The ME Global Chronicle

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 # 15 – February 2016

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

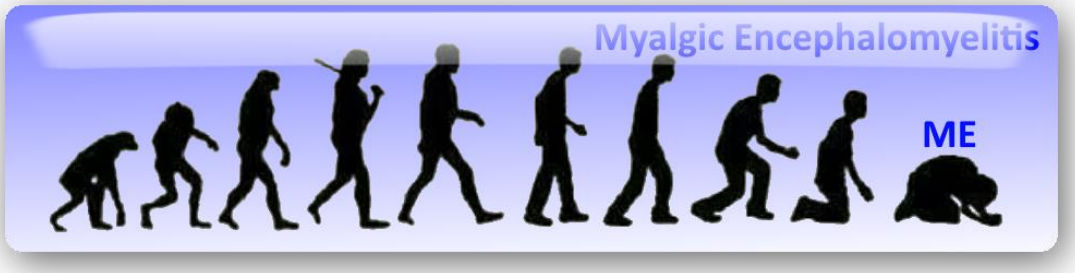
Picture front page: ***Greg & Linda Crowhurst, Eddy Keuninckx***

2. Table Of Contents

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.

Errata

*Last edition we reported info on the Vancouver CCDP clinic. This info was gathered from **Leela Play**'s private page where she stated that the info was reported and she was awaiting confirmation. She did not give her permission to post the info. A few days later we received a mail that the said clinic is bona fide and searching for ways to provide care for ME/CFS patients. Those who live in the region and contemplate contacting the clinic, would do best to inform themselves about the reliability of this claim. Our apologies to **Leela Play**.*



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

3. Introduction

Dear readers,

First of all, we want to express our gratefulness to the many of you who submitted articles to this issue of the MEGC. In this way it is being turned more and more into what it is really meant for: a platform for all patients, patient advocates and organizations, caregivers, clinicians, scientists and researchers to exchange opinions and data. To try and reach that one supreme goal by joint forces: recognition and treatments of ME.

It appears to us the community lacks focus. We all do our upmost best in the field we are good at, but we do not join our forces. That would maybe different if we for ourselves would form four priority areas, for example:

- The (wrong or inadequate) financing of research in the USA
- Continue to challenge the British controversial PACE-trial from 2011
- To get, with joint forces, the freedom of the Danish ME-patient **Karina Hansen**
- Focus all attention on the Dutch citizen initiative, that hopefully will lead to opportunities to achieve a better case definition and treatment in the Netherlands. Which is, after the Norwegian government recognizing the injustice done to the ME-community, able to cause a knock-on effect.

With that in mind, the editors of the MEGC will try to group the magazine more around these themes. You will find a first step regarding PACE and financing in this issue.

We look forward to receive your constructive criticism and suggestions via info@let-me.be.

Send copy for the April-issue (preferable also with intending activities around the world-ME day) before April 10th, 2016 via contribute@let-me.be.

Appearance of the next issue around April 20th, 2016.

We encourage you to exchange opinions and articles on http://www.facebook.com/groups/TheMEGlobalChronicle/

The editors

4. Grassroot

Cartoon Djanko

Forgotten Plague

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, The USA-Community Against The PACE-Trial

First of all: sign this petition: http://bit.ly/1PZg9wh
Especially in Europe the actions and articles of dr. David Tuller and Prof. James Coyne to get the rawdata of the follow-up study of 2012 (?) of the PACE-trial of 2011 are widely known. In this cluster of articles there's attention to that branch of actions. On February 4, 2016 MEAction sent out an email which gave a good survey of the actions by the American community since autumn 2015, against the PACE-trial and its tremendous influence on the diagnosis and treatment of ME-patients all over the world for the last four years: http://bit.ly/1PdcKMR

We'd better include the presented material in chronologic order:

In **November 2015**, a group of U.S. organizations sent a letter (http://bit.ly/1PZgmiR) to the U.S. Health and Human Services (HHS) requesting a review of the concerns raised with PACE in a series of articles (http://bit.ly/1L56enE) by journalist **David Tuller**. Based on these concerns and the call by the National Institute of Health (NIH) Pathways to Prevention report to retire the Oxford definition because it could "impair progress and cause harm", the letter recommended the following steps as appropriate and necessary to protect patients:

- The AHRQ revise its evidence review to reflect the issues with PACE and with Oxford studies in general;
- The Centers for Disease Control and Prevention (CDC) remove findings based on PACE and other Oxford studies from current and planned medical education;
- HHS use its leadership position to communicate these concerns to other medical education providers;
- HHS call for *The Lancet* to seek an independent reanalysis of PACE.

The Agency Responses

In AHRQ's response (http://bit.ly/1S6EWVt) of **December 24, 2015** the authors of the evidence review noted that the review had already considered some of the concerns raised by **Tuller** and that the additional information would not change the review's conclusions. Yet, the evidence review ranked PACE as a "Good" study with "undetected" reporting bias, a rating that is not consistent with the long-known concerns with PACE but one that could presumably influence conclusions. Further, AHRQ's response did not address the concerns with using Oxford studies as the basis of recommendations of treatment benefits and harms for ME/CFS patients.

The Response of the CDC

CDC's response (http://bit.ly/1NVZiJn) of **December 23, 2015** further clarified by a follow-up email, stated that the IOM and P2P "have placed the findings of the PACE trial in an appropriate context for moving the field forward." They stated the need for research and that CDC would be conducting a collaborative initiative to prepare new medical education materials. However, CDC's response did not address the question of whether findings and recommendations based on Oxford studies would be allowed in new medical education materials for this disease. The CDC has been asked to specifically respond to this question. That response will be shared when it is available.

HHS did not respond to the request to call on *The Lancet* to seek an independent review.

Follow-up letter by patient organizations and advocates

On **February 3, 2016**, a group of patient organizations and advocates (including #MEAction) sent a followup letter (http://bit.ly/1mjAKnh) to the Agency for Healthcare Research and Quality (AHRQ) further detailing concerns with the 2015 AHRQ Evidence Review and reiterating their request, originally made in November 2015, to reanalyze the conclusions of AHRQ's Evidence Review in light of the long-known concerns with PACE and with the Oxford definition. #MEAction signed onto the original letter after running a poll which showed almost unanimous support from our members.

Source: MEAction, http://bit.ly/1PdcKMR

PACE, PACE Trial's Forbidden Fruit

PACE Trial's Forbidden Fruit: Charities Must Echo Patient Calls For Data Release

I recently wrote (http://bit.ly/20fPFw6) about the Freedom of Information (FOI) request that the Information Commissioner upheld, ordering Queen Mary University of London (QMUL) to release the data requested from the PACE trial. I provided an example (http://bit.ly/1nOA8qX) of exactly what data was requested to demonstrate that the release would not include any personal identifiers of patients from the trial.

I also highlighted the scaremongering of the PACE authors and their institutions that is misleading people into thinking the data is personal data when it is not. Before that, I wrote about why we must be allowed to see the data (http://bit.ly/20z4LCq).

QMUL released a statement about the case, stating that they were seeking advice of patients, but they have not explained how this advice is going to be sought or under what conditions.

Many ME/CFS patients will obviously want to have their opinions taken into account. It is clearly a matter that patients feel strongly about. A recent petition concerning the PACE trial (http://bit.ly/1NBoXbe), signed by over 11,000 people (mostly, it is reasonable to assume, patients) included a call for:

"the study authors… to give independent researchers full access to the raw data (anonymised by removing trial identifiers and all other data superfluous to the calculation, such as age, sex or location)"

My suspicion is that QMUL and the PACE authors will seek the support of ME/CFS charities who have supported them in the past. But our charities should neither support the withholding of the data nor passively wait to be contacted: they should be all over this issue. Patients rightly expect the charities to speak up on their behalf, to earn the donations and membership fees we give them. The charities must ensure that the PACE authors can't just cherry-pick the advice from patients that suits them.

Previously, some of the charities have done a good job of challenging the flaws in the PACE trial and others have fallen short. Some past statements suggest that some ME/CFS charities may not understand the problems with the trial. However, this is too important for the charities to fail to inform themselves of all the facts. There is now plenty of well written information about the problems with PACE. Whereas patients may be too sick to do the necessary reading and thinking, our charities have a duty to study the facts.

They must not allow themselves to be be misled by the PACE authors or sit on the fence through ignorance; either will be unacceptable to patients, who will not forgive such a failure on this key topic. Charities representing patients, particularly, but not exclusively in the UK, can have an important impact and I am calling on them to stand up for patients on this crucial issue.

I encourage readers to contact ME/CFS charities and ask them to contact QMUL to tell them that patients want the data released. Crucially, not just the charities that have been supportive of patients already but also those that some may feel have let them down on this issue before. Judge each charity by its subsequent actions. Below are the contact details of a list of the larger UK charities which you may wish to contact.

I will be writing to ME/CFS charities who represent UK patients in two weeks' time to ask what their official stance is, and what they are doing about it. I hope that they will publish their letters to QMUL on their own websites so that I can link to it. If you also want to post a copy of your email/letter/the gist of your phone-call, then feel free to do that here – I think it would be good to have the views of patients on the public record.

Here is what I will be sending to each of the below charities. Feel free to copy the text – adapting it if you like – to save yourself some time.
I believe this is really important. We have limited energy, but if we don't spend it to do this then QMUL will find it easier to present a one-sided view of what patients want that will not represent us well.
(Example of a letter under this link http://let-me.be/download.php?view.27)

Clark Ellis

UK Charities: Contact details for the larger UK ME/CFS charities:
The charities are listed in alphabetical order. While some informed themselves early about the problems with PACE and have, to their great credit, actively campaigned to protect patients from the misinformation that surrounds it, others have not. The latter charities in particular now need to realize that they must act in a way that reflects reality and patients' needs before they lose their reputations for good: and all charities now need to come together and speak with one voice.
Please write and tell them!
Action for ME https://www.actionforme.org.uk/contact/
AYME http://www.ayme.org.uk/web/guest/contact-us
Invest in ME http://www.investinme.org/contact.htm
ME Association http://www.meassociation.org.uk/contact-us/
ME Research UK http://www.meresearch.org.uk/about-us/contact-us/
Tymes Trust http://www.tymestrust.org/contactus.htm

Submitted by **Erica Verrillo** - Source: http://bit.ly/20Nribh

PACE, Bound To Fail

PACE, The Answer Is No, No, A Thousand Times No

The Answer is No, No, A Thousand Times No
Last month (Dec. 2015, ed.), four respected researchers asked for data from the PACE trial. This is the umpteenth request, and, predictably, it was denied.

But this time the reason given was not that 1) the request was "vexatious," 2) the trial participants might somehow be harmed, 3) it might infringe on intellectual property rights, or 4) the study might be criticized.

None of the above. Their excuse this time was that "participants may be less willing to participate in a planned feasibility follow up study." In other words, if people with ME/CFS knew how bad the PACE trial really was, they might not be willing to participate in another trial.

Imagine a situation in which a drug is administered to a group of ill people, who then become more ill. But the authors of the trial hide the data and claim that the ill people appear to benefit. When asked for the data they refuse, because they don't want participants to know the drug is harmful in case they do future studies.

How illegal would that be?

The PACE trial authors have no moral compass. They are planning on rehashing their study endlessly to milk it for all its worth. They will continue to spin their "results" until someone in authority puts a stop to it.

Source: http://bit.ly/1TKi9hP

PACE, An Open Letter To The Lancet, Again

10 February 2016

On November 13th, five colleagues and I released an open letter (http://bit.ly/1NXXCUf) to *The Lancet* and editor **Richard Horton** about the PACE trial, which the journal published in 2011. The study's reported findings–that cognitive behavior therapy and graded exercise therapy are effective treatments for chronic fatigue syndrome–have had enormous influence on clinical guidelines for the illness. Last October, Virology Blog published **David Tuller**'s investigative report (http://bit.ly/1NBp079) on the PACE study's indefensible methodological lapses. Citing these problems, we noted in the letter that "such flaws have no place in published research" and urged **Dr. Horton** to commission a fully independent review.

Although **Dr. Horton**'s office e-mailed that he would respond to our letter when he returned from "traveling," it has now been almost three months. **Dr. Horton** has remained silent on the issue. Today, therefore, we are reposting the open letter and resending it to *The Lancet* and **Dr. Horton**, with the names of three dozen more leading scientists and clinicians, most of them well-known experts in the ME/CFS field. We still hope and expect that **Dr. Horton** will address–rather than continue to ignore–these critical concerns about the PACE study.

Prof. Vincent Racaniello & **Ronald W. Davis**, **PhD**, **Jonathan C.W. Edwards**, **MD**, **Leonard A. Jason**, **PhD**, **Bruce Levin**, **PhD**, **Vincent R. Racaniello**, **PhD**, **Arthur L. Reingold**, **MD**, **Dharam V. Ablashi**, **DVM**, **MS**, **Dip Bact**, **James N. Baraniuk**, **MD**, **Lisa F. Barcellos**, **PhD**, **MPH**, **Lucinda Bateman**, **MD**, **David S. Bell**, **MD**, **Alison C. Bested MD FRCPC**, **Gordon Broderick**, **PhD**, **John Chia**, **MD**, **Lily Chu**, **MD**, **MSHS**, **Derek Enlander**, **MD**, **MRCS**, **LRCP**, **Mary Ann Fletcher**, **PhD**, **Kenneth Friedman**, **PhD**, **David L. Kaufman**, **MD**, **Nancy Klimas MD** , **Charles W. Lapp**, **MD**, **Susan Levine**, **MD**, **Alan R. Light**, **PhD**, **Sonya Marshall-Gradisnik**, **PhD**, **Peter G. Medveczky**, **MD**, **Zaher Nahle**, **PhD**, **MPA**, **James M. Oleske**, **MD**, **MPH**, **Francois-Xavier Bagnoud Professor of Pediatrics**, **Richard N. Podell**, **M.D.**, **MPH**, **Charles Shepherd**, **MB**, **BS**, **Christopher R. Snell**, **PhD**, **Nigel Speight**, **MA**, **MB**, **BChir**, **FRCP**, **FRCPCH**, **DCH**, **Donald Staines**, **MBBS MPH FAFPHM FAFOEM**, **Philip B. Stark**, **PhD**, **Eleanor Stein**, **MD FRCP(C)**, **John Swartzberg**, **MD**, **Ronald G. Tompkins**, **MD**, **ScD**, **Rosemary Underhill**, **MB BS**., **Dr Rosamund Vallings MNZM**, **MB BS**, **Michael, VanElzakker**, **PhD**, **William Weir**, **FRCP**, **Marcie Zinn**, **PhD**, **Mark Zinn**, **MM**

Source: Virology Blog http://bit.ly/1O6kqgb
Link to the letter: http://let-me.be/download.php?view.29

PACE, In defense

In defense of publicly available data sets for published papers

Alex Holcome's brief nugget in *The Conversation,* Science is best when the data is an open book (http://bit.ly/249DDJt) is one of the better statements about the necessity of journals' requiring authors to provide public access to data as a condition for publishing. Some excerpts:

Many scientific societies recognise this. For many years now, some of the journals they oversee have had a policy of requiring authors to provide the raw data when other researchers request it.

Unfortunately, this policy has failed spectacularly, at least in some areas of science. Studies have found that when one researcher requests the data behind an article, that article's authors respond with the data in fewer than half of cases (http://t.co/CN6SDUVXZp). This is a major deficiency in the system of science, an embarrassment really.

The well-intentioned policy of requiring that data be provided upon request has turned out to be a formula for unanswered emails, for excuses, and for delays. A data before request policy, however, can be effective.

Implicit in **Alex**'s blog post is the assumption that authors of published papers should not have veto power over who re-analyzes their data.

My colleagues and I have had **positive experiences when data was available to us** at a public depository. In one instance (http://bit.ly/249DLJ1), we were able to show we could replicate investigators' original findings in *Proceedings of the National Academy Of Sciences* using their data, but we were also able to show that random numbers yielded essentially the same effects. This has to be an important qualification to the authors' claims about their original data.

Negative experiences in requesting data are more likely to occur when access depends on the willingness of investigators to release their data in response to a formal request. One of my negative experiences came when I asked for data to reanalyze results that the principal investigator claimed to demonstrate an effect of attendance of group therapy on the survival of patients with early breast cancer. My colleagues and had published a critique of the study showing that any such claims were dependent on multivariate analysis of dubious appropriateness (http://bit.ly/1WqWxFW). But to delve further into the study, I needed access to some simple statistics that should have been included in the original report. When I formally sought request of these data, the principal investigator refused me, her university claimed that the data were intellectual property, and the US Office of Research Integrity responded with a statement that they had no authority to enforce sharing, despite sharing being mandated.

Public Library of Science Journals (PLOS) (http://bit.ly/1PQ1G6K) is a large player in scientific publishing and a prime mover in the push for routine data sharing. PLOS is a family of seven journals. The largest of them, PLOS One, publishes over 30,000 articles a year

On August 12, 2012, the PACE investigators published a paper in PLOS One (http://bit.ly/20Dhn6g). In doing so, they incurred a responsibility to make their data available.

The article was published in 2012; the PLOS data policy that applies to the article is that for submissions prior to March 3, 2014, which is outlined here: (http://bit.ly/2186mMr). The policy expects authors 'to make freely available any materials and information described in their publication that may be reasonably requested by others for the purpose of academic, non-commercial research'. The policy also notes that access to the data should not compromise confidentiality in the context of human-subject research.

It's been almost 100 days since I requested the data from the PLOS One article. I have not received the data. My request has been turned into a Freedom of Information Act, which is decidedly what it was not. I've been deemed "vexatious" for having made it.

In a follow-up blog post, I will review restrictions that have been suggested for making the PLOS One *PACE data available. Some of these proposed restrictions are irrelevant. Others make false assumptions about what was promised to patients in the consent process for the study. I will show why the data should be unconditionally available. Not doing so is a bad precedent for future data-sharing.*

***Prof. James Coyne**, February 14, 2016*

Full version: (*http://bit.ly/1onSWxo*) *abrieved by the editors of the MEGC*

PACE, The Young ME Sufferers

The Young ME Sufferers Trust (Tymes Trust) joins call for independent analysis of PACE Trial data | 15 February 2016

As if there were not enough concerns about the PACE trial, we at Tymes Trust have the added concern, on behalf of parents and families of children with ME, that a children's version of PACE is being set up. Below is the text of a letter we have sent to QMUL which was of course set out on our headed paper.

LETTER TO QUEEN MARY UNIVERSITY LONDON

Records and Information Compliance Manager, QMULCopy to:
Professor Simon Gaskell, Principal, QMUL

RELEASE OF PACE TRIAL DATA

Dear Sir

We understand from your December 2015 statement that you wish to receive patients' views on the release of the PACE trial data.

Tymes Trust is the longest established UK service for children with ME and their families. We are frequently contacted by parents whose children's condition has deteriorated after various regimes of graded exercise, graded activity, and graded school attendance, with its demands upon both body and brain. Therefore, we are extremely concerned that, before any fresh analysis of the PACE trial data by independent scientists has taken place, a PACE trial for children (under the appellation MAGENTA) is being set up. This will subject children to graded exercise therapy.

Given the many concerns about the methodology used in the PACE trial, and given the fact that its conclusions are starkly at odds with the findings of patient organisation surveys into graded exercise therapy, which consistently show three quarters of patients reporting deterioration as a result, you must surely agree that parents are entitled to have access to the results of an independent analysis of the PACE trial data before agreeing to subject their children to this therapy.

You may be aware that the published information about the MAGENTA trial confidently states: "There are no risks of participating in the study." Contrast this with one of the latest patient messages we have received: "Save our children from GET. I know what I am talking about, from an ex triathlete who went from mild to severe ME because of GET."

We are well aware of the controversy surrounding the release of the PACE trial data, and are amazed that you appear so reluctant to put a speedy end to this potentially damaging and unseemly stand-off between yourselves and a world renowned group of scientists who are only the latest among many to request the release of this data. We hope you will reconsider, rather than fighting the Information Commissioner's order to release the data. It is surely the responsible thing to do.

Yours sincerely

Jane Colby
Executive Director
The Young ME Sufferers Trust

NIH Clinical Study

MEadvocacy published a blog NIH Clinical Study: A Case of Continued Institutional Bias**,** (http://bit.ly/1LuTvuH)**,** on 9 February 2016 about the posted protocol of the US NIH Intramural Study of CFS (archived link (http://bit.ly/1PSECUU), the original webpage (http://1.usa.gov/1oM3dDY) content was deleted so that a blank page appears).

We presented detailed flaws of the 'fatigue' study, using the Reeves criteria. This criterion was created by the CDC's **William Reeves**, **Elizabeth Unger**, **James Jones**, **Suzanne Vernon**, **et al**. It was highly contested for its many flaws by experts and stakeholders. This flawed criteria appearing on the protocol page caused patients and advocates to rise up in outrage. With **Drs. Unger** and **Lipkin** advising this staff, how could they have gotten this so wrong? The study's plan to compare an ME cohort with enigmatic conditions such as psychogenic functional movement disorders and asymptomatic post-Lyme patients would only confound results. If comparisons should be made, then comparing to similar diseases such as MS or HIV would be more appropriate. But with such a small sample size, the money instead would be better spent on a larger ME cohort to advance biomarker identification.

We warned about the danger of **Dr. Nath** presenting a misperception of the disease to thousands of physicians listening to the CDC's Grand Rounds on 16 February, 2016. MEadvocacy initiated a petition (http://bit.ly/1PSF2up) calling on NIH to stop the 'fatigue' study, and to cancel **Dr. Nath**'s presentation. We demanded an overhaul of the study design with a vigorous study of ME patients meeting ME criteria created by ME experts, with ME experts and ME patient input.

MEadvocacy published another blog Further Analysis of NIH Clinical CFS Study, (http://bit.ly/1PSFd94) explaining why the design is faulty (not just the criteria) and should be scratched. The petition ran for 5 days, collected **725 signatures** and was emailed with an introductory letter to NIH and CDC officials on 15 February 2016. See NIH and CDC: You've Got Mail (http://bit.ly/1STUdti).

Various unofficial promises to a handful of advocates have compounded the confusion for ME patients. In our letter to US health officials we asked that communication to our community be open and public.

MEadvocacy is waiting for an official reply from NIH to the petition. **Dr. Nath**'s presentation was not cancelled, though the study was further modified compared to the last unofficial NIH communication to select advocates.

Visit http://www.meadvocacy.org for updates.

#MEPedia

Help us expand the MEpedia page on the Reeves criteria to give more background and context on its usage:
http://me-pedia.org/wiki/Reeves_criteria

This page is especially important in light of the recent NIH announcement of its new intramural clinical trial which will use this definition to recruit patients:
https://www.facebook.com/MEActNet/posts/1696144644001268

Never contributed to MEpedia before? Here's how to get started:
http://me-pedia.org/wiki/How_to_contribute

For technical support, join the discussion here:
http://my.meaction.net/local_chapters/mepedia

Jennifer Brea

Introducing Mary Dimmock's Summary

'Thirty Years of Disdain' http://bit.ly/1PxHMAt
Hillary Johnson wrote the epic book 'Osler's Web: Inside the Labyrinth of the Chronic Fatigue Syndrome Epidemic', where she depicts the history of the disease, spending nine years investigating the failure of the medical establishment to take the disease seriously as well as repeated governmental health agency malfeasance. Her book documents the history from 1984 to 1995.

Since then, there has been a lack of documentation recording the history of events and actions that reflect the concerted institutional effort to bury the disease ME.

Mary Dimmock, ME advocate, along with her son, **Matthew Lazell-Fairman**, who suffers from severe ME, stepped up to the plate with their document:

'Thirty Years of Disdain: How HHS and a Group of Psychiatrists Buried Myalgic Encephalomyelitis' full version: http://bit.ly/1NI5Y4a
This is an invaluable account of her and her son's personal story trying to navigate the medical labyrinth of this disease, as well as an in-depth, referenced historical and political account of the disease that encompasses **Johnson**'s account and expands to the present time.

The community was eager to read this important historical report.

Some have asked **Mary** if she would deliver a shorter version for patients for whom reading long text is taxing. Again, **Mary** and **Matthew** came through and delivered their short summary version to our community http://bit.ly/1PxHMAt
This strategic document is very timely.

The necessity of this type of historical documentation has come to the forefront again.

We are in the midst of yet another struggle with the Department of Health and Human Services (HHS), accepting ME as the distinct neuro-immune disease that was identified in the early 1930's.

Thanks to **Gabby Klein** & **Jan van Rooijen**

History Preceding the Launch of the US IOM Criteria for ME/CFS

In the October 2012 meeting of the US Chronic Fatigue Syndrome Advisory Committee (CFSAC), voting members urged HHS (http://1.usa.gov/1VYj9xg) to adopt the 2003 Canadian Consensus Criteria (CCC) with a recommendation to convene a workshop of ME/CFS stakeholders to advise whether updating was needed. Top ME/CFS researchers had already started using CCC criteria in addition to the Fukuda criteria for determining patient cohorts. Since the NIH only recognized the Fukuda definition for grant applications, researchers could not just evaluate per the CCC criteria.

In September 2013, clinicians, researchers (http://bit.ly/1Pr1hY2) and advocates (http://bit.ly/1TKqPEV) entreated HHS to recognize and adopt the 2003 CCC criteria, which was an updated and more accurate than the 1994 Fukuda Criteria used by HHS.

HHS did not heed the community's voice. They stubbornly and secretly contracted with the IOM to create, yet again, another HHS supported disease definition. The IOM panel produced the 2015 report: Beyond Myalgic encephalomyelitis/Chronic Fatigue Syndrome (http://bit.ly/1UT0yT5) including the IOM criteria (http://bit.ly/1nOSiZD) excluding guidance on treatments, as instructed by HHS.

Some in the community have accepted the new IOM clinical criteria as a perceived improvement because of its requirement of post-exertional malaise (PEM), the hallmark feature of ME. Many others, including MEadvocacy, argue that it actually falls short of the already available CCC and ICC criteria. They believe that this new IOM criteria is too broad, inclusive and does not describe the serious neuro-immune disease, ME.

Why are Case Definitions Consequential?

In the preface to the ICC, its authors explain the need for accurate definitions: "*There is a poignant need to **untangle the web** of confusion caused by mixing diverse and often overly inclusive patient populations in one heterogeneous, multi-rubric pot called 'chronic fatigue syndrome'. We believe this is the foremost cause of diluted and inconsistent research findings, which **hinders progress**, **fosters scepticism**, and **wastes** limited research **monies**."*

HHS has not requested new **research** criteria. There is evidence they will start using the new IOM criteria for their research initiatives, based on **Francis Collins**' recent statements of approval of the IOM. HHS ignored CFSAC's August 2015 recommendation to adopt the CCC as the research criteria. See HHS' reply (http://1.usa.gov/1ST5KHv).

Using the proper criteria is vital as highlighted in a recent paper by Norwegian scientists titled: 'What exactly is myalgic encephalomyelitis'. It states: *"The use of **broad inclusion criteria** has created a heterogeneous patient population, also within research. **This has increased the risk of erroneous conclusions, misdiagnosis and incorrect treatment**. For myalgic encephalomyelitis, the Canadian criteria and the International Consensus Criteria have in our view **increased the accuracy** of diagnosis due to their greater specificity and clearer delineation of the disorder from other forms of fatigue."*

How Well Does The IOM Criteria Select ME Patients?

In **Dr. Leonard Jason**'s paper 'Reflections on the IOM's systemic exertion intolerance disease' (http://bit.ly/1PZvRaF), he ran an analysis to answer this question. His study shows that the prevalence rates of IOM patients will dramatically increase, partly due to the lack of exclusionary illnesses. This will result in the inclusion of misdiagnosed patients. **Jason**'s paper 'Unintended Consequences of not Specifying Exclusionary Illnesses for Systemic Exertion Intolerance Disease' (http://bit.ly/1UT1eYA) states: *"findings indicate that many individuals from major depressive disorder illness groups as well as other medical illnesses were categorized as having SEID [IOM's replacement term for ME/CFS]."*

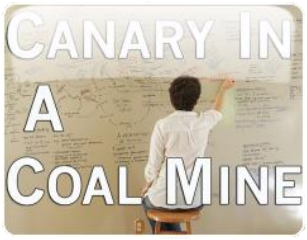
Frank Twisk published a paper; 'A Critical Analysis of the Proposal of the IOM to Replace ME and CFS by a New Diagnostic Entity Called SEID' (http://bit.ly/1KwR7Iz). In this paper, he proposes that some of the characteristic symptoms of ME, as described by **Dr. A. Melvin Ramsay** (http://bit.ly/1PZw8u8), are not present in the IOM criteria. These include muscle fatigability, circulatory impairment and exhaustion of the central nervous system after minor physical activity, as well as the chronic relapsing course of the disease. There are two reasons for these omissions, **Frank** proposes:

- These symptoms have not been adequately investigated. (lack of quality research and studies)
- It is mainly CFS diagnosed patients that have been studied, in the research relied upon [during the IOM's evidence based evaluation], as opposed to ME patients.

Twisk's second point is really key. If most of the research and studies that the IOM panel relied upon used CFS patients as per Oxford or Fukuda criteria, the resulting criteria will reflect those findings. **In essence, the IOM criteria is a CFS criteria, not ME**.

http://www.MEadvocacy.org

Canary in a Coalmine



I am thrilled to announce the latest addition to Team Canary, **Kim Roberts**, an extraordinarily talented and experienced editor. She's won an Emmy and has edited four Oscar-nominated documentaries.

I will be heading to LA next week to help set up the second phase of our edit there.

Please join us in welcoming **Kim**!

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

Jen

Conflicts of Interest

Conflicts of Interest - an unpublished letter from Dr. Lucinda Bateman in defense of earlier accusations

There are accusations of strong financial conflicts of interest about researchers/clinicians in the field. Such accusations have been directed to Dr. Lucinda Bateman who, apart from running a FM/ME/CFS-clinic in Salt Lake City, USA has been a panel-member of the IOM-committee which recommended new clinical diagnostic criteria for what used to be called CFS in the US and ME in Europe, and a new name to replace CFS in a final document of exactly a year ago.

When we as editors confronted Dr. Bateman straightaway with these accusations, she sent us the following letter to CoCure which seems to never have been published, accompanied by the following comment:
"I'm attaching a letter I wrote to someone at Co-Cure earlier in 2015 about this issue of pharma money. This is ridiculous. Why wouldn't we try to solicit pharma money, and federal money, and any other money to help our cause? Our field desperately needs financing. I'm offended by the accusation that I am somehow keeping the money for myself. My salary remains in the lowest 10% of internists in the US---all because of working for MECFS. Our community needs to get the facts straight. I don't know ONE MECFS researcher who is getting rich by working in the field. We also need to recognize that---although the governmental and pharmaceutical deep pockets have historically excluded us---we can only succeed by finding ways to entice them to support us."

When asked about her financial interests by taking part of the IOM-panel, she answered: "I didn't get paid anything for participation on the IOM committee. The IOM paid for my plane tickets and hotel costs when I went to Washington DC for the interval meetings. Otherwise all the WORK was done voluntarily without financial compensation over the year of our project."

Anyone wishing to react on this, please do so straight to Dr. Bateman or through info@let-me.be. If a further discussion will arise on this topic we will publish about it in further issues of the MECG, as the magazine is meant to be an open platform for patients, patient advocates, caregivers and scientists, clinicians and researchers as well.

Re: Dollars for Docs
Date 02/13/2015 (02:15:19 PM MST)
I appreciate the strong support for the ME/CFS community and all the work advocates. I follow Co Cure and have seen it as a rich resource. So I was a bit surprised by the letter written by Patricia Carter and posted by Jan van Roijen on 2/13/15 entitled "Dollars for Docs." I decided to speak up about these issues because of the desperate need in our field for clinicians and researchers, and for Centers of Excellence. It may be important for the patient and advocacy community to understand the stark financial realities of medical practice.

I am a general internal medicine specialist who changed my career path in 1999 to assist patients with chronic fatigue and pain who were not getting good medical care and respectful recognition. I am self-employed and have a small but devoted staff. Self-employed physicians, and especially those who see ME/CFS and FM patients, often have difficulty financially. We all must find ways to pay the rent, or our clinics--which are few enough already-- will disappear. It is very frustrating, but my clinic can only see about 20% of the patients who call asking for an appointment, because the need for care is so great compared to our meager clinic resources. We are working at full capacity and yet can barely keep our doors open due to financial stress.

Most of the doctors listed by Ms Carter in the letter are my trusted friends and respected colleagues. We all struggle with financial issues. Some make the business survive by charging a cash fee to patients; others bill for labs, procedures or tests done on site to help improve income; many take insurance as only partial payment; a rare few get donations through a charity or have other subsidization. Many who work at academic institutions are pressured to make choices that would bring in more income---see more patients per hour, or stop seeing ME/CFS or FM patients at all.

I am one of the few clinics I know of that accepts low paying insurance as payment, including Social Security Disability patients on Medicare. Because we are hoping to build a Center of Excellence to provide care to even more patients, we recently had a financial feasibility study done. The expert was stunned to inform me that we lose $600 per year seeing established patients and $2000+ per year seeing new patients (because we take much more time with new patients).

