The ME Global Chronicle

www.let-me.be

 # 18 – August 2016

1. Colofon / Personalia

Scientific reviews: ***Richard Podell***
Advisory board: ***Leonard A. Jason***
Cartoons: ***Djanko***
Editor/Editorial team: ***Eddy Keuninckx, Rob Wijbenga***
Included in this issue are texts and/or pictures from:

Annet Lindhout
Bente Kubin
Bente Stenfalk
Brenda Vreeswijk
Dr. Neil Abbott
Dr. Richard Podell
Eddy Keuninckx
Eileen Holderman
Els van Hoof
Emily Beardall
Emily Taylor
Erik Lang
Gabby Klein
Greg & Linda Crowhurst
Jane Colby
Jelle Bouwhuis
Jennie Spotila
Jennifer Brea
Jo Best
Katharina Voss
Kit-Cat
Linda Tannenbaum
Llewellyn King
Lyn Wilson
Mary Dimmock
Mike Harley
Mel Smith
Prof. Leonard Jason
Regina Clos
Rob Wijbenga
Russell Logan
Sarah Louise (Feather) Jordan
Team M. Missing Holland
Tom Kindlon
Utting Wolf
Valerie Eliot Smith

Distribution: ***Eddy Keuninckx -*** *Layout:* ***Eddy Keuninckx***
Archive: http://let-me.be - Facebook: https://www.facebook.com/groups/TheMEGlobalChronicle/
The editorial team doesn't accept any responsibility for any possible incorrect information that it has been supplied with and which has been published in this issue. Anyone can subscribe to this free magazine by sending his/her email address to: subscribe@let-me.be. You can un-subscribe by sending a mail to: unsubscribe@let-me.be. Textual contributions for the October issue need to be supplied in Word by 10st October and sent to: contribute@let-me.be. The next issue will come out on October 20nd,2016.

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***

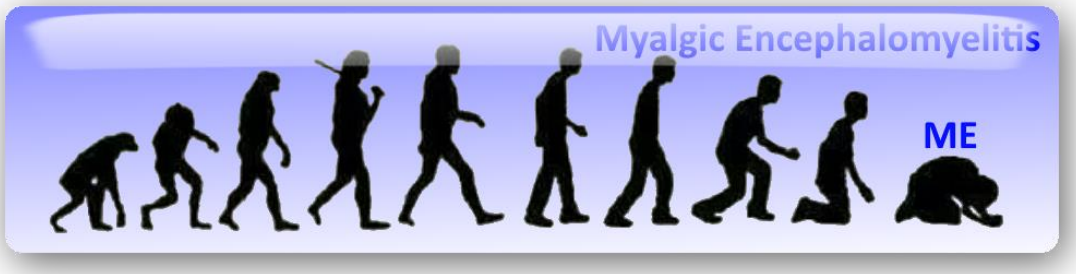
Errata MEGC 17
- Emily Beardall *drew our attention to the fact that her title isn't Dr. She's a pharmacist and we might use the title MRPharmS (Member of the Royal Pharmaceutical Society).*
- Right person, wrong picture
The picture of ***Clyde Behney*** *which we included in the MEGC 17 appeared to be of* ***Victor J. Dzau****, president of the NAM.* ***Herewith*** *a picture of* ***Clyde Behne****.*

Our apologies.
The editors

---

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.



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

3. Introduction

Dear friends,

In this August 2016 issue of the MEGC we, of course, elaborate on the two most important achievements reached in the past few weeks. First, the mandate of the British Information Commissioner to the Queen Mary University of London to release the raw data of the PACE-trial of 2011, due to perseverance of the Australian patient **Alem Matthees** and the efforts of lots of others including the American science reporter **David Tuller**.

And secondly, the additions of the AHRQ-report from 2014, that proves the glorified results of CGT and GET to this illness by British biopsychosocial researchers to ME (actually rather CFS) disappear without a trace like snow before the sun once it appears.

This all makes the Dutch petition to the Health Council to change the composition of the commission that should evaluate ME/cfs more actual and also more urgent. In it that same school with four out of ten members is severely overrepresented, while there actually should not have been any seat for them at all. Therefore, please all sign this petition, when you haven't done yet, and circulate the link everywhere: http://bit.ly/1YtAEH8 Don't forget to confirm your signature in the email you receive afterwards.

Also more news about 27 September 2016 – the second worldwide Millions Missing protest day. Unfortunately, no news about **Karina Hansen**; we wait in tension whether the Danish advocate **Cristina Poblador** definitely decides if she wants to handle her casus.

Anyway, enough news from past two months to read and look at.

Textual contributions for the 19th issue of the MEGC of October can be sent before October 10th to contribute@let-me.be

We wish everyone on the northern hemisphere a beautiful late summer and on the southern hemisphere a promising spring.

Take good care of yourselves and the ones you're loved by.

The editors

4. NIH/CDC/HHS


NIH
National Institutes of Health
CDC
Centers for Disease Control and Prevention

CFSAC - Public Comment.

CFSAC - Public Comment
May 18, 2016
Eileen Holderman

The Chronic Fatigue Syndrome Advisory Committee (CFSAC) in Washington, DC held its biannual meeting May 17 & 18, 2016 via webinar. Advocates and stakeholders gave testimony about various issues facing the ME community. I served as the Patient Advocate on CFSAC from 2010-2014 and now give testimony as an independent advocate. What follows is the testimony I gave live at the CFSAC May webinar meeting addressing my concerns about the NIH Intramural ME/CFS Study

"Good afternoon to the Advisory Committee Members and to all stakeholders listening.

My name is **Eileen Holderman** - I'm an advocate for ME, GWI and other neuroimmune diseases.

Recently, I served as consultant to MEadvocacy, an organization advocating on behalf of nearly 1 million American men, women and children suffering from Myalgic Encephalomyelitis (ME).

Specifically, I collaborated on their blogpost titled, "NIH Sidesteps Critical Problems with the ME/CFS Study," which is a detailed analysis of the numerous problems with the study design and protocol and which offers solutions to those problems. The organization has given their consent for me to talk about the blogpost.

The blogpost outlines many problems such as: multiple and ever-changing criteria - some which are deeply flawed, biased and/or inexperienced investigators and advisors such as **Walitt**, **Gill**, **Saligan** and **Unger**, additional problems with the study design such as a small cohort size, excluding patients who are most severely affected such as the homebound and bed bound, the use of Lyme Disease comparison groups which will cloud the results, the exclusion of the 2-day CPET testing for PENE, the refusal to release the specific budget for the study, the exclusion of ME experts when designing the study, and finally, the failure to set up a transparent, 2-way communication and participation process between NIH and the ME community (researchers, clinicians, advocates, patients, and caregivers) at every step of the way.

Obviously, with just 3 minutes allotted for public comment, I cannot address all the problems mentioned, but invite all of you to visit the web site http://MEadvocacy.org and click on the blogpost for a detailed analysis that proposes solutions.

Therefore, with the remaining time I have, I will focus on the critical issue of the study's criteria.

It is of utmost importance that the strictest criteria - the CCC or ICC - developed by our ME experts - not by the CDC or Government agencies - be used in studying ME, in order to ensure that investigators are looking at a homogeneous patient cohort.

The NIH Intramural ME/CFS Study has changed criteria 6 times. First, NIH announced they would use the Reeves' criteria - which has been rejected by mainstream scientists and denounced by CFSAC. After backlash from advocates, NIH announced the study would utilize the CCC, IOM, Fukuda and Reeves'.

After more protest from advocates, NIH then announced they would use multiple consensus criteria, including Canadian criteria. Then **Dr. Nath** stated that NIH would use the Fukuda and CCC. After the NIH Telebriefing, a new web site for the study showed one specific criteria to be used - the CCC. Finally, **Dr. Koroshetz**, in his letter to MEadvocacy, stated that the CCC and IOM would be used for selecting patients for the NIH study.

For over 30 years, US Government health agencies have created erroneous definitions and names for this specific neuroimmune disease - Myalgic Encephalomyelitis - causing devastating harm to patients. And other nations, like the UK, who created the flawed Oxford definition used in the PACE Trial, have done the same.

Our community needs NIH to step up and officially state that the Reeves' criteria and questionnaires will not be used in the NIH Intramural Study for ME/CFS; resolve the outstanding problems with the study design and protocol; and establish a transparent, 2-way communication and participation process with all ME experts.

Thank you."

Submitted by **Eileen Holderman**

HHS Refuses To Correct Their Wrongful Branding

I wish to thank advocate **Eileen Holderman** for her contributions to this blog post.

The Department of Health and Human Services (HHS) refuses to use the name myalgic encephalomyelitis (ME) in spite of the fact that it is being used worldwide by ME experts, advocates and patients. Instead, HHS insists on using their demeaning moniker – chronic fatigue syndrome (CFS). Their refusal to use the proper name for this disease ignited a long course of government malfeasance, corruption and marginalization of one million American men, women and children suffering from ME.

Naming and Classifying the Disease

In the mid-1950's, an epidemic broke out at the Royal Free Hospital in London. Following that epidemic, the name myalgic encephalomyelitis was first used by ME pioneer **Dr. Melvin A. Ramsay** (as suggested by **Dr. Donald Acheson**).
Since 1969, the World Health Organization (WHO) has classified myalgic encephalomyelitis under Neurology – ICD-10, G93.3.

However, in the 1980's, following the Lake Tahoe, Nevada outbreak of ME, the U.S. Centers for Disease Control and Prevention (CDC) chose a different name for the disease. In their quest to minimize the seriousness and potential huge impact of the disease, CDC coined it with the trivializing name – chronic fatigue syndrome (CFS).

In 2015, The Institute of Medicine (IOM) was contracted by HHS to devise another government constructed name and criteria. IOM created a new demeaning name for the disease – systemic exertion intolerance disease (SEID), which has been rejected by the majority of experts, advocates, and patients. The name is misleading because it implies that patients are only ill when they exert themselves and are otherwise fine if they don't – which of course is not true.

The Fiction of CFS

The name – chronic fatigue syndrome – along with the government criteria, are an HHS fictional construct. In their attempt to disappear the serious neuroimmune disease ME, HHS deliberately chose the name chronic fatigue syndrome because it could be easily conflated with the common condition of chronic fatigue. Their intention was to create a false impression that those with CFS were primarily contending with one symptom – fatigue – rather than a vast number of symptoms affecting multiple body systems.

The scientific and medical communities are responsible for naming and developing criteria for diseases – not governments. ME expert researchers and clinicians named the disease myalgic encephalomyelitis and developed accurate criteria for the disease (CCC, ICC). HHS should not hijack the private scientific and medical sector's authority.

The Reality of ME

Myalgic encephalomyelitis is a neuroimmune disease (with an infectious component and/or etiology) appearing in epidemic and sporadic forms. ME affects multiple systems of the body: neurological, immune, cardiovascular, endocrine and energy systems. The illness typically has an acute onset of a viral or bacterial infection or toxin or chemical exposure.

The symptoms of ME are numerous and include but are not limited to the following: post-exertional collapse, muscle and joint pain, enlarged lymph nodes, chills, low-grade fever, headaches, extreme fatigue and weakness, cognitive impairment (delayed processing, aphasia, short term memory loss, etc.), orthostatic intolerance, dizziness, sleep dysfunction, allergies, mold and chemical intolerance, frequent reactivated infections and co-infections. The symptoms of ME leave patients severely sick and disabled for decades and many die prematurely from complications of the disease. Currently, there is no cure for the illness.

About one million American men, women, and children suffer from ME and about 17 million worldwide. Most patients are disabled and cannot work and about 25% are bedbound and cannot care for themselves. Studies (http://bit.ly/2aOtzOi) show that the quality of life for patients with ME is one of the poorest compared to other chronic diseases.

"In my experience, it [ME] is one of the most disabling diseases that I care for, far exceeding HIV disease except for the terminal stages."
Dr. Daniel Peterson

Gabby Klein

Read entire blog post here http://bit.ly/2aOtzOi

Ron Davis' Response To The NIH's Request For Information (RFI)

Ron Davis' response to the NIH Request for Information (RFI):
Input for New Research Strategies for ME/CFS

Our mission at the Stanford Chronic Fatigue Syndrome Research Center is to discover causes, a molecular diagnosis, and treatment options for ME/CFS. Through our research efforts, collaborations with the ME/CFS research and clinical community, and extensive engagement with patients, we have defined several elements of importance for future ME/CFS research programs.

- It will be crucial that calls for proposals allow for open, unbiased, multifaceted, and systematic research. Broadening the scope of ME/CFS research will create opportunities for engaging researchers in other disciplines.

  Similarly, investigating numerous organ systems and biological pathways perturbed in ME/CFS may well reveal informative parallels to other diseases – for example, we and others have observed symptomatic, transcriptomic, and metabolic overlap between ME/CFS and neuro-degenerative disorders like Parkinson's Disease. Big data approaches and high throughput, large scale molecular profiling should therefore be prioritized.

  Such efforts hold promise to identify key genes or pathways underlying ME/CFS. Similarly, large scale in vitro drug screening efforts would help point to a variety of molecules and molecular processes as therapeutic targets.

- Understanding the molecular etiology of ME/CFS is another important opportunity. A long-standing belief in the field is that an infectious agent causes the disease, and that the pathogenicity of the as-yet-undiscovered organism is responsible for the severity of the illness.

  The search for novel infectious agents should continue, but research efforts should also focus on understanding individual host susceptibility and response to infection. For example, it may not be a particular infectious agent that results in the disease, but rather a particular host state as a function of numerous biological and external factors that governs an individual's susceptibility. Characterizing host to infection and understanding the mechanisms of the longterm sequelae may reveal insights into ME/CFS that are relevant to numerous other diseases of infectious origin, such as chronic Lyme disease and post-Ebola syndrome.

- Another major challenge is our lack of understanding of the prevalence and landscape of ME/CFS, which is largely due to the difficulty in diagnosing the disease. The search for precise molecular biomarkers is a great opportunity afforded by this research program, which would be accelerated through multi-omics approaches in large patient cohorts.

- Because of these complex scientific challenges, ME/CFS research presents an excellent opportunity for developing and piloting novel methods and technologies in discovering biomarkers, elucidating disease mechanisms, and revealing therapeutic possibilities.

The methods we need to understand this complex disease may very well not exist yet. Engineering and technology development efforts towards highly sensitive, quantitative molecular profiling and/or measuring novel cellular properties, as well as novel computational analyses that integrate multiple datatypes to define disease mechanisms, should be encouraged.

Maintaining an open structure in RFAs will allow scientists to develop and refine their hypotheses as research progresses, as appropriate for the unknown/uncertain nature of the field.

As highlighted in several places above, the opportunities for collaborative efforts within and beyond the ME/CFS research community to understand and treat this disease are numerous. There are numerous experts spread across the world, each taking their own approaches based on their own expertise.

We believe future funding programs should not only encourage, but establish frameworks for highly collaborative data sharing and strategizing that bring together researchers and clinicians. All data should be made publicly available as early as possible.

As we have all seen, the ME/CFS patient community is extremely active, engaged, and eager for actionable results. We thank you once again for the opportunity to provide input on this matter, and look forward to the new strategies for ME/CFS research efforts put forth by this working group.

Yours sincerely, **Ronald W. Davis**, **Ph.D.**

Extracted from http://bit.ly/2b3D9mD

NIH's Request for Information on ME/CFS Research & response of the community

The US Trans-National Institutes of Health (NIH) ME/CFS Working Group, has published the responses (http://bit.ly/2aYijmf) received to their Request for Information (http://bit.ly/2bng1LW) seeking input into research strategies with respect ME/CFS. There are 296 pages of responses from individuals, 55 pages of responses from patient advocacy organizations, and 111 pages of responses from researchers and healthcare providers.

From the Microbe Discovery Project (MDP) teams perspective it was great to see Microbiome research highlighted as important by so many, along with other major priority areas! There were many excellent, comprehensive responses, and it was heartening to see people highlight crucial work at the Center for Infection and Immunity by **Drs. Lipkin** and **Hornig**. There were far too many areas covered for us to post about - so do peruse the responses to see more if you have the energy to scan through these.

