The ME Global Chronicle

www.let-me.be

 # 22 –April 2017

1. Colofon / Personalia

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Advisory board: ***Leonard A. Jason***
Cartoons: ***Djanko***
Editor/Editorial team: ***Eddy Keuninckx, Rob Wijbenga***

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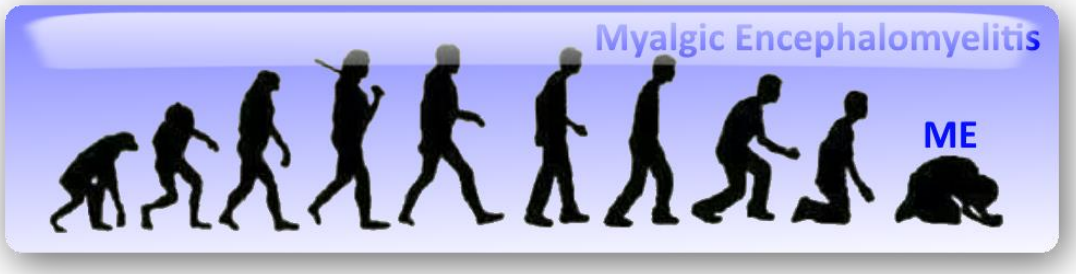
We are no association or society, just a bunch of idealists who want to give our best efforts towards recognition of this terrible disease. By trying to help connecting to each other all patients all over the world. Anyone who expresses the wish to receive the Newsletter will be added to the list: that's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

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

2. Table of Contents

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



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

3. Editorial

Dear readers,

We're glad to offer you April 2017's ME Global Chronicle 22, albeit with some delay.

An increasing number of you are submitting articles or suggestions for articles, and we're being given the impression that more initiatives are being taken on a worldwide scale to bring ME to the attention of the common healthy public as well as politicians and other authorities.

Hence why it is also becoming increasingly difficult for the MEGC editors to consider and choose the articles to be included in the magazine, and hence we wholeheartedly apologize if we've missed any things you deem important, and instead focused on less significant items.

The potential of art in the field of ME advocacy is gradually growing bigger and more and more art projects are being set up to garner awareness and funds for ME research. An example of this are the projects of Dutch ME patients **Anil van der Zee** and **Rieke Kogels** (see for both under News from the Netherlands) and the Bedfest project of British **Elizabeth d'Angelo**.

Currently, there are several important petitions running. We've made a summary of these on a separate page, so you'll be able to see how to support your fellow patients everywhere. Though, make sure to mind the deadline and the total times you're allowed to sign. At times you have to confirm by clicking a link you'll receive.

The rituximab study and IOM report have also garnered attention towards ME in Norway and the US respectively, and the same is the case with **Jen Brea**'s Unrest movie, which was screened in Copenhagen in April and ended up attracting a lot of publicity.

Paired with the diligent efforts to keep **Karina Hansen** at home after getting her returned there, the progress is also being made from Denmark. So keep donating to the **Save4Children** fund, which supports these processes for as far as the budget stretches.

In the Netherlands, there's still the petition ("ME isn't MUPS") against the specific constitution of a special ME/CFS committee by the Dutch Health Council, which contains 4 exponents of BPS. Simultaneously, the expectations are that the recommendations given by this committee to the parliament will be released before summer.

The committee also contains two representatives of patients' interests who hence have to deal with an over-representation of BPS in their camp.

Much more information can be scavenged in this month's publication. Simply click on the title of the article in the table of contents to be redirected instantly - this saves a lot of time otherwise spent searching.

Contributions for June's edition are to be submitted before June 10th to contribute@let-me.be

The editorial staff wishes those on the southern hemisphere a wonderful fall and a hopefully not too strong winter, and those on the northern hemisphere a great spring season and beginning summer. But above all, be sure to take good care of yourself and your friends.

The editors

4. PACE

Prof. Leonard Jason About "Pacing"

Prof. Leonard Jason about "pacing" and the criteria used in the PACE trial
http://journals.sagepub.com/doi/abs/10.1177/1359105317695801

Already a lot has been written about the falsehoods contained within the PACE trial, but Prof.Jason expands in this publication upon two aspects of it:

- the exact definition of "pacing"
- the method with which patients were selected

It's remarkable that the PACE results in accordance with the authors' definition of "pacing" (namely, adaptive pacing therapy (APT)) and the experiences of patients with known pacing have a very large gap between them.

APT is an authors' interpretation of pacing, and therefore not the same as the version experienced by patients. With APT, patients were urged not to use more than 70% of their available energy, effectively being slowed down the entire time. This may cause unintended problems such as social isolation.

The APT from the PACE study gave the same advice to all patients: slowing down. However, the propensity to do too much rather than too little isn't the same across the patient community.

A different form of pacing is the energy-envelope theory conceived by **Jason** himself. The key instruction of this theory being: do whatever your available energy allows you to; not more, not less. The idea is to remain as active as possible whilst still remaining below the "envelope threshold" in order to alleviate the symptoms, i.e. retain more stability. This stability ideally provides for higher capability long-term. Studies prove that this is an effective strategy.

The intervention deemed the "control group" by the authors, but of which ALL participants were subjects of aside from their APT, CBT or GET, was standard medical care. This was ostensibly also influenced by pacing-elements such as general advice about preventing extremes in activity and rest. Hence the varying interventions were not variant enough to adequately assess what was and wasn't effective.

As a result of the PACE publication, the idea of pacing not being effectual, garnered a lot of attention, which may have negatively influenced any support by medical staff and their peers. This could have a severe impact on the continuing stigmatization of a vulnerable group.

There exist studies that have found improvement for CBT. However, these changes disappeared in a follow-up study in which patients that were disqualified halfway through were still counted.

The CBT model is based on the assumption that the level of activity is a mediator between illness attribution and physical limitation, but, in a study by **Sunnquist** and **Jason**, this connection was only found in patients meeting broader criteria.

This concluded the fact that using broad selective criteria can greatly affect the results of CBT studies. Therefore, it makes sense to have a good look at which patients were selected for participation in the PACE study.

PACE primarily used the Oxford criteria, which stipulated fatigue as the main symptom. 47% of PACE participants were afflicted by a psychiatric condition, and the authors mentioned that CGT was responsible for the largest decrease in their depression.