Fortunately, we have survived because of our involvement in research. We maintain a highly respected, professional research department and do only studies that further knowledge of ME/CFS or FM. We provide contracted research services to outside institutions, which includes pharmaceutical companies (Hemispherx), foundations or non-profit organizations (CFI, OFFER) and federal institutions (NIH, CDC). My research staff (2 research coordinators) bring in about half of the income to the business, and the other half comes from 3 medical providers (and 3 support staff) seeing patients in clinic.

When the fibromyalgia drugs came on the market, they were the first potential candidates to be FDA approved for treatment of the hyperalgesia (pain amplification) of FM. It made good sense that the drugs should be tested in my clinic, where my patients are nurtured as we recognize and treat their illness. Because we are a clinic that sees a variety of patients across the FM and ME/CFS spectrum, we were easily able to enroll interested patients in the studies, and so became a major site for testing all 3 approved FM drugs (Cymbalta/Lilly, Lyrica/Pfizer and Savella/Forest). In addition to helping with the drug safety and efficacy trials prior to FDA approval, I went to many doctors' offices as a pharmaceutical speaker, which provided many opportunities to teach primary care physicians how to identify and diagnose FM [and I usually got a few words in about ME/CFS as well]

Just to be clear, all payments that "Lucinda Bateman" receives from the drug companies go into the gross income of the clinic [not my own bank account] which employs 8-10 full time people, pays the rent, telephone, internet, copiers, supplies, insurance, accounting, payroll, billing and all the miscellaneous. I do not work for the government, a university or a hospital that can help with benefits or expenses.

If I hadn't participated in the FM pharmaceutical research for those few years of FM drug development, I'm pretty sure my clinic would now be closed and out of business. Then I wouldn't have been able to participate, along with my research coordinators and hundreds of ME/CFS patients, the NIH funded XMRV study, the Chronic Fatigue Initiative, the CDC multisite study, the post-exercise gene expression studies with Alan Light, etc, etc. Each year we scramble to find enough external income to continue seeing patients who need care across the spectrum.

In addition to personal salary below the 10th percentile of general internists in the US, a specialty of practice that isn't respected by the medical field---both of my own conscious choice--- I now have caustic criticism from patients with ME? What is that about?

So, please, let's take on the bad guys. My sister had ME/CFS and later died of Non Hodgkin's Lymphoma. I love my patients and have a close relationship with most of them.

We are an Ampligen site. Why do you think I am somehow not part of this community? A person who takes care of both FM and ME/CFS patients may be the most qualified to know the differences! Is there not room in our community for a number of roles?

Let me know if I can answer any of your concerns or questions. Seriously!

Lucinda Bateman MD

RFA Ticker 02/08/2016

Superb and simple survey each week by **Jennie Spotila** of the incredible amount of funds attributed to ME/CFS research by the NIH with **Dr. Francis Collins** promise on 11.23.2015 to give a tremendous impulse to research https://youtu.be/nDjJLgA6Ex0 : zero to date.

The editors

Total RFAs Issued by NIH: 131 (October 2015 to date)
Total Dollars Committed to RFAs: $1,545,000,000 (October 2015 to date)
Total RFAs for ME/CFS: **ZERO** (October 2015 to date)

Week Beginning	RFAs Issued	Total Commitment	RFAs for ME/CFS
02/01/2016	8	$26,000,000	Zero
01/25/2016	6	$11,550,000	Zero
01/18/2016	2	$4,500,000	Zero
01/11/2016	10	$71,200,000	Zero
01/04/2016	0	$0	Zero
12/28/2015	0	$0	Zero
12/21/2015	3	$10,260,000	Zero
12/18/2015	5	$20,260,000	Zero
12/11/2015	27	$765,090,000	Zero
12/04/2015	6	$26,600,000	Zero
11/27/2015	4	$21,000,000	Zero
11/20/2015	15	$134,400,000	Zero
11/13/2015	2	$16,100,000	Zero
11/06/2015	10	$22,850,000	Zero
10/30/2015	7	$49,800,000	Zero
10/23/2015	10	$33,200,000	Zero
10/16/2015	0	$0	Zero
10/09/2015	13	$332,450,000	Zero

If you want more background on the RFA Ticker, read the inaugural post. http://bit.ly/1QoMEo4

Jennie Spotila http://www.occupycfs.com/?author=1

Cancer 'Moonshot' Has Paltry Dollars, Losers

Whenever the government wants to be seen to be doing something huge, it invokes the Manhattan Project or the moon landing. So the new cancer initiative of the **Obama** administration is called the "moonshot."

But it's neither the equivalent of the Manhattan Project, which developed the atomic bomb during World War II, nor **President Kennedy**'s ambitious program to land a man on the moon, after the Russians appeared to have stolen a march with the launch of Sputnik, the first satellite in space.

Those programs succeeded because they were tremendous national commitments without regard to funding. The $1 billion in proposed funding for the "moonshot" cancer initiative is somewhere between modest and paltry. In the world of biomedical research, $1 billion simply doesn't buy much.

The pharmaceutical industry estimates that it costs well over $1 billion to bring just one new drug to market. Cancer needs many drugs.

The lead agency in this new iteration of the war on cancer, declared in 1971, is the National Institutes of Health. It has an annual budget of $32 billion on which there are demands from many deserving fields of biomedical research besides cancer.

President Obama has asked **Vice President Biden** to lead the cancer moonshot effort. I've been with the vice president when he has talked about his commitment to the cause of cancer research and the death of his son, **Beau**, from brain cancer. His sincerity and his commitment to cancer research is palpable, but he won't have the dollars to get the job done.

The biggest contribution to the research for a cancer cure may be the stimulation the moonshot will give to extant cancer efforts, but it's not without a downside.

Many other diseases fear they may be undercut by the cancer initiative. In the world of biomedical research, there is finite funding and talent — and a new initiative tends to draw the best research minds. The top magnets for good biomedical researchers these days are cancer and AIDS, and many other deserving diseases lose out. Biomedical research requires stability, so that decades of a scientist's life can be devoted to a single line of endeavor.

I follow one of the more obscure diseases, one that that has been pitiably starved of public and private funds: Myalgic Encephalomyelitis, also known as Chronic Fatigue Syndrome. Compared to any other disease affecting a large number of people (1 million victims of ME/CFS in the United States, according to the Centers For Disease Control), it has been funded so little by the government as to amount willful neglect. It receives a miniscule $5 million a year in funding.

Last year, after public and media pressure that has been applied for years, NIH Director **Francis Collins** announced that things would be rectified. But he didn't mention a dollar figure; not when he made the announcement in October and not to date. No moonshot here, not even a Fourth of July firework.

Yet the suffering of those with ME/CFS is truly awful. I've been in the sick rooms and interviewed the few doctors who specialize in the disease, and the situation is one of unabated misery. Those who are the most affected can't tolerate light or sound, and must pass their days in the silent dark. For years, one poor young man has had to take refuge from the disease in a modified closet. Others suffer from a world in which they're punished for doing everyday things: A dinner with friends can mean days in bed for recovery.

There seems to be no light at the end of the victim's physical pain and mental fog, despite decades of pleading from advocates and caregivers that some serious research be funded by NIH.

While we've been the world's powerhouse in research in all sciences, biomedical is now being starved of research dollars. Recently America's most revered virus hunter, **Dr. Ian Lipkin**, director of the Center for Infection and Immunity at Columbia University's Mailman School of Public Health, has had to resort to crowdfunding. He and his deputy, **Dr. Mady Hornig**, can be found on YouTube eating red-hot chili peppers in an attempt to raise money for their ME/CFS research.

Dollars in across-the-board biomedical research are falling when they should be rising. Recently, NIH's budgets have been 25 percent smaller in constant dollars than they were in 2003.

Research pays. Most of it doesn't yield dramatic stuff, like a moonshot, but rather solid, incremental gain. In science, incremental gain is the equivalent of compound interest. But it needs sustained funding. Not rhetoric.

Llewellyn King

Source: http://whchronicle.com/?p=3211

Solve ME/CFS Initiative Grades HHS Response to CFSAC Recommendations

In late January, the U.S. Department of Health & Human Services released its response to the recommendations put forth by the Chronic Fatigue Syndrome Advisory Committee at its August meeting. The Solve ME/CFS Initiative has assigned a letter grade to HHS for each recommendation based on how well the agency responded, given last year's Institute of Medicine and Pathways to Prevention reports, which unequivocally called for federal agency focus on ME/CFS.

The grades the organization gave on the HHS response to the 13 CFSAC recommendations range from an A- (one) to an F (four). In cases in which low grades were given, it was largely because of federal process issues, which were described by HHS as preventing forward movement.

"Knowing that the CFSAC has deep knowledge of the disease and HHS has deep knowledge of how to navigate through federal processes, a goodwill discussion regarding how to effect these recommendations would be a sensible next step," said Solve ME/CFS Initiative President **Carol Head**, while acknowledging that the responses were written in late October, before the first Trans-NIH Working Group meeting.

Head will continue to press these issues through her role on the CFSAC subcommittee, which will meet again in May. "The report card is a way to continue a constructive, problem-solving dialogue regarding how our federal government can live into the Institute of Medicine's and P2P's mandates," **Head** said.

To view the report card, go here http://bit.ly/20s6ioy
To view the CFSAC recommendations and the full HHS responses, go here http://bit.ly/1LkuFh3

Submitted by **Jeryldine Saville**

In Memoriam – Raymond Colliton

(March 10, 1947 - January 29, 2016)

Longtime ME patient **Raymond Colliton** died last week of respiratory issues (bronchitis/¬emphysema/ pneumonia). He was 68.

Ray was the founder of the Co-Cure project and also was involved in the ME Society of America website.

From the tribute of his good friend **Maryann Spurgin**:

It is with great sorrow and sadness that I must announce the death of my close friend and our colleague, **Raymond F. Colliton**, known to his friends and family as a brilliant, witty, erudite, kind and giving person, an entertaining conversationalist, and devoted to his family. **Ray** died peacefully in hospice care on January 29, 2016, with his loving wife, **Bernice Melsky**, at his side. He was 68 years old.

Ray is known in the ME community as the owner and manager of the Co-cure project, an email list serve and (now-archived) website that kept the community of researchers and patients informed on the science and politics of ME for decades. **Ray** also did all of the webmaster work on my "ME Society of America" website. He spent much time, energy, and money keeping the ME community informed as well as helping patients, although he had not been involved in Co-cure for the last two years due to illness & retirement He kept a very low online / internet profile, staying out of the limelight and working behind the scenes.

My heart goes out to his caring wife, **Bernice Melsky**, his brother **Edward**, sisters **Margie** and **Maggie**, daughter **Carrie** and many other family members who loved him. My heart is very heavy because he was one of my best friends EVER, another close friend gone too soon.

May his adoring family find peace in wonderful memories, and may those of us with ME be grateful for the massive amount of work he did to help patients as he worked behind the spotlight. He will live in the hearts of those of us who knew him.
Ray, you are missed.

This post was approved by his brother, **Edward V. Colliton**, Ph.D.
The Co-Cure project is archived here: http://bit.ly/1PdnU4m

Dutch Citizen Initiative

Dutch Citizen Initiative to recognize ME as a Biomedical Disease

Collecting of signatures during a flower parade at Leersum, the Netherlands: even the princesses of the day signed the petition to recognize ME in the Netherlands as a biomedical disease

In the introduction of this issue, the editors of the MEGC suggested to make this initiative one of the four priorities, regarding the grass-root activities for the recognition of, and the appropriate diagnostic criteria for ME. Therefore, we post some extracts below from previous reports on the important happening in such a small country.

At the moment, the Health Council is composing a committee which will consider the request for advice from the government.

Wherever possible, we will inform you about the progress of this process and on updates of the Groep ME Den Haag.

The editors

- Fall 2011: a group of ten independent patients starts collecting signatures to request the government to recognize ME as biomedical disease, knowledge about which should be disseminated among practitioners and in medical education, and to redefine ME and look for possible treatments. Currently there's only a CFS-guideline for practitioners which advises CBT and GET as the only possibly effective treatments of the symptoms of ME.
- While 40.000 signatures are needed, in October 2013 a delegation of the Dutch dHHS is presented with 56.000 ones.
- Fall 2014: the parliament commissions the Health Council of the Netherlands to evaluate the current state of knowledge about ME, with special attention to:
    - The definition of ME and diagnosing the disease
    - Start, progress and prevalence
    - Possibilities to prevent and treat ME
    - Impact of ME on the patient, his environments and participation in society
    - Organization of treatment and support of patients with ME in the Netherlands
    - Current scientific developments and perspectives (**MEGC 11**)

The following international doctors or ME-experts have pledged their cooperation in writing to the Groep ME-Den Haag:

- **Prof. Alan Light**, research professor of the neurological system. ICC
- The late **Dr. M. Lerner**, internist and infectious disease specialist. CCC.
- **Dr. A. Kogelnik**, microbiologist, immunologist and infectious disease specialist
- **Prof. Mady Hornig**, epidemiologist, internist, infectious disease specialist in special cytokines / cooperates with **Dr. Ian Lipkin**
- **Dr. Nigel Speight**, paediatrician. ICC
- **Prof. Leonard A. Jason**, psychologist
- **Prof. P. Powles**, respiratory system and sleep disorders. CCC, ICC
- **Dr. Spurr**, doctor specially focused on ME
- **Dr. Lucinda Bateman**, internist. ICC, IOM
- **Dr. Byron Hyde**, geophysicist, enterovirus researcher, fully dedicated to ME
- **Dr. Ellie Stein**, psychologist
- **Dr. Dan Peterson**, internist, ME-doctor since outbreak in Lake Tahoe in the seventies. CFIDS, CCD, OMI
- **Dr. John Chia**, infectious disease specialist. OMI
- **Prof. Gordon Broderick**, endocrinologist. ICC
- **Prof. Patrick McGowan**, epigeneticist. (**MECG13**)

[*In the meantime other researchers and scientists have pledged their cooperation in whatever way possible.* ***The editors***]

"Given the recent developments concerning the PACE trial, via blogs from **David Tuller** and **James Coyne**, which all of us will not have missed, and the sharp criticism of them as well as other independent, prestigious scientists on the methodology, analysis, interpretation and presentation of results from the PACE trial, the call for release of the PACE data and for carrying out an independent reanalysis, or even withdrawing of the study, we, as Burgerinitiatief Erken ME (Citizen Initiative recognize ME)/Groep ME Den Haag sent an extra letter to the Health Council early this week [at the start of December, ed.].

In the letter addressed to the Health Council, we informed them about above mentioned developments and requested them to take note of this (we added an extensive references list with links to several blogs/articles/reports). We have also insisted the yet to be formed commission that will review the state of science with respect to ME and will submit a recommendation report to the Parliament, to be extra critical regarding this subject (CGT/GET), given the state of science, and requested them to take published criticisms into account." (**MECG 14**)

Karina Hansen, The Ghost in the Room

***January 2016**. A young woman sits in a wheelchair in a Danish rehabilitation centre. She mumbles incomprehensibly to herself from time to time but is otherwise unresponsive. With her is a close family member. She shows no signs of recognizing him.*

*Is this the fate of "**Karina Hansen**: Prisoner of Denmark" (http://bit.ly/1U34qTi)?*

The History

Karina (pictured above) first became ill as a teenager. After much debate and disagreement between various health professionals, she was eventually diagnosed in 2010 with a severe case of Myalgic Encephalomyelitis -ME (http://www.name-us.org/). However, as often happens with this illness, the diagnosis was disputed. Her parents continued to care for her in the family home.

Given her vulnerable state and the disputed diagnosis, **Karina** and her family arranged for her parents to be granted power of attorney on her behalf. At this time, she was deemed competent to make the decision.

In **February 2013**, **Karina** (by now aged 24) was forcibly, and without warning, removed from her home in Holstebro, Denmark. This process was carried out by a large team of people consisting of police officers, social workers, doctors and a locksmith. There had been a similar but unsuccessful attempt at removal some months earlier. She made desperate phone calls for help to her family until the battery in her phone died.

Karina was taken to Hammel Neurocenter (http://bit.ly/1RFDNTT) (described as "The Research Clinic for Functional Disorders") which treats patients with neurological damage and diseases. It seems that a number of doctors have been involved in **Karina**'s 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.

As is frequently the case with ME patients (in Denmark and elsewhere), Dr. **Balle Christensen** and **Fink** believe that ME is a "functional disorder" (http://bit.ly/1PWId7O) i.e. effectively a psychosomatic condition. As a result, their recommended treatments are exercise therapy/physical rehabilitation, psychotherapy, "sensory" (occupational) therapy and antidepressants. Whilst these treatments can sometimes help patients with apparently similar conditions (who are often misdiagnosed with ME or – so-called – "chronic fatigue syndrome") (http://bit.ly/1Tl4Ipb), patients who genuinely have ME are very likely to deteriorate with these treatments – often with serious and long-lasting effects.

After her admission to Hammel, **Karina** was diagnosed with PAWS (http://bit.ly/1Tl4X3D) – also known as pervasive refusal syndrome. This is characterized by a patient engaging in obstructive behavior which is designed to resist treatment. It is usually applied to children rather than adults and is not a formally-recognized psychiatric condition. It is also tantamount to blaming the patient for the failure of inappropriate or dangerous treatment.

In September 2014, **Karina** was moved from the main clinic to a "rehabilitation centre" which is connected to the institution. She remains there to this day.

What is Karina's status as a patient and why does it matter?

Karina was removed from home under the specific doctrine of "*nødret*" – which roughly translates as *"necessity".* This is a fundamental principle common to many jurisdictions. In **Karina**'s case, the state believed her to be at risk whilst in the care of her family so a decision was taken (presumably in consultation with the relevant agencies) to remove her from home. Later investigations produced two reports from the Danish Board of Health; no further action was taken against her family.

Karina was detained for a short time under the *nødret* provision. After that, her status seems unclear. She was being treated by psychiatrists but whether she was classed as a psychiatric or a medical patient is uncertain. Hammel Neurocenter treats a range of conditions and diseases described as neurological rather than psychiatric although there is inevitably a crossover between the two. Significantly, it is claimed that all such patients at Hammel are there on a "voluntary" basis and no one is compulsorily detained.

The reason this matters is because there is a specific complaints/judicial procedure for psychiatric patients who are being detained *involuntarily*. The Danish process is set out in a 2012 article from *International Psychiatry* [1] from which this extract is taken: "*The MHA* [Mental Health Act of 1989] *does not specify time limits for compulsory detention or treatment. However, in appeal cases it has been stated that if no improvement occurs within 6 months the patient should not be kept any longer for a 'treatment indication'.*"

Since **Karina** was apparently classed as a so-called "voluntary" patient then the protection of the Danish complaints and review procedure would not have applied. The UK has a similar – though rather more rigorous – independent review process; in this country, it would be very unusual for any psychiatric patient – involuntary or otherwise – to remain as an inpatient for as long as three years.

The workaround?

In **Karina**'s case, it appears that an alternative strategy was used. Despite her status as a "voluntary" patient, she was now found to be *incompetent* to make her own decisions, reversing the earlier finding of competency. This resulted in a guardian being appointed by the state *(see next section)* to make those decisions on her behalf.

Presumably, the argument put forward was that she refused to communicate with anyone – quite possible, given the PAWS diagnosis. However, rather than simply interpreting that as showing incompetency, it seems reasonable to expect that the full background to her case would have been properly examined. Such an examination ought to have revealed her desperate efforts to resist admission to Hammel and the obvious reason for her subsequent withdrawal. Despite a number of court hearings, the outcome has remained the same; however, without more detail of the judicial process, it's impossible to speculate further.

*(**Note**: Some of the legal documentation is available but not, as yet, in English so I cannot access it. Online translation tools are insufficient for this purpose. If the documents become available in English, then I will be able to review them properly. The groups I have contacted have not been able to assist me with this so far.)*

The reasons for **Karina**'s extraordinarily prolonged stay at Hammel are shrouded in secrecy. That in itself is extremely alarming. Whatever the real facts behind this case, she is likely to have become so institutionalized that, on any view, the future does not bode well.

Conflict of interest?

Following her initial detention, **Karina** was deemed incompetent and therefore lacking capacity to manage her own affairs. As a result, the power of attorney of her parents was overridden and she was assigned a state-appointed guardian to represent her and protect her interests.

Despite her obvious acute distress at her removal from home, she has been allowed almost no contact with her family. There have been a couple of brief visits by family members but she appeared not to recognize them. As a result of the change in guardianship, her family has been allowed no further input into her care; they have received periodic but sometimes conflicting updates on her condition.

I understand that **Karina**'s new (and now permanent) guardian, **Kaj Stendorf**, was the chief of police in charge of **Karina**'s district at the time of her removal from home. He is now retired from the police service. However, on the face of it (and without knowing what evidence was before the court when the decision was made to appoint him as permanent guardian) this appears to be an untenable conflict of interest and one which requires urgent public scrutiny.

Total systems failure

Three years on, there appears to have been a complete failure of all the checks and balances which would normally be in place to prevent such an apparent abuse of the welfare of a citizen in a supposedly democratic European country. The medical, social and legal processes all appear to have defaulted on their statutory duty to protect a highly vulnerable constituent of the Danish state. And – worst of all – no one appears to be accountable.

During my professional career as a British lawyer, I was often part of the process whereby the courtroom becomes a forum for collaboration between all the relevant agencies charged with protecting the interests of the most vulnerable in our society. Sometimes it works well, sometimes rather less so. Nevertheless, it is usually the last remaining barrier between a vulnerable person and the final destruction of their lives. I am beyond baffled as to how Denmark has so manifestly failed one of its citizens in such a manner.

Karina and her family have had some legal representation during the devastating events of the last four years. Those who are closely involved with the family's efforts to protect **Karina**'s interests continue to work on her behalf. Inevitably, funding is an issue and has left the family at a significant disadvantage.

Various rights groups have intervened with a letter to the Minister for Health, a petition for an independent review of **Karina**'s diagnosis and a submission to a Danish parliamentary hearing in 2014. In October 2015, a letter raising **Karina**'s case signed by over 600 supporters was sent to the newly-elected Prime Minister; it has not been answered. Other similar efforts have achieved little or no progress.

Deprivation of liberty

Whatever the claimed justification for **Karina**'s continued presence at Hammel, the result is that she remains in *de facto*, if not actual, detention by the state. Whether or not due process (http://bit.ly/1KkJiWG) has taken place remains unclear. The question of whether or not her case could be taken to either of the European Courts dealing with human rights issues is often raised. Generally speaking, this could only happen once the legal process has been exhausted in Denmark's domestic courts. In UK terms, this would be the equivalent of having concluded proceedings in the Supreme Court (the highest level national court).

Deprivation of liberty without due process is a clear breach of both Article 5 of the European Convention on Human Rights (http://bit.ly/1Wn3CY4) and Article 6 of the Charter of Fundamental Rights of the European Union (http://bit.ly/2450ohG).

Other Articles may also apply to **Karina**'s situation. These provisions are incorporated into the domestic law of all member states; *Denmark is a signatory to both the Convention and the Charter.*

Open justice and balance

As yet, I have been unable to obtain details of the various court hearings which have taken place. There are reports of some irregularities in the process but without further information and verification I can't pursue that line of inquiry further at this stage.

Interestingly, the Courts and Tribunals Judiciary in the UK put out a media release (http://bit.ly/1RFHJE6) in November 2015 about increasing transparency in the Court of Protection (COP). The COP is responsible for the affairs of those who lack capacity (i.e. vulnerable persons); it is the British counterpart of the court which has jurisdiction over **Karina**'s case. The first four paragraphs of the release read as follows:

- Public and media will gain greater access to Court of Protection hearings after a pilot scheme starting next year.
- The specialist Court makes decisions about the personal welfare (e.g. medical treatment) and the property and affairs of persons who lack capacity to make them themselves, applying a best interests test.
- With rare exceptions, such as serious medical cases, hearings have usually been in private with only those directly involved in the case attending.
- The pilot will reverse this approach and the Court will normally direct that its hearings will be in public and make an anonymity order to protect the people involved.

I started work on this post some time ago. In the interests of balance and as a further attempt to gain more background information, I asked an academic colleague to contact some of the protagonists in the process which has brought **Karina** to her current situation. My colleague is an expert on open justice in European countries and has researched the area extensively.

The following people have been contacted directly and asked for comment:

- The Minister for Justice
- The Minister for Health
- **Per Fink**
- **Nils Balle Christensen**
- **Jens Gyring** (consultant at Hammel Neurocenter)

Per Fink

So far, there have been acknowledgments from the two ministries but no substantive replies. However, **Per Fink** has replied on behalf of himself and **Nils Balle Christensen**. The (predictable) gist of his response is as follows:

That he cannot comment on individual patients; all treatment at the clinic is on a voluntary basis and no one is compulsorily detained; that there are some inaccurate stories being put out via the internet/social media; patient satisfaction at the clinic is high and there is a 1.5 year waiting list for treatment there.

If/when any further responses are received, I will either update this post or write a new one setting out the details.

Media scrutiny

My searches reveal a few articles in the Danish press but nothing recent. Where is the mainstream media scrutiny which might have begun to uncover what has gone so wrong with **Karina**'s treatment, not only by the medical profession but also the executive and the justice system?

High-profile attention from outlets such as Fox News (http://fxn.ws/1RFIzAO) and the Boston Globe (http://bit.ly/1KkKfhG) certainly helped to stimulate public awareness of the predicament of American teenager **Justina Pelletier** in **2014**. **Justina**'s story was very similar to **Karina**'s (although, happily, **Justina** was eventually returned to her family); in both cases, grave concerns are raised not simply by a disputed diagnosis ***but by an entire state process***. This is why the issues continue to require urgent investigation by international media organizations.

A note on verification

The information which I have used to write this post is in the public domain. I have carried out due diligence as far as possible but it has been impossible to verify everything directly with the sources. Understandably, the family are concerned about the effect on both **Karina** herself and their access to information about her if they discuss the matter publicly any further at this stage.

In a Facebook post (http://on.fb.me/1QgMFQU) by the Justice for Karina Hansen (http://bit.ly/1oDxcxT) group dated 8 November 2013, it was stated that the family were told by the Chief Physician at the clinic: *"if you* [the family] *don't agree with and support the treatment* ***Karina*** *have* [sic] *been put under by the psychiatrist in charge of treatment,* ***Nils Balle Christensen****, you will not have access to see* ***Karina****."*

Valerie Eliot-Smith

The same post also says: "*We would also like to inform you that it was **Karina**'s choice to go public with this story. In the month of May last year* [2012]*, when the Danish Board of Health (Sundhetsstyrelsen) tried to incarcerate **Karina** for the first time, **Karina expressed a wish herself that we should contact the media, hoping to stop this abuse, and get some approval and recognition of the horrible disease that Myalgic Encephalomyelitis is**.*"

It is for this reason that I have written about **Karina**'s situation – both previously (http://bit.ly/1RFCSCV) and now – despite the highly sensitive and deeply personal nature of the topic and the problems with verification. It would seem that **Karina** believed – as I do – that, in certain circum-stances, the public interest in open debate outweighs the counterbalancing need to preserve both privacy and dignity.

If anyone has evidence that anything in this post is inaccurate then please contact me (*see* About http://bit.ly/1Vgtapx) and I will make any appropriate corrections.

The Ghost in the Room

There is no dispute that, prior to her incarceration at Hammel, **Karina** was extremely ill. She was very limited in what she could do but was able to communicate with her family and was being cared for in her own home, according to her express wishes as a competent adult.

Contrary to the views expressed by many psychiatrists and experts in psychological medicine, many members of the international ME community (around 20 million patients worldwide) know from their own bitter experience that there is still *no* proper treatment for this illness. Exercise and psychological therapies are generally of no benefit and often actively harmful (http://bit.ly/1LpxKwm). Patients are routinely neglected, stigmatized and even abused. This has been the situation for many decades in all countries where ME patients exist.

The young woman in the description at the beginning of this post is barely even a ghost of the person who was snatched from her family three years ago. And there are other **Karinas** in other countries, both children and adults; unbelievably, this situation is by no means unique. In the UK alone, the TYMES Trust (http://bit.ly/1R4iaui) dealt with 121 similar cases involving children between 1989 and 2014.

Where is the transparency and accountability which would subject these state missteps to public scrutiny and avoid future repetition of such catastrophic failures?
Too many ghosts in too many rooms.

Valerie Eliott Smith (http://bit.ly/1oj5Ey5)

Karina Hansen, High Court

The **Hansen**-family lost a case in High Court on trying to get another guardian for **Karina**, the present one doing whatever he can to keep **Karina** where she is.

In Denmark there's a law which states that the judge or court can decide if and which witnesses are going to be heard in court or if no witnesses are going to be heard at all. The judge in **Karina**'s case decided not to call upon any of the witnesses, not even upon **Nils Balle Christensen**, the psychiatrist responsible for **Karina**'s 'well-being'.

The lawyer of **Karina**'s parents is now trying to bring the issue about an appointed lawyer to the Supreme Court in Denmark, but he experiences a lot of trouble in doing so. Witnesses are denied and enclosures are not copied correctly and some are missing in the files.

I have written about this case to the minister of law, **Søren Pind** but he does not find it alarming… (as I already expected). But I am not finished with this 'case'.. I will talk about it and try to write letters in papers about it. It is so unfair. Please feel free and do the same and write and talk about it wherever you deem fit and fruitful.

In the meantime, the Danish Civil Rights Movement joined the case to help the parents for free.

Right before Christmas **Karina**'s father succeeded in getting access to **Karina**. At that moment a physiotherapist was working with **Karina**, and no one of the staff was present. So the father was led in. **Karina** was sitting in a wheelchair, clean and looking nicely, but she could not recognize her own father. She could not talk and she did not answer to what he said. Her face was making grimaces all the time; she could not control it. The symptoms probably demonstrate that she is heavily medicated. It is so painful to know.

David Tuller is coming to Denmark around the first of March to talk with **Karina**'s parents. They know a really skilful young woman, **Tina**, who will be present at the meeting at their home and will help translating.

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 will be collected at the S4C site: http://www.geef.nl/doel/save4children
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 December 2015-issue of the MEGC **€ 22,58** has been donated, which brings the current credit balance to **€ 1.489,59**. Thanks to all those who donated.

5. Science

Rich' Reviews: …

Flexeril (cyclobenzaprine): An Under-appreciated Treatment for Fibromyalgia Pain, Sleep Problems and Daytime Fatigue

Flexeril (cyclobenzaprine) is FDA approved for the short term relief of "muscle spasm associated with acute, painful musculoskeletal conditions." It's not approved for long term usage or to treat Fibromyalgia.

Still, Fibromyalgia specialists sometimes prescribe Flexeril for use as a sleeping aid and to reduce Fibromyalgia pain. But, at standard doses, Flexeril's sedating effect often carries over to the next day, worsening fatigue.

This essay reports on a better way to use Flexeril, a way that improves sleep and pain, but actually lessens feelings of daytime fatigue.

Two key innovations:

- 1.By taking a lower than usual dose of Flexeril at night-- in the 2 mg to 5 mg at night instead of the usual 10 mg dose.
- 2.By taking Flexeril every night for many weeks, not just as an intermittent sleeping pill.

The lead author of this key research study is **Harvey Moldofsky**, **M.D.**, now **Professor Emeritus** at the University of Toronto. **Dr. Moldofsky**'s career-long research on Fibromyalgia has been made major contributions to understanding our field. For example, **Dr. Moldofsky**'s 1975 article was the first to prove the relationship between Fibromyalgia pain and abnormal patterns of sleep. His most recent publication on Fibromyalgia was in 2015.

In a 2011 study, **Dr. Moldofsk**y's Toronto team conducted a double blind study of 36 patients with FM. Half were given "low dose" Flexeril/cyclobenzaprine starting at 1 mg and working up to the 4 mg range. The others received a placebo. These were taken every night over 8 weeks.

The outcomes: low dose cyclobenzaprine made a positive difference with very few major side effects. Patients on placebo did not improve.

Here are the main numbers:

- PAIN: Pain intensity levels were scored prior to starting treatment and after 8 weeks. For the Flexeril group pain severity decreased by 26.1%. The "P value" was less than .01. (That is, the probability (P) of this result being obtained by chance was less than one chance in 100. A P value of <.05, is considered to be "statistically significant".)

- The placebo group had no change in their pain

- DAYTIME FATIGUE: For those taking Flexeril, fatigue scores decreased by 14%. This difference was statistically significant (P=.039). For those on placebo daytime fatigue did not improve.

- SLEEP: Patients taking Flexeril increased their average sleep time by about one half hour. Those on placebo slept about the same as they did before. Flexeril may also have improved the quality of sleep by reducing the occurrence of disruptive brain wave patterns.

- ANXIETY/DEPRESSION: Many patients with chronic Fibromyalgia suffer a degree of anxiety and/or depression.

- After 8 weeks patients taking low dose Flexeril improved on their anxiety/depression score by 24.1%. (P=.012). The placebo group's anxiety/depression score decreased also, but by just 3.8%.

- After 8 weeks, patients were asked to rate whether they had improved since starting treatment. Those taking low dose Flexeril tended to rate themselves as improved (P=.001). Those taking placebo did not.

- The treating doctors (who did not know which person was taking Flexeril versus placebo—these doctors agreed that Flexeril patients had improved, while placebo patients had not.

- Side effects in this relatively small study were mild and occurred about as often in both groups. The only adverse event that was rated as severe was a headache. This occurred in a patient taking placebo

Clinical thoughts:

As medicines go, Flexeril at 5 mgs (the lowest commercially available dose) is relatively safe and relatively inexpensive.

Therefore, if you have Fibromyalgia consider discussing an option like this with your clinician: Perhaps start with a 2.5 mg dose at night (one half of a 5 mg pill). If 2.5 mgs don't make you too tired the next day, then consider increasing to 5 mg each night for an 8 week-long trial. If 5 mg makes you tired, go back to 2.5. Don't prejudge whether Flexeril actually helps until the full trial is done.

(I contacted **Dr. Moldofsky**, who said that there were no interim measures of effectiveness done between baseline and 8 weeks. My guess is that the maximum benefit from low dose Flexeril would take more than a few days to be noted, but fewer than 8 weeks.)

Side effects: The most serious potential side effect for Flexeril (cyclobenzaprine) is prolongation of the QT interval on the electrocardiogram. This can be important since a long QT interval increases the risk for serious heart rhythm problems.

In fact, a fair number of medicines you might use also increase the QT interval. Among these: antibiotics (e.g. Zithromax, Biaxin, Cipro, Levaquin); heart medicines (Amiodorone, Flecainide); several cancer medicines; anti-nausea drugs (Odansetron/Zofran, procholorperazine/Compazine); many antipsychotic medicines, and tricyclic antidepressants such as Elavil (amitryptiline), or Pamelor (nortriptyline). Clinicians might consider which patients should have an EKG read out of their QT interval.

Also, several commonly used medicines tend to increase the blood level of Flexeril/cyclobenzaprine thereby increasing Flexeril's effect on prolonging the QT interval. This interaction is most likely for medicines that compete with Flexeril for the same liver detoxification pathways/

Your doctor probably has not memorized all these potential interactions. But your pharmacist's computer should know. Ask your pharmacist specifically whether any of your medicines increase the QT interval and whether any of your medicines use the same liver pathways as Flexeril (Cytochromes P450 3A4 or P450 1A2, or to a lesser extent P450 2 D6.)

Persons with liver disease, certain heart rhythm abnormalities or a known prolongation of their QT interval might best avoid Flexeril (and other drugs that prolong the QT interval.)

Key Article: ***Moldofsky, H, et al.,*** *Effects of Bedtime Very Low Dose Cyclobenzaprine on Symptoms and Sleep Physiology with Fibromyalgia Syndrome: A Double-blind Randomized Placebo-controlled Study, The Journal of Rheumatology, 38: 2653-2663, 2011.*
To obtain the full article go to http://www.jrheum.org/content/38/12/2653.long

Information about prolonged QT interval and medicines:
http://drugs.emedtv.com/medicine/qt-prolonging-medications.html

FDA label information about Flexeril (cyclobenzaprine):

http://www.accessdata.fda.gov/drugsatfda_docs/label/2003/017821s045lbl.pdf

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The Role Of Mitochondrial Function In ME/CFS-Part 2

From an interview with **Dr. Sarah Myhill** conducted by **Niki Gratrix** at the Abundant Energy Summit (August 24-31, 2015). The full interview, as well as presentations by 28 other experts, can be purchased at Abundant Energy.

You can block mitochondria by stacking things on top of the mitochondrial membrane. It's no good making ATP if you can't get the ATP out of the mitochondria and into the cell where it's needed. Mitochondrial membranes are made up of proteins that act like a little shuttle that takes ATP out of the mitochondria and then brings ADP back into the mitochondria where it is turned into ATP. There are lots of things that can block that shuttle. We can do tests to determine what those blocking factors are.

As an aside, I got interested in ME when I started seeing farmers with sheep dip flu. They had been poisoned by organophosphates. Organophosphates inhibit oxidative phosphorylation. That is how they block the mitochondia's ability to make ATP. Broadly speaking those blockers fall into two groups: they can be toxins from the outside world, such as pesticides and heavy metals, or they can be products from within the body. I suspect a major source of those is products from the fermenting gut.

Q: And inflammatory processes lead back to the gut.
Myhill: Mitochondria are important, but I spend as much time with my patients talking about diet, and talking about gut function. So many problems start with the gut.

Q: Mitochondrial malfunction explains the illness brilliantly, but it's not the cause, it's the effect.
Myhill: The whole thing is circular. We all come into this area with different theories, but we all end up offering similar patterns of treatment – diet, detoxing regime, nutritional supplements, correcting hormones, and so on. But mitochondria are central players.

Q: Diet, pacing, micronutrients and sleep are your four foundational things. Do you want to expand a little on that, especially pacing?
Myhill: It's back to square one. Fatigue is a mechanism that protects us from ourselves. If someone is experiencing fatigue because they are overdoing, they are constantly stressing their mitochondria and their energy supply and they are constantly going into anaerobic metabolism and producing lactic acid. Let's talk about anaerobic metabolism. Normally, mitochondria function on oxygen. When you burn a molecule of sugar in the presence of oxygen, you'll produce about 26 molecules of ATP.

But when you stress your mitochondria and switch to anaerobic metabolism, burning a molecule of sugar only produces two molecules of ATP. If you do this on a regular basis you get a buildup of lactic acid. To convert that lactic acid back to pyruvic acetate takes six molecules of ATP.

What that means is if you overdo things it takes an awfully long time to get back to square one. The point of pacing is to avoid getting into anaerobic metabolism. So, pacing is crucially important. People will get better if they pace. If they don't pace, eventually there is tissue damage and inflammation sets in, which kicks another hole in the energy bucket.

Q: You have a basic protocol for micronutrients, what is that?

Myhill: Although I began by seeing patients with ME, I have come to the conclusion that no matter what a patient comes to me for, there is a basic package of treatment that we should all be doing. In terms of diet, this consists of a "stone age diet": meat, fish and eggs, nuts and seeds, lots of veggies, and low-fructose fruits, such as berries.

Number two is sleep. Most people are sleep deprived. If you need an alarm clock to wake up in the morning you are sleep deprived. The third thing I talk about is micronutrients. Because modern farming depletes the soil of minerals, we should all be taking a basic package of micronutrients – vitamins, minerals, and amino acids.

Q: Talking further about the Stone Age Diet, are you recommending a grain-free diet?

Myhill: Grains are too toxic for humans to consume. So, remove all gluten completely. The fermenting gut is a very big problem. The upper gut should be a near-sterile carnivorous digesting gut to deal with meat and fat. The lower gut, which is teeming with bacteria, digests vegetable fiber. So, the lower gut is a fermenting gut. If we overwhelm our liver with sugar, for example, we switch into the fermenting gut and have all the problems of metabolic syndrome. What I am saying is that a modest amount of carbohydrate is fine if you've got perfect digestion.

But my ME patients don't have perfect digestion. So, carbohydrates are a major risk factor for chronic fatigue syndrome. I consider being vegetarian a major risk factor for chronic fatigue syndrome for two reasons. Vegetarian foods tend to be high GI, that is, grains and fruits. They are also high in the major antigens: dairy, gluten, and yeast.

Note: the first part of this interview has been published in the MEGC 14 of December 2015 (http://let-me.be/request.php?25)

You can find out more about **Dr. Myhill** at http://DrMyhill.co.uk
Source: ProHealth,
http://www.prohealth.com/library/showarticle.cfm?libid=21203

An Evidence-Based Approach To Diagnosis And Management Of ME/CFS By Clinicians

A review article from **Dr. Alison Bested** and **Dr. Lynn Marshall** on ME/CFS, published recently in Reviews on Environmental Health, 2015; 30(4): 223–249.

From the contents

The purpose of this article, as long-standing clinicians with considerable experience re ME/CFS, is to educate other clinicians about how to diagnose and manage patients with ME/CFS. Currently only 20% of patients are actually being diagnosed and given appropriate management using the available evidence.

In order to diagnose ME/CFS using the Canadian Consensus Criteria (CCC), exclusion criteria must first be applied to rule out other treatable illnesses with similar symptoms. Then the patient must have the following criteria: pathological fatigue, post-exertional fatigue and malaise (PEM), sleep dysfunction, pain, cognitive dysfunction, and two symptoms from the following symptom categories: autonomic, neuroendocrine or immune. The patient needs to have had the illness for a minimum of 6 months if an adult and 3 months if a child.

Treatment Approach

A specific treatment is not available for ME/CFS. Supportive symptomatic treatment helps patients cope with and manage their symptoms.

Pacing for fatigue and sleep

Patients benefit from pacing their activities during the day. It is best to avoid pushing themselves and aggravating symptoms or crashing the next few days. Pacing is resting before and after activities to prevent fatigue. It involves setting an alarm before the activity starts to signal when to stop the activity. This is needed because patients have lost their sense of time passing and will unknowingly continue the activity "just to finish it" and crash as a result.

The time for the activity or rest period is very individual and based on the specific energy available to the patient - see the Functional Capacity Scale. It helps patients to keep a daily diary to figure out what pattern of activity and rest work best for each individual patient. If patients do not pace in the evening, they will often get a second wind at night or an adrenaline rush. Patients describe this as going to bed “tired and wired”. This interferes with restorative sleep. The following day patients have “crashed” and wake up exhausted with aggravation of their symptoms.

Energy is spent in 3 ways: physically, mentally or emotionally. If energy is spent being on the computer, it is not available for physical activities. Some small improvements can begin to occur in many patients when they learn to pace and stop crashing.

Medications for fatigue are not generally recommended.

Pain
Pain is best treated by multiple modalities. The pain medications range from over the counter anti-inflammatories and pain medications, muscle relaxants, to prescribed central desensitizers and narcotic analgesics in extreme cases. Individual patients have been helped by a variety of treatments including massage, meditation, gentle walking within the patient's available energy, acupuncture etc. All modalities need practitioners experienced with ME/CFS.

Cognitive dysfunction
Pace activities that use mental energy e.g. time spent doing emails on the computer, paying bills. Mental tasks need to be treated like physical activities and have a time limit set before started. If patients do not stop in time, they will crash or have relapse of symptoms just as they would after doing physical activities.

Emotional events such as an argument with a spouse also uses energy. Patients may also crash after emotional events - whether happy or upsetting.

The Future
More research is needed to unravel the cause and explore specific treatments for ME/CFS.

Submitted by: **Alison C. Bested**, **MD FRCPC**

Full article: http://bit.ly/1RvFD9T

Special thanks to **De Gruyter**, publisher, for their generosity in releasing the article for free.

qEEG / LORETA

qEEG / LORETA in Assessment of Neurocognitive Impairment in a Patient with Chronic Fatigue Syndrome: A Case Report

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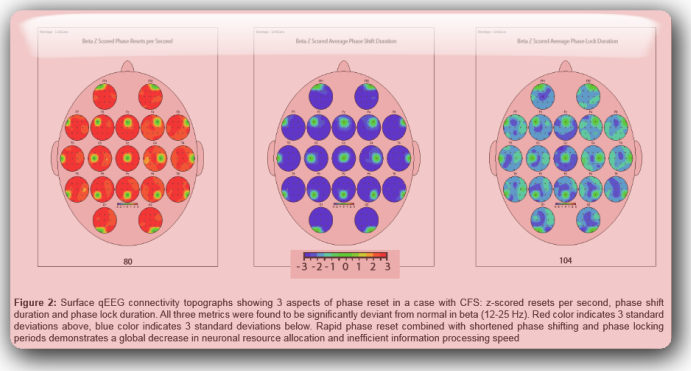


Figure 2: Surface qEEG connectivity topographs showing 3 aspects of phase reset in a case with CFS: z-scored resets per second, phase shift duration and phase lock duration. All three metrics were found to be significantly deviant from normal in beta (12-25 Hz). Red color indicates 3 standard deviations above, blue color indicates 3 standard deviations below. Rapid phase reset combined with shortened phase shifting and phase locking periods demonstrates a global decrease in neuronal resource allocation and inefficient information processing speed

Importance: Chronic Fatigue Syndrome (CFS) is a chronic disease resulting in considerable and widespread cognitive deficits. Accurate and accessible measurement of the extent and nature of these deficits can aid healthcare providers and researchers in the diagnosis of this condition, choosing interventions and tracking treatment effects. Here, we present a case of a middle-aged man diagnosed with CFS which began following a typical viral illness.

Observations: LORETA source density measures of surface EEG connectivity at baseline were performed on 3 minutes of eyes closed deartifacted19-channel qEEG. The techniques used to analyze the data are described along with the hypothesized effects of the deregulation found in this data set. Nearly all (>90%) patients with CFS complain of cognitive deficits such as slow thinking, difficulty in reading comprehension, reduced learning and memory abilities and an overall feeling of being in a "fog." Therefore, impairment may be seen in deregulated connections with other regions (functional connectivity); this functional impairment may serve as one cause of the cognitive decline in CFS. Here, the functional connectivity networks of this patient were sufficiently deregulated to cause the symptoms listed above.

Conclusions and significance: This case report increased our understanding of CFS from the perspective of brain functional networks by offering some possible explanations for cognitive deficits in patients with CFS. There are only a few reports of using source density analysis or qEEG connectivity analysis for cognitive deficits in CFS. While no absolute threshold exists to advise the physician as to when to conduct such analyses, the basis of his or her decision whether or not to use these tools should be a function of clinical judgment and experience. These analyses may potentially aid in clinical diagnosis, symptom management, treatment response and can alert the physician as to when intervention may be warranted.

Link to full article: http://bit.ly/1Tg79t9

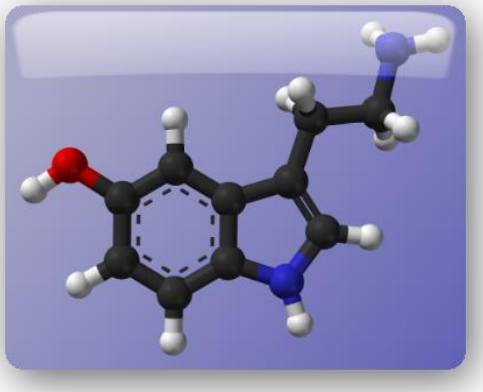
Omega-3 Fatty Acids, Vitamin D & Brain Serotonin

*As many ME-patients have discovered the use of Omega 3 and vit. D can be useful; this review might be interesting as it explains one of the why's (**the editors**)*

Although essential marine omega-3 fatty acids and vitamin D have been shown to improve cognitive function and behavior in the context of certain brain disorders, the underlying mechanism has been unclear. In a new paper published in *FASEB Journal*, serotonin is explained as the possible missing link tying together why vitamin D and marine omega-3 fatty acids might ameliorate the symptoms associated with a broad array of brain disorders.

In a previous paper published last year, authors **Patrick** and **Ames** discussed the implications of their finding that vitamin D regulates the conversion of the essential amino acid tryptophan into serotonin, and how this may influence the development of autism, particularly in developing children with poor vitamin D status.

Here they discuss the relevance of these micronutrients for neuropsychiatric illness. Serotonin affects a wide-range of cognitive functions and behaviors including mood, decision-making, social behavior, impulsive behavior, and even plays a role in social decision-making by keeping in check aggressive social responses or impulsive behavior.



Many clinical disorders, such as autism spectrum disorder (ASD), attention deficit hyperactivity disorder (ADHD), bipolar disorder, schizophrenia, and depression share as a unifying attribute low brain serotonin. "In this paper we explain how serotonin is a critical modulator of executive function, impulse control, sensory gating, and pro-social behavior," says **Dr. Patrick**. "We link serotonin production and function to vitamin D and omega-3 fatty acids, suggesting one way these important micronutrients help the brain function and affect the way we behave."

Eicosapentaenoic acid (EPA) increases serotonin release from presynaptic neurons by reducing inflammatory signaling molecules in the brain known as E2 series prostaglandins, which inhibit serotonin release and suggests how inflammation may negatively impact serotonin in the brain. EPA, however, is not the only omega-3 that plays a role in the serotonin pathway. Docosahexaenoic acid (DHA) also influences the action of various serotonin receptors by making them more accessible to serotonin by increasing cell membrane fluidity in postsynaptic neurons.

Their paper illuminates the mechanistic links that explain why low vitamin D, which is mostly produced by the skin when exposed to sun, and marine omega-3 deficiencies interacts with genetic pathways, such as the serotonin pathway, that are important for brain development, social cognition, and decision-making, and how these gene-micronutrient interactions may influence neuropsychiatric outcomes. "Vitamin D, which is converted to a steroid hormone that controls about 1,000 genes, many in the brain, is a major deficiency in the US and omega-3 fatty acid deficiencies are very common because people don't eat enough fish," said **Dr. Ames**.

This publication suggests that optimizing intakes of vitamin D, EPA, and DHA would optimize brain serotonin concentrations and function, possibly preventing and ameliorating some of the symptoms associated with these disorders without side effects.

Story Source:

The above post is reprinted from materials (http://bit.ly/1QbMWED) provided by UCSF Benioff Children's Hospital Oakland (http://bit.ly/1KKeaQn).

Source : http://www.sciencedaily.com/releases/2015/02/150225094109.htm

BIG DATA, A Plea From Dr. Ronald Davis

Stanford, December 29, 2015

For more research funding before his son, and others like him, die from this horrific disease. Please donate today, before the year ends, so that maybe in the year 2016 we can find answers for all of the patients suffering in silence.

"My son **Whitney** woke me this morning to inform me that he is dying. **Whitney** has severe chronic fatigue syndrome (CFS). He did not say he is dying – he cannot speak. He did not write he is dying – he cannot write.

He used scrabble tiles to spell out his message. I did not answer him – he cannot tolerate anyone speaking to him. The note said he is willing to go to the hospital even though the experience will be unbearable – hospitals are totally naïve on how to treat CFS patients because of years of denying the existence of the disease. We need to surgically insert a feeding-tube into his small intestine because he cannot eat.

This tells me I am running out of time. I must find out soon what is causing the disease and how to cure it. I know I'm not the only one working on this disease but there are too few researchers, too few medical specialists, too little research funds, and too many patients. I know I, or someone, can figure this out. It requires a lot of new data and a lot of thinking.

For the past 2 decades I have been involved in innovation of medical technology and automation to generate massive amounts of Human data (BIG DATA) but how do we speed up the thinking?

I spend more than half of my time thinking about this disease, comparing the limited data on CFS and many other diseases. I try to track back the symptoms to a possible molecular mechanism. The brain and gut problems could be caused by dysfunctional mitochondria (the organelle for energy generation in every cell) but what is the molecular reason for the dysfunction. Given there are over 1,600 genes involved in mitochondria this is a daunting task. I work on these 7 days a week and will continue to do so until we have an answer."

Dr. Ronald W. Davis

Donate here: http://bit.ly/1mwCrOb
Source : http://www.facebook.com/cfsresearchcenter/?fref=photo

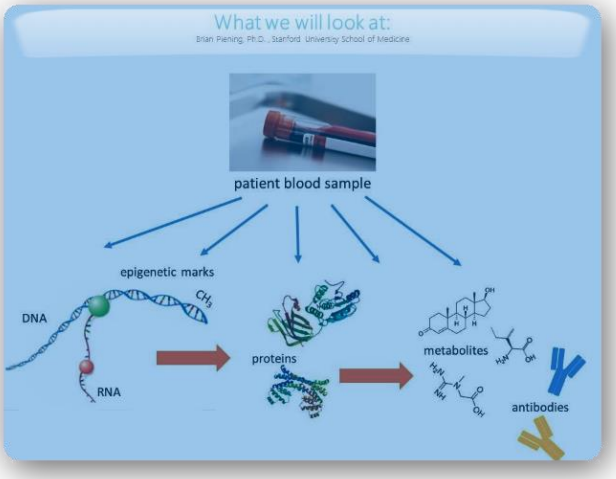
BIG DATA, More Tests Added To The ME/CFS Severely Ill-BIG DATA Study

Thanks to the generous donations and increased knowledge, we have added more tests to the OMF ME/CFS Study (http://bit.ly/1ItLneh) that has been launched.

We've uploaded an updated tests list (http://bit.ly/1PHq8XE) and an updated full description of the study (http://bit.ly/1TgdZ1G).

As always, **Cort Johnson** has done a great job in explaining what we now have in our plans in an article he wrote on Health Rising. (http://bit.ly/1PRc15L)

We are so excited that this groundbreaking initiative has received so much support, from both patients and scientists. Just imagine having a diagnostic biomarker for this disease. This is one of the main goals of this study.



To do that, we plan a Phase II that will test the abnormalities in those with the disease who are more functional. And we will also run some tests in people with similar, but different diseases, to make sure we have a distinctive biomarker.

But reliably identifying ME/CFS is just the start. We are working to End ME/CFS. If you would like to join the effort, why not do your own fundraiser. We've got a quick "how to" (http://bit.ly/1ox4Xkp). It's easy and can be fun too.

Source : http://bit.ly/20ZgR4o

BIG DATA, Dr. R. Naviaux Joins OMF Scientific Advisory Board

Dr. R. Naviaux joins OMF Scientific Advisory Board

We've captured the interest–and will now benefit from the experience, knowledge, and skills–of another esteemed scientific expert. **Dr. Robert K. Naviaux** has joined our ME/CFS Scientific Advisory Board (http://bit.ly/1o9tSL8) and is internationally known for his work in human genetics, metabolism, metabolomics, and mitochondrial disease.

Having **Dr. Naviaux** join our team fits the pattern we set last year: create a scientific advisory board of noted experts in the biology systems that could be contributing to ME/CFS symptoms. These well-known researchers and doctors bring with them their network of relationships with labs and other scientists – and their knowledge and prestige – so we can move the research from the fringe and shadows into an exciting and respected field. And most of all, get fast results.

Dr. Naviaux is an ideal scientist to add to our esteemed board because of his deep understanding in mitochondrial dysfunctions, virology, tumor immunology, and natural killer cell biology.

Dr. Naviaux runs the Robert Naviaux Laboratory at UC San Diego (http://bit.ly/1owHkbT), which is doing genetic research into mitochondrial dysfunctions. He is founder and co-director of the Mitochondrial and Metabolic Disease Center at UCSD. Additionally, he is a former president of the Mitochondrial Medicine Society and a founding associate editor of the journal *Mitochondrion*. He studied biochemistry at Georg-August University in Göttingen, Germany.

Dr. Naviaux discovered the cause and created the diagnostic test for Alpers syndrome, a mitochondrial disease. He also works in oceanographic ecosystems research and is the director of the first FDA-approved clinical trial to study suramin as a treatment for autism.

Submitted by **Linda Tannenbaum**

BIG DATA, The Severely Ill Big Data Study Has Started

OMF has just received another generous **$142,000** donation for the continuing OMF End ME/CFS Project; the second donation from an anonymous donor-more coming this year from them.

The Severely Ill Big Data Study has started and is projected to take 9-12 months.

Things are happening in a big way because of you!

THANK YOU for your support! We could not do this without you.

With sincere gratitude and hope,
Linda

Linda Tannenbaum
Executive Director
Open **M**edicine **F**oundation
http://www.openmedicinefoundation.org

Viral Persistence

Persistent virus infections induce host derived immunosuppressive factors that attenuate the immune response and prevent control of infection.

Although the mechanisms of T cell exhaustion are being defined, we know surprisingly little about the underlying mechanisms that induce the immunosuppressive state and the origin and functional programming of the cells that deliver these signals to the T cells.

We recently demonstrated that type I interferon (IFN-I) signaling was responsible for many of the immune dysfunctions associated with persistent virus infection and in particular the induced expression of the suppressive factors IL-10 and PDL1 by dendritic cells (DCs). Yet, mechanistically how IFN-I signaling specifically generates and programs cells to become immunosuppressive is still unknown.

Herein, we define the underlying mechanisms of IFN-I mediated immuno-suppression and establish that the induction of factors and the generation of the DCs that express them are separable events integrally reliant on additional inflammatory factors.

Further, we demonstrate a similar derivation of the suppressive DCs that emerge in other diseases associated with prolonged inflammation and immuno-suppression, specifically in HIV infection, Mycobacterium tuberculosis and cancer, indicating a conserved origin of immunosuppression and suggesting that targeting the pathways that underlie expression of immunosuppressive cells and factors could be beneficial to treat multiple chronic diseases.

For the entire paper:
http://bit.ly/1PRiDRI

Thanks to **Rob Soltysik** for making us attentive to this publication.

National Centre for Neuroimmunology and Emerging Diseases

The National Centre for Neuroimmunology and Emerging Disease is a world leader in Chronic Fatigue Syndrome / Myalgic Encephalomyelitis (CFS/ME) research. To continue this work, we need your help!

We aim to continue our current studies in 2016 by investigating:

Immunological and genetic studies in CFS/ME.
Requires complete of a questionnaire which can be completed online over the internet or a hard copy version can be sent. Participants in this study will be asked to donate 80ml of blood that will be collected by a qualified phlebotomist.

The NCNED has collection centres at **Griffith University** (**Gold Coast campus**), **Robina Hospital**, **Tweed Heads Hospital**, **Logan Hospital** and **Royal Brisbane Women Hospital**. In some cases, we are also able to arrange house visits for those who may find it challenging to travel to a collection location. For a single home visit, we are able to collect blood samples from multiple participants, including healthy controls if they can attend the same location.

Brain structure and function using Magnetic Resonance Imaging (MRI)
This study will involve a brain scan on a small number of participants using an MRI machine located at the **Gold Coast University Hospital**. For the scans, participants will be required to make their way to the hospital radiology department accompanied by a companion or carer.

We require new participants for these studies including healthy controls as well as those with CFS/ME.

If you are willing to participate or would like further information, please contact us at **ncned@griffith.edu.au**
or (07) 5678 9283.

A Memory Of Past Infections

Immune System Maintains A Memory Of Past Infections By Priming Genes For Future Encounters

Our ability to fight off recurrent infections, such as colds or flu, may lie in the 'immunological memory' found in a newly discovered class of gene regulatory elements, according to research from the University of Birmingham, supported by the BBSRC and Bloodwise.

The team, led by **Professor Peter Cockerill**, demonstrated that a single cycle of activation of the T cells within the immune system leaves behind imprints in the chromosomes within these immune cells. This imprinting occurs at the genes that need to be switched back on as soon as immune cells are reactivated. They propose that this forms the basis of a long-term memory which allows for an immediate response when the body encounters an infection and T cells are activated for a second time.

Rather than immune cells remaining 'switched on' permanently to fight infection continuously, they return to a dormant state but are altered by the initial infection and remain in a partially active state primed to combat any recurrence.

Professor Cockerill explained, "The initial immune response switches on certain regions within chromosomes of previously inactive T cells to leave them in a more open structure so that they can then sit poised, ready to respond much faster when activated again in the future."

Being able to silence the immune system until it is required to fight infection is also vitally important, else there would be a risk of damaging cells that are part of the host. The team identified a mechanism that allows cells to remain poised without producing the molecules associated with inflammation that are used to fight infection. If this tight control breaks down then it can be the cause of a number of inflammatory or autoimmune disorders, when healthy cells are targeted as if they were foreign.

Source : Science Daily
http://www.sciencedaily.com/releases/2016/01/160121121647.htm

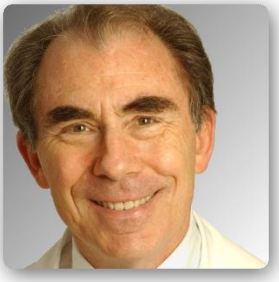
University of Birmingham. "Immune system maintains a memory of past infections by priming genes for future encounters."

Why Not

"The name Chronic Fatigue Syndrome was first coined in 1988 by a group convened by the CDC. As a member of that group I would note that we were focused really on developing a case-definition. No one really thought about a name and when someone proposed the name Chronic Fatigue Syndrome, we people sort of said: "why not".

That was a big mistake.

Many of the patients and clinicians believe that that name, Chronic Fatigue Syndrome, trivializes and stigmatizes this often devastating illness.
And I certainly agree."



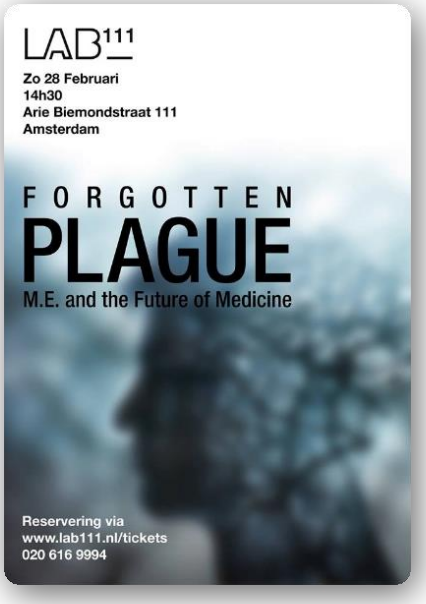
Prof. Antony Komaroff,
While speaking at the CDC-grand rounds of Tuesday, February 16, 2016

6. Events


Calendar
SUNDAY MONDAY TUESDAY
4 5 6 7 8 9 10
11 12 13 14 15 16 17
18 19 20 21 22 23 24
25 26 27 28 29 30 31

SCREENING Of FORGOTTEN PLAGUE

From a press release on January 25, 2016:



American writer-reporter and ME-expert **Dr. David Tuller** will attend the Dutch try-out of Forgotten Plague, **Ryan Prior**'s documentary on Myalgic Encephalomyelitis. The film, presenting a confronting picture of the reality of this severe disease, clearly pictures the present reality and developments.

After the screening of the film Tuller will give a lecture and answer questions.

Location: Lab111, Arie Biemondstraat 111, 1054 PD Amsterdam.

Date and Time: Sunday February 28, 2016 at 14.30 pm

Booking via: http://lab111.nl/film/forgotten-plague

Sold Out (un)fortunately!

Or Call: +31 (0)20 - 6169994

Tickets: € 10, --

75% of the revenue will be donated to the 'End ME/cfs project' of the Open Medicine Foundation: the very first biomedical research focusing on severe presentations of ME

TRAILER: https://youtu.be/VsQcmKT3zSo

Events & Actions In The UK

Joan McParland announced that 73 Northern Ireland branches of Boots Pharmacy would be receiving the Invest in ME Matchstick Campaign brochures in an information pack. You can read more in our January update on the Matchstick Campaign (http://bit.ly/1PimJR7).

Sinéad Kearns (http://bit.ly/1Q4Ngi5) decided to do Dry January for Invest in ME to show support for the upcoming Kilimanjaro Climb being done by **Richard Pughe** and **Amanda Kayes** in March. That's not all they have planned for the year ahead, so watch this space for more news.

Walk for ME 2016 was launched (http://bit.ly/1nZytzr) in preparation for ME Awareness Week in May, and is again supporting Invest in ME. A few fundraising pages have been set up already, such as by **Rachel Green** & **Chris** (http://bit.ly/1nZytzr), **Jacqui Redmond** (http://bit.ly/1Sd865a), and **Ellan Brown** (http://bit.ly/1K9a7gs).

Having done a Reservoir Walk for ME last year, **Amanda Buckley** (https://www.justgiving.com/Amanda-Buckley9/) is doing a sponsored swim with her friend **Rachael** in May.

After their cycle ride for Invest in ME last year, **Ash & Rob** (http://bit.ly/1nUEdK9) are doing a triathlon in May.

Ian Potter (http://bit.ly/1Pin06A) is once again doing a half-marathon along Hadrian's Wall for Invest in ME, and for Sheffield Hospitals Charity and The Cystic Fibrosis Trust.

Mike Sutton (http://bit.ly/20ltpkx) is doing a Long Walk along the Camino de Santiago for Invest in ME as his friend **Joel** has ME. He raised an amazing £1000 in the first 24 hours of setting up his fundraising page, and matched that with another £1000. His new target is £3000. He wrote on his blog (http://bit.ly/1PLB0rc), "To say I'm blown away is an understatement – I was thrilled to tears – sobbing as I read the messages of support and having my faith in humanity rekindled to a blaze. Thank you so very much."

Jo Smith has set herself a target to raise £500 for Invest in ME in 2016 by organising various things throughout the year and has set up a fundraising page (http://bit.ly/23UaTUV).

Young **Makayla Nunn** (http://bit.ly/23UaTUV) has her sights set on raising yet more awareness and funds for Invest in ME, building on from her tremendous efforts and enthusiasm last year.

If you or anyone you know collects their loose change and would like to use it to support Invest in ME, **Sue Page** has extended 'Small Change to Change ME' for another year, on JustGiving (http://bit.ly/1onk1ky) and Facebook (http://on.fb.me/1QSkXGM).

We updated our page on The Big Sleep for ME (http://on.fb.me/1QSkXGM) for May Awareness 2016.

28 EU Marathon Man, **Mike Harley**, posted his January Update, (http://bit.ly/1QBu0vR) including a big shout to **Tony Bradstock** for creating a widely appealing promo picture (http://on.fb.me/202eI5R) and for the 11th Invest in ME Conference IIMEC11 (http://investinme.eu/) in June 2016.

Alison Orr invited others to join her in setting up a shop on Phoenix Trading with profits to Invest in ME. Buying quality cards & stationery from her shop Cards for Invest in ME (http://bit.ly/1k07cLd) is a nice and easy way to generate donations to the charity at any time of the year.

Becca Hams & **Ali Head** got busy organising Secret Valentine 2016. (http://on.fb.me/1nyTekF). The closing date is 2nd February, so don't delay if you'd like to take part. Never forgetting our furry, feathered or scaly friends, this year there is also a Secret Valentine for Pets!

Looking for a Valentine's gift for a loved one or to treat yourself? **Lynne Allan** sells lovely hand-crafted jewellery online from her shop ME2UDezignz (http://etsy.me/1WWEA31) on Etsy, with all her profit to Invest in ME.

Source: Let's Do it For ME http://ldifme.org/january-updates/

IMEC 11

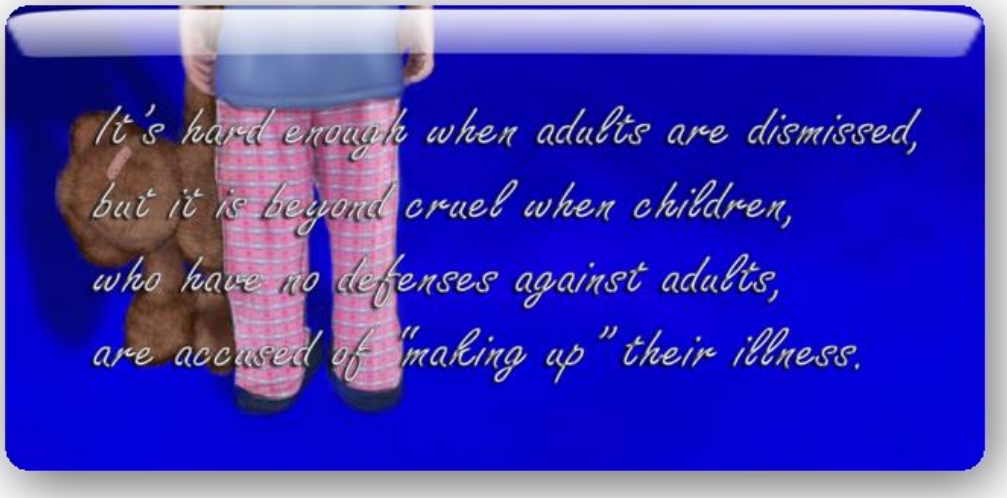
The eleventh Invest in ME-conference in Westminster, London,UK will be on Friday, June 3, 2016

The BRMEC Colloquium, a two-day research meeting prior to the conference, will be on 1st & 2nd June 2016

Info and possible ways and means to help:
http://www.investinme.eu/IIMEC11-news-0801.shtml

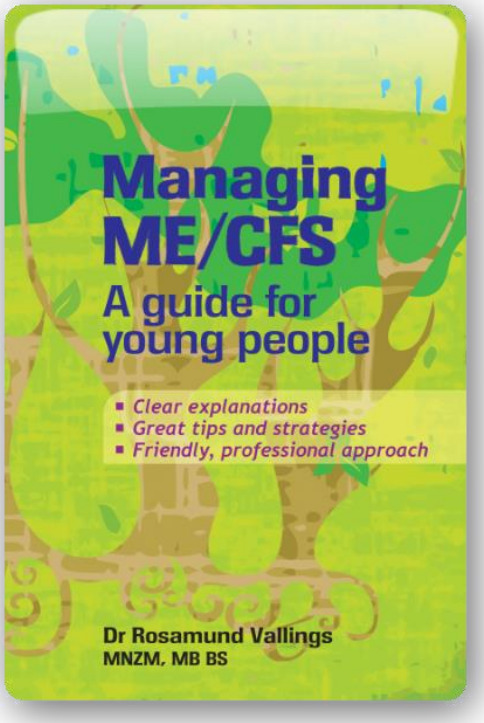
The 4DVD conference-video of all presentations of the 10th international conference on May 29, 2015 can be ordered here:
http://www.investinme.eu/IIMEC10-DVD-Order.shtml

7. ME And Children



Managing ME/CFS: A Guide for Young People

By **Dr Rosamund Vallings**
published by Calico Publishing
http://www.calicopublishing.co.nz



If you are a young person who has just been diagnosed with ME or Chronic Fatigue Syndrome (that's CFS), and even if you've had this condition for a while, you will find a sympathetic voice in this new book by **Dr Rosamund Vallings**.

Teenagers are particularly prone to ME/CFS (Chronic Fatigue Syndrome) and **Dr Vallings** has written her book specifically for them. **Vallings** is a medical doctor of considerable experience and a leading world specialist in ME/CFS. She has been helping those with this condition for more than 40 years. She writes with great empathy and explains this complicated and at times baffling illness in an accessible way.

The book is full of great suggestions for managing everyday tasks and working through the ups and downs of the illness, and there are lots of tips on how to create the best chance of recovery. **Dr Vallings** has even included stories from young people who are managing this illness.

Her message to young people is to learn as much as you can about ME/CFS and to actively take charge of your health. As she says, 'Only you know how you really feel.' She encourages everyone affected by the illness, including family and carers, to find out as much about it as possible, as people with a good support network around them have a much better chance of recovery.

Dr Vallings is also the author of *Chronic Fatigue Syndrome/ ME: Symptoms, Diagnosis, Management*, which provides a thorough overview of the illness and is now widely regarded as 'a much-needed bible of information'. It has helped thousands of people around the world.

Both books are available from http://www.calicopublishing.co.nz or can be purchased as ebooks.

8. Severe ME

Rebecca

My daughter, 28, having lived with CFIDS-OI-chronic pain – and all the other associated co-occurring diagnoses for most of her life, was found on the floor of her apartment by her friends, on January 11, 2015. The coroner's report stated it was "natural causes," probably sudden cardiac arrhythmias secondary to chronic dysautonomia.

Although **Rebecca** was not diagnosed until she was 8, I had known since she was an infant that something was terribly wrong: sleep difficulties, pain, apneuic intervals, racing heart, digestive disturbances, disorientation, purple hands and feet.

During our rounds of doctors in search of answers, we had been told, "It was all in her head," or "It was all in my head." I was accused more than once of Munchhausen by Proxy, a suspicion that has lived on.

Nonetheless, **Rebecca** was determined that CFIDS would not rule her life. Whenever she could get out of bed or off the couch, she would go to class/school/ hang out with friends/play soccer/cheer her sibs on/rebel and rail against me (Mom) and all the restrictions in her life (diet, meds, doctor's visit, physical therapy, homework, exhaustion, cognitive fog, pain, a bleeding disorder, etc.

Much of what she accomplished was due to the indefatigable efforts of her sibs and friends…They literally carried her to and from the soccer field so she could conserve enough energy to play.

I carried her on my back so she could accompany her class on school trips. She became a NICU nurse, although her career was interrupted frequently by going on disability.

She was a grad student when she died. She hoped to become a nurse practitioner in genetics to add to patient and family knowledge of health challenges, particularly in CFIDS and its related disorders.

When she was 13, she was given the "keys to our town" by the mayor for outstanding scholarship and participation in community affairs, particularly in the area of diversity, and for participation in extra-curricular affairs. She was also named the "most trusted student" in her school community. In high school, she had paintings and drawings exhibited in private art galleries in town.

She was given a grant by a local electric company to photograph/video a diverse group of kids, practicing energy conservation. It became the basis for a commercial they later used. In college and at work, she received multiple awards for her participation in patient-centered research and practice.

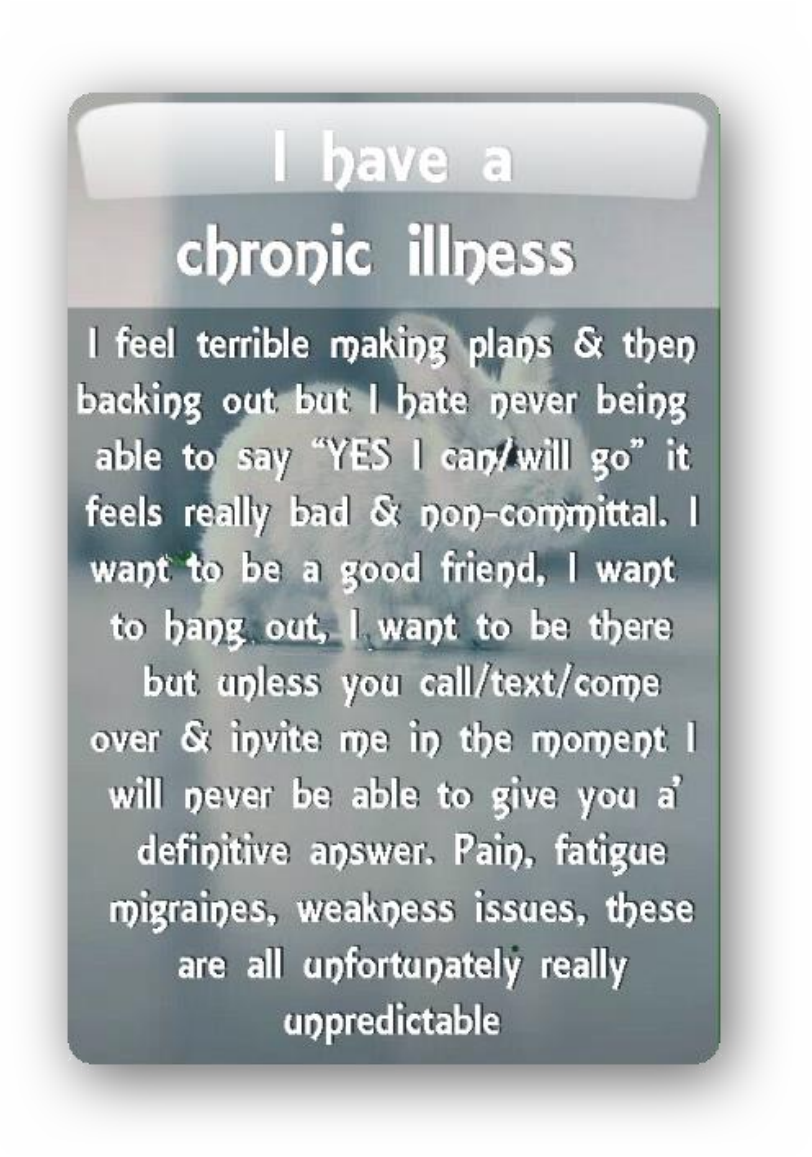
Always, her "outside life" was punctuated by her private pain and exhaustion, tearful phone calls asking me to pick her up because she literally could not move, her friend's panicked cries for help because she had collapsed on the field, calls from colleagues and roommates that she was wracked by pain, that her heart rate was above 200, that she did not have enough energy to speak, that she had lost the ability to swallow…..

She had more than one head-on collision in her car due to fogginess and exhaustion….so she bought a bike. It sits in my basement in its box. She tried to strike a partnership with CFIDS and/or waged a war. I'm not sure which side won. She did live every moment of her life to the fullest, but her life was shortened.

We must find the cause, treatment, and cure so more lives are not abbreviated and are not lived on the battlefield of pain and exhaustion

Nancy Gen

Source: MEAction, comments on http://bit.ly/1SfF2Kq



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://www.geef.nl/doel/save4children

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://www.geef.nl/doel/save4children

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

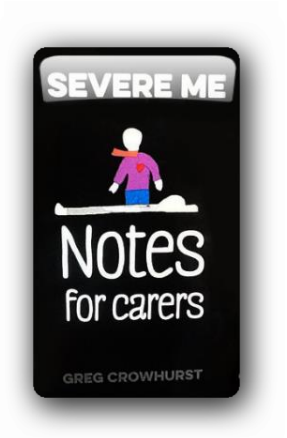
Two videos about **Karina** from 2013:
http://www.youtube.com/watch?v=Dk3e8IWj7M0
http://www.youtube.com/watch?v=JTkkcvlvYf8

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.

The Pain Of Watching



Few are able to bear the pain of watching, waiting, being with the person who suffers, especially if that pain is drawn out over years and years.

There is pain in caring for someone as ill as my wife; I made this list:

1. The pain of my presence, my voice, my thinking even, my attempts to try and be quiet, increasingly being too much for her to bear.

2. The pain of her total suffering, paralysis, deep isolation from anyone and everything, the absolute littleness of her life.

3. The pain of the immensity of the illness, in its face we are only a dot - at least that is what came to me in a reflective drawing recently- a powerful dot of fire though, that will never give up!

4. The pain of the hours spent coping, my wife never comfortable, never finding any relief anywhere, moving from lying to sitting, always being pulled back into paralysis and exacerbation of symptoms.

5. The pain of feeling less and less confident, hopeful, certain of a cure one day.

6. The pain of getting older, it has been more than two decades now, realising my body is slowing, is not as strong as it used to be, to help.

7. The pain of witnessing the psychiatric lobby still going from strength to strength, in contrast to our diminishing situation.

8. The pain of being so alone; knowing there is not one ME group that is waging an effective fight.

9. The pain of fighting so hard, yet the illness is still left untreated and is taking its tragic course, regardless.

10. The pain of my wife whispering to me, at 2am that the pain is too much to bear.

We have found that love gives strength in the bleakest, most barren, pain-wracked place.

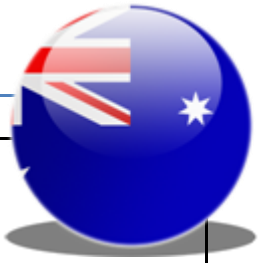
(from "Severe ME; Notes for Carers")

http://stonebird.co.uk/Notes/index.html


I would NEVER use the term FATIGUE.
I have paralysis, muscle spasms, photophobia, profound hyperacusis, hyperesthesia, parasthesia, intense head and body pain, visual disturbance, gastroparesis, MCS, numbness, lack of motor control, poor coordination, severe cognitive dysfunction, gastric reflux, nausea, severe dysautonomia, muscle weakness and muscle wasting.
I would never call any of this fatigue; such a simple, offensive, inappropriate word, used to wrongly describe my reality.
Holy Way

9. News from

Australia



BRISBANE & LOGAN CITY Fibromyalgia Support Meeting, 3rd Thursday of the month at Logan Hyperdome Library, 66-70 Mandew Street, Shailer Park - 2 pm	**Judy Everett** Info packs, monthly newsletter & phone support	(07) 3806 5601
BRISBANE WEST ME/CFS/FM/MCS Support & Activism	**Sylvie** sj.dakini@hotmail.com	(07) 3876 7938
CROWS NEST Support Group Phone support only	Group Leader: **Berrie Cawthorne**	(07) 4698 4715
FRASER COAST FM/CFS/ME Support Group Maryborough Community Health Centre, Conference Room, inside front door and turn left 167 Neptune Street, Maryborough 1st Monday of each month from 9.30 – 11.30am (except January)	**Judy Vickers** **Anaree Nelson** **Jenni Ghill** CONTACT 9am – 3pm painfatiguefogfc@hotmail.com	(07) 4121 6910 (07) 4123 5518 Mobile: 0409 453 397 (07) 4123 6803 Mobile: 0499 465 229
FIBROMYALGIA, CFS/ME Gold Coast 2nd Thursday of the month 11am – 1pm @ Southport Library	Group Leader: **Carol Baker**	Mobile: 0406 154 766
LOGAN ME/CFS/FM Phone or email only	Group Leader: **Lee Rowe** Telephone between 8.30am -12pm or 7pm – 9pm leeann50@bigpond.net.au	(07) 3200 8223
NORTHERN SUNSHINE COAST (FM/CFS/ME) Self Help Group Phone support only	Group Leader: **Sandy Eastman**	(07) 5471 0039
ROCKHAMPTON Phone Support Only	**Marilyn Gavranovic** leviti@bluemaxx.com.au	Mobile: 0403 391 388
ROSEWOOD FMS Support Group 10 am—11.30 am 3rd Thursday of every month	Contact person **Judy Rosewood** Community Centre School St	(07) 5464 2227 (07) 5464 2965
TAMBORINE MOUNTAIN Support Group Phone Support Only	Group Leader: **Jeni Uhlig**	(07) 5545 3134
TROPICAL NORTH QUEENSLAND SMITHFIELD cfs_me_tnq@yahoo.com.au	**Peter Ashley** ahinds@smashman.net	(07) 4057 5920
TWEED HEADS CFS/ME/FMS Support Group 10.45am 1st Friday of the month South Tweed Sports Club	Group Leader: **Bronwyn Sonter** bronwynsonter@hotmail.com	(07) 5593 9319

Belgium

Press release Wake-Up Call Beweging Association Antwerp December 21, 2015

CFS centres: NO GO!

The Belgium government finances CFS policy (€2.3 million) where nobody wants to corporate with.

The newspapers announced the start of new diagnostic centres for CFS only from September 1th, 2014. On the new management agreement between the RIZIV (National Institutes of Health and multidisciplinary diagnostic centres for CFS was not less negotiated as six years long. To cap it all it turned out now the latter have not signed the agreement.

The RIZIV is offside with this, because it turns out the centres themselves are just open but without an agreement with the RIZIV. In this way the hospitals boycott the plans to bring the therapy (CGT & GET) closer to the patients and the centres avoid the obligation for an evaluation on the results of their approach after four years, which appeared repeatedly disappointing in the past. (KCE Report 88A - http://let-me.be/download.php?view.28).

The Wake-Up Call Beweging (WUCB) finds the hospitals avoid their responsibility in this and are failing to finalize the diagnostics in CFS.

The interest group is asking for enhancement of the diagnostics in CFS because we are now confronted with a countless amount of misdiagnoses and a total lack of interest for the biomedical components present in CFS, making it a chronic, complex neuro-immune disorder.

The WUCB will now urge the Minister of Health to cancel the present RIZIV agreement with the multidisciplinary centres for CFS because it turns out to be nothing more than just on paper.

Submitted by **Eddy Keuninckx** and **Gunther Crick**

http://www.stopdediagnosecvs.be/

Canada

Save ME/CFS Patients: Dedicated Care Unit in Toronto Hospital Needed

http://chn.ge/1TROzH4

People with ME/CFS represent an exceptionally vulnerable population with unique needs when it comes to institutionalized care such as hospitalization and Long Term Care. For Canadian healthcare to be truly universal, it must include appropriate services for its entire population - including patients with ME/CFS.

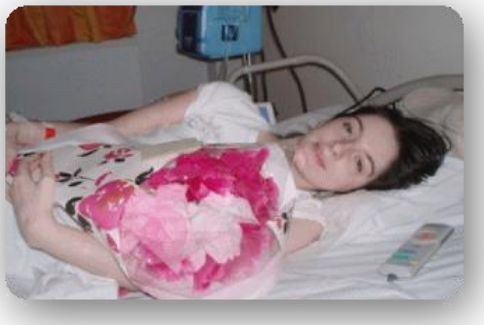
Myalgic Encephalomyelitis/Chronic Fatigue Syndrome is a neuro-immune illness that affects cognitive and physical functioning. It was found to affect 1.4% of Canadians in a 2010 CCHS study. Twenty-five percent of the afflicted are estimated to be severely affected, being bedridden with little to no functioning. This population has been shown in studies to have the lowest functioning of any chronic illness, comparable to end-stage AIDS or end-stage renal failure. There is no known cause or cure, though autopsy findings report dorsal root ganglionitis - a type of inflammation of the spinal cord - confirming its' status as a neuro-immune illness. Some people improve with time while others are bed-bound for decades.

To die of this illness is atypical; however, to hover in an in-between state where one experiences a 'living death' is quite typical.Despite the ravages of this illness, it is one of the least funded in terms of research dollars, receiving slightly more funding per year in the US than Hayfever.

Many people with ME/CFS cannot tolerate the hospital environment as it currently stands, and end up dying or relapsing because they refuse to go to a hospital that cannot care for them properly. Conversely, many do go to the hospital and end up dying or relapsing because the care did not suit their basic needs.

People in 'first world' countries should not be dying of malnutrition, starvation or dehydration at home just because they cannot tolerate being in a hospital environment in order to get a g-tube inserted to feed them when they cannot swallow; they should not become paralyzed or lose their ability to speak because hospital conditions depleted their sleep; they should not die a slow, torturous death because medical institutions did not care for them properly; they should not be forced to walk to dining areas or bathrooms when they need a wheelchair to avoid exacerbation of symptoms or severe relapse.

Graded Exercise Therapy is not tolerated by the very severely ill. Medical experts need to realize ME/CFS patients are the experts of their own experience and that 'treatment' programs must be individually created by the team (which includes the patient) to suit the individual, and not just to suit the guidelines set out by the Ministry of Health.



In memory of ME/CFS patient, activist and author, **Emily Collingridge**, who died March 18, 2012 just shy of her 31st birthday (in hospital), I ask that a dedicated care unit for people with ME/CFS be created in a Toronto Hospital so this group has a safe, healing place to go when they need Long Term Care, hospitalization or respite for themselves or their caregivers. **Emily** was not the only person with ME/CFS to relapse from standard hospital care, but I truly want her to be the last.

Sign & share: http://chn.ge/1TROzH4

With thanks to MEAction & **Liisa Lugus**, who started this petition

Northern Ireland

Professor Coyne, how can we thank you enough?

Professor Coyne delivered some strong words at two recent Belfast events organised by the charity Hope 4 ME & Fibro Northern Ireland. Talking on "The Scandal of the £5m UK PACE trial: What can be done?" the good professor did not shy away from exposing the deeply rooted problems with both the PACE trial itself, and the manner in which patients have been vilified by the media.

In both talks **Professor Coyne** spoke of his experiences growing up with his severely disabled brother, and of the discrimination his family experienced as a result. He gave this as one of the reasons that he has long been a champion of the underdog.

He also talked of his position as an outsider to the ME world, and to British science circles. He said as a result of this he can say things that patients cannot say. He spoke of how he has intentionally said a few controversial things on Twitter to draw upon himself the same contempt that is usually reserved for patients.

When describing the faults of the PACE trial, **Professor Coyne** didn't mince his words. *He called the PACE trial a "wasteful train wreck of a study..... virtually assured to produce misleading results*."

He talked to both audiences about the major problems with the PACE trial, including the conflicts of interest of the authors, the switching of outcomes and the misrepresentations of those outcomes by both the investigators and the media. He emphasised that all of this produced a "clear harm to patients".

His cynical view is that investigators, and the Department of Work and Pensions who part funded the trial, want - "to claim therapy is effective so patients can lose their benefits if they are not enrolled in therapy."

Professor Coyne seemed very aware of the influence that the PACE trial has had worldwide. He thinks getting it discredited in America will be an important step. On the matter of data sharing, he told us about the PACE paper published in the online journal PLOS, where data sharing is a condition of publication. He expressed amusement that his request for data was turned down for being "vexatious", but said that the current stand-off between PACE authors and the PLOS journal is being watched internationally.

Professor Coyne's two talks each had a slightly different emphasis, but in both he expressed his disgust at how patients were being misrepresented in the media, and also how their status as a patient was being used to invalidate their opinions on scientific matters.

He said that there are human rights issues in the way patients are being portrayed and treated.

During the Stormont presentation on Tuesday 9th, **Professor Coyne** took pleasure in reporting the letter sent by the ME Association to Queen Mary University of London, urging the release of the PACE trial data and supporting the petition from ME Action. He described this as an act of rebellion, and a very positive move.

Professor Coyne also took the opportunity to question the use of the Lightning Process. He was totally scathing about the so called science behind its working, and drew our attention to the Advertising Standards Agency adjudication on the Phil Parker Group. He then challenged the Health and Social Care Board of Northern Ireland to explain why they were listed as one of Phil Parker's clients.

Professor Coyne was also angry at the use of the Lightning Process and Graded Exercise Therapy in studies involving children. The SMILE study and the recently announced MAJENTA study were both mentioned in discussion during the Question and Answer sessions.

Questions were also asked about the perception of ME as a psychological illness, and why, if the illness was physical in nature, was the majority of research funding allocated to trials run by psychiatrists?

Today as I reflect on the two events, and as feedback is coming in from others, I can't help but feel that something momentus happened in Northern Ireland for the global ME community.

PS One message Hope 4 ME & Fibro Northern Ireland received after the events said that we gave patients, "Hope in our Hopelessness", and I feel that sums up how many patients see these latest developments.

Longer report, also links to slides and the video (once available) at http://bit.ly/1XrotuE

Sally K. Burch

Spain

We are happy to announce that ASSSEMBiomedics, a new ME patient led research and treatment group in Barcelona, Spain, is starting a new ME Immune Biomarker research study with samples from 100 people with ME and from 100 healthy controls.

With this new study ASSSEMBiomedics wants to corroborate the preliminary results shown by a previous study by Barcelona's IrsiCaixa Research Lab, led by **Dr Julian Blanco**'s team, with whom ASSSEMBiomedics has a close relationship. ASSSEMBiomedics, along with other ME patients' groups were the ones that helped finance the IrsiCaixa's ME Tregs study through a Crowdfunding in 2014.

ASSSEMBiomedics did a preliminary ME immune biomarker study with 200 ME patients over the past two years, (results of which cannot be published as it was a tentative study without an ethics committee). But the results were promising! They showed, in people with ME, an inverse relationship of the two Natural Killer markers, a relationship which had not yet been discovered between CD57s and NKp46s. This could indicate profiles of viral reactivation of EBV and CMV in people with ME.

This aspect was pointed out to ASSSEMBiomedics by the new Natural Killer Expert Group in Barcelona, under the leadership of **Dr Lopez-Botet**, experts in NKs and who are the co-discoverers of the biomarker NKG2C. (They are not researching on ME, despite their interest in ASSSEMBiomedics' work).

ASSSEMBiomedics thinks that they can determine these new biomarkers in NK cells (NKG2C, NKG2A, KIR-ILT2) in people with ME in their new study, and that it would be coherent with how Rituximab works and with the percentage of health improvement that the Norwegians have been able to achieve (2/3): reactivation of EBV in B Lymphocytes and autoimmunity.

The ASSSEMBiomedics' team is led immunologist **Dr Milagros García-Ormaetxea**, specialist in autoimmune illnesses in the Barcelona Clinic Hospital. The blood samples will be taken at the Centro de Diagnóstico Biomédico in that hospital.

For this new project ASSSEMBiomedics needs 18,000 euros and that is why they have initiated a Crowdfunding campaign which will end in one month (March 24). ASSSEMBiomedics has no government nor private sector funding. It is totally funded by donations from ME patients and their allies. 18,000 euros might not seem a lot in some other countries but in Spain, with such low salaries, high unemployment and lack of patient pensions, that amount is staggering.

That is why ASSSEMBiomedics is turning to ME associations in other countries. Also, as the results will benefit ME patients all over the world, perhaps ME associations in other countries will want to help out.

The fundraising video below is in Spanish with English subtitles and with parts in English: https://youtu.be/76xDTRTmqGI

Any donation would be of great help, as the size of the sample depends on the amount of funds obtained, and the simple size is crucial so that the results will be relevant. We would like to be able to apply the results of the study for clinical diagnosis as soon as possible.

This is an ME patient led and funded research project so there might not be much money available but there is a lot of motivation and enthusiasm!

Thank you for sharing this video and information with your contacts, and for any donations you can give.

Banking information to make a donation:
Account owner: ASSSEM
Concept: BIOMARCADORES
Bank: BBVA
IBAN: ES0901828732100201553888
SWIFT/BIC: BBVAESMMXXX

Source: http://bit.ly/1O10BXy

The Netherlands

Citizen Initiative

In no other country (as far as we know) the ME-community managed to collect enough signatures to present a petition to the parliament for recognition of ME as a biomedical disease.
Currently, the Citizen Initiative is entering a new and decisive stage. The Dutch parliament ordered the Health Council of the Netherlands to form a committee which will investigate the disease and come with advices.

The MEGC will try to pay as much attention as possible to this subject, as it should be one of the focuses of the entire global ME-community, in the editors' opinion. If, after Norway, a paradigm-shift could be caused in the Netherlands, it might have a domino-effect on other countries. For further information and a short survey, see under Citizen Initiative, section grass root.

Screening of documentary Ryan Prior's Forgotten Plague

On Sunday February 28, 2016 there will be a screening of Forgotten Plague, followed by short presentations of the American journalist and patient advocate **Dr David Tuller** and the Dutch cardiologist **Frans Visser**, who both also will answer questions.

The event has been organized by the Dutch ME/cvs Vereniging in cooperation with Dutch severe ME-patient **Anil van der Zee**, who ironically is living in Amsterdam but is too ill to be able to attend. He came with the idea and worked it out, together with the foresaid association. The event starts at 14.30 CET. More info in the section Events of this issue.

Science to Patients

As announced in earlier issues of the MEGC, the team Science to Patients is working on the Dutch subtitles of seven short webinars with the British neuropsychiatrist **Dr. Neil Harrison** at the moment.

As that work has proceeded very well thanks to the almost superhuman efforts of just a few very severe patients, a broadcast schedule of these webinars is already available:

3/8, webinar 75: Me & ME
3/22, webinar 76: ME & fatigue
4/5, webinar 77: ME & the brain, part 1
4/19, webinar 78: ME & the brain, part 2
5/3, webinar 79: ME & inflammation, part 1
5/17, webinar 80: ME & inflammation, part 2
5/31, webinar 81: ME & diagnosis

Most probably there will be occasions to ask **Dr. Harrison** questions during chatwing-sessions on
3/18,
4/15,
5/13 &
6/10, from 17:00-17:45 Amsterdam-time.

As these data aren't yet sure, we would advise you to keep an eye on the page of the website of the ME/cvs Vereniging:
http://www.me-cvsvereniging.nl/broadcasting-science-to-patients-2014

10. Poem – ME and ME

I have a disease
that nobody sees.
I cry to God
and fall to my knees.
I've tried and tried
a thousand times
to crack the code,
to find reason and rhyme.

Years go by
and I learn to adapt.
Have glimpses of light
and a life in the gap.

Between health and hell,
suffering and pain,
for ten years now,
life has not been the same.

The hardest part,
strangely enough,
is not the constant exhaustion,
having run out of puff.
Not the brain fog, confusion,
the aching and pain.

But the sense that no one
quite gets ME,
believes ME,
or understands.

Ainslie Eccleston

Source: The Queensland Communicator, February 2016

ME/CFS/FM Support Association Qld Inc.,
Mission Dept. St Vincent's Hospital, Scott Street, TOOWOOMBA 4350, Australia

11. Column – Thirteen Years Ago

Thirteen years ago today, I woke up to a life I thought I knew the shape of. One that was reassuring to carry and to keep in the palm of my hands. Every day, I walked out into the world. I could wrap my coat around me (the coat my brother laughingly told me made me look like an Eskimo) and jangle my keys in my pocket as I went on my way. I was growing up. I was beginning.

I could smile at strangers. I could stand beside my friends. If there was a place I wished to be, I only had to choose to go there. Open spaces and fresh air were ordinary and they were mine. They were as mundane as my father's hissing attempts at whistling as he started the day, or the mad scrabble of my dog's paws on the windowsill when he saw the postman coming up the road. I didn't know those things were miracles too.

I did understand that I was ill then, but not that it was serious. It was unexpected and frightening when I took sick, early that morning, in a deserted street. Everything was quiet. The front doors of the houses were primly shut and the curtains were drawn, so the windows were closed eyes, and the bricks themselves were resting after a busy, suburban week. I crumpled liked old paper and the pain migrated around me, like the winter birds while I held onto my heart, and the nearest lamp-post.

I realised I had to get help but I didn't think I could speak if I found someone so I decided I must manage to get home. We live up a hill and I was a road away from the first step of that climb. I used the parked cars to steady myself and I just kept moving until my house could be seen, perched reassuringly at the top of the summit ahead, with its bright paintwork and our little silver car, preening happily outside in the sunlight.

By the time I made it near enough to have to contemplate the seventeen steps that still stood between me and the brass doorknocker, my parents were running to reach me and carry me. To call a doctor and do the only sensible thing that anyone can ever do in a crisis; to make good tea.

I've been housebound ever since. Although I have been lucky enough to have a little starlight and sunshine again lately.

There is no way to explain how the life you have claimed can shrink so much and so suddenly, until you must fit all of who you are into a small and dimly lit gap of existence. I can't tell you what that is like, unless it has happened to you too. (I am so very sorry if it has happened to you too). I have found it to be frequently unbearable to have all manner of dragons crowding into such a little space with me, breathing with their hot, dark breath on my skin, and pinning me there without any sign that they can hear me asking them to let me go.

I have learnt how to call everything I need to consider this a life, to be here to abide with me. I've had to beckon it, til it is curious enough to come closer. I have let myself believe in the things that are necessary, so ardently, that they can always exist inside my own mind, and I do not go without them.

I feel, today, like I am climbing that hill home. That those thirteen years have folded in on themselves until those moments that marked an ending to so much of what I knew, are happening right now. My life is messy and painful, but isn't everyone's? My life is beautiful and extraordinary, and isn't yours as well? So much of what happens to us is not of our choosing. So much of what is taken and what is given is not what we expect.

Sometimes that really makes me want to cry but, when I look at who I know and the hopes I have, I think that maybe that's the only way it could ever be without it losing something immeasurably important.

I have decided; I will take my life as a lover over and over again. Even when I am weary of its wild ways and broken promises. It may threaten to leave me, but it hasn't done so yet. Perhaps, after all, we are meant for each other.

Sarah-Louise Jordan

https://www.facebook.com/sarahlouiselula.jordan

12. 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."