no-where for GPs (who have expressed a lack of confidence in diagnosing and treating these illnesses) to send patients for consultant care.

Joan Mcparland of Hope 4 ME & Fibro NI said: "We are both shocked and dismayed that the many years of work since our first meetings with HSCB have been wasted. We have now been informed that the previously assured improvements to NHS services will be not implemented under the current HSCB.

Committee members from advocacy groups are all patients, working on a voluntary basis and with extremely limited health and energy. To be told we now have to basically start again from scratch is deplorable given the amount of effort and commitment we have invested since 2009.

Submitted by **Sally K.Burch**

http://bit.ly/1SEtuLS

Hope 4 ME & Fibro NI
2016 Conference

Chasing Competent Care

for ME, Fibromyalgia & Chronic Fatigue Syndrome

Monday 6th June 2016

6.30 - 9.30pm Stormont Hotel, Belfast.

Main Speaker:

Dr Mady Hornig, Columbia University
on Developing Disease Understanding

Hope 4 ME & Fibro Northern Ireland

Supporting Speakers:

Dr Joe McVeigh, Researcher at University of Ulster - The Exercise Dilemma with Fibromyalgia
Natalie Boultin, Voices from the Shadows - The Parents' Perspective
Dr Pamela Bell, Pain Alliance, - The Problem with Pain
Louise Skelly, Patient & Client Council - Amplifying the Voice of the Patient
Dr William Weir, Infectious disease consultant - What hope for the Future?

Tickets and Costs to follow. To join email alerts: hope4mefibro@outlook.com
CPD points applied for from Royal College of Physicians.

Norway

The National Knowledge Centre for CFS / ME on 18th April 2016, did hold a "Research Seminar on CFS / ME and the most severely ill patients."

EMEA Norway (Norges ME Forening) and M.E. Network in Norway are concerned by what we perceive as a somewhat exclusive focus on biopsychosocial explanatory models for ME, which was reflected in the selection of professionals who did present at the seminar. Both patient associations were particularly puzzled over the choice of **Trudie Chalder** as the main speaker.

Chalder is one of the main authors of the PACE study, a study that has faced increasing criticism, both in terms of method and interpretation of results. Both prominent researchers, clinicians, and a large number of patients are now asking for the background data for the study to be released, so that the study's conclusions can be verified. Norges ME Forening and M.E. Network in Norway are deeply concerned about how such a seminar as this will affect the view of the sickest patients. Both patient associations are aware today of cases of egregious abuse of ill patients. Very ill patients are denied the help they and their families want, and "remedial measures" are imposed leading to serious deterioration of their situation. Some patients are so traumatized by contact with those who should be helping that they no longer dare to have contact with support agencies.

The abuse is often based on the belief that the patient should be active and that cognitive therapy and graded exercise are good treatments for ME. Norges ME Forening and M.E. Network in Norway believe this seminar is missing several speakers with a biomedical understanding. In particular we miss any focus on the phenomenon of PEM (post-exertional malaise or exertional symptom exacerbation) since it must be central to any approach to coping with ME.

A representative of Norges ME Forening has agreed to hold an introduction to the seminar, because it is important that patients' voices are heard. It is extremely important that patients 'and families' experiences emerge as a counterweight to some of the seminar's other lecturers. Today there is an increasingly dwindling amount of research into very severe ME. These patients are rarely in contact with their doctor or other healthcare professional, since they are unable to leave home.

In a situation without reliable research data it is essential that health professionals have the ability to listen to patients and their relatives, and to respect and accept the patients' experiences and wishes.
Further Information:

1. NMEF Site (http://bit.ly/1RIoCcs)
2. Link to Seminar Agenda (http://bit.ly/1TFLJpm)

Submitted by **Ellen Piro**

Lecture by **Dr Hanne Thürmer**, Notodden Hospital

From a lecture given at the local department of the Norwegian ME-association of Notodden, avd Telemark, February 8th 2016. **Dr. Hanne Thürmer** is a senior consultant in the field of internal medicine and cardiovascular diseases, and has been involved in ME since 2009. She is also a member of the Norwegian ME-association's Board of Medicine.