CBT has been proven to be an effective method of combating depression, ergo mixing these groups makes it extremely difficult to interpret who is being treated for what during the clinical trial.

This problem doesn't just occur in intervention studies, but also when it comes to estimating the frequency of CFS instances. For example, an English study found that 2,6% of the study's population would have to be suffering from CFS, but when psychological conditions weren't accounted for, the percentage slimmed to 0,5%.

The fact that ostensibly people without the illness participated in the PACE trial is also evidenced by the significant lack of core symptoms in the population. Only 72-77% reported memory/concentration problems, and 82-87% had PEM. This insinuates that there were participants without CFS.

A consensus regarding a more specific case definition henceforth remains a critical task for the researchers, considering the lack of a stipulated definition of ME in research makes it remain unclear whether the results of different studies are comparable.

It is not clear whether or not non-specific factors such as encouragement and frequency of contact in CBT and GET influenced the results of these treatments. The APT intervention may have wrongfully suppressed activity. The broad selection of patients did not sufficiently eliminate the possibility of participants without the illness. These are solid obstacles blocking a credible interpretation of the PACE study results.

References for this article are available at:
http://journals.sagepub.com/doi/abs/10.1177/1359105317695801

Summary and report: ME Centraal
English translation: **Jelle Bouwhuis**

Hopeful!

The ME/CFS committee of the Dutch Health Council is replete with representatives of the biopsychosocial (CGT, GET, MUPS), hence why the petition "ME isn't MUPS" exists. As is already known, two representatives of patients' interests - one of which has contributed to the establishment of ME Central - are also participating. In Observant, the official magazine of the University of Maastricht, committee-member **Professor Dr Jan Willem Cohen Tervaert** was invited to give his perspective on (issues regarding) ME.

Read here what he has said, and let it speak for itself:
Myth: ME is a psychological disorder. To the realm of fairy tales.
Patients aren't just a little exhausted; they're always tired to death. Sleeping barely solves anything- if they are able to fulfill a good rest at all, that is, and physical efforts often incur a heavy toll: being even more fatigued than before, for days.

According to the current state of medicinal practice, behavior therapy (which would aid them in dealing with the symptoms) and physical exercise would be sufficient in treating patients suffering from the chronic fatigue syndrome of ME. A large study led by British researchers, published in 2011 in The Lancet, confirmed this statement. "The outcome of this study resulted in bad blood with patients.

Some spend the entire day lying in bed, and are already out of energy after merely scaling a staircase. Many patients report a cumbersome sense of tiredness lasting for days after an exercise - the so called post-exertional malaise: PEM. There were doubts about whether the study was accurate," says internal medicine and immunology scholar **Jan Willem Cohen Tervaert**.

In 2016, the patients' association succeeded in "getting the trial data released". You know what was discovered? Numbers were played with, and the results ended up being very slim in scope. No more than 6.8% of participants restored after behavior therapy- 4.4% including those with additional exercise. From the control group, which hadn't been treated to either form of therapy, 3% recovered.

Cohen Tervaert says: "ME sufferers feel left in the dumps. Their illness, which sometimes spontaneously pops up, occasionally after Pfeiffer's or Lyme disease or a period of exhaustion, is often being dismissed in the Netherlands as merely being an illusionary condition."

Albeit not in last place, since years are already being spent (mostly in vain) on finding a cause. A research project at the Radboud University of Nijmegen ran for a while, but when the lead expert of the CFS center retired, the project's integrity ended up diluting, as known by **Cohen Tervaert**.

In the Netherlands, there's such a lack of fundamental scientific research that the patients' association initiated a petition which entailed parliamentary questions, which in turn resulted in a ME committee being constituted by the Dutch Health Council for the purpose of giving advice.

Cohen Tervaert is a member of this committee. He's an expert when it comes to vasculitis and autoimmune diseases. In addition to his scholarship, he also works in a treatment facility in Groningen where a cardiologist, internist, psychiatrist and - if necessary - a neurologist guide these patients.

The initiative by the patients' association has spawned a critical article in the NRC of **Professor Harald Merckelbach**, forensic psychology scholar at the UM. He too views CFS as a psychological disorder and refers to a cardiologist's remarks of frequently prescribed physical therapy bearing potentially disastrous effects and may cause the physical state of patients to depreciate and end up in a wheelchair as "cavalier misinformation".

"ME is a harrowing, but not a psychological, disorder," says **Cohen Tervaert**. "While ME is usually flagrantly dismissed as nonsensical whining in the Netherlands, the prestigious American National Academy of Medicine (formerly IOM) has concluded in a report that we're speaking about a 'system illness'.

Likewise, in Norway, where much research is being performed and where the prime minister implored people to help out these groups of patients, the very same conclusion is being drawn. Various systems in the human body malfunction or don't function at all. The immune system is blanking out, their hormones are shifting, they're being sleep-deprived, and the energy production in the cells is being hampered. A hypothesis is that said energy production is in a state of hibernation, which is enticing to believe; patients have no energy because they cannot produce any." A different hypothesis posits that the autonomous nervous system (which cannot be controlled by will) is in a permanent mode of peril, which makes patients extremely sensitive to stimuli.

Momentarily, the Health Council's committee is compiling a research agenda for ME. "We need funds to conduct a fundamentally scientific study anyway." It's also important to make the distinction. "When is one simply tired and when does one actually have ME? The committee has discussed about this frequently. Someone with a physician's degree who takes care of three children should be tired, but doesn't have ME. Hence why we need to be strict. Americans say that a patient must be suffering from PEM; still being tired for days after a strenuous effort. That should be a good indication for a ME diagnosis."

Riki Janssen
(This is a series in which scientists refer to misconceptions in their area of research as fairy tales)
Source: http://bit.ly/2nboYjx

*(This article is being followed by reactions on it by **Prof. Peter White**, **dr. David Tuller** and **dr. Mark Vink**)*

Countering PACE

Reactions on Hopeful, the interview with Dutch professor and member of the ME/CFS panel of the Health Council of the Netherlands, included in this issue of the MEGC as well.

Shortly after the publication of the said interview, **Prof. P.D. White** has been informed about its publication. The three main PACE-trial researchers reacted in Observant with the title Myth-busting a myth busting http://bit.ly/2mvUcmb

Essence of their message was that "as **Professor Cohen Tervaert** said, some data from the PACE trial were released last year under the UK Freedom of Information Act. Some patient activists, aided by two statisticians, re-analysed just the recovery data – not the main outcome results. They used more stringent thresholds for defining recovery, such as only counting people who were "very much better".

Unsurprisingly, they found that smaller numbers of patients met their criteria for recovery. Using different thresholds to assess recovery will clearly result in different recovery rates. There is no universally agreed definition of recovery, so we cannot be sure which figures are most accurate, but previous trials and studies of patients found similar figures to ours.

However, one chooses to define recovery, the main findings of the trial stand - that CBT and GET are both safe and effective in reducing fatigue and improving functioning. In such a chronic and disabling illness, it is good to have a hopeful message for patients that, like previous researchers, we found not one but two treatments that are moderately effective and safe for patients with CFS/ME. To suggest that this is not the case is to propagate a myth."

Profs Chalder, **Sharpe** & **White**

"No scientific ground to stand on"

Dr. David Tuller, lecturer in public health and journalism at the University of California, Berkeley, has written extensively about "the flaws of the PACE trial". He thinks that "the PACE authors have no scientific ground to stand on".

As a reaction on the authors of the PACE-trial's comment he wrote a fierce criticism which after a couple of days has been included prominently in Observant and in which he states: The PACE investigators continue in their refusal to actually address the key concerns raised about their study. First, they continue to refer to this as a "secondary" paper. While it is true that the PACE authors for reasons only they know designated "recovery" as a secondary outcome in the PACE protocol, "recovery" is surely not of secondary importance to patients, so dismissing the paper's significance in this way is unwarranted.

They dismiss the difference in recovery outcomes between their paper and the reanalysis as just a matter of opinion, because the reanalysis used stricter guidelines. They fail to mention that the reanalysis only used the specific criteria the PACE investigators outlined in their own protocol, and then abandoned in favor of ones that allowed them to report statistically significant recovery rates. They received absolutely no approval from oversight committees for this redefinition of recovery.

In their detailed protocol, they included four very clear criteria for recovery. In the paper as published, every one of these four criteria was significantly weakened, in ways documented by **Wilshire et al.** For two of the four criteria - physical function and fatigue - participants could get worse and yet still meet the "recovery" thresholds because that revised threshold represented worse health than the entry criteria. Thirteen percent of the trial participants met one or both of these "recovery" criteria at baseline.

They have referred to these thresholds as being within the normal range. Yet this is an utterly dishonest argument. They generated their absurdly expansive "normal ranges" by using the wrong calculation to calculate them. They applied the method of finding the normal range for normally distributed populations - the mean plus/minus one standard deviation - and applied it to population samples that they knew were highly skewed in a positive direction. **Dr. White** himself, in a 2007 paper he co-wrote, had explained how using this method to determine a purported "normal range" for the SF-36 physical function scale yielded distorted findings. This caveat was not included in the Lancet or Psychological Medicine papers.

The authors themselves know that what they are referring to as a "normal range" is not the standard statistical "normal range" that includes two-thirds of the values but a wildly generous "normal range" that includes upwards of 90 percent of all the population values.

That's why they ended up with the absurd "normal range" of 60. The same strategy applies to the fatigue normal range - they developed in the same intellectually dishonest way, and yet continue to refer to it as a "normal range".

They have never explained why they used the wrong statistical method to develop normal ranges from highly skewed samples. Moreover, **Dr. Chalder** has never explained why she referred to these absurd "normal ranges" as "getting back to normal" in the Lancet press conference.

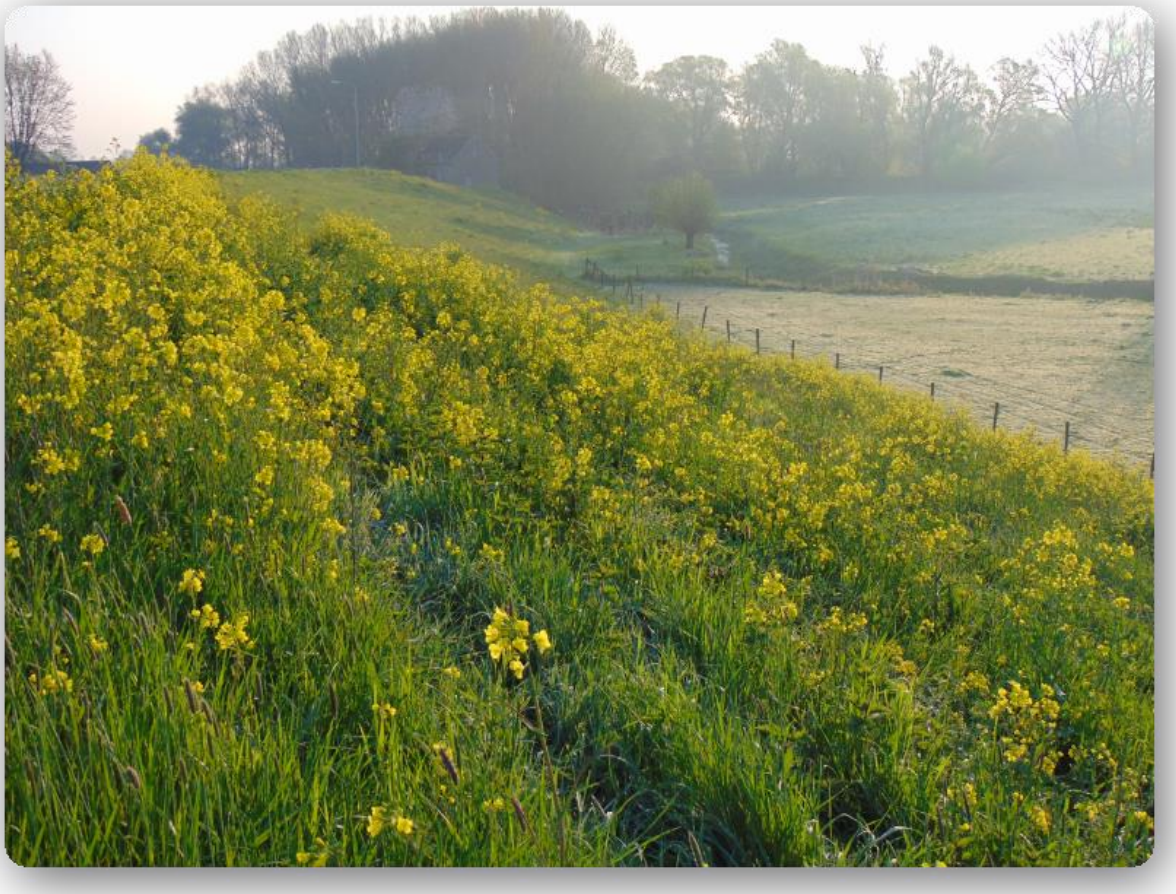
They have recently argued, in response to **Wilshire et al.**, that it doesn't matter that some participants were recovered on the physical function or the fatigue outcomes at baseline because there were other recovery criteria. This is truly a bizarre response for researchers to make. It is also a serious violation of the rules of honest scientific inquiry.