There were also personal heartfelt testimonies and it was also interesting to see physicians with sick family writing in, here is a short extract from one such response on page 93 of the individual responses:

Dear NIH:
Please fast track both research and treatments for ME/CFS. My once brilliant son and Stanford student […] has been ill for 2.5 years. He is now bedridden with encephalopathy-sleeping 23/24 hours per day, severe hyperacusis, extreme photophobia, and likely bulbar palsy-drinking all nutrition through a straw for the past 6 months. He is still "there." He wrote on a piece of paper to me one day: ?Ampligen ?Rituxan ?plasmapheresis.

As a physician, I knew nothing of this disease until my son unfortunately developed this disease. What I have learned simply leaves me stunned at the history of this disease and neglect of these patients. To become afflicted with this disease in the past decades is to have 3rd world medicine in the richest nation on earth.

*We have millions missing their lives-patients and caregivers. NIH scientists: Please look at the forest rather than the trees. Generously fund **Ron Davis** and **Ian Lipkin**. These are brilliant proven successful researchers that are highly motivated to understand and find cures for this disease. Without fast tracking, […] could easily die of this disease, adding his name to the obituaries like outstanding […] (Harvey Mudd graduate) or […] (MIT and Stanford graduate).*

Dramatically and swiftly increase funding and physician education. This is decades overdue.

*Look at the big picture and fast track the research. Go with those who have outstanding proven track records. They know the technical details of what needs to be researched far better than I. Trust them. They are motivated to solve this problem and help these patients. I don't want my son […] to die, so please don't leave researchers like **Davis** and **Lipkin** poorly funded. They are our greatest HOPE.*

Read more on the NIH site (http://bit.ly/2aYijmf)

It has been communicated by email that:

"**the Trans-NIH ME/CFS Working Group will review all of the responses** and these comments to help guide research strategies and initiatives to advance our knowledge of ME/CFS and eventually find a treatment for this devastating disease. Once the responses are reviewed, the Working Group will prepare a summary that will be posted online."

You can view this email information on Phoenix Rising here http://bit.ly/2bbWbCL

Researcher's can make headway if thousands of us make donations. You can help **Dr. Lipkin** and **Dr. Hornig**'s research at the Columbia University Center for Infection and Immunity through donating on their secure site here http://bit.ly/MhhQLT.

See the MDP homepage to find out more http://microbediscovery.org/.

Source: http://bit.ly/2aOu8If

AHRQ Evidence Review Changes its Conclusions

In respons to requests by U.S. patient organizations and advocates, the U.S. Agency for Healthcare Research and Quality (AHRQ) has issued an Addendum (http://bit.ly/2bH3Hsy) to its 2014 ME/CFS evidence review. This Addendum downgrades the conclusions on the effectiveness of cognitive behavioral therapy (CBT) and graded exercise therapy (GET), and this has tremendous implications for medical education and treatment recommendations.

At Long Last, AHRQ Undertakes Reanalysis

The 2014 AHRQ evidence review had originally reported that treatment with CBT and GET improved fatigue, function, global improvements, and employment in ME/CFS patients. This conclusion was based on an analysis that combined studies using any of seven CFS and ME definitions as though they represented the same disease.

We highlighted this fatal flaw in our comments on the draft evidence review. The review itself acknowledged that CFS definitions did not require hallmark symptoms of the disease, that no treatment studies used ME/CFS or ME definitions, and that the Oxford definition was so broad that it would include patients with other diseases and should be retired.

The 2015 NIH Pathways to Prevention report concurred that Oxford should be retired, stating that it could "impair progress and cause harm." And yet, the 2014 AHRQ evidence review maintained its conclusion that CBT and GET could benefit some "ME/CFS" patients, based in substantial part on studies that used the Oxford definition.

Following the publication of **David Tuller**'s PACE analysis (http://bit.ly/1NBp079) in October 2015, ME organizations and advocates called on AHRQ to reanalyze the PACE trial, to analyze the results of Oxford studies separate from studies using other definitions, and to analyze CBT studies separately from other forms of counseling.

Following requests in November 2015 (http://bit.ly/2bskbEt) and again in February 2016 (http://bit.ly/1mjAKnh), AHRQ agreed to ask the authors to reanalyze studies by definition and to separate out CBT from other counseling studies. They declined to reanalyze the PACE trial, which they had ranked a good trial with "undetected" reporting bias.

This new analysis was published in late July as an Addendum to the original report (see pages 1-16 of the linked report http://bit.ly/2bH3Hsy). This updated review reanalyzed the effectiveness of GET, CBT, and other forms of counseling, first with Oxford studies included and then after Oxford studies were excluded. As we predicted, breaking out the Oxford studies forced a significant downgrade in the review's conclusions. GET is Ineffective for ME Patients

The 2014 evidence review had combined four GET studies and two other exercise studies (qigong and orthostatic training) in its analysis and concluded, "GET improved measures of fatigue, function, and clinical global impression of change compared with controls."

The Addendum reanalyzed just the four GET studies, three of which used the Oxford definition. When all four GET studies were analyzed together, the Addendum reported a moderate strength of evidence of improved function and global improvement and low strength of evidence of improved fatigue and employment. But when Oxford studies were excluded from the analysis, the Addendum reported that there was insufficient evidence of effectiveness of GET on any outcome.

Study Outcome	Results with Oxford Studies	Results Excluding Oxford Studies
Function	Moderate strength of evidence	Insufficient evidence
Fatigue	Low strength of evidence	Insufficient evidence
Quality of Life	Insufficient evidence	Insufficient evidence
Employment	Low strength of evidence	Insufficient evidence
Global Improvement	Moderate strength of evidence	Insufficient evidence

CBT Is Barely Effective

The 2014 evidence review combined CBT and other counseling therapies in its analysis and concluded that collectively, these therapies improved fatigue, function, quality of life, and global improvement.

Acknowledging that "CBT is a unique approach with disputable underlying rationale regarding the fear avoidance theory contributing to the perpetuation of symptoms in ME/CFS," the Addendum reanalyzed the seven CBT studies separately from the other counseling studies.

The Addendum also analyzed the Oxford CBT studies separately from the Fukuda CBT studies, although one study (Deale 1997, 2001) appears to have been incorrectly classified.

When all seven CBT studies were reanalyzed, the Addendum reported low strength of evidence for improved function, fatigue, and global improvement; insufficient evidence of improvement in employment; and low strength of evidence that CBT did not improve quality of life.

When Oxford studies were excluded from the reanalysis, the Addendum found insufficient evidence of effectiveness of CBT on function, employment and global improvement and a low strength of evidence of improved fatigue.

Study Outcome	Results with Oxford Studies	Results Excluding Oxford Studies
Function	Low strength of evidence of improvement	Insufficient evidence
Fatigue	Low strength of evidence of improvement	Low strength of evidence of improvement
Quality of Life	Low strength of evidence that CBT does not impact quality of life	Low strength of evidence that CBT does not impact quality of life
Employment	Insufficient evidence	Insufficient evidence
Global Improvement	Low strength of evidence of improvement	Insufficient evidence

Implications and What Next

The Addendum reaches a damning conclusion, cloaked in dry language:

This addendum has delineated differences in treatment effectiveness and harms according to case definitions, highlighting studies that used the Oxford case definition and how these studies impacted our conclusions. Additionally, results of studies evaluating CBT have been considered independently from other counseling and behavioral therapies.

Our sensitivity analysis would result in a downgrading of our strength of evidence on several outcomes which can be attributed to the decrease in power, dominance of one large trial, or lack of trials using criteria other than the Oxford case definition for inclusion. Blatantly missing from this body of literature are trials evaluating effectiveness of interventions in the treatment of individuals meeting case definitions for ME or ME/CFS.

In other words, there is no evidence that supports the conclusion that CBT and GET are effective treatments or ME or ME/CFS patients.

And THAT is a ground breaking conclusion.

CBT and GET still remain the most common treatment recommendations across mainstream "evidence-based" medical education today. Recommendations for CBT and GET have been based directly on Oxford studies like PACE, or indirectly through evidence reviews such as AHRQ and Cochrane that have relied heavily on Oxford studies.

At the same time, these treatment recommendations have ignored numerous patient surveys that have reported harms from CBT and GET. The resultant medical education, including that from CDC and key medical education providers such as UpToDate, confuses medical providers on the nature of the disease and puts patients at significant risk of harm from inappropriate treatment.

Recommendations for CBT and GET have become so pervasive that they are also found in the educational plans of medical societies. The American Academy of Family Physicians issued a 2016 needs assessment for education of members that specified that CBT and GET "improved fatigue, work and social adjustment, anxiety, and postexertional malaise" and called out the need for more training of doctors in the use of exercise therapies.

The problem, as this reanalysis found, is that when you remove the Oxford studies, the positive effect of CBT and GET disappears. The Addendum notes that "using the Oxford case definition results in a high risk of including patients who may have an alternate fatiguing illness or whose illness resolves spontaneously with time." CBT and GET appears to help these patients to a limited extent. However, the recommendation of either of these therapies for ME and ME/CFS patients is inappropriate.

This Addendum highlights a key issue that has perverted medical education and evidence reviews in this field for a long time. It is medically inappropriate to make recommendations for disease treatment based on studies in patients who do not have the disease.

CDC, UpToDate, AAFP, and other medical education sources must change their recommendations for ME/CFS treatments. Furthermore, NIH must address the gap in treatment trials for ME and ME/CFS patients by funding intervention studies on these patients.

There is no evidence that CBT and GET are effective treatments for us, and therefore, these treatments can no longer be recommended. If CDC and others persist in recommending treatments for which there is no evidence of effectiveness in ME/CFS patients, it will not only perpetuate confusion but also put patients at risk. Such an unscientific recommendation goes against the principles of evidence-based medicine and is not accepted in other diseases. It will not be tolerated here.

Jennie Spotila, with credits to **Mary Dimmock**
Source : http://bit.ly/2bsjo6G

5. Dutch Citizen Initiative

Petition

A petition is running to expel four members with a biopsychosocial approach of ME out of ten from the Committee of the Dutch Health Council, which is to evaluate the state of the art of ME:

ME is not MUPS http://bit.ly/22r5cKN

In view of the recent developments (addenda AHRQ-report which leaves the BPS-approach with empty hands, and the IC-verdict re. QMUL and the release of the PACE-data), this petition is more actual than ever.

Please sign it, if you didn´t yet. And share.

Negative developments in the Netherlands could adversely affect our hope for progress in the field of bio-medical ME research all over, already because the dominance of the biopsychosocial model is at risk to be implemented and even strengthened. Thanks to the Health Council of the Netherlands.

Don’t let your fellow Dutch ME patients behind.

Cartoon Djanko

6. Grassroot

Tribunal Orders Release Of PACE Trial Data

(QMUL v the IC and **Matthees**)

The First-Tier Tribunal judgment in this case has just been published. QMUL's appeal has been roundly dismissed and therefore the Tribunal has decided that the requested data from the PACE trial should be released.
(http://bit.ly/2b96IAQ)

I have just skimmed the 48 pages of the judgment and so have only taken in a small amount so far. However, it appears that this is a defining moment for the international ME community and the PACE Trial. **Alem Matthees** (the original requestor of the data) has done an extraordinary job.

However, it is important to remember that, in theory, QMUL could still seek leave to appeal against this judgment to the Upper Tribunal so it will be a bit longer before we can be absolutely certain that this judgment will stand.

I will write a longer post with a more detailed analysis in due course (health permitting).

Background note for new readers
In March 2014, **Mr Matthees** sought some of the data from the controversial PACE trial (http://bit.ly/1SAcC92), using the process set out in the English Freedom of Information Act (FOIA) (http://bit.ly/2aQZQcM). This information is held by relevant public authority, Queen Mary University of London (QMUL) (http://bit.ly/2aXrhm7). QMUL refused to disclose the data.

In due course, **Mr Matthees** complained to the Information Commissioner (IC) (http://bit.ly/2beA5PG) who, in October 2015, ordered that the information be disclosed (http://bit.ly/2bk9aVE). QMUL appealed against the IC's decision; that appeal was heard by the First-Tier Tribunal (http://bit.ly/2aWnAar) on 20-22 April 2016 in central London. QMUL and the IC were legally represented and QMUL called witnesses to give evidence. **Mr Matthees** had been joined as a party to the proceedings. He was not legally represented and did not attend the hearing but made written submissions. Judgment is awaited.

[Note: the PACE trial, which was published in 2011 (http://bit.ly/2bC9KAc), relates to certain treatments for the condition known as "chronic fatigue syndrome" (CFS). CFS is often conflated (confusingly) with myalgic encephalomyelitis (ME) (http://bit.ly/1Wc37CC) and referred to as CFS/ME or ME/CFS, to the detriment of genuine ME patients. This is the situation in many countries and has been for decades; it is the cause of significant confusion and distress to many patients worldwide.

The results of the PACE trial appear to promote psychosocial treatments which many patients find either ineffective or actively harmful. As a result, some patients have been using FOIA to try to obtain the trial data in order to understand how these results were achieved. However, most requests have been denied and, five years on, most of the data is still unavailable.]

Valerie Eliot Smith, August 16, 2016

http://bit.ly/2aYkvK8

Thank You Alem

Perth resident **Alem Matthees** has done the international ME/CFS community proud with his advocacy and research efforts over the last few years.

In March 2014 **Alem** lodged a freedom of information request for anonymised data from the PACE trial. This information holds the potential for disclosing the truth behind disputed claims from the PACE research.

This was not the first request for PACE data and the Queen Mary University of London (QMUL) indicated to **Mr Matthees** from the start that they would not make the information available and that their refusal would be upheld by the Information Commissioner, just as previous requests had been. **Matthees** was not dissuaded and has persisted in his request at a significant cost to his own health.

In October 2015 **Alem**'s first appeal to the Information Commissioner resulted in an order for QMUL to release the data. QMUL refused and appealed that decision. In April 2016 that appeal was heard and now in August QMUL have again been ordered to release the data. It is an important outcome for patients around the world who have been subject to harmful medical interventions and is also a step toward greater transparency in clinical trials. (Note that QMUL do still have a right to further appeal.)

The success at both levels of appeal are a testament to the quality of **Alem**'s efforts in outlining the importance of releasing the data for independent analysis and clarifying the weaknesses in the PACE trial, including faulty analysis and dubious claims. Investigative journalist **David Tuller** has described **Alem**'s work as "incredible" and "amazing". We agree!

We encourage you to have a read of the articles listed at the bottom of this article for more detailed background information.

If you would like to send a thank you message to **Alem**, we have multiple options for you below. You can choose more than one option. Remember to keep your messages short and use neat handwriting to make them easier to read. We would love to see people writing their country or state somewhere in their thank you message. This will show how far around the world all of the support and appreciation is spread.

Privacy
Please remember that any thank you messages you post online are public and cannot be deleted. If you would like to send a private thank you message, then you can either email your message directly to us, or post us a card to deliver to ***Alem****.*

Group e-card

You can leave a public message on an online group e-card, which is similar to a guestbook. Head on over to http://www.groupcard.com/c/8l2DPogN98e to have a look and sign your message today.

Messages via email

You can send a thank you message via email which we will pass on to Alem, and which includes your name and email address. If you do not wish for your name and email address to be forwarded on, and only want us to forward your message, please indicate this in your email.
thankyoualem@mecfslymewa.org.au

Cards via postal mail

For those who like the old fashioned personal touch of a handwritten card, feel free to post one in to our office where we will later hand them* to Alem. Written messages and cards can be posted to:

Alem Matthees
ME/CFS and Lyme Association of WA
The Niche, 11 Aberdare Rd,
NEDLANDS WA 6009

(*)envelopes will be opened and the cards will be collated.

Thank you for showing your support and appreciation.