"In Notodden it all started with a young and very sick patient whom the doctors at the hospital tried to help. The doctors got curious and tried to learn more. This way they increased their knowledge about ME and became one of the larger Norwegian clinics. At Notodden we use the Canadian Criteria and the International Consensus Criteria. Notodden has had approx. 400 patients since 2009.

We still do not have well established knowledge about this disease, but there is a lot developing now. We have a rush of new data and new theories, a lot is tried and discarded underway. It is very difficult to be a patient – and it is not too easy being the doctor either.

As of today, the diagnose is based on criteria and we have to rule out any other disease. We have 20 different sets of criteria, and some are almost the same! SEID might be able to connect the different sets of criteria.

Important advice to ME-patients: Never go to meetings on your own!

Illnesses that need to be ruled out before the patient can get diagnosed with ME are infections, immune diseases, it is important to check the metabolism, cancer and other serious illnesses, celiac disease, deficiency diseases, abuse of pills and other narcotics, depression etc.

There has not been found fungus, virus or bacteria in the bodies of ME patients. On the other hand, the function of the B-lymphocytes is a possible contributing factor (this is a theory). B-lymphocytes are a type of white blood cells and they are a part of the immune system.

ME-patients must be in control, live controlled, the frame is limited. The patients need to adjust according to their level of functioning. There is a big individual difference in how much activity that is tolerated. One method can be to keep track of reactions 2–3 days after any kind of activity and then evaluate if this was on the right level. It is very important to stay within the limits."

Notodden Hospital is one of the centers where research on Rituximab is carried out (http://bit.ly/20DEq2q).

Full text of the presentation: http://bit.ly/1oZVPo7

Submitted by **Gro M. Andersen** and **Stine Aasheim**

The Netherlands

The screening for the ME-documentary Forgotten Plague has been a great success in the Amsterdam Cinema Lab111. A few weeks in advance, the audience was already completely sold out.

After showing the movie of **Ryan Prior** and **Nicole Castillo** there followed presentations of the American science journalist **David Tuller** and the Dutch cardiologist and ME/CFS-doctor **Frans Visser**.

Prof. Visser gave an overview of the current situation regarding ME and gave hope to the audience by the appearance of the IOM-report and the activities of the OMF and the research results from i.a. **Mady Hornig** in her cytokine-study.

Tuller explained the release and the flaws of the British PACE-trial and called CGT and GET a cult, an ideology based on nothing. According to him, the Lancet should retract the article because research results has been manipulated to favor bright results and because the authors have a conflict of interest. He hopes and expect that to happen this year: https://youtu.be/1fS6Gzc52VI. After his presentation, he answered questions for half an hour.

On march 25, the president of the Health Council installed the ME/CFS Commission, which has to review the state of ME and should come up with recommendations for this disease on request of the parliament.

After publication of the commission members on the website of the HC, strong protests have erupted and i.a. patients started a petition called 'ME isn't MUPS' https://meisgeensolk.petities.nl, with the call to the HC to replace four members who have MUPS-publications (Medically Unexplained Physical Symptoms) on their name by foreign experts in the ME field.

The Groep ME Den Haag and other patient advocates urged for this to the HC several times, but without result. (The Groep ME Den Haag collected 56,000 signatures and that citizen initiative caused the parliament to ask advice to the HC).

The three largest organizations also sent a letter of protest with the same tendency to the HC, ten days after the installation of the committee.

More on this topic in an article called 'The Dutch Citizen Initiative' at page 44 of this issue of the MEGC.

United Kingdom

ME Research UK

"Breakthrough" magazine: Spring 2016 edition

Our Spring 2016 "Breakthrough" magazine has gone out free in the post to friends and supporters. The contents include ME Research UK-funded research on visual stress & discomfort and neurological biomarkers in youngsters with ME/CFS. The magazine is free to patients and their families, clinics, academics and research groups, so please email us with your address if you live in the UK and would like a hard copy. The electronic copy will be on our website shortly at http://bit.ly/1kCPjNs

Overviews

Our recent overviews of research papers include:

MicroRNAs in ME/CFS

A large number of different microRNA molecules are now linked with different illnesses, including cancer, epilepsy, malaria and multiple sclerosis. **Dr Robert Petty** and **Dr Jonathan Kerr** have just published a paper in the journal PlosOne on the role of microRNAs in ME/CFS. Read more http://bit.ly/1qbD0zf

Genome-wide associations

The most comprehensive genome-wide association study of an ME/CFS cohort yet conducted has been published by a consortium of researchers from Nevada, USA, Hungary and Russia. Read more http://bit.ly/1qbD0zf

Mortality in ME/CFS

A study published in the Lancet found that the death rates from all causes, including cancer, were no higher in ME/CFS patients than in the wider population, though there was a very small but statistically significant increase in suicide. Read more http://bit.ly/23ozKz6

Orosomucoid in blood serum

Researchers at the Second Military Medical University, Shanghai have examined the blood of ME/CFS patients and found levels of orosomucoid (ORM, or alpha-1-acid glycoprotein) that are far higher than in healthy people. Read more http://bit.ly/1MYGyPQ

Walking & Co-ordination Problems

'Automaticity' involves being able do things automatically, without the mind being occupied with more basic tasks. A new report by researchers from Antwerp shows 'gait automaticity' to be dramatically reduced in people with ME/CFS. Read more http://bit.ly/20dJXwj

Welcome to CureME

CureME is a new site for listing research news about ME/CFS. Each post will be a stand-alone article, and aim is to create a free 'one-stop portal' for research news about the disease.

All you need to sign-up is an email address, and thereafter you can access the list anytime using a password – dead simple. We think it's a good idea to bring all the information into one place, and the link gives further details http://bit.ly/1TFOvL9

Submitted by **Dr. Neil Abbott**

Invest in ME supporters made March another marvellous mixed bag of awareness & fundraising for the charity's biomedical research funds for myalgic encephalomyelitis. Thank you each & every one!

Actor **Jon Campling** took along his Invest in ME charity collection box to another Comic Con event, this time in Oxford: "Huge Thanx 2 all who #rattledmybox" Next stop Scarborough!

Joe Jarvis (http://bit.ly/1qzGY5v) and **Kelly Samuels** (http://bit.ly/1NdpBvL) went sugar-free.

Elaine English completed her blog marathon (http://bit.ly/1S1ef27) for charity – 27 short blogs in 27 days on the theme of gratitude, and well worth a read if you missed them through the month.

Kirsty Rankin (http://bit.ly/1S1eiv3) and **Chris Dusgate** (http://bit.ly/1S7kCEg) kindly celebrated their birthdays by inviting donations to Invest in ME Research Funds, including a very generous £1200 to the Invest in ME Rituximab Trial Fund.

Amanda Kayes (http://bit.ly/1RUMF4B) & **Richard Pughe** (http://bit.ly/25Pb0lA) reached the summit of Kilimanjaro, raising over £9000 between them and a great deal of awareness. You can see their outstanding awareness flyer in our blog here (http://bit.ly/1Sj9u18).

Tanya Mawer published her plans for her 2016 Walk for ME. "Why do this? Because I WANT, NEED, to get better! I have cared for and watched my daughters suffer with this illness and now have it myself which is limiting my ability not only to care for them but also for myself. I have so many lists of plans I want to fulfill and can't right now ~ hopefully with the research by Invest in ME I will be able to tick them off in the future. Til then it's a case of life on hold." Click here (http://bit.ly/1RUMYwa) to read and share her full story.

Wonderful 'willing wellie' friend to people with ME, **Mike Harley**, published a great video (http://bit.ly/1SEweZS) answering questions on his 28 EU Marathons. He was also asked by The Guardian to write an article on his challenge, and to be a blogger for 'The Running Bug'. His website (http://bit.ly/1SUBqLK) URL is now .eu instead of .com. Do check it out and please share widely –

http://www.mikeseumarathons.eu/

More on http://ldifme.org/march-updates/

10. Miscellaneous

#MEAction is excited to announce its first protest in Washington DC!
(Now rescheduled for May 25, 2016)

Please join us May 25th for a protest outside of the Health and Human Services building in Washington DC. Our goal is to raise the visibility of this illness and the people living with it.