It is unclear to me why we all have to waste so much intellectual time and energy simply to demonstrate that studies in which participants can be disabled and recovered simultaneously on key indicators should never have been published and, once published, need to be retracted immediately. The PACE authors have no scientific ground to stand on."

Reactions of
dr. Mark Vink
(PACE trial misrepresents their own results again, http://bit.ly/2nPhO2y)

and
Carolyn Wilshire
(Stunned by the absence of critical thinking, http://bit.ly/2n4yOod)

have also been published by Observant after the publication of the comment of **White et al**.



Joint Commissioning Panel For Mental Health

MUS Report: http://www.jcpmh.info/wp-content/uploads/jcpmh-mus-guide.pdf
Note by the editors: The JCPMH recently issued a Guidance for commissioners of services for people with medically unexplained symptoms (MUS) to which ME is considered to belong in the UK, and other European countries as well. Long-term carer to his severily ill wife Greg Crowhurst wrote a letter to the Panel to point out that and why ME isn't a biopsychosocial or MUS-disorder

Thank you for your email dated April 20th. Even though you have stated that the Government recognises Myalgic Encephalomyelitis as a Neurological Disease, patients like my wife are left for decades to suffer, in agony, with no appropriate medical service, no clinical expertise to advise, no investigation, no cure and little hope.

The health system does not accommodate or understand their complex needs. Patients with the most severe forms of this illness suffer decades without proper or appropriate input or medical recognition.

Rather than identifying the underlying physical cause of illness, discovering the specific underlying physiological malfunctions and treating them biomedically, the focus is on fatigue and an inappropriate, indeed often harmful, psychosocial response.

In your response, you use the term "CFS/ME", however there is no such WHO Classification as "CFS/ME". ME is a neurological disease with multi-system dysfunction. CFS is a made -up construct of heterogeneous nature.

The ill-defined hybrid condition "CFS/ME" has never been entered in the ICD and is not consistent with WHO ICD rules. No one is served by having the conglomerate made up term, "CFS/ME", that does not accurately diagnose their disease.

I am not certain why you advised me to take up the issue with NICE's Chief Executive, Andrew Dillon as I have already clarified with NICE that they do not list ME as a Somatoform Disorder.

My concern is that the Royal College of Psychiatry and the Royal College of General Practitioners, have specifically informed Commissioners, in contradiction of NICE and the Government, through the JCPMH, that Myalgic Encephalomyelitis is a mental disorder, while claiming, quite wrongly, that their stance is in line with NICE guidelines.

Having spent the last two decades fighting for a biomedical service for people with ME, which will support and effectively meet the needs of the most severely affected, I am extremely concerned, as I stressed in my letter to you, about the impact of the JCPMH's Report on service provision.

This is not about the NICE Guideline, it is about holding the Royal Colleges to account for the misinformation they have supplied to Health Commissioners.

It is my understanding that the Royal Colleges are accountable to the Secretary of State. Please can you confirm this?

If not, can you tell me who they are accountable to?

How can the Royal Colleges be made to acknowledge and retract the incorrect information they have provided to Commissioners and the public, immediately, in order to protect people with ME, from being even more mislabelled, misinterpreted and mistreated?

Specifically, please can you tell how I can make a formal complaint that will effectively investigate and address the serious issue that I have raised?

The Royal Colleges must surely be held accountable for their grave misrepresentation of the physical disease Myalgic Encephalomyelitis as a mental health disorder?

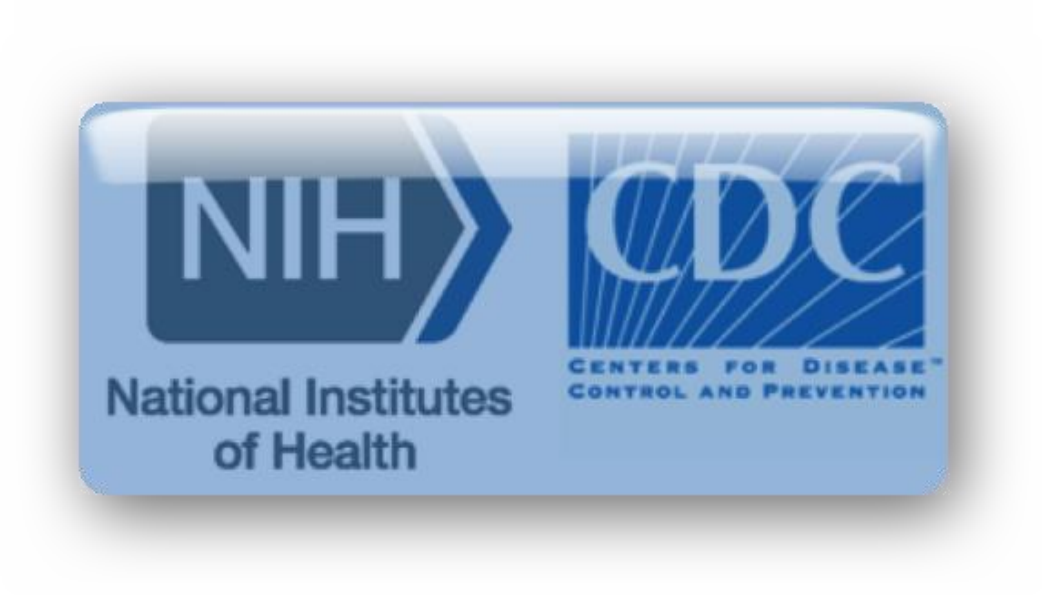
Many thanks

Greg Crowhurst

This is my reply to the Department of Health, many thanks for all your comments, which were extremely helpful in formulating my response.

Special thanks to **Jerrold Spinhirne:**
https://www.facebook.com/jerrold.spinhirne

5. NIH/CDC/HHS


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

Moving Toward Answers in ME/CFS

To date, most studies in ME/CFS have looked at relatively small numbers of people with ME/CFS and employed different methods—and rarely has a finding been replicated. Given the heterogeneity of the illness and complexity of the assays, rigorous confirmatory studies in larger groups of people with ME/CFS are necessary to provide the evidence base for effective therapy development. ME/CFS, as much as any other disorder, is in need of a concerted effort by the scientific community to understand its biological basis.

The NIH is committed to stimulating additional research to reveal the causes of this debilitating disease. ME/CFS is such a complex condition, affecting so many body systems, that we do not know where the answers will come from. Informed by results from a 2014 ME/CFS workshop [9], NIH initiated a call to action to all of its relevant Institutes and Centers in October 2015.

The resultant NIH research effort, led by Trans-NIH ME/CFS Working Group, leverages an impressive scope of expertise across the NIH to attack this research gap.

The Trans-NIH ME/CFS Working Group recently solicited research applications to seed a nationally coordinated approach to understand the cause(s) and mechanisms of ME/CFS. In January, NIH issued two Funding Opportunity Announcements (FOAs).

These FOAs seek to establish a research consortium for ME/CFS research, including a coordinating center to facilitate collaborative science among the sites and enable widespread data sharing. The consortium will provide a foundation upon which rigorous ME/CFS research can build to make new discoveries, validate research findings, and attract new investigators from various disciplines to study ME/CFS.

The research consortium is just a first step toward growing an innovative and vigorous research community to focus on this disease. The NIH is always open for other scientists to submit research grants on ME/CFS, and most NIH funding goes to these regular grant proposals, which are reviewed on a three times per year cycle. In addition, a variety of other research initiatives were recently launched.

The NIH awarded seven Administrative Supplements to expand ME/CFS research in current grants. These projects use state-of-the-art technology to pinpoint genes that may be involved in the disease and to reveal how specific immune cells play a role in ME/CFS. Some of these projects will zero in on potential biomarkers, which are desperately needed to help with diagnosis and for tracking disease progression.
Descriptions of these awards can be found at: http://bit.ly/2hfHEM5.

The NIH is also initiating ME/CFS research at the NIH Clinical Center in Bethesda, MD. Led by **Dr. Avindra Nath**, an expert in neurovirology and infections of the nervous system, dozens of investigators from seven of NIH's Institutes and Centers will carry out an extremely detailed and comprehensive evaluation of several dozen people with ME/CFS, focusing on those whose symptoms can be clearly traced to an infectious-like illness and who have been sick for less than five years.

These volunteers will undergo a comprehensive battery of tests, including blood draws and brain scans, to help researchers learn more about the clinical and biological features of this disease.

One of our goals is to improve communication about these research efforts to individuals with ME/CFS and advocates who have been affected by this devastating disease. We host regular telebriefings, which enable NIH staff to update the community on our activities and provide ME/CFS stakeholders with an opportunity to ask questions and offer their perspectives.

You can learn about NIH's ME/CFS-related efforts and briefings by visiting the ME/CFS website at http://www.nih.gov/mecfs. If you would like to receive periodic updates from NIH by email, please visit the ME/CFS website and click on "Join our listserv."

We recognize and empathize with the suffering experienced by people with ME/CFS and their frustration that so little is known and so little research has been done to find answers. We aim to change that. The NIH is committed to unraveling the underlying biologic cause(s) of ME/CFS as swiftly as possible, and promoting research that will inform the development of effective strategies for treatment and prevention of this devastating condition.

Dr. Walter Koroshetz and **Dr. Francis Collins** (http://bit.ly/2pn0HFJ)

Note: **Walter Koroshetz**, M.D. is Director of the National Institute of Neurological Disorders and Stroke (NINDS), NIH; **Francis Collins**, M.D., Ph.D., is the Director of the National Institutes of Health (NIH).

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

6. Cartoon Djanko

7. Grassroot

Patty's Lawyer

How Patty's Lawyer Never Told Her What She Needed to Know

(nb although the protagonist of this blog suffers from Lyme's disease, this information might be practical for ME-patients as well. ***The editors****)*

Quite sadly, ***Patty*** *did not win her disability case. Quite happily,* ***Patty*** *is an angel who wants to share what she learned so that you can win your disability case!* ***Patty*** *has some super good, super helpful advice. Read on.*

My lawyer was from a well-known firm in Boston that claimed a 97% success rate with disability cases. They told me they would not have taken my case unless they thought I would win.

I believed I had a strong case. I had an MRI showing 4 lesions, bulging C4, and degenerative changes. Plus, I had three positive Lyme tests. My records included a consistent history of regular doctor's visits and ongoing medical treatment including a PICC line and infusions.

My doctor filled out an excellent function form detailing my limitations and stating that I was unable to work, plus I had two years of evidence of biweekly visits to a therapist for anxiety, depression, and PTSD. I also had a strong work record with a 15-year career as a Registered Nurse making $80,000, which I left behind when I became disabled.

I was with my lawyer for 15 months and he never once suggested that anything was wrong or that I needed to do anything different.

If I can help anyone else win their case, I will share what I learned. These are the four things my lawyer never told me.

"You are Seeing the Wrong Doctor"

When I first became sick, I saw an infectious disease doctor, but then she referred me to a Lyme Literate Naturopathic Doctor. I had no clue that this switch would hurt my disability case. I was just happy to get treated and get help. For two years, I continued to see the Naturopath and never knew that anything was wrong. In the end, Social Security said my doctor was not an MD and did not give weight to his records, treatments or lab tests.

"You are Seeing the Wrong Therapist"

I saw my therapist biweekly for 2 straight years. I even got my entire chart copied for hearing. If I had known that Social Security does not like counselors, I could have switched to a psychiatrist or psychologist. At the hearing, the only question the judged asked me about my mental health was, "Did you drive yourself to the therapy visits?"

"Get Testing for Every Condition"

One of my diagnoses was peripheral neuropathy. I was treated unsuccessfully for two years with various meds. However, I never got any nerve testing done. (I didn't need any tests to tell me I had peripheral neuropathy because I could feel it in hands and feet). Had I known a test was necessary, I would have gotten it before my court date. In the end, Social Security did not consider my neuropathy because they said I did not have any proof.

"Ask a Different Doctor to Sign Your Paperwork"

I got an RFC form a few months before my hearing. I had learned from my Lyme group that I needed to explain everything to my doctor so that my form included the amount of breaks I needed during the day, the amount of time I laid on my back, how long I could stand consistently, and details on my persistent neuropathy and fatigue. My form had everything I needed, but my lawyer never mentioned that the form needed to be signed or co-signed by the right kind of doctor.

At My Hearing

My lawyer called me the night before my hearing to prep me. Like many people with Lyme, I have memory issues, concentration problems, difficulty focusing, and anxiety. Over the phone, we reviewed 25 questions he knew they would ask and we tweaked the way I would word things. He emailed my responses so I could study them overnight. I was a complete basket case and couldn't retain a thing even with the pages in front of me. I wish they had given me a week to prepare! At the hearing, the judge seemed heavily concerned with: Who cooks the meals? Who does dishes and laundry? Who runs errands? Who does groceries? Who cleans the house? Who gets your four kids up for school? Who drives your kids to activities? Is someone at your house helping you shower or toilet?

I explained to the judge that household activities were a collective effort between myself, my husband, and my mother and sisters. I described how I could not stand for more than 15 minutes, and often could not type, write or hold objects.

Social Security said that I could be a fruit picker, a truck driver, or a post office worker. This still makes me laugh.

Patty Skelton Preston

Epilogue

Patty's story has a semi-happy ending. Her health turned a corner and she returned to part-time work. "Previously, I worked 12-hour shifts and juggled 7 patients and a charge nurse. Now I do home care for one patient, two hours a day. I still can't work a full day or even every day." **Patty** did not continue to pursue disability. She wanted to share her story to help others.

Sleepygirl

Source: http://bit.ly/2n5XRFQ

How To Tell If Your Test Results Are “Good Enough”

Are my test results "good enough?"

As a general rule, if your doctor thinks your test results are meaningful, Social Security will usually accept your doctor's opinion. Your doctor must be an acceptable medical source. It is super super super (super super super) great if your doctor can include or mention these test results in their RFC form or doctor's letter.

How can I get my doctor to do this?

When you meet with your doctor to request an rfc form or letter, bring a copy of your test result. Make sure to keep it to one page so your doctor will read it. If you have more than one test result you are happy with, bring a brief list of each test date, location, and quote any abnormal outcomes or findings.

Why in the world would I do this?

My doctor already knows what tests I took. Your doctor is not going to know/remember every test you've had. If you are expecting that your doctor will start combing through your medical records looking for this information, you are about to be disappointed.

What are the best tests to take?

I can't answer this question. Possibly no one can. However, here is a list of some tests other people have found helpful.
https://howtogeton.wordpress.com/2017/03/25/how-to-get-tested/

Will test results help without my doctor's support?

If you do not have a doctor who is supporting your application, it is possible that your test results may be helpful on their own if the test was performed or signed by an acceptable medical source. Sometimes a test will be helpful even without your doctor and without any acceptable medical source, but you can't rely on that happening.

How many tests do I need?

I said it before and I'll say it again. You do not need a million tests. One or two tests with abnormal results are enough to win a claim.

Please don't spend all your time, money and energy on tests. Save up some of your time, money and energy on the next super-important-you-cannot-miss-this step: proving you can't function.

Sleepygirl
Source: https://howtogeton.wordpress.com/

End ME/CFS Worldwide Tour

OMF Launches the End ME/CFS Worldwide Tour

A Personal Note From OMF CEO Linda Tannenbaum:

Dear Friends,

Ten years ago, our beautiful daughter became ill with sudden onset ME/CFS. That morning, she went to school perfectly fine. What happened during that day changed the course of our lives forever. That day my husband Don and I started on our journey to find a cure for this terrible disease.

Over these past 10 years, we have had the privilege to meet many who share our dream to create a world without ME/CFS.

With you in our hearts and minds, we are excited to announce that we are launching OMF's End ME/CFS Worldwide Tour 2017 to join forces with other parents, patients and caregivers. We know that ***parents' and patients' movements are key to impacting change and we want to partner with you.***

In April 2017 we will begin our tour in the US and continue it throughout the year. In May and June we will be visiting our friends in Europe - England, Republic of Ireland, Northern Ireland, Isle of Man, Belgium, Sweden and Norway. Several of these meetings will be with government officials and medical professionals to strengthen their knowledge of ME/CFS.

As a part of our worldwide tour, May 31 - June 2, Dr. Ronald W. Davis, Ashley Davis Haugen (Event & Marketing) and Raeka Aiyar, PhD (Communications Director, Stanford Genome Technology Center) will join me and Don in London at the Invest in ME Research International Conference *(http://www.investinme.eu/index.shtml). OMF will be hosting an exhibitor table so that we can meet with friends from around the globe. If you are attending the conference, please stop by and say hello. We will share more details about our conference participation soon.*

We welcome you to join us in building the End ME/CFS Worldwide Tour 2017. We invite you to join a community meeting for your area. Please check out our current schedule *(http://www.openmedicinefoundation.org/end-mecfs-worldwide-tour/) .*

We also would welcome the opportunity to visit other areas of the US this year. If you have an active group in the US and can gather a group of 50 or more parents, patients, caregivers, and friends, please contact us and together we can explore a visit to your area.

We look forward to seeing you in person!

Warmly,

Linda Tannenbaum - CEO/President

Forgotten Plague

We're so thrilled to announce that HR 170 has passed unanimously in the House of Representatives for the State of Georgia.

The resolution has 5 co-sponsors from the House's Health and Human Service Committee, and the final vote total in the full body was 165-0.

The resolution urges public health agencies in the state to do more to address ME/CFS patients' needs and to improve educational efforts.

The resolution helps open doors for advocates and public health officials and is a much-needed public acknowledgement by government officials that ME/CFS is prevalent, severe, and in dire need of greater attention.

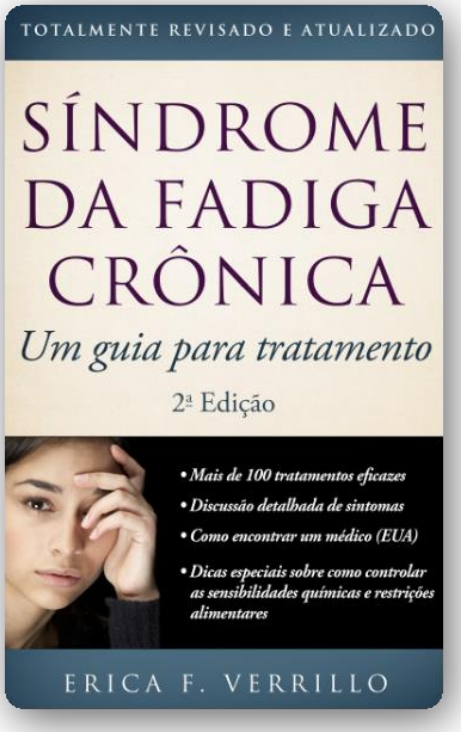
This resolution is one of many that are in the works in state legislatures around the US and is proof that sustained, tenacious advocacy can create real-world results!

To read the full text of the resolution, visit the link: http://bit.ly/2oXCSqq

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

Ryan Prior

Chronic Fatigue Syndrome



Chronic Fatigue Syndrome: A Treatment Guide, 2nd Edition translated into Portuguese

While prevalence of ME/CFS in Brazil and Portugal is roughly equivalent to the UK, there is almost no information available about the disease in Portuguese.

In part, this is due to a reluctance on the part of GPs in those countries to diagnose the disease. Patients are left with very little recourse other than to "let nature take its course." This is the first time a comprehensive resource about the disease has been made available to the Portuguese-speaking community. The book is available on Amazon, Barnes & Noble, Apple, Kobo, and Scribd. (Electronic version only.)

If anyone would like to help translate this book into other languages, please let me know at everrillo@yahoo.com. Most of the proceeds from sales go to the translator.

To get a taste of Portugese:
Síndrome da Fadiga Crônica: Um Guia de Tratamento – agora completamente revisado e atualizado – inclui mais de 100 tratamentos eficazes, desde antivirais até vitaminas, bem como locais de especialistas e clínicas, informações para comprar pela Internet e organizações nacionais, locais e internacionais sobre a SFC/EM. Seções novas e ampliadas incluem protocolos e pesquisas de médicos sobre as causas e mecanismos da doença, todos escritos em linguagem concisa e fácil de entender.

Cada aspecto da doença é examinado detalhadamente, do diagnóstico a uma discussão profunda dos sintomas, de terapias tradicionais à alternativas até estratégias essenciais para lidar com a doença. A nova edição contém capítulos para pessoas lidando com sensibilidades a vários produtos químicos e restrições alimentares, bem como uma seção ampliada sobre crianças e adolescentes com a SFC/EM. Síndrome da Fadiga Crônica: Um Guia de Tratamento, segunda edição, ainda é o guia de referência mais completo sobre essa doença.

Submitted by **Erica Verrillo**

Marathon Mike

Relatively quick update after my post-marathon hibernation of late last year!

I'm back running again and 5 weeks into Barcelona training having had some very quiet running weeks of no more than 10 miles per week for a couple of months. Last October's two marathons in 4 weeks took a lot out of me mentally and physically so it was good to power down and catch up with friends and family.

I tried not to stop running altogether as I remember only too well how hard it was to get going again after my injury-plagued January last year. But with a race more than 4 months into the future, it was hard to get out there and run just for the fun of it; something I've always struggled with.

So what have I been doing? Well, I've entered two more races for 2017, taking my total to 5 again. And they're both in October again, and only 2 weeks apart, eeek.

Number 13(!) will be Amsterdam on October 15th followed by Ljublana on the 29th which will take the challenge to the halfway point (14 of 28). Why am I doing 2 in one month again? Quite simply, because I have to.

The schedule of races is such that nearly all the countries I need to run in have October races as it's optimum weather (not too hot/wet/cold). What results is an insanely complicated logistical challenge to try to fit in 5 across the year when I can't be in two places at once. I don't want to be left with lots of October races that land on the same day so to get the challenge done by 2020 this is what I need to do.

Read more: https://mikeseumarathons.blogspot.be/2017

The ME/CFS Biomarker Rollercoaster

Biomarkers are a holy grail for ME/CFS because they have the potential to help diagnose disease, track disease progression or progress and help inform which treatments might help.

The need for biomarkers is immense and researchers will identify many possible ones. It is encouraging that there have been more possible biomarker reports recently. It can be so hard to hold onto hope, and the news of progress helps so many of us hang in there when living with this disease is so tough.

As ME/CFS slowly heads into a new era with increased research, our community should begin to see increasing numbers of biomarker headlines. Yet many people may start to feel quite confused: so many reports, but where is the one true biomarker?

A tale of caution

Each report of a promising new biomarker can lift our spirits very high, only for them to crash down again if the biomarker doesn't progress. Media headlines can be quite sensational, designed to attract readers and often promising more than the research has delivered. Of course, researchers need to battle for funding dollars, and media attention can help their grant applications so there's always the temptation to hype their current work.

Over the years many promising biomarkers have been reported, but as yet not one has quite made it to the finishing line. Our team would like to encourage caution as more findings get reported. There is much work and many hoops to jump through before biomarkers can reach the finish line at the doctors' office.

Acclaimed science writer and author **Julie Rehmeyer**, a well-known ME/CFS advocate, recently wrote about biomarker claims on her Facebook page. She has kindly let us share her comments:

"A note of caution to my ME/CFS friends: Many research groups have claimed recently that they're close to having a biomarker, and it's thrilling to finally see some really good biomedical research happening.

Some of the recent findings have enormous potential.
BUT. We're probably still years away from having a biomarker.

Here's the thing: Imagine yourself as a scientist working on this disease. You of course want to find a biomarker, because we really, really need one. So, you focus your work on that, and you get some kind of interesting but preliminary result, and some journalist comes along and asks you why it matters.

Watcha gonna say? You're going to say, "This will lead to a biomarker." Especially because you're only going to get funding to continue your research if the right people think you're on the right track.

But most early results are wrong. And even when they're right, it's usually more complicated than anyone thought, with big big problems that arise along the way and have to be solved. It's just a really long and uncertain road to go from some promising result to a test you can order at Quest.

So yes, we've got some great scientists doing great work, and that's a BIG CHANGE we should be thrilled about. And of course, we should hold them accountable to produce real-world results that matter to us. But we should also be realistic. Science is hard. It's really, really hard — even in the best of circumstances, without the huge political problems facing ME/CFS."

Beware the biomarker rollercoaster

The picture for ME/CFS is complex. Biomarkers have to make it through a long journey of investigation and require thorough validation. A lot of work is required to clarify how they may relate to the disease pathophysiology, and compare them with other diseases. It's particularly important to compare findings with patients who have diseases with similar symptoms, to show that the biomarker is specific for ME/CFS and not a general marker of fatigue or ill-health.

Large studies are needed on many well characterized patients across age and stage of disease, and different subgroups to really understand what they might mean and their possible overall usefulness. It is likely that different biomarkers or sets of biomarkers may be needed for different subgroups.

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

Common Misconceptions Concerning ME-Patients And Their Families

Misconception no.1: *ME-patients just want a pill and no other form of help.*

Wrong! ME-sufferers want help and they do want to get well. It is as simple as that. If some of the patients wish and are able to test one or more of the hundreds of good advices they get over the years, it is of course perfectly fine. But please do not force it onto all orhers. Everybody has a right to say no in this country.

No. 2: *ME-patients prefer their illness not to be psychological.*

Wrong! ME-sufferers don't care whether the illness would prove to be psychological in the end. The only thing they don't want is to be ill and loose year after year of their lives. And as the results from research keep ticking in, confirming there are biological causes of this illness, they understand why they kept getting worse every time they tried one of the good advices (http://wp.me/p3VLNe-78).

No. 3: *ME-patients do not believe in the people who say they have recovered by use of methods like The Lightning Process (LP) and Cognitive Behavioral Therapy (CBT).*

Wrong! ME-sufferers believe these people when they say that they are recovered, and wish them well. But they also believe in those who say that these treatments had no effect, and in those who say trying LP, CBT and Graded Exercise Therapy (GET) made them worse, a lot worse.

Nobody knows why there is such a big difference in the effects these interventions have on the patients – yet. One of the reasons could be that for decades health workers have been a bit sloppy in diagnosing the patients. At the same time, a lot of doctors have been unsure of what to look for to diagnose ME and have given the diagnosis to people with different diseases that has fatigue as a main symptom. We will probably know much more about this fairly soon, as scientists all over the world are now working to find a biomarker.

No. 4: *ME-patients are lazy and all they do is playing with their tablets or computers. They certainly have the strength to be on-line!*

Wrong! A lot of patients do not have the strength to be on-line. For other patients, being on-line is the only connection they have with the outside world. And *lazy* is certainly not the right word.

No. 5: *ME-patients cannot possibly be as sick as they claim to be. «I saw a person I know in the shop yesterday!»*

Wrong! They are even sicker than they say. When you see them, you see, you may be the first person to see them in maybe 4 weeks. And that short trip to the shop you saw can send them back to bed with earplugs and sleeping mask – some for weeks.

No. 6: *Fatigue (exhaustion) in the name Chronic Fatigue Syndrome explains it all.*

Wrong! Fatigue is only one of many symptoms in ME. Fatigue also occurs in hypothyroidism, anaemia, coeliac disease, depression, psychological illnesses, MS, cancer, Sjögren's syndrome and several other conditions and illnesses, as well as a consequence of treatments for cancer.

No. 7: *ME-patients sleep all the time.*

Wrong! Most ME-sufferers have disturbed sleep patterns, but most do not sleep all the time. Some have difficulties falling asleep, others wake up too early, or several times during sleep, and some sleep for many hours. Regardless the type of sleep disturbance, the sleep they do get is non-refreshing.

No. 8: The mothers of ME-patients are neurotic and focused on symptoms.

Wrong! ME-sufferers have carers of both sexes, and mothers and fathers are equally worried. So are brothers, sisters, children, husbands, wives, aunts, uncles and close friends.

No. 9: *ME-patients and their carers think they know everything and are prejudists.*

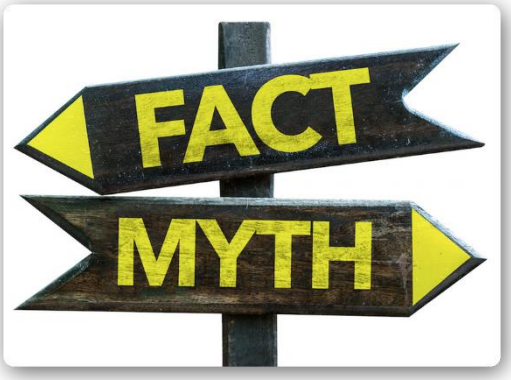
Wrong! ME-sufferers and their carers find it necessary to educate themselves in international science and research to be able to help their loved ones as much as possible. The reason for this being that the newest international research has not yet reached the medical community in this country. Thus, a lot of doctors lack the knowledge and experience in diagnosing; how the illness presents itself; and the best way to treat it.

No. 10: *ME-patients and their families do not want a broad approach to research.*

Wrong! ME-sufferers do want as much research as possible. The research has been «narrow» for years – concentrating on CBT, GET and biopsychosocial treatment of «CFS/ME». We now welcome the biomedical science, researching well defined and diagnosed groups of patients, giving us results that might help us getting the right treatment for the right patient for the right illness.

All too often we see that doctors and other health workers lean on research that is controversial, like the PACE-study and similar research. Fortunately, we also have good doctors and health workers who pay attention and/or participate in biomedical science now underway. They make it perfectly clear that the disease is in the blood and not in the patients' head, and