Share this page and details

Head to our Facebook page and reshare our Facebook post with all the details and a link to this web page.
http://bit.ly/2bn6ciQ

If you want to share this web page and all the above details with others so that they too can show their support, you can use this shortened URL to make it easy:
http://bit.ly/2b9JTLV

Source:
http://bit.ly/2bDP6uJ

Forgotten Plague

Our team at The Blue Ribbon Foundation has been busy this summer! Read about the exciting things happening with our website, fellowship, and screenings of Forgotten Plague!

Screenings, new platforms, and ramping up for 2017 fellowships! A busy summer at the Blue Ribbon Foundation!

This week we saw two very notable screenings occur. Center for Disease Control held a screening of Forgotten Plague to an audience of over 50 people on August 3.

A huge success for our fight to educate the health and medical profession on ME/CFS! **Jennifer McQuinston**, Deputy Director for High Consequence Pathogens and Pathology said, "*Overall, it was very well received. It is important for us to understand the history of the response to this illness, and to have a better understanding of just how profoundly some ME/CFS patients are affected*."

CEU Concepts of Atlanta screened Forgotten Plague at Emory University Hospital August 2 during the "Lunch and Learn" to an audience of nurses, social workers and case managers. Before the Q&A began, **Mary Prior** asked the audience who had ever heard of ME/CFS. Few people raised their hands.

A screening of *Forgotten Plague* for the CDC was well-attended, with over 50 people in attendance! Our team is thrilled so many were able to watch.

Hopefully by the end of this year, CEU Concepts will be able to offer Forgotten Plague on-line for nursing CEU credit! We see this as a large crack forming in the ice, and a breakthrough for patient advocacy.

We are also excited about the updates to our website! In July we launched a "Share your Story" platform for people in the ME/CFS community to write us to share their experiences.

Our first post came from **Ashley Davis**, who wrote about the heartache of her brother, **Whitney Dafoe**, missing her upcoming wedding.

From there, submissions quickly grew to include Whitney's mother, **Janet Dafoe**, and a heart-wrenching but upbeat post from **Jamison Hill** where he writes, "*It's anything but peachy and I'm a pretty optimistic guy, but I've found that hope and love always trump desperation and despair. Luckily I have hope and love through my friends, family and the MECFS community. And in this single moment in time that's all I need.*"

Ryan Prior speaking at the Millions Missing protest in May. Our team plans to attend the second round of protests in September. Watch for more updates on how you can participate!

All of the work we at the Blue Ribbon Foundation has one mission in mind: to foster an international dialogue toward finding the cause, cure, and prevention of neuro-immune diseases. We seek a world in which all medical students are educated about ME/CFS.

We do this through screenings of Forgotten Plague, and the Blue Ribbon Fellowship, which pays for medical students between their first and second year of med school to spend it with scientists who are at the forefront of ME/CFS research.

The majority of the work done at the Blue Ribbon Foundation is done voluntarily, and we need help funding the work we do to advocate for patients, either to fund the fellowship or pay employees to help us get programs running. Every little donation we receive is put to meaningful use, to further the education and research done on ME/CFS.

THE BLUE RIBBON FOUNDATION

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

Ryan Prior

August 1 Meeting With Dr. DeSalvo From HHS

On August 1, 2016 **Jen Brea**, **Terri Wilder**, **Carol Head**, **Jennie Spotila**, and **Mary Dimmock** met with **Dr. Karen DeSalvo**, acting assistant secretary for health. The purpose of the August 1 meeting was to impress upon **Dr. DeSalvo** how woefully inadequate the response to this disease from the U.S. Department of Health and Human Services (HHS) has been—that it is still too slow and too little—and to call on HHS to dramatically step up its commitment to ME.

Also participating in the meeting from HHS were **Andrea Harris**, **Dr. DeSalvo's chief of staff**, and **Dr. Nancy Lee**, deputy assistant secretary of health, from the Office on Women's Health.

The discussion focused on the need for a fundamental change and some options to achieve that change, such as a community/agency task force. We discussed the many reasons why such a fundamental change is needed: the level of debility of ME patients and the number of patients affected; the long history of neglect and stigma of the disease; the definitional challenges; the lack of research and researcher funding, which has had a chilling effect on researchers, academic centers, and pharmaceutical companies; the inaccessible and often inappropriate medical care and disbelief of doctors; and HHS's failure to meaningfully engage the community or follow up on the recommendations of its own advisory committee, the CFSAC.

As **Dr. DeSalvo** had seen in her experience in New Orleans after Katrina, these factors have left ME patients with a sense of being left for dead by all those who should be helping.

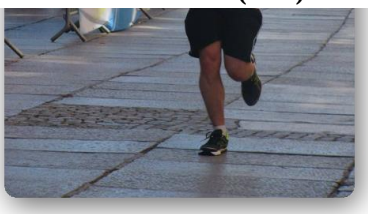
Dr. De Salvo asked a number of insightful questions about these issues and also asked about opportunities with efforts like the Precision Medicine Initiative. The other important topic that was discussed was the critical need to include ME in the transition plan for the next administration to ensure that current efforts do not stall.

Dr. DeSalvo agreed to reach out to the Precision Medicine Initiative and also to her counterparts at the Veteran's Administration and the Department of Defense to identify additional opportunities. She has agreed to meet again in October. In the meantime, we will follow up with the **Dr. DeSalvo**'s office with specific requests to get additional information and to follow up on suggestions made in the meeting. Examples include a request to NIH on its funding commitment by institute for the next three years and a summary of HHS's current and planned initiatives for this disease.

Submitted by **Emily Taylor**

Marathon Mike

Mike In Poland (4:25)



Running a marathon in each EU member country (28 currently) for Invest In ME (www.investinme.org) for biomedical research to treat and cure ME.

#7 Gdansk (Pol) 15/08/16

Wow that was tough. No shade throughout and a real challenge but got back in 4.25, a Summer PB at least. The finish was superb, amongst the best I've experienced, I ran over the line with my Invest In ME flag and got snapped a lot (hope to show soon). Cheers everyone for your good wishes, dedicating that race to everyone with ME but especially Juli Persson and our Polish ME Support Group. Off to drink beer on a boat now! You're next Belgium!

#8 Brussels (Bel) 02/10/16 - #9 Toulouse (Fra) 23/10/16
#10 Barcelona (Spa) 12/03/17 - #11 Luxembourg (Lux) 27/05/17

Change in schedule!

First up, I've booked my 2nd race for 2017 (to follow Barcelona Marathon on March 12th) and it's going to be the exciting Luxembourg Night Marathon. Exciting for many reasons, not least that it starts at 7pm which will no doubt be the latest kick off of all 28 that I do. It presents all kinds of dietary conundrums but hopefully I'll be able to deal with that, I get a lie-in I guess! Will be strange finishing a race at circa 11pm, eating dinner and going to bed!

ING Luxembourg Night Marathon, race number 11 of 28.

I've never been to Luxembourg and really don't know what to expect from it. Maybe some cobbled streets, smart alfresco restaurants and nice squares mixed in with some imposing business-district buildings? I'm not sure given the small population that I'm likely to make contact with any ME patients/groups but I'll certainly try to look and do what I can there.

Impulse buy

So, the other change is a very last minute entry into **Brussels Marathon** on October 2nd this year. I toyed with this a lot. Major considerations were cost and whether I could physically do 2 marathons in 3 weeks. But as I'm feeling good and could get cheapish flights and accommodation I thought I'd give it a go. I've been to Brussels before but only for a few hours before heading off to Bruges (where I proposed to my wife, Cat). We went to the main square and it looked amazing, I'm looking forward to going back and exploring it properly. I've already made contact with **Nancy Van Hoylandt** from the Belgium ME/CFS Association (already members of the European ME Alliance) so hopefully we can meet up and get some press/raise awareness on this one.

Mike Read more here: https://mikeseumarathons.blogspot.be/

In The Expectance Of Recovery

Misleading medical research and welfare reform by **George Faulkner**

This report came out in April but is still topical. A lot of it is about ME/CFS specifically. Highly recommended especially if you are in the UK.
http://www.centreforwelfarereform.org/…/misleadi…/00270.html
Release: 14.04.2016

Misleading medical research underpins disability cuts

A new report from the Centre for Welfare Reform explains how a current scientific controversy relates to the debate surrounding welfare reform and cuts to disability benefits.

The 'biopsychosocial' model of disability has played an important role in shaping recent reforms to disability benefits, yet important claims about the value of biopsychosocial approaches have been founded upon evidence which was always potentially misleading, and can be shown to have been exaggerated and distorted in ways that further misrepresent the reality of living with ill health and disability.

The biopsychosocial model has been used to create new obligations for those suffering from common health problems, such as the responsibility to "recognize that the sick role is temporary, in the expectation of recovery." However, it is not clear that these new obligations are reasonable. There is a danger that the belief that it is acceptable to encourage 'positive' views of ill health, disability and the efficacy of treatments have affected the design and reporting of medical research, encouraging unreasonable expectations of recovery.

A large and expensive assessment of biopsychosocial interventions, PACE, the only such trial to have received funding from the Department of Work and Pensions (DWP), provides a clear example of the problems which can affect academic research and distort our understanding of important issues. This report explains how problems with the design of this trial, and the presentation of its results, led to seriously misleading claims about patients' recovery rates.

In a Lancet commentary, reviewed and approved by the trial's researchers, patients were classed as having fulfilled a "strict criterion for recovery" even though the criterion used was in fact so loose that patients could have reported a worsening of all their symptoms and yet still have been classed as recovered.

Despite the problems identified with the presentation of results the trial's team continue to fight against releasing important data from this publicly funded research, with pre-specified primary outcomes remaining unreported. There have even been attempts to portray Freedom of Information requests about this trial as a form of harassment and stigmatise patients' concerns about the way in which the efficacy of potential treatments are being misrepresented to them.

With growing numbers of the international scientific community speaking out about the problems surrounding this trial, the Information Commissioner ruled that data which could correct many of the misleading claims made about the trial's results should be released. The trial's researchers and their institutions are appealing against this ruling, and an information tribunal is now due to take place on 20-22 April.

Dubious claims of biopsychosocial expertise have been used to serve the interests of influential institutions and individuals in government, medical research and the insurance industry, where concerns about money and reputation will inevitably compete with concerns about public health and patients' rights. While there is a growing popular awareness of the problems with nonblinded or poorly controlled trials being used to make unjustified claims about the value of alternative medicine, there is also a widespread failure to acknowledge that more mainstream rehabilitative approaches can be built upon a similarly poor evidence base. Greater honesty about this is needed, especially as attempts to cut welfare spending lead politicians to turn to rehabilitation as a key part of their policies on disability, and as something which may become compulsory for those claiming disability benefits.

This report, written by **George Faulkner**, shows the need for more critical engagement with biopsychosocial medical research. There is a danger that the lives of millions of people have been damaged by judgments based upon inaccurate and misleading claims, shifting power away from those suffering with ill health and disability by presenting policies which reduce their options and income as benevolent and empowering interventions.

Further reading

There are several published articles already which draw attention to the serious flaws in this research. In particular:

- PACE: The research that sparked a patient rebellion and challenged medicine http://www.stats.org/pace-research-sparked-patient-rebelli…/
- Results of the PACE follow-up study are uninterpretable http://www.thelancet.com/…/PIIS2215-0366(15)00551-9/fulltext
- An open letter to The Lancet, again http://bit.ly/2aVgUeu

Comments

Dr Simon Duffy, Director of the Centre for Welfare Reform said:
Misleading medical research is particularly dangerous when politicians are looking to blame social problems on minority groups, as they have with disabled people. While it is encouraging that some of the academic community is beginning to challenge this problem, it is sad that so many continue to fight to protect their own interests, and we are particularly grateful to George Faulkner for carrying out this important research.

The report is available to read online and download as a pdf here:
http://bit.ly/expect-recovery http://bit.ly/expect-recovery

Tom Kindlon

What Can Nurses Do To Support ME/CFS Patients?

Many nurses will encounter ME/CFS patients, particularly in primary care.

Nurses often have the capacity to form close therapeutic relationships with patients. Offering empathy and understanding to patients experiencing distressing symptoms is a central part of the nursing role.

In the absence of a cure for ME/CFS, nurses are well placed to provide supportive care. By understanding the symptoms generated by the illness, nurses may be able to offer patients better care.

ME/CFS severity varies from mild to severe and patients experience the illness in different ways. Some sufferers may be able to continue work on a limited basis, while others may be bed-bound, reliant on family and carers. Retired nurse **Greg Crowhurst**, a care-giver to a wife with severe ME/CFS, writes eloquently about how nurses may support patients with the illness.

Practical tips for nursing practice are as follows:

- Sufferers experience profound fatigue – nurses may be able to ensure patients are not left in waiting areas for long periods of time.
- Sufferers experience cognitive problems – nurses may assist patients in medical consultations, perhaps asking whether the patient understands the information provided.
- Sufferers experience sensory overload – nurses may ask patients if they require a quiet area or darkened room, or on home visits, nurses may avoid causing sensory distress by speaking quietly and ensuring mobile phones are turned off.
- Sufferers symptoms vary and fluctuate – nurses should liaise with family members or care-givers to get a personalised account of the patient's health status and care needs.
- Sufferers often feel disbelieved and anxious – nurses may reassure patients, particularly if they convey empathy and knowledge of the illness to the patient.

Nurses also have an another important role as advocates for ME/CFS patients, helping to liaise between the patient and doctor and also helping to promote the patient voice in the public domain. However, to fulfill this important role, nurses need to better understand the illness and to understand that ME/CFS is by no means 'all-in-then-mind'.

Most people feel fatigued following illness, stressful events, or after working long hours.

This is quite different from the severe fatigue and the range of symptoms that patients with ME/CFS endure, including: unrelenting painful joints and muscles; cognitive dysfunction, including memory problems; gastrointestinal complaints; transient paralysis; hypersensitivity to light, noise and touch; unrefreshing sleep; post-exertional malaise after minimal effort; and the inability to maintain an upright posture for any significant period.

Overwhelming evidence shows that these symptoms are not psychosomatic.

Nurses have a valuable role to play in assisting and supporting patients with ME/CFS.

Nurses should not underestimate the power and importance of the nursing position to relieve suffering, prevent harm and promote better care for ME/CFS patients.

Taken from: http://bit.ly/2aVgQMb

In Memoriam - Tom Jarrett

April 16, 1977-July 22, 2016
It is with very heavy hearts that we report the passing of our friend and fellow ME advocate, **Tom Jarrett**.

Tom came to MEadvocacy in the fall of 2014 looking for help with a protest against the Pathways to Prevention Workshop (P2P) at the National Institutes of Health (NIH). Despite being in constant pain and needing to lay in a zero gravity recliner, **Tom** organized on very short notice an awareness event, traveling 10+ hours to protest at the NIH, with himself, church and family members, including his wife and two young boys, in attendance. It was a very cold winter day. A cameraman from the documentary, "Canary in a Coalmine" stopped by to film.

Toms death was announced by his wife **Christine**:

"*Dear Friends,*
*It is with a heavy heart that I tell you that **Tom** passed away Friday morning. He took his own life. This came as a great shock to me as **Tom** never wanted this to be the way his story ended. He never wanted to dishonor God or to leave his family. The pain had grown so intense to a constant 10 unrelenting every minute of every day for years. He tried to hide the intensity of his pain from the boys and I so that we would not suffer along with him. He left a lengthy letter explaining his heart that I will share soon*."

A Tribute to M.E. Patients, by **Tom Jarrett**: https://youtu.be/MR1qizwZf8k
Tom tells how **Louie Zamperini** shows the ultimate respect for author and M.E. patient **Laura Hillenbrand**, and makes the case for why all patients with M.E. deserve respect.

https://youtu.be/eAGMN5PFOfY : in his KnoW M.E. Challenge **Tom** challenges **Gordon** to say three times Myalgic Encephalomyelitis without erring

This video has been posted by his wife **Christine** on December 31, 2014:
https://youtu.be/mmhHLrAskCA

One of their sons, **Andrew Jarrett** (8 years old) tells his idea to give Christmas money to help people like his Dad with ME (Myalgic Encephalomyelitis).