Can't make it to DC? We are also looking for community leaders to organize satellite protests in cities around the country, especially regional HHS offices in: Boston, New York, Philadelphia, Atlanta, Chicago, Dallas, Kansas City, Denver, San Francisco or Seattle.

Because of the nature of our condition, we can expect to see many patients in their wheelchairs, stretchers, or laying down. All patients are welcomed and we encourage you bring your family / friends / caregivers for support. In fact, we would like to emphasize that even if patients can't attend, their support system is welcomed!

When: May 25th 2016 at 12pm
Where: Health and Human Services Headquarters in Washington, DC
Why: Urgent Need to Increase ME/CFS Funding

The protest is being organized by #MEAction member Stacy Hodges. Stacy is looking to put a team together to plan and execute the flagship protest in DC, as well as satellite protests at HHS offices around the country. If interested in helping, email ME.Protest@gmail.com.

Interview with **Dr. Derek Enlander**, in Llewellyn King's & Deborah Waroff's project ME/CFS Alert: https://youtu.be/tVU8V4OWbVY

#Spoonie Virus - 4
https://youtu.be/P_RfbuiE56M?list=PLvX-06vtGjR590vqaAofP2A48AiTbOgmK
ME-patient **Barry John Evans** about viral infection

https://stepville.com/2016/04/11/in-going-to-visit-a-friend-whos-sick/
Going to Visit a Friend Who's Sick.
Impressive blog by **Stephanie Land** about **Whitney Defoe Davis**, **Dr. Ron Davis**' son who's suffering from very severe ME

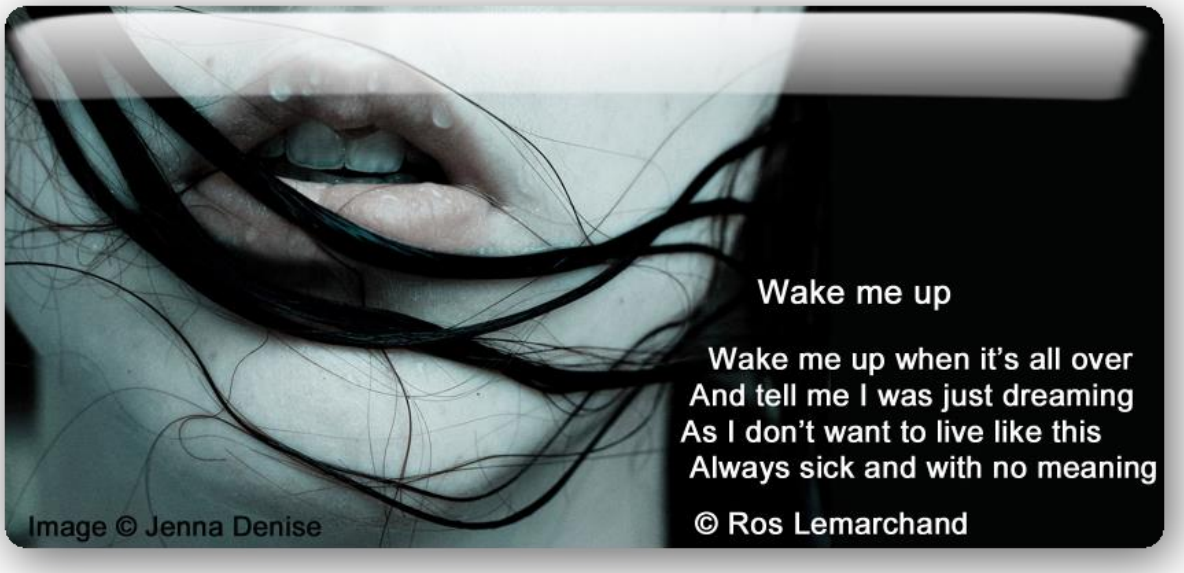
'It Isn't Just In My Mind!': Four Problems in Diagnosis and Treatment of ME/CFS.