He asks others to join him. **Andrew** was inspired to do this December 2014 after watching a 2-part news feature on **Pauline** and **Adele**, sisters from Germany with ME.

Part 1: http://bit.ly/2b7tsni and
Part 2: http://bit.ly/2bV4Azg

He challenges people to give to 3 groups making a difference for people with ME right now:

(1) The End ME/CFS Project
Fundraising for a Cure.
https://ww.openmedicinefoundation.org/the-end-mecfs-project/

(2) The Microbe Discovery Project: Dr. Ian Lipkin
http://www.microbediscovery.org/

(3) National PR Campaign for ME
http://bit.ly/2bLWfMR

With thanks to MEAdvocacy & ME/CFS Memorial Page
https://ww.facebook.com/groups/MEMemorial/

Finding The Difference

Finding The Difference Between Accepting My Chronic Pain And Giving Up

I have a chronic pain condition. It is incurable, but can be managed, they say. It comes and it goes. Sometimes it seems to come and stay. When it goes, I spend quite a bit of time being afraid of when it will show back up. So I manage, because it is the only choice I have. And I assure you that I have run through the choices. Doctor after doctor, pill after pill, acupuncture, therapy, oils, diet and in my greatest of desperation, even brain surgery, but the pain persists. I have gotten great at hiding it except on the days I can't.

I have a sweet friend who is also a nurse. She used to text me daily asking how my pain was that day. I always answered, often with a number. One day, I looked at the phone and was tired of talking about pain. I texted her back and told her that she was so kind, but to start asking me how my life was instead of how I felt.

Those two questions seem almost the same.
How do you feel?
How are you?

But they are so different. I think that I got so used to answering the first question that I forgot how to live the second.

Everything I read tells me how important acceptance is to an illness. That at some point I need to use all the energy I keep putting into fighting this pain into living. Books, therapists and friends who have been here parrot the same thing. They tell me to just figure out who I am here. That this version of me will be different, but no less full, if I just let it. They ask me if I even know who I am here.

So I start to tell them. I tell them the girl here juggles doctor's appointments, pills and manages her pain. I think about the things I have lost and can no longer do and the silver lining in me even tries to say a few things I have learned in the process. But this is just a list. This is a comparison of who I was before and who I am forced to be after. They remind me again to figure out who I am here. I keep answering the same way.

One day in the car I turned the radio down and I said ever so quietly over the loud of the traffic, "I might never get better."

In the moment, I wasn't sad or angry. I was not even sure that I believed it. I think it was something that I just needed to hear in my own voice. Nothing magic happened. I didn't feel any better or different or worse. However, I felt like this quiet part of me just breathed some kind of sigh of relief, like it had been let out of a dark closet and given some space next to me. I sat there in the quiet for a few seconds, wondering what should happen next.

I said it again, this time more fearfully, worried that maybe saying it a second time makes it more real. My voice, I have learned, doesn't make things any more or less true. They just are. Or they aren't.

That moment was months ago. It was not some magic turning point. Actually, that day I just turned the radio back up and sang along. I put that tiny piece of acceptance right back in the dark closet I had let it out of. Like my pain these days, it comes and goes. Recently I have let it stay a little bit longer each time.

I have been struggling to figure out the difference between acceptance and giving up. I am willing to find the first, but not do the other. Just like the similar questions my friend asks me, they are not the same thing. One whispers truth in the car, the other keeps asking for help. They are both good voices to have. They both help give me answers to that question that keeps coming up — who am I here? I have been so worried that being here means I can't go anywhere else. Eventually, I remember that on a map, here is always where you begin.

Michelle Hurst,
writing about chronic pain for
The Mighty http://bit.ly/2b38W4Q

The Age of Ignorance

This was a difficult post to write as I was unsure whether or not to ignore such ignorant writing concerning ME, depriving it of the oxygen of publicity, or to confront the idiocy. Such is the level of scientific illiteracy displayed in the book, 'Exhaustion, A History' by **Anna Katharina Schaffner**, I felt I had no choice but to adopt the latter option.

Schaffner is another supporter of the BPS model and, given the number of times they are mentioned, a keen admirer of both **Sir Simon Wessely** and **professor Edward Shorter**. Concerning the title, I'm not sure about the age of exhaustion but given such books are able to be published and that a large proportion of US citizens believe **Donald Trump** is a viable presidential candidate, I believe the age of ignorance would be a more accurate description.

Reading through her monograph it is notable how often tenuous supposition is presented as fact. Her thesis is 'interesting', it's certainly the first time I've been accused of suffering from 'cultural pessimism', although as an example of the inane waffle ME sufferers have to endure from the ignorati it's hard to better.

Her comprehension of history is limited – she believes the recent banking crises are 'unprecedented in their severity and scale.' The South Sea Bubble, the economic problems in Weimar Germany, the economic Depression of the 1930s, suggest otherwise

Her introduction outlines various issues confronting inhabitants of the modern world, 'these serious social, political and environmental concerns, all of which centre around the idea of exhaustion.' Do they? It's a hypothesis but not one supported by much evidence; it's certainly the first time I've read that Global Warming is a consequence of exhaustion.

Schaffner enjoys quoting **Edward Shorter**, an unpleasant historian who counts a day without abusing ME sufferers as wasted and whose knowledge of the body's physiological processes is limited. His psychosomatic model of disease is apparently 'thought provoking'; personally I'd say unscientific and abusive. **Dr Schaffner** trots out the 'fashionable diseases' line, so beloved of **Wessely** and co., of which ME apparently is one.

Shorter is a historian, and makes a frequent show of demonstrating his scientific illiteracy. I find it fascinating that the likes of **Shorter** and **Schaffner** (who studied General and Comparative Literature) so readily expose their ignorance of basic scientific contexts. I studied for a BSc in the Natural Sciences and an MSc in Medicinal Chemistry, because science, especially molecular biology, fascinates me.

It is when **Schaffner** writes about a 'bacterial-infection model' (possibly she means germ theory but she's quoting from a book I have not read so I must plead ignorance) that she exposes her breath-taking level of ignorance re infectious disease. **Schaffner** mentions malaria, tuberculosis, ulcers and gastritis to support her claim that 'psychological factors play a major role in whether the body is able to fight off these bacteria': nothing in that sentence is true.

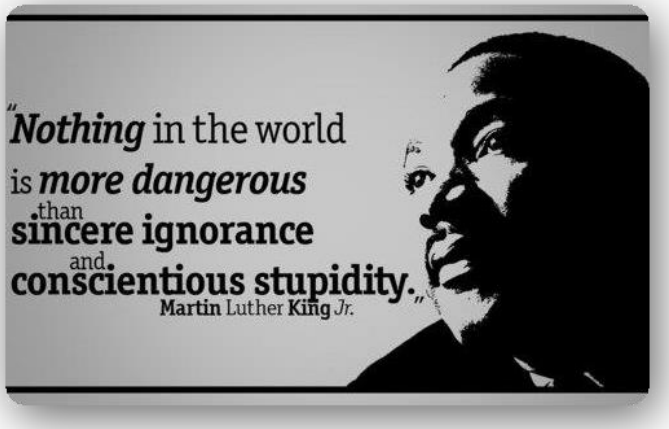
Given her contempt for diseases caused by pathogenic bacteria, I do wonder if **Dr Schaffner** uses antibiotics when suffering from a severe bacterial infection, presumably not, instead ensuring she has the correct psychological attitude to ward off such irritating germs. If only she'd been available in the 14th century, so many lives could have been saved.

Schaffner regurgitates another favourite of supporters of the psychogenic disease model, questioning why ME sufferers become so upset with a psychiatric diagnosis. Many patients are upset about a psychiatric diagnosis for ME because ME is not a psychiatric condition. Cancer or Parkinson's disease patients, even someone suffering with influenza, would not be happy with a psychiatric diagnosis either; **Schaffner** is being willfully disingenuous and abusive here.

There is no other chronic and debilitating condition for which sufferers are continually told their illness and symptoms are imagined. I'm confident that if MS patients were told their disease did not exist (of course they once were) and only required a course of CBT for a cure, they would also be angry towards the medical professional that propounded such beliefs.

Schaffner is not original, she follows a long, undistinguished line of cod philosophers who think they can explain away chronic illness in a non-scientific fashion, and why not? Real science is hard; molecular biology is hard, signalling pathways are complex as is the immune system. Why waste time and energy studying this when you can claim it is all imagined, after all, you have a good chance of gaining a knighthood without any of the hard work.

Taken from a blog of **Utting-Wolf Spouts**
Full text: https://uttingwolffspouts.com/2016/08/02/the-age-of-ignorance/



Canary In A Coalmine

Last week, at the TEDSummit in Banff, Canada, I gave the first TED talk about myalgic encephalomyelitis (ME), the disease I have been battling for the last five years.

Memorizing a 2600 word, sixteen-minute talk taxed my brain in ways I did not imagine was possible. I had to pull out every single trick I have just to get on stage. During the talk, more than once I ran into a brick wall where there was nothing but blank – no words, no thoughts. But everyone stood and silently cheered and sent up love and support when I stumbled. And I made it! To the end! It was hard because the old me, the me that I was and still am, wants to nail it, wants everything to be flawless. And I realized on stage that it's OK to let what is broken be broken. That it's more important to be true.

I may never understand exactly what alchemy happened in that room. The support has been incredible, overwhelming, and has given me more hope than I have ever had since the day I first got sick that we can change the conversation. And with visibility and recognition I believe will come the care and research that millions have been waiting for, for decades.

The success of the talk has stepped up the timeline for our outreach campaign. We had hoped to bring on professional public relations and strategic support after the documentary film's festival premiere in 2017. However, this fall when the talk goes live, it has the potential to reach millions around the world in dozens of languages. We are already receiving media inquiries; offers of partnership and support that our tiny team just does not have the capacity to absorb. I have been told by many who have spoken before at TED that we will be flooded with thousands of emails.

I need your help to take full advantage of this unique moment. Help us grow our team. Please consider making a donation today.

Jen
Donate here: http://bit.ly/2aVmuxI

#Millionsmissing – Round 2

Join us for **#MillionsMissing Round 2** this September 27th

On May 25th, you took to the streets in 13 cities around the world. You helped us trend the #MillionsMissing hashtag. Together, we made history.

This September 27th, we want to get louder, bigger, stronger. More cities, more mobilization, more press coverage.

Will you join us?

Fill out this form: http://bit.ly/2bsrsCP or visit http://www.meaction.uk

Catalogue Articles

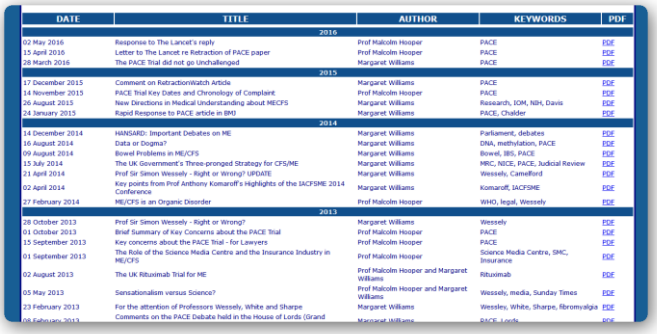
Catalogue articles **Margaret Williams** & **Prof. Malcolm Hooper**

http://www.margaretwilliams.me/

Articles on ME/CFS by **Margaret Williams** and **Professor Malcolm Hooper**

1986-2016

With contributions from **Eileen Marshall** (1994-2007) and others.



DATE	TITLE	AUTHOR	KEYWORDS	PDF
	2016			
02 May 2016	Response to The Lancet's reply	Prof Malcolm Hooper	PACE	PDF
15 April 2016	Letter to The Lancet re Retraction of PACE paper	Prof Malcolm Hooper	PACE	PDF
28 March 2016	The PACE Trial did not go Unchallenged	Margaret Williams	PACE	PDF
	2015			
17 December 2015	Comment on RetractionWatch Article	Margaret Williams	PACE	PDF
14 November 2015	PACE Trial Key Dates and Chronology of Complaint	Prof Malcolm Hooper	PACE	PDF
26 August 2015	New Directions in Medical Understanding about MECFS	Margaret Williams	Research, IOM, NIH, Davis	PDF
24 January 2015	Rapid Response to PACE article in BMJ	Margaret Williams	PACE, Chalder	PDF
	2014			
14 December 2014	HANSARD: Important Debates on ME	Margaret Williams	Parliament, debates	PDF
16 August 2014	Data or Dogma?	Margaret Williams	DNA, methylation, PACE	PDF
09 August 2014	Bowel Problems in ME/CFS	Margaret Williams	Bowel, IBS, PACE	PDF
15 July 2014	The UK Government's Three-pronged Strategy for CFS/ME	Margaret Williams	MRC, NICE, PACE, Judicial Review	PDF
21 April 2014	Prof Sir Simon Wessely - Right or Wrong? UPDATE	Margaret Williams	Wessely, Camelford	PDF
02 April 2014	Key points from Prof Anthony Komaroff's Highlights of the IACFSME 2014 Conference	Margaret Williams	Komaroff, IACFSME	PDF
27 February 2014	ME/CFS is an Organic Disorder	Prof Malcolm Hooper	WHO, legal, Wessely	PDF
	2013			
28 October 2013	Prof Sir Simon Wessely - Right or Wrong?	Margaret Williams	Wessely	PDF
01 October 2013	Brief Summary of Key Concerns about the PACE Trial	Prof Malcolm Hooper	PACE	PDF
15 September 2013	Key concerns about the PACE Trial - for Lawyers	Prof Malcolm Hooper	PACE	PDF
01 September 2013	The Role of the Science Media Centre and the Insurance Industry in ME/CFS	Prof Malcolm Hooper	Science Media Centre, SMC, Insurance	PDF
02 August 2013	The UK Rituximab Trial for ME	Prof Malcolm Hooper and Margaret Williams	Rituximab	PDF
05 May 2013	Sensationalism versus Science?	Prof Malcolm Hooper and Margaret Williams	Wessely, media, Sunday Times	PDF
23 February 2013	For the attention of Professors Wessely, White and Sharpe	Margaret Williams	Wessley, White, Sharpe, fibromyalgia	PDF
08 February 2013	Comments on the PACE Debate held in the House of Lords (Grand	Margaret Williams	PACE, Lords	PDF

The articles in this catalogue have been available on the internet or elsewhere for many years but now for the first time have been brought together in one place.

The intention is to provide a valuable historical resource for researchers, advocates, patients and anyone interested in the illness Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. These articles illustrate how the "Wessely School" have ignored the biomedical science on ME/CFS for almost 30 years.

Margaret Williams is the pen-name used by someone who spent her professional life in the British National Health Service (NHS), latterly in a senior clinical capacity for many years until severe ME put an end to her career. For professional and personal reasons, she does not wish her own name to be in the public domain.

Malcolm Hooper is Professor Emeritus of Medicinal Chemistry at the University of Sunderland in the UK, and is an advocate for ME/CFS patients.

He chaired the International Invest in ME Conference in 2008, 2010, and 2011. He is also the Chief Scientific Adviser to the British Gulf War Veterans Association.

Source : https://www.facebook.com/VoicesfromtheShadows/?fref=nf

How To Get The Caregiver of Your Dreams

I am home bound with ME/CFS and sometimes bedridden and I am in an amazing home care program that has totally saved my life!

This is a great program that gives people with disabilities and chronic illnesses free help in their home with personal care (eating, bathing, dressing, mobility) plus household help (shopping, cleaning, cooking, doctor's appointments).

This program is especially amazingly great because you **can choose your own caregiver**. You can choose a friend, a loved one, a family member, or someone else. They will get paid for caring for you. These programs are often called "self-directed care" or "consumer-directed care" or "participant-directed care." If you are a Veteran they are called "veteran-directed care"

I applied for this program after my CFS/ME became much worse and I was unable to care for myself. Now I have a caregiver every day who helps me with everything I need. I was able to select someone I know and like and it is a great match for me. It takes a lot of stress and burden off my family and loved ones, and it is a comfort for me to know that if my caregiver ever moves away or gets a different job I will always be able to find a new caregiver.

Self-directed home care programs also save the government money. The purpose of this program is to keep people out of nursing homes, and allow them to live in their own homes and get help from a caregiver of their choice. The government saves money because nursing homes are so expensive.

This program has made such a difference in my life that I wanted to share it with other people with CFS/ME who are disabled and not able to care for themselves. Most people do not know it exists. There is very little information online about how these programs are run, and pretty much nothing at all about how to apply and qualify.

If you know other people who are home bound, bedridden or unable to care for themselves, please share this with them.

Self Directed Home Care Around The World

I live in the US, so this article is mostly geared towards the US. However, it appears that similar programs exist in other countries. I would be interested to hear from anyone in this program in other countries.

Please write and let me know about your experience and I can update this section. These programs are often called self-directed home care.

Here are a few leads:

- Program in Australia (http://bit.ly/2b8PG4o).
- Programs in Canada (http://bit.ly/2bOxWiT).
- Program in New Zealand (http://bit.ly/2bGVLYD).
- Programs in Scotland (http://bit.ly/2b65dQK).
- Program in England (http://bit.ly/2byt7oY)

Here are two tips: Ignore if it says the program is for seniors. Call them anyway! Sometimes they will take younger people with disabilities. Also, pay a lot of attention to the personal care questions. Please read what I have written in the section below. Even though I am writing about the US, these rules appear to be the same in other countries.

Thank you for reading. Please let me know if you have any ideas to change, improve or add to this post. If you have any questions, I am happy to share what I know.

Kit Cat on the forum of Health Rising

For further info, also about this program in the USA: click the source of this article http://bit.ly/2bsfgmY

The Importance of Patient Advocacy

ME/CFS Alert, Episode 81: **Llewellyn King** interviews **Tom Kuhn** about how important it is to stand up for patients.

https://youtu.be/t62E4E268gU

Tom Kuhn is the chairman of the Edison Electric Institute, the largest electrics trade organization in America. His position also comes with being a super-lobbyist with open access to American presidents, members of congress and ambassadors.

Aside from that, and the main reason for the interview, **Tom** has been active within the MS movement for 30 years, at the time motivated by a good friend having MS. At first he worked raising funds and also as being the head of New York's MS community; later on he became chairman of the national MS association in the United States.

In the interview, he explains among many things that the MS association in New York has existed since 1930, and how patients felt so embarrassed about their illness to the point of keeping it a secret. Nowadays there are approximately 400,000 patients in the USA who are very well organized and are in contact with politicians, which made it possible for research into cause and treatment conducted by the National Institutes of Health in 2015 to receive a 94-million-dollar subsidy.

The budgets for 2016 and 2017 are 98 million dollars. **Tom** has somewhat developed his interest in ME and thinks that, given MS being of equal severity as ME, a similar subsidy should be due. The pitiful 5 million with which the NIH subsidized ME/CFS-research in 2015 is barely conducive, according to him.

A few noteworthy points in the interview:
Raising awareness: one body with a very solid website for information (about e.g.: doctors, the illness, possibilities, advocacy). "It is remarkable what one can achieve simply by bringing people together".

Slogan: the MS movement has the slogan "Stop the destructive illness of MS", but knows many side purposes:

- To inform doctors;
- To offer assistance to family members of an MS sufferer;
- Fundraising;
- Raising awareness of patients' interest, on a state level, but also locally.

Political influence: the most efficient way of reaching your own parliament is an approach via a member of parliament familiar with the illness, willing to be a poster person of sorts. Should you have any friends in the parliament; you should absolutely make use of that.

ME and the NIH: several illnesses pertaining to the central nervous/immune system are related to each other (MS, ME, Lupus, Parkinson, dystonia).

Anytime a research group receives a subsidy for a study, an increasing number of people are pondering what that research could mean for a related illness. (Example: several ME researchers succeed in soliciting sizable subsidies for a study into Gulf War syndrome/veteran illness, and at the same time use it to delve into ME).

Celebrities: it can be helpful to have a famous person as your case representative, but it is not a necessity.

7. Karina Hansen, Save4Children

Help **Karina Hansen** – donate to Save4Children

http://let-me.be/page.php?11 is the donation-button for all major languages
The charity Save4Children has been created by the editors of the ME Global Chronicle (http://www.let-me.be) and helps parents whose children have been forced into psychiatric wards by authorities, to try and set them free by legal procedures.

After the release in 2015 of the German girl who came to be known as **Joanna**, it was decided to focus the fund entirely on **Karina Hansen**, who is kept hostage of the Danish psychiatric system since February 2013. There's hardly any news to report on **Karina**, save that there's ongoing contact with her parents **Kitty** and **Per**, and the new most proficient lawyer **Christina Poblador** is studying the case and trying to find openings. Donations made to this fund will presently solely be used to provide financial support for expenses, needed to try and set free **Karina**.

A sum of € 100, = has been donated since the publication of MEGC 17. Obviously if mrs. **Poblador** will continue to work on **Karina**'s case, fees to her will have to be paid. So please continue to donate. We published a very detailed and extensive article by Valerie Eliott Smith in MEGC 16 (http://let-me.be/request.php?31, p. 48-52)

So all the reason to continue to donate to the fund: http://let-me.be/page.php?11

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

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

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

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

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

8. Science

Rich' Reviews: NEW Form Of MAGNESIUM: Can It Help Brain Fog And FM Pain?

Background

Cognitive function tends to declines as we age. For most people the decline is modest. This "semi-normal" decline is thought to be due to a decrease in the ability of cells to communicate with each other through connections called synapses. A similar defect is seen with Alzheimer's disease.

Magnesium for fibromyalgia

Animal studies show that one way to increase the number and function of synapses is to raise the brain's level of the mineral magnesium. When scientists increase brain magnesium in lab rats, the rats become smarter. They can think more rapidly and accurately than they did before.

But, most forms of oral magnesium don't pass easily from the blood into the brain. An exception is a new form of magnesium developed by a research team from MIT specifically for the purpose of passing from the blood into the brain. This form is magnesium threonate. It is being developed by Neurocentria, Inc., a pharmaceutical company, under the brand name of MMFS-01.

The Study

Neurocentria's team recently published a very important study. Their results strongly suggest that MMFS-01 can substantially improve mild cognitive function in aging humans. MMFS-01 is not yet commercially available. However, a "generic" magnesium threonate is available from the Life Extension Foundation under the brand name of Neuro-mag. Likely other "generics" are or will soon be available.

What is truly remarkable about the MMFS-01 study is that improvement in over-all cognitive function was seen within just six weeks. Improvement continued through 12 weeks, the full length of the study. Subjects treated with placebo did not improve overall.

Volunteers for the Neurocentria study were age 50 to 70. All had test score evidence of mild cognitive impairment. Twenty-five subjects took MMFS-01 and 26 took placebo. The treatment dose was between 1.5 and 2.0 grams per day in divided doses. Four different cognitive tests were taken before treatment and again at six and twelve weeks. These tests measured executive function, working memory, attention and a concept called episodic memory.

Findings

With magnesium threonate executive function significantly improved compared to placebo at 6 and 12 weeks. Working memory improved significantly at six weeks but at 12 weeks the placebo group had improved also.

So, the difference for working memory was no longer statistically significant. Attention improved in the MMFS-01 group compared to baseline, but this improvement was not statistically better than for those taking placebo. Episodic memory improved with MMFS-01 by week 12, but was not significantly better than that seen with placebo.

However, when overall cognitive ability was calculated by combining results from the four tests, subjects taking MMFS-01 scored significantly better than subjects taking placebo. This was true at week 6 (P=.017) and at week 12 (p=.003). As important, subjects taking MMFS-01 who had the greatest increase in red blood cell magnesium levels were alsomost likely to show major cognitive improvement. There were no major side effects.

Separate research suggests that magnesium might also help for fibromyalgia pain. This benefit might be because magnesium tends to inhibit the activity of NMDA receptors. Activation of NMDA receptors is believed to be one mechanism that creates fibromyalgia pain. A recent open label study from Mayo Clinic found that transdermal magnesium chloride spray taken twice daily for 3 weeks was followed by a reduction in fibromyalgia pain.

Take Home Thoughts

Should physicians treating FM or ME-CFS "brain fog" by offer magnesium threonate as a potential treatment?

The arguments against:

- We don't know whether brain fog in fibromyalgia or ME-CFS has any relationship to the cognitive decline that is common with aging.
- We have only one clinical study to support the beneficial effects of magnesium threonate.

The argument for:

- Brain fog is a major problem for our patients
- We have no proven treatments
- For most (but not all patients), side effects from magnesium are minimal—mainly diarrhea if we get the dose up too high.

Should patients with FM or ME-CFS try magnesium threonate on their own? I strongly recommend that all patients work with their doctor. Certain patients should not take extra magnesium, especially those with any degree of kidney dysfunction. Also, it would be useful to obtain a baseline red blood cell magnesium level and to monitor that level as treatment proceeds.

Since MMFS-01 is not available, using Life Extension's or other generic equivalents is reasonable. Of course, ideally, some angel would fund a proper controlled study. But, as usual, that's not likely to happen anytime soon.

If any readers decide to work with their doctors and try magnesium threonate, I and other readers would be grateful to learn whether or not it helped. In the absence of research funding the best way for us to learn which treatments help will be for each of us to report our personal anecodatal experience along to each other. We look forward to your comments.

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

OMF ME/CFS Severely Ill Big Data Study Update: Sample Collection Completed

OMF is excited to announce that sample collection has been completed for the ME/CFS Severely Ill Big Data Study. The completion of sample collection means we now have the most multi-faceted and down-reaching data ever gathered to analyze and test in our search for a cure.

The clinical research team selected candidates, and traveled to patients' homes to draw samples and conducted EEG, sleep and cognitive studies.

The process included processing hundreds of sample tubes immediately after collection, biobanking samples, testing samples locally, sending out for tests to other leading laboratories, keeping track of every detail and recording the results.

We are also tremendously grateful to the patients that gave of themselves to make a big personal sacrifice for the pursuit of groundbreaking science.

Read more: http://bit.ly/1ItLneh

OMF Metabolomics and Genetics Study Update: Sample Collection Beginning

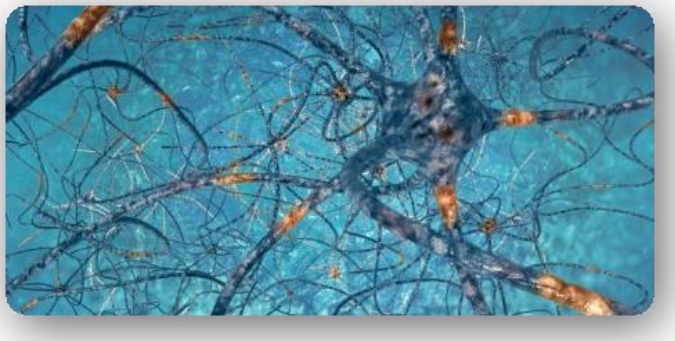
Patients have been previously chosen and sample collection is underway for this exciting study which will take a look at the inner world of cells.

In May 2016, we launched an Expanded ME/CFS Metabolomics and Genetics Study led by **Dr. Robert Naviaux** (at UC San Diego), and **Dr. Ron Davis** (director of OMF's Scientific Advisory Board), in collaboration with **Dr. Eric Gordon**, **Dr. Paul Cheney**, and the Stanford Genome Technology Center. The purpose of this study is to validate earlier findings of a possible diagnostic signature for ME/CFS by measuring metabolites and to evaluate the contribution of genetics to the variation in observed metabolic signatures in this disease.

Previously, **Dr. Naviaux** and his team completed an initial study of 90 participants (both healthy controls and patients) that showed abnormal metabolites in patients. The abnormalities suggest the mitochondria is in hypo-metabolism due to a chronic cell danger response state in ME/CFS patients.
Read more: http://bit.ly/2b6NETd

Neuromuscular Strains

In the diagnosis and assessment of ME/CFS, there is a great need for simple objective measures that can differentiate the condition from other chronic illnesses, particularly after 24 or 48 hours when the effects of exercise can become most apparent.



To date, researchers at Antwerp University Hospital have found upper limb muscle recovery is be slower in ME/CFS patients, and they have also shown that 'timed-loaded standing' with a dumbbell (intended to simulate the performance of the torso during everyday activities) is shorter in women with ME/CFS than others, revealing a relative lack of endurance in the muscles of the trunk and arm.

Similarly, an ongoing program of research at Johns Hopkins University has also shown that simple physiological challenges can have abnormal effects. These researchers have uncovered preliminary evidence that ME/CFS patients' symptoms can be aggravated by 'neuromuscular strain', and that young people with the illness have more areas of the body with an 'abnormal range of motion' than healthy youngsters.

In fact, in the young patients, they found that adding a longitudinal strain to the nerves and soft tissues provoked symptoms, suggesting that the nervous system and connective tissues of the ME/CFS patients is less compliant, i.e. more sensitive to mechanical movement, than normal.

Continuing its investigations, the group's most recent report describes work on 60 people with ME/CFS and 20 controls, who underwent either a real neuromuscular strain for 15 minutes (passive supine straight leg raise or SLR) or a sham leg raise that minimised strain. The SLR, which involves raising and holding up one leg while the person lies on their back on an examination table, is most often used for low-back examinations; in fact, it is a test of nerve root irritation, most often seen in sciatica or lumber disc herniation. In this case, however, it was used only to give a mild to moderate strain to the muscles and nerves.

Their most interesting finding was that ME/CFS patients undergoing the SLR, which actually strained their muscles and nerves, had more body pain and concentration difficulties during the procedure than those with the sham leg raise. Not only was the mean composite symptom score significantly greater during the manoeuvre (difference of 3.52 points) in the SLR group than the sham leg raise group, but it was also greater after 24 hours (4.30 points). Also, more patients in the SLR group reported at least a two-point increase in at least three symptoms after 24 hours (44 versus 18%, respectively).

As the authors say, "a sustained longitudinal strain applied to the neural and soft tissues of the lower limb was associated with an increased intensity of cardinal symptoms during the manoeuver and for up to 24 hours afterwards".

They explain the results by pointing to the fact that, in everyday life, the nervous system has to adapt to changes as the body moves, including changes in fibre length and the sliding of nerves within their protective coat of fascia. Passive SLR exerts a pulling force on a large range of structures (lower limb peripheral nerves, dorsal root ganglia, lumbosacral nerve roots, etc.) and probably gives an elongation strain to the entire length of the spinal cord. Such increased mechanical strain may also cause the spinal blood vessels to narrow, and may stimulate mast cells to release biologically active substances, such as histamine, that worsen both acute and delayed symptoms.

Prof Kevin Fontaine, a co-author of the report, says that the findings "have practical implications for understanding why exercise and the activities of daily living might be capable of provoking CFS symptoms…If simply holding up the leg of someone with CFS to a degree that produces a mild to moderate strain is capable of provoking their symptoms, prolonged or excessive muscle strain beyond the usual range of motion that occurs during daily activities might also produce symptom flares."

Overall, the results suggest that increased mechanical sensitivity may be a factor in the symptoms people with ME/CFS experience after even mild exertion, and the researchers' next steps are to tease out the particular effects of strains to muscles and nerves, and to elucidate whether neural or muscular factors predominate.

Day-to-day impairments in basic functioning of people with ME/CFS – which can be easily measured objectively in the consulting room, and can be provoked by simple manoeuvres like the SLR – tend to be overlooked by healthcare professionals today, but may well have diagnostic or pathophysiological value.

Source: http://www.meresearch.org.uk/news/neuromuscular-strain/

Non Coeliac Gluten Sensitivity: Intestinal Cell Damage & Systemic Immune Activation

A new research paper titled 'Intestinal cell damage and systemic immune activation in individuals reporting sensitivity to wheat in the absence of coeliac disease' has just been published in the BMJ Open Gastroenterology Journal 'Gut'. Many individuals with ME/CFS have gluten or wheat sensitivity, often anecdotally reporting a decrease in some symptoms with removing gluten from their diets. Many patients also report that removing diary or following a FODMAPs diet or other diets - have decreased some ME/CFS symptoms. However, this is not the case for everyone with ME/CFS and it is far from touted as a 'Cure'.

This new research paper by **Dr Armin Alaedini et al.** from the Department of Medicine at the Columbia University Medical Center, has some interesting findings in people who are sensitive to wheat but do not have Celiac Disease. Note this is a different part of Columbia University from **Drs. Lipkin** and **Hornig** at the Center for Infection and Immunity.

Abstract

Objective Wheat gluten and related proteins can trigger an autoimmune enteropathy, known as coeliac disease, in people with genetic susceptibility. However, some individuals experience a range of symptoms in response to wheat ingestion, without the characteristic serological or histological evidence of coeliac disease. The aetiology and mechanism of these symptoms are unknown, and no biomarkers have been identified. We aimed to determine if sensitivity to wheat in the absence of coeliac disease is associated with systemic immune activation that may be linked to an enteropathy.

Design Study participants included individuals who reported symptoms in response to wheat intake and in whom coeliac disease and wheat allergy were ruled out, patients with coeliac disease and healthy controls. Sera were analysed for markers of intestinal cell damage and systemic immune response to microbial components.

Results Individuals with wheat sensitivity had significantly increased serum levels of soluble CD14 and lipopolysaccharide (LPS)-binding protein, as well as antibody reactivity to bacterial LPS and flagellin. Circulating levels of fatty acid-binding protein 2 (FABP2), a marker of intestinal epithelial cell damage, were significantly elevated in the affected individuals and correlated with the immune responses to microbial products.

There was a significant change towards normalisation of the levels of FABP2 and immune activation markers in a subgroup of individuals with wheat sensitivity who observed a diet excluding wheat and related cereals.

Conclusions These findings reveal a state of systemic immune activation in conjunction with a compromised intestinal epithelium affecting a subset of individuals who experience sensitivity to wheat in the absence of coeliac disease. Science Daily has covered this so far, and it would be surprising if this does not make more headlines considering the number of people who now go gluten free in the world.

This new paper is interesting with respect to ME/CFS due to many being sensitive to gluten and other foods, and the theories regarding 'Leaky gut', but there are more points of interest. There was a recent paper published about ME/CFS that analyzed similar inflammatory and immune system markers by **Dr Maureen Hanson et al.** from Cornell University. We posted about this recent paper titled `Reduced diversity and altered composition of the gut microbiome in individuals with myalgic encephalomyelitis/chronic fatigue syndrome' and there seems to be some similar findings the results section states:

Results
We observed elevated levels of some blood markers for microbial translocation in ME/CFS patients; levels of LPS, LBP, and sCD14 were elevated in ME/CFS subjects. Levels of LBP correlated with LPS and sCD14 and LPS levels correlated with sCD14.

Through deep sequencing of bacterial rRNA markers, we identified differences between the gut microbiomes of healthy individuals and patients with ME/CFS. We observed that bacterial diversity was decreased in the ME/CFS specimens compared to controls, in particular, a reduction in the relative abundance and diversity of members belonging to the Firmicutes phylum.

In the patient cohort, we find less diversity as well as increases in specific species often reported to be pro-inflammatory species and reduction in species frequently described as anti-inflammatory. Using a machine learning approach trained on the data obtained from 16S rRNA and inflammatory markers, individuals were classified correctly as ME/CFS with a cross-validation accuracy of 82.93 %.

Some good news regarding this research by **Dr Armin Alaedini**, is that he has teamed up with ME/CFS specialist **Drs. Bateman** and **Vernon** from the Bateman Horne Center to work further in this area specifically on ME/CFS. A $200,000 grant from the NIH was awarded for the research, check this out on the project on the NIH reporter.

Source: The Microbe Discovery Project http://bit.ly/2aRZYDO

9 Potential Diagnostic Tests For ME/CFS

Highlights of the IACFS submission to NIH RFI on new research strategies
By **Russell Logan**

Though there are as yet no readily available, well-accepted, objective diagnostic tests for ME and CFS, work is ongoing in several key areas to develop one.

One objective measure, the 2-day CPET (http://bit.ly/2aTzzvA), is gaining acceptance and has been used with success in legal presentations. A drawback to this measure is its potential for harming patients.

And there are good subjective or self-reported diagnostic measures (http://bit.ly/2bpLNZx), though these are of limited value in clinical diagnosis.

In its response to the recent NIH solicitation for input into new research strategies for ME/CFS (http://bit.ly/2bng1LW), the International Association for Chronic Fatigue Syndrome/ Myalgic Encephalomyelitis (IACFS/ME) documented emerging opportunities, research needs, and continuing challenges, but in particular highlighted promising work on developing a diagostic test or biological marker for the illness (http://bit.ly/2bqwxuo).

The IACFS/ME (http://bit.ly/2bpMbaj) authors — **Lily Chu**, **Fred Friedberg**, **Staci Stevens**, **Steve Krafchick**, and **Jon Kaiser** — noted: "Some tests might not be suitable for clinical use but might provide a gold standard test for research purposes [and] may also provide clues to the pathophysiology of this disease and even to future treatments."

They identified 9 key areas of investigation requiring urgent need of government support and funding.

- Low natural killer cell activity
- 2-day repeated cardiopulmonary exercise testing
- Neuropsychological testing related to information processing
- Tilt table testing
- Neuroinflammation
- Unrefreshing sleep, heart rate variability, and sympathetic predominance
- Familial studies
- Energy metabolism issues and lactate processing in muscle and brain
- Post-infectious triggers

Source: http://bit.ly/2b7Oo8p

Note: the links to short descriptions of the 9 key areas mentioned can be found in **Russell Logan**'s blog itself, with the link mentioned above

New Theory On Neuro: AfME's Latest Research Round-Up

Each month, Action for M.E. Volunteer Pharmacist **Emily Beardall** explains some of the recently published research studies on M.E. Please note this is not an exhaustive list – we have selected to highlight the studies that we think are most likely to resonate with the daily lives of those affected by the condition. We will also report separately on further studies of significance, as and when they are published.

You can search online (http://bit.ly/2bfcHon) directory PubMed for most studies about M.E. published in peer-reviewed journals. The following studies were published online between 22 June 2016 and 21 July 2016. In each case, we have used the same name for the illness as the researchers publishing the paper.

New theory for the underlying mechanism in neurological conditions

An article in Molecular Neurobiology (http://bit.ly/2b7SqxH) suggests that the underlying problem in chronic neurological conditions such as CFS might be due to a cell chemistry process called "hypernitrosylation." The chemical nitric oxide is created when cells are damaged and plays a part in cell communication to regulate the immune system and alert our body to repair damage.

Nitric oxide itself can be harmful to cells, so the levels of this chemical are kept in check by a system called "nitrosylation," where proteins mop up any excess to prevent further damage to cells. In chronic inflammation this safety mechanism is overwhelmed, leading to hypernitrosylation. After reviewing the literature on this subject the authors propose that hypernitrosylation leads to the problems found in CFS with autoimmunity, the autonomic nervous system, and the way mitochondria provide energy for cells.

Brain scans in teenagers with CFS

A study published by PLOS ONE (http://bit.ly/2b7Sr4G) compared the brain scans of teenagers with CFS and healthy controls of the same age. The scans revealed less activity in the salience network which links areas of the brain concerned with interpreting information. Less activity was found in the part of this network responsible for attention and alertness in the teenagers with CFS, which coincided with their high fatigue scores.

The activity in the part of the salience network responsible for dampening pain sensation was also lower, so this might explain an increased sensitivity to pain. These results have also been found in previous studies of adults with CFS and the authors conclude that the abnormal activity in these brain networks may contribute to CFS symptoms:
"These findings may also have broader implications for how abnormalities in fatigue and pain perception arise from a complex interplay among brain networks and stress-related alterations in chronic fatigue syndrome."

Muscle strain worsens symptoms in CFS

This study, also published by PLOS ONE (http://bit.ly/2aLetOw), looked at the effects of a real and fake straight leg raising exercise for 15 minutes in CFS patients and controls. The CFS patients doing the real exercise experienced a significant increase in their fatigue, body pain, light-headedness, concentration difficulties, and headache scores during the exercises and at 24 hours afterwards. The authors suggest this is due to increased mechanical sensitivity in CFS.

Mast cells in moderate and severe CFS/M.E.

A study published in the Asian Pacific Journal of Allergy and Immunology (http://bit.ly/2bfdxBo) compared mast cells (a type of white blood cell) in the blood of people with moderate and severe CFS/M.E. with those of healthy controls. Mast cells release histamine, cytokines, and other substances involved in allergic reactions and inflammation. Although this was a small study, it found significantly more of one type of mast cell present in the blood of the people with CFS/M.E.

In addition to this, the people with severe CFS/M.E. had many more immune system receptors on the surface of their mast cells compared with those with moderate CFS/M.E. and healthy controls. The authors suggest further investigation is needed to determine the role of mast cells in CFS/M.E. symptoms.

Blood volume in CFS

A study in Open Heart (http://bit.ly/2bfdaqI) looked at blood volume in CFS patients and found that the volume of blood pumped by each heartbeat was much less than in the healthy controls, and that the total volume of blood in the bloodstream was also much lower. The thickness of the heart muscle wall during contraction was also less. Patients with more severe CFS had even lower blood volumes. The authors point out this must not be related to deconditioning, or being unfit due to being immobile, because the findings weren't related to the length of time the patients have been ill:
"*This study confirms an association between reduced cardiac volumes and blood volume in CFS. Lack of relationship between length of disease, cardiac and plasma volumes suggests findings are not secondary to deconditioning. The relationship between plasma volume and severity of fatigue symptoms suggests a potential therapeutic target in CFS.*"

Another study this month also looked at the hormones which control blood volume, this time in the Journal of Cardiology (http://bit.ly/2aTCap7). The volume of blood in our bloodstream is partly regulated by the kidneys filtering fluid from our blood into urine. The amount of fluid retained is controlled by the renin-angiotensin and antidiuretic hormone systems.

The study found that the levels of these hormones were much lower in CFS patients, meaning less fluid is retained, giving a lower blood volume. Half of the patients in this study responded well to desmopressin, which is a medicine that helps to increase blood volume by restricting the amount of urine produced.

Source: Action for ME http://bit.ly/2b39VlA

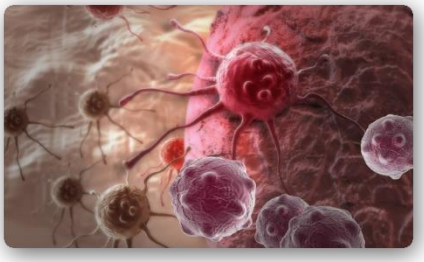
Found: A Potential New Way to Sway the Immune System

A new international collaboration involving scientists at The Scripps Research Institute (TSRI) opens a door to influencing the immune system, which would be useful to boost the effectiveness of vaccines or to counter autoimmune diseases such as lupus and rheumatoid arthritis.

The research, published August 1, 2016, in The Journal of Experimental Medicine, focused on a molecule called microRNA-155 (miR-155), a key player in the immune system's production of disease-fighting antibodies.

"It's very exciting to see exactly how this molecule works in the body," said TSRI Associate **Professor Changchun Xiao**, who co-led the study with **Professor Wen-Hsien Liu** of Xiamen University in Fujian province, China.

An Immune System Tango



Our cells rely on molecules called microRNAs (miRNAs) as a sort of "dimmer switches" to carefully regulate protein levels and combat disease.

"People know miRNAs are involved in immune response, but they don't know which miRNAs and how exactly," explained TSRI Research Associate **Zhe Huang**, study co-first author with **Liu** and **Seung Goo Kang** of TSRI and Kangwon National University.

In the new study, the researchers focused on the roles of miRNAs during the critical period when the immune system first detects "invaders" such as viruses or bacteria. At this time, cells called T follicular helpers proliferate and migrate to a different area of the lymph organs to interact with B cells.

"They do a sort of tango," said **Xiao**.
This interaction prompts B cells to mature and produce effective antibodies, eventually offering long-term protection against infection.

"The next time you encounter that virus, for example, the body can respond quickly," said **Xiao**.

Identifying a Dancer

Using a technique called deep sequencing, the team identified miR-155 as a potential part of this process. Studies in mouse models suggested that miR-155 works by repressing a protein called Peli1. This leaves a molecule called c-Rel free to jump in and promote normal T cell proliferation.

This finding could help scientists improve current vaccines. While vaccines are life-saving, some vaccines wear off after a decade or only cover around 80 percent of those vaccinated.

"If you could increase T cell proliferation using a molecule that mimics miR-155, maybe you could boost that to 90 to 95 percent," said **Xiao**. He also sees potential for using miR-155 to help in creating longer-lasting vaccines.

The research may also apply to treating autoimmune diseases, which occur when antibodies mistakenly attack the body's own tissues. **Xiao** and his colleagues think an mRNA inhibitor could dial back miR-155's response when T cell proliferation and antibody production is in overdrive.

For the next stage of this research, **Xiao** plans to collaborate with scientists on the Florida campus of TSRI to test possible miRNA inhibitors against autoimmune disease.

In addition to **Xiao**, **Huang**, **Liu** and **Kang**, authors of the study, "A miR-155-Peli1-c-Rel pathway controls the generation and function of T follicular helper cells," (http://bit.ly/2bjtsvD) were **Cheng-Jang Wu** and **Li-Fan Lu** of the University of California, San Diego; **Yi Liu** and **Alexander Hoffmann** of the University of California, Los Angeles; **Shunbin Xu** of Wayne State University; **Guo Fu** and **Nengming Xiao** of Xiamen University; **Ye Zheng** of The Salk Institute for Biological Studies; and **Hyun Yong Jin**, **Christian J. Maine**, **Jovan Shepherd**, **Mohsen Sabouri-Ghomi** and **Alicia Gonzalez-Martin** of TSRI.

Source: http://www.scripps.edu/newsandviews/e_20160815/xiao.html
Madeline McCurry-Schmidt,
News and Views of The Scripps Research Institute

9. Severe ME

GroupCard


groupCARD™
share the love
NOW PRINTABLE!
Greg and Linda Crowhurst received the greeting card you signed and wanted to say thank you!
A message from Greg and Linda Crowhurst:
Thank you all so very much for sending us these beautiful well-timed messages and a huge thank you to Leela for creating it specially for us. Each message means the world to us and they have lifted our spirits greatly. We have felt so battered recently, the love has overwhelmed us. Bless you all, we send you all our best love too and miss you, love Greg and Linda xxx

10. 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

2016 SMCI Webinar Series

The Solve ME/CFS Initiative (SMCI) is pleased to announce the second half of its webinar series for 2016. The series, which features thought leaders from academia, industry, and government agencies, is always free of charge and will normally take place once a month on **Thursdays** at **1:00 p.m. eastern time** / **10:00 a.m. Pacific time** (unless otherwise specified).

Registration for these webinars will be available soon at
http://solvecfs.org/2016-webinar-series

Webinars are scheduled as follows:
September 1: **Maureen Hanson**, PhD, professor of molecular biology and genetics at Cornell University

September 8: **Beth Unger**, MD, chief of the Chronic Viral Diseases Branch (CVDB) of the Division of High-Consequence Pathogens and Pathology (DHCPP) at the National Center for Emerging and Zoonotic Infectious Diseases (NCEZID), a part of the Centers for Disease Control and Prevention (CDC)

October 20: **Christopher Armstrong**, PhD, from the Bio21 Institute, Department of Biochemistry and Molecular Biology at the University of Melbourne

November 10: **Anthony L. Komaroff**, MD, Simcox-Clifford-Higby professor of medicine at Harvard Medical School and senior physician at Brigham and Women's Hospital in Boston, Massachusetts

December 15: **Zaher Nahle**, PhD, MPA, vice president for research and scientific programs at the Solve ME/CFS Initiative

TBD: **Mady Hornig**, MA, MD, director of translational research at the Center for Infection and Immunity and associate professor of epidemiology at Columbia University Medical Center's Mailman School of Public Health

Other webinars addressing urgent and timely matters in the field of ME/CFS may also be added, as needed.

Please check our website at http://SolveCFS.org/webinar or our Facebook page at https://facebook.com/SolveMECFSInitiative for registration notifications, links, and updates on future webinars.

Submitted by **Emily Taylor**

11. ME And Children

News from Tymes Trust

The big news is that we have won the case in the Supreme Court against the Scottish Government's imposition of a state guardian (Named **Person**) for all children in Scotland. The Judgement was handed down in July. It was to have been a compulsory scheme overseeing all Scottish families, dubbed a "state snooper" by the media and panned by families, some of whom have already had bad experiences with the pilot schemes that have been tried. We joined with the Christian Institute to fight this. The Act that had been passed in 2014 has now been struck down and is not law.

Lesley Scott of Tymes Trust says about this ruling:
https://twitter.com/tymestrust/status/765188486378946560?s=02

"*It puts parents back in charge of the raise of their children. That's one of the major issues that we had with it: the potential within this legislation for the state to take over in the prescription of medical procedure and education provision was in fact huge.*

And what this ruling does, is actually put parents back in charge of that, and in making what they consider to be the best decisions for their children".

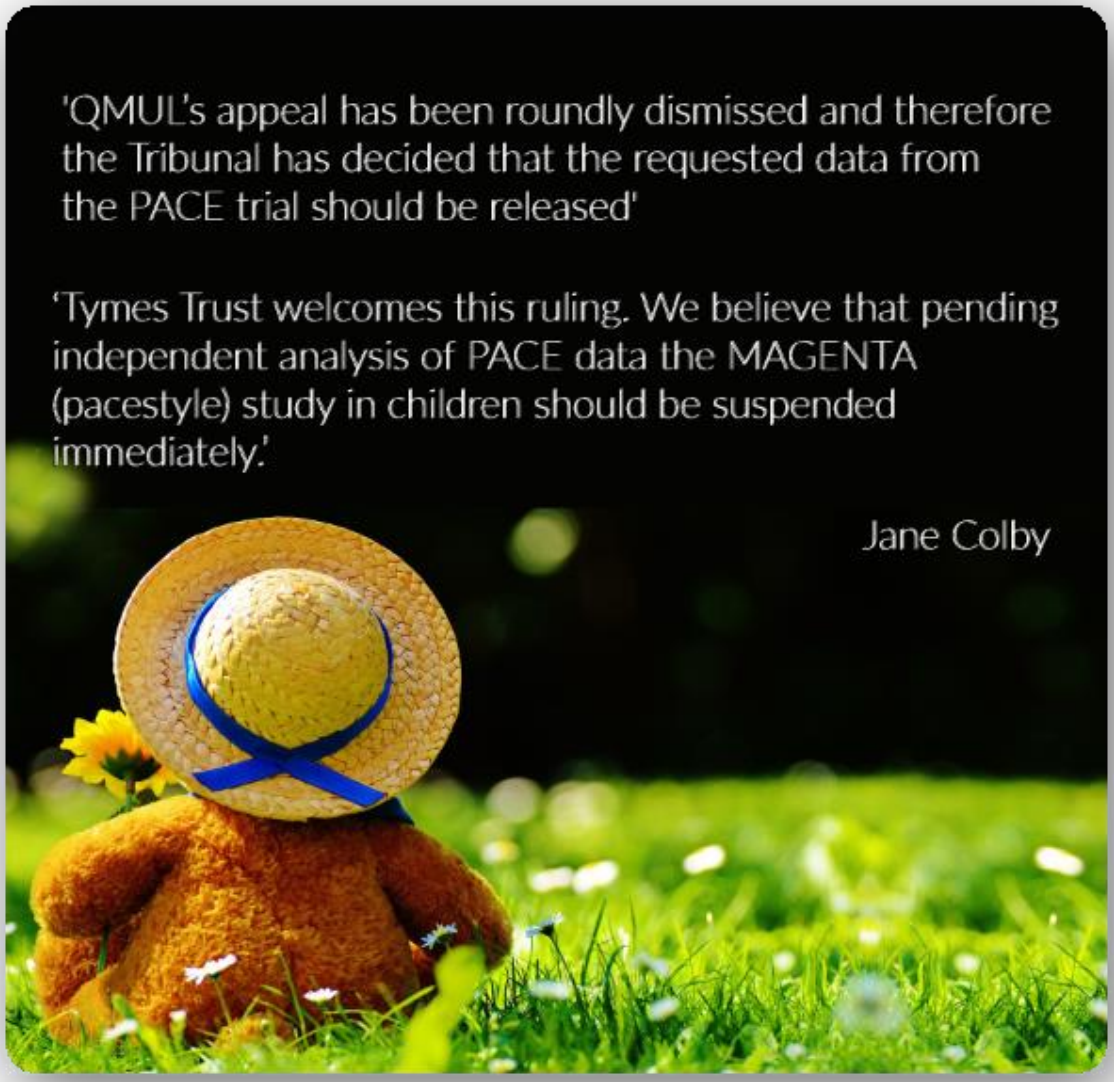
"**The T Rex In The Room**"

Jane Colby's speech given at the House of Lords on June 30th to introduce our new leaflet for families and GPs.
http://www.tymestrust.org/pdfs/mecfsseidintro.pdf

Plus the leaflet itself: "Paediatric ME, CFS, SEID For Families and GPs". Are there risks with graded exercise therapy? NICE Guidance and education. Printed copies free for a limited period as part of Tymes Trust's **Dr Alan Franklin** memorial event. http://www.tymestrust.org/pdfs/mecfsseid.pdf

Also:
"The Quick Tour of ME and Tymes Trust Services" (Updated 2016)
http://www.tymestrust.org/pdfs/quicktour.pdf

Submitted by **Jane Colby**


'QMUL's appeal has been roundly dismissed and therefore the Tribunal has decided that the requested data from the PACE trial should be released'
'Tymes Trust welcomes this ruling. We believe that pending independent analysis of PACE data the MAGENTA (pacestyle) study in children should be suspended immediately.'
Jane Colby

Help Karina – Donate To Save4Children

http://let-me.be/page.php?11 is the donation-button for all major languages

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

After the release in 2015 of the German girl who came to be known as **Joanna**, it was decided to focus the fund entirely on **Karina Hansen**, who is kept hostage of the Danish psychiatric system since February 2013.

There's hardly any news to report on **Karina**, save that there's ongoing contact with her parents **Kitty** and **Per**, and the new most proficient lawyer **Christina Poblador** is studying the case and trying to find openings.

Donations made to this fund will presently solely be used to provide financial support for expenses, needed to try and set free **Karina**.

A sum of € 100,= has been donated since the publication of MEGC 17. Obviously if mrs. **Poblador** will continue to work on **Karina**'s case, fees to her will have to be paid.

So please continue to donate.

We published a very detailed and extensive article by **Valerie Eliott Smith** in MEGC 16 (http://let-me.be/request.php?31, p. 48-52)

12. News from

Australia

Support meetings Queensland
September …. 7th September 2016
10.00am – 12.00pm Caring and Sharing

October…. 5th October 2016
10.00am – 12.00pm Caring and Sharing

Dr Price Room, 6 Little Street Toowoomba, Queensland
Phone/Fax: (07) 4632 817

Source: The Queensland Communicator

Write local politicians

Now that the Federal election is done and dusted and before MPs get too comfortable in their seats, it's a good time to write to your local politician to see what they plan to do to support ME/CFS.

Statements were made during budget talks in May about possible changes to the DSP and issues around housing and funding for research are still on the agenda.

You might like to use the template on our website at http://bit.ly/2byuzIj or draft your own comments.

Source : https://www.facebook.com/EmergeAustraliaInc/

UniSA 2-Day Testing Study

Researchers at the University of South Australia (http://bit.ly/2byv30I) are looking for ME/CFS sufferers and healthy controls aged 18-65 to take part in a study which aims to investigate how non-invasive heart rate measures can be used to monitor post-exertional malaise.

The study employs a 2-day maximal testing protocol, which has previously been shown to provide information on post-exertional malaise in ME/CFS patients, and may in addition be able to provide evidence on a reliable biomarker within the ME/CFS population.

Testing will all take place at the University of South Australia High Performance and Exercise Physiology Clinic (http://bit.ly/2b8Rl9W) located at the UniSA City-East campus (http://bit.ly/2bCtmju) on the corner of North Terrace and Frome Road (http://bit.ly/2b8Ruuk). Testing will consist of one short familiarisation session (45 minutes), and two maximal testing sessions (90 minutes each). The maximal testing sessions need to be completed on consecutive days.

The researchers are also looking for matched healthy control participants to take part in the study. Healthy controls need to be healthy and injury free, and of a similar age/body mass index/gender as the CFS/ME participants.

The ME/CFS patients will get a detailed report on their post-exertional malaise, and for the healthy participants they get information on their VO2 max and overall fitness. Usually a consult of this type costs $150 at our clinic, so they get that part for free!

For further information, please see the information sheets below, or contact:
Mr Daniel Clark (Daniel.Clark@unisa.edu.au, ph 8302 1365); or
Mr Max Nelson (Max.Nelson@unisa.edu.au, ph 8302 1502).

Download:

ME 2-day test Info sheet  (DOCX, 26 KB) (http://bit.ly/2bCtq3C)

ME 2-day test Info sheet 

(PDF, 442 KB) (http://bit.ly/2br08rh)

Submitted by **Mel Smith**

Belgium

There are some associations that claim to be committed to ME here in Belgium. Some of them even get government grants. And especially those funded associations only organize coffee clatches for their own members.

When you visit their website, you'll see immediately what I mean. The last update is dated two years ago. So much cannot be expected from such associations. Maybe that's what is expected; receiving money to do nothing.

On the other hand, there are associations that are really committed to ME-patients, selflessly and without grants. "Contradictio in terminis".

The WUCB organizes an information day in Antwerp on October 15th (subject to change). This will already be the fourth in a row. We're working hard at the program, but note already that it will certainly be well worth it.

For more information, you can always request the last situation on the website www.stopdediagnosecvs.be

Millions Missing Belgium is a fact

A member of the Wake-Up Call Movement association has committed to set up a Facebook- and Twitter page for the benefit of the global ME (Myalgische Encephalomyelitis) protest Millions Missing. (An initiative of #ME-action.net)

Do you have a Facebook- and/or Twitter account, then share as much as possible the pages with friends and family to raise awareness to the global and large scale protest Millions Missing.

Facebook: https://www.facebook.com/millionsmissingbelgium
Twitter: https://twitter.com/MMBelgium
Any questions can be sent by mail to info@millionsmissing.be

Millions Missing Belgium supports Millions Missing Holland on 27 September 2016: Because too little lime is left to prepare carefully for a protest in Belgium, it is decided to support the protest in the Netherlands (The Hague) via Millions Missing Belgium.

Next year we'll think about how the protest in Brussels can be organized.

How can you help?

- By sending shoes to the activists in the Netherlands.

All information can be found below this message or on the Facebook pages of:
MM Belgium https://www.facebook.com/millionsmissingbelgium
MM Holland https://www.facebook.com/MillionsMissingHolland/?fref=ts

- Come to support the protest in person in The Hague at September 27th.

Millions Missing Holland will campaign in The Hague at 27 September from 10h till 16h.

- Send all your information to info@millionsmissing.be and we put the label on a pair of donated shoes.

We'll check whether there is sufficient interest to deploy a bus via this question survey: https://www.survio.com/survey/d/L3T5Q8R2N6E2Q4N2R

Eddy Keuninckx

Canada

National Youth Forum on Disability

(for Canadian residents aged 15-30)

There will be a one-day disability forum for young people aged 15 to 30. It will be held in Ottawa sometime in November. Applications to attend must be received by September 15th. If you are chosen, travel and accommodation costs will be covered.

More information and the application form can be found by clicking on "national youth forum": http://bit.ly/2buSCIj

If you want to attend, please apply directly (though the National ME/FM Action Network would appreciate knowing about your application!) If we can help you apply, do not hesitate to get in touch.

If you would like to participate but think the travel would be too strenuous, please feel free to suggest to the organizers that you be allowed to participate by internet. This is done with many conferences and we are very surprised that this was not put forward as an option.

If you are interested in participating but your health would not allow it, please feel free to notify the organizers. We are not sure that they are even aware of the number of young Canadians who are homebound or bedbound and this could be a real eye-opener for them.

Opportunity for Individual Input

The key question for you to address is – what would make you feel more included in Canadian society? To find out how to submit your input, click on "how to participate".at http://bit.ly/2bvbyaA

Source : https://www.facebook.com/MEFMActionNetwork/

Denmark

The Board of Health in Denmark is still doing its best to turn all physical diseases into functional diseases. They use 'big time' manipulation and demagogy. They don't even want to mention the name ME anymore. As if the disease will disappear if they don't mention it. The two ME-centers of knowledge have changed their names into Centers of Functional Diseases.

They didn't collect any knowledge about ME at all, so from that aspect it's okay, but I'm sure they changed the names so they don't have to admit that ME exists. They are openly dishonest and all the HPV-girls are being sent to centers where they are being treated with mindfulness, cognitive therapy and training, and are getting the diagnosis functional disease.

But we don't give up..

The other day we got 274 comments + answers on functional diseases on a fb-post of the social workers, where someone employed at **Per Fink**'s Research Clinic for Functional Diseases in Århus, tried to promote functional diseases. She tried to coerce the social workers to spot the 'functionally ill persons' in the job-centers and then recommend them to be treated by psychiatrists.

And it is NOT right a social worker does something like that, so we created a 'raid'. The social workers on fb did not react, but we copied all the comments and sent them to their union.

See: http://bit.ly/2c1GiU8 (in Danish, ed.)

So small victories are here now and then. A lot of people now know about functional diseases and we are trying to create more awareness. Our goal is to 'dry out' the clinics from new 'functional disorder customers'. That's what we can do when we can't change the things from the top to bottom, like from the Board of Health downwards.

Submitted by **Bente Stenfalk**

Germany

Stop the blinkers policy!

Katharina Voss' letter to the science magazine "Spektrum" which recently published an article on Maureen Hanson latest research results. (**Maureen Hanson** has detected an altered gut microbiome in ME/"CFS" patients.)

I'm pleased when there's a report on biomedical studies of Myalgic Encephalomyelitis! But ME patients ask at times, how many years it will probably take until the public - and that includes the majority of the science journalists - realizes that this disease is not about "chronic fatigue". ME patients are no more tired than other chronically ill people. But no one would argue that the main characteristic of cancer is fatigue and no one would get the idea to describe cancer as a "chronic cancer-fatigue syndrome"!

Myalgic Encephalomyelitis (ME) - classified by the ICD under code G93.3 - is a serious chronic neuro-immunological multisystem disorder that occurs both sporadically and in epidemics and clusters. [**Hyde**, 1992; **Dowsett** & **Colby**, 1997]. Core symptom of the disease is not fatigue, such as the misleading and inaccurate term Chronic Fatigue Syndrome (CFS) suggests. Core symptom is the pathological fatigability of muscles, which often leads to a dramatic exhaustion after only minor strain. [Ramsay 1986]

This exhaustion (or neuro immune post-exertional malaise) is called post-exertional neuro-immune exhaustion, in short PENE [**Carruthers et al**., 2011] because the overwhelming exhaustion is accompanied by an abundance of neuro-immune symptoms including e.g. flu-like symptoms and extremely debilitating cognitive dysfunction. [Carruthers et al., 2012].

Already for some time, many patients are well aware that, for instance, the gut microbiome in ME patients is affected, not least because of the symptoms they suffer from. Even though it is good to hear that the study presented by **Maureen Hanson et al**. has again been able to present possible further biomarkers, studies like this one consistently divert from investigating the true cause(s). And thus distract from much needed treatment options.

It was the very same **Maureen Hanson**, who discovered in 2011 (retroviral) MLV-like gag sequences with infective potential in an ME-patient cohort from the state of New York. And exactly these murine leukemia retroviruses which have nothing to do with the laboratory artifact XMRV might cause a damaged gut microbiome. (Let us not forget that the disease occurs both in epidemics and in clusters!).

Also in patients with other retroviral infections (HIV and HTLV 1) changes of the microbiome have been found. [**Openshaw**, 2009; **O'Brien et al**., 2013; **Ruscetti et al**., 2008]

So **Hanson** could know better and plead for treatment trials with HIV drugs, which in individual cases are reported to bring patients in remission. Instead, she muses about diet recommendations and probiotics - but thousands of ME patients have already tested these options, however, without striking success.

So why does a researcher like **Maureen Hanson** concentrate on the effects of the disease, although she would have the potential to get to the bottom of its cause? Quite simply because doing so would be politically incorrect and they would simply not be able to raise any research money for such studies.

However, it is irresponsible how politics evade causal investigation, because the number of sufferers is constantly on the rise and more and more children are - some of them seriously – affected by it. Only within the last 2 ½ weeks, the international Internet community of ME patients has lost four fellow patients who died much too early because of the sequelae of the disease.

Time to take off the blinders!

Katharina Voss, July 1, 2016

Source: http://bit.ly/2bFQKMs

Sweden

Swedish ME-seminars

Västerbotten County Council and RME are inviting those interested to a Swedish seminar on ME/CFS in Umeå, held October 19, 2016.

This will be a one-day seminar on ME/CFS, organized by Västerbotten County Council and the National Association of ME patients (RME), with speakers from ME/CFS clinic at Large Sköndals Neuro Rehab in Stockholm; University College London, UK; and Bateman Horne Center, USA.

The seminar will be held in the Bergasalen at Norrland University's hospital. It is also possible to participate via video link at the following locations: Gävle Hospital, Hudiksvall hospitals, Östersund Hospital, Sollefteå Hospital, Örnsköldsviks hospital, Sundsvalls hospitals, Lycksele hospital, and Skellefteå hospital, Landstingshuset Lulea.

Registration: http://www.rme.nu/umea-2016 (Swedish)

Seminar on ME/CFS in the County Hall in Stockholm, October 20, 2016

In Stockholm, a Swedish seminar of half a day will be held on October 20, 2016

In addition to several of the above speakers **Dr. Øystein Fluge**, oncologist involved in ME-research at Haukeland Hospital in Bergen, Norway will provide an update on the ongoing ME-treatment study with the immunomodulatory agents Mabthera (rituximab) and Sendoxan (cyclophosphamide).

Registration: http://www.rme.nu/sthlm-2016 (Swedish)

More information on the conferences:
Umeå: http://bit.ly/2beafze
Stockholm: http://bit.ly/2bhSeNN

Source: http://www.rme.nu/

The Netherlands

On August 8, 2016 in the Netherlands a new fb-wall has been launched, called ME Centraal:
https://www.facebook.com/MECentraal/home

Support and stimulate them and like their page, we'd suggest. Until an English version will be produced as well, google-translate suffices to understand the (Dutch) posts and columns published right now. In their introduction it reads:
"This is not about trains or train stations, even if such images may arise in one's thoughts.

The mission statement of this page, and perhaps eventual website - if enough desire warrants it - is to finally offer a platform which is exclusively about Myalgic Encephomyelitis, completely irrespective of the argument of whether brain inflammations have been evidenced. The term CFS needs to become obsolete.

Severe ME-day - August 8th, today - is our starting point of this initiative. The day on which we take a moment out of our day to show awareness for those whose lives are - out of the public eye - being debilitated by ME, as well as those who have already fallen victim to it. We will keep repeating the severities of ME like a mantra and make it dwell through everyone's minds. If ME proves to be lethal, it's largely due to the lack of knowledge surrounding it.

A now vaunted statement by **professor Leonard Jason**: the names attributed to illnesses can stigmatize. Every one of us knows that that is more than definitely the case with the name CFS. As long as concessions are being made to the name "ME" by calling it CFS, or alternatively ME/CFS, the positions of ME-sufferers are being compromised.

Because it has been a point of engagement to use the biopsychosocial approach to conditions that are hard to assess in order to deem ME a SOLK (somatic insufficiently explicable condition). Due to that having happened over the course of the last decades, there now exists a worrisome over-representation of SOLK peddlers in the committee of the Dutch Health Council who have to re-evaluate ME, giving them a big opportunity to print their watermark on it. The consequences will only make themselves known.

The argument that many ME-patients were diagnosed with "CFS", which isn't an illness, but merely a symptom uncharacterized by ME, is a very shoddy argument to cut corners on the name. This just illustrates the intellectual poverty pertaining to ME, and undermines the true severity of the illness, which is only evolving its destructive property over time.

The Dutch didn't collect 56,000 valid signatures to have ME be recognized as a biomedical condition and patients be given the proper diagnose and treatment for nothing.

Information being published and exchanged here will thus be about ME. For clarification: We're taking liberty to translate CFS as ME in (discussed) publications based upon either: The International consensus criteria (2011) or the Canadian Consensus Criteria (2003) (both can be combined with the Fukuda criteria).

Welcome to ME Central. Where ME patients are the focal point. No other platform to replace what already exists. A platform where no concessions are being made to trivializing names, but where the possible causes for what's already being referred to as the plague of the century are the center of attention. That's up to research to show. In clearly defined ME cohorts.

Textual contributions (also in English) to: mecentraal@gmail.com
Tweets: @MECentraal"

#MillionsMissing Day of Protest in the Netherlands

#MillionsMissing, an initiative of MEAction Network, is an international protest by patients with Myalgic Encephalomyelitis (ME), their caregivers and their loved ones for improved diagnosis, better treatment, more biomedical research and better training of doctors. Action group MillionsMissing Holland is part of this global protest.

Preparations for a Dutch #MillionsMissing Day of Protest were launched in June 2016. The action group created a Facebook page (393 followers) and a Twitter channel (155 followers) where a lively exchange is taking place.

Permission to demonstrate in our "Hofstad" The Hague has been granted. This then finalizes the date, time and place of the protest manifestation:
Tuesday, September 27th from 10:00 to 16:00 pm
at the Plein in **The Hague**
in front of the parliament building

Great effort is underway to draft the program for September 27th. One important part of the protest is to put shoes on the Plein in The Hague. Shoes sent by ME patients, labeled with their name, age, date of illness and what they miss most.

Thus they too can be seen and heard, most of all those who are invisible in society through being housebound and/or bedridden. The current standing is 100 pairs of shoes and that number is still rising! The goal is 600 pairs of shoes which amounts to 1200 shoes on the Plein. Furthermore, politicians have been invited. And the program will likely have several speakers.

Throughout the country, people are gathering additional shoes. Patients who do not have shoes to spare or cannot send a package, can reserve such a donor couple and are therefore still represented on September 27th. Actions have also been started to fund the necessary materials for the MillionsMissing Protest.

The design team will make beautiful posters of statements that patients and caregivers can send to the action group MillionsMissing Holland. These will be shared on Facebook and Twitter after express consent. The posters will demonstrate to the public what the impact of ME is in the life of ME patients and their close circle. At the same time, they are an invitation to support the #MillionsMissing Protest.

The Dutch #MillionsMissing Day of Protest, as indicated, is part of a worldwide protest. There is international cooperation through the MEAction Network with other countries who also (want to) organize a protest day.

Contact details MillionsMissing Holland:
E-mail: millionsmissingholland@gmail.com
Facebook: https://www.facebook.com/millionsmissingholland
Twitter: @MMissingHolland

United Kingdom

Prescription Charges Coalition Campaign For Free Prescriptions

A campaign has been launched by a group of organisations calling for an end to prescription charges in England for working people with long term conditions. Visit the Prescription Charges Coalition website (http://www.prescriptionchargescoalition.org.uk/) to find out more about the campaign. The website makes it easy to join in by generating an email to send to your MP.

At the moment, people in Scotland, Wales and Northern Ireland don't pay for their prescriptions, whereas in England, those who are working do, unless they have "medical exemption". This exemption is only available to people with conditions such as diabetes, epilepsy, and some forms of cancer.

The prescription levy rose to £8.40 per item in April this year, so it's creeping ever closer to the £10 mark. This can be really costly every month, especially if someone needs several prescription-only items.

If you're struggling to pay for your prescriptions, there's information about applying for exemption due to low income and prescription prepayment certificates on NHS Choices (http://www.nhs.uk/NHSEngland/Healthcosts/Pages/Prescriptioncosts.aspx)

Emily Beardall (taken from http://bit.ly/2bbLxfk)

Breakthrough magazine: August 2016 edition

Our August 2016 "Breakthrough" magazine has gone out free in the post to friends and supporters. The magazine is free to patients and their families, clinics, academics and research groups, so please email us with your address if you live in the UK, are not already on our mailing list and would like a hard copy. The electronic copy will be on our website shortly at http://www.meresearch.org.uk/category/breakthrough/

Overviews

- **Neuromuscular strains**

A report from Johns Hopkins University shows that a simple physiological challenge – a straight leg raise causing a neuromuscular strain for 15 minutes – increases the intensity of ME/CFS symptoms for up to 24 hours afterwards. **Prof Kevin Fontaine**, a co-author, says that the findings "have practical implications for understanding why exercise and the activities of daily living might be capable of provoking symptoms…excessive muscle strain… might also produce symptom flares."

Read more http://bit.ly/2aMrTuH

Reduced cardiac volumes

An ME Research UK-funded report in the journal Open Heart outlines findings that confirm the presence of cardiac abnormalities in people with ME/CFS. It remains unknown, however, whether these are caused by ME/CFS and its consequences per se or whether a (pre-existing) reduced cardiac volume may make people more vulnerable to the development of the illness.
Read more http://bit.ly/29ISg0I

Being dependent on others

Chronic illness and physical limitations are a fact of life for people with ME/CFS, but how do they feel about having to depend on other people? When researchers from the University of the West of England explored the experiences of patients physically dependent on others for help day-to-day, they found 'themes' coming up again and again, including the loss of independence, the 'invisibility' of the illness, and 'catch-22'.
Read more http://bit.ly/1txM03Q

Brain white matter abnormalities

Researchers at Griffith University, Australia have performed repeat MRI scans on ME/CFS patients first scanned 6 years before. Their main finding was a decrease in the volume of brain white matter (which contains the bodies of nerve cells) in specific areas, something not seen in the healthy control group.
Read more http://bit.ly/1Ud3bQv

Telomere shortening

Telomeres are 'caps' of DNA and protein at the end of chromosomes. They become shorter with age, but a new study has found that telomeres can be shorter than normal in people with ME/CFS.
Read more http://bit.ly/24oZVpQ

Vision impairments

Problems with eyes and vision are common in people with ME/CFS, and **Rachel Wilson**, an MPhil student at Leicester University has completed a thesis on the subject, with funding from ME Research UK and the Irish ME Trust.
Read more http://bit.ly/1XDGwBn

Submitted by **Dr. Neil Abbott**

Bristol FM.E United will be running a Free Introduction FME toolkit Self-Management Workshop for sufferers and carers who are new to our Fibromyalgia ME/CFS world.

13. Poem – Towards the Battle

This isn't a poem,
It is an echo of the song the warriors sing
When they open their tents to greet the morning
And remember everything they still have left to fight for.
It is the reflection of their faces in the river, as they drink deep and talk of those they love;
While their breath makes clouds and the birds take flight like dark-winged dreams.

This isn't a poem,
It is the feel of the names of the fallen on the warriors tongues
As they reach for their swords and polish their armour, looking at their comrades one more time,
In case this is the last chance they have to be together.
It is the colour of the warpaint they use upon their skin, to make intricate patterns with beautiful meanings.
It is the sound of their footsteps and the soft whinny of the horses as they saddle them up.

This isn't a poem,
It is the sight of the warriors riding into battle,
Moving towards the waiting mountains
With only their bravery to keep them safe.
It is the breeze that ruffles the gold-red flag in the arms of the flag bearer
And the soft murmuring applause of the trees as the troops ride slowly past.
It is the knowledge that not all of those who go will be returning

This is not a poem,
It is the promise of friends to stand together, through the ages of endurance,
Until the last day comes,
Knowing those who once battled with them and were lost
Will stand forever in their hearts and help them go on living.
It is the taste of the tears shed by the soldiers
When they see Pain testing his instruments of torture on somebody they love, who they know they cannot save.
It is the long journey home to the crackling campfire, with its flames dancing wildly into the night
While good and heartening food is cooked and shared.

This isn't a poem,
It is the hush as the warriors sleep;
And the way that whilst they dream, the glory of their hope
Unfurls like brightly-coloured string
And drifts out into the world
To tie their faith to something sacred,
It is the understanding that victory is not about the way this ends but about who it is we face our lives with,
It is about how much strength we carve from the stone of who we are

This is not a poem,
It is the kindness and the courage in your eyes
Sarah-Louise Jordan 'Feather'

*__Sarah Louise__ wrote this poem just after the death of **Theda**, with whom she was in close contact and of whom **Russell Logan** reports:

The lack of services for severe ME patients was underscored in the case of Perth (Australia) ME sufferer **Theda Myint** whose health deteriorated to the point where she considered suicide but repeated pleas for an in-home pain relief treatment were knocked back by the hospital treating her.

After a ten-year battle with the illness, on July 25 2013, just one day after her last medical appointment in which a neurologist advised her that she had tried all options available for pain management, Theda "euthanased" herself. http://bit.ly/2b7GQ5w

14. Column – Being Bedridden

Not being able to stand on your own two legs. Having to be carried to the bathroom as a result of this, not being able to scale a staircase by yourself, requiring assistance when showering, being unable to get something to eat or drink- so not being able to survive on your own. Being bedridden at 21. Life around you goes on, without you being able to take part in any of it. Everyone around you continues with their lives, but you're just lying there. In that dark, soundless room. Unable to wear normal dresses. And most of the time too ill to allow visits from friends and family, carry on conversations or even to take a quick look at your cell phone. Every second of the day, you're suffering from excruciating neuralgia, and also joint and muscle pains. But also from cognitive problems, which result in the simplest concepts appearing as though they're in Chinese, you not being able to convey your words, forgetting what you heard just a second ago, and sometimes trying to use your sandwich as a remote control for the TV. Oh uhmm, wait.. Haha. Each day, you're suffering from multiple attacks which completely paralyze your brain and body and literally turn you "off". Being unable to move your own limbs because there's no power at all in your body. Being under constant fear of losing consciousness. Not being able to tolerate light, sound, smell and certain foods. And total exhaustion unbeknownst to "normal" people. Sounds appealing? I am Bente and this is my life with a severe form of ME: myalgic encephalomyelitis. I dare to bet that 80% of the readers of this article has never heard of this condition, and that the other 20% has no idea how awful it truly is. Did you know that many doctors today still put their fingers in their ears and you're being sent from pillar to post, sometimes with the remark "I have no idea, it must be psychosomatic." It is unfathomable. ME, a devastating, physical multisystem condition, is being turned a blind eye to. #MillionsMissing http://millionsmissing.meaction.net/

I miss my life. I miss singing, performing with my band, dancing with my friends, fooling around with my parents and chit-chatting with my sister. But above all… I miss myself. 17 million people on this planet are missing their lives just like me, as a result of ME. 17 million lives which have come to a permanent halt. 17 million people who, time after time, bump head-first into a deluge of a lack of understanding of their condition, and who do not get proper care. Change is a thing most desperately needed now; it makes the difference between being able to live your life and merely existing… So, spread the words!
#MagicEveryday
Help ME and sign this petititon! http://bit.ly/1T2Aus9

Ed.note: This column has been chosen as a guest column and has been published in the Dutch version of Metro on Friday 5th August. Tens of thousands of Dutchmen most probably have read this. Bente is a Dutch severe ME-patient and skilful writer who has an own wall: Magic Everyday https://www.facebook.com/MagicEveryday/

15. 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."