Four of the most common issues in the diagnosis, and treatment, of this life altering condition:

1. There's no test to prove it
2. Because of this, there is a lot of misdiagnosis...
3. No cause has been confirmed
4. There is a woeful lack of treatment available

Tayana Simons, writer & journalist, in The Huffington Post, april 13, 2016
http://huff.to/1Sb4MTL

11. Poem – Wake Me Up



12. Column – Watch ME

In slow motion I look at the fast world from behind a proverbial thick wall of glass. A world which I'm actually barely part of and where I can look outside, but people don't really see me.

I had the most fantastic job where I worked simultaneously for three lawyers. I enjoyed the hectic, the hassle, the challenge to get everything flawlessly finished on time, the caring. Once it seemed just usual to get up and go to work. To come home and still have energy for my son. Thereafter be able to cook and work out. It was actually exceptional.

How special it was to just get me washed and dressed, make my breakfast and start the day. Nowadays my morning stops after I get myself washed and dressed. At noon I have to go to bed because otherwise I won't make the day. With some luck I can do something small in the afternoon. I manage to make a meal 2 or 3 times a week and at the moment I can go outside for about 1 or 2 times a week. Even in independently do grocery shopping with the mobility scooter I don't succeed anymore without having to restore for a couple of hours.

How special it was to take a shower to get energy.
There's nothing that gives me more energy anymore. Even not from things I like doing. Even sitting up is becoming increasingly difficult. After half an hour I start to get really tired. Now being tired means something else to me than for a healthy person. Being tired means to be exhausted in body and mind, struggling to think clearly or to find words, messing up with numbers, muscle aches, sore throat, acute heat in my body, having to lie down, need to drink immediately and so much more I can't think up right now.

How special it was to visit friends or to welcome them.
Apart from the energy that I don't have for visiting friends, I'm only able to welcome them occasionally for a short time. Afterwards I lie down for about 10 hours with my head no longer being able to think and much pain. When I'm lucky I can grab some food or drinks when I'm hungry. Well, I don't have to worry about this because most of my friends let me down. On average I see a friend about 4 to 6 times a year

How special it was to turn on the radio.
The intolerance for sounds makes me barely able to go anywhere. Not even on a good day, because the music is put on everywhere and that exhausts me in no-time. At home the radio is never turned on anymore and when the TV is on and someone wants to say something, the TV sound, which was already very low, is put out. Multiple sounds together are too much.

How nice would it be to just have a fun trip or to be able to go on a nice vacation where you see more than only your room.

Even a vacation with the Zonnebloem (red. A Dutch charity, organizing vacations for physical disabled persons) is too much. I wouldn't even be able to participate with such a vacation. I'm completely exhausted from all the stimuli around me when I'm driven in a wheelchair for half an hour. If in my wheelchair I would be pushed on the street, I would probably stay sitting because I'm barely able to react. When a car would enter the street, that wouldn't change a thing. There's just nothing anymore. I'm sitting totally washed out behind that wall of glass while seen from the outside I still seem to be part of the world.

How nice would it be to be able to shop and try on clothes. Just a break.

How great it was when you did your best for something and you got result from it. People with ME/cfs fight with everything within them to get better. I've followed all available therapies, followed all advices and nothing works.

How nice would it be if when you ask for help with a diagnosis like ME, after you told what you all did to became better, you wouldn't get the response: "but what do you do now to become better?" … How nice would it be to be taken seriously.

Asking for help is not easy. It takes many years before you're ready. That you've accepted that you can't do it yourself anymore. It is not easy because I actually don't even have the energy to ask for help at official institutions. My GP might think I'm a bit better because he hasn't seen me for six months. But the truth is I didn't have the energy to visit him. Not even when I needed him. And when he sees me, he doesn't know I have been waiting for the right time for this for weeks and it is likely I have to restore for at least two weeks from this visit.

How nice would it be when the physicians became aware this is a very debilitating and disabling disease. When they could step away from the psychosomatic story. How nice would it be if there would be a physician who could help me, if there would be a medicine that gave hope for the future.

I probably won't get my old life back. But it would be nice if it was not just me looking through glass to the world outside, but the reverse: that me and all other ME patients finally would be seen.

Have a nice day and thank you for having been willing to see ME for a moment.

X Windy

13. Connecting You To M.E.

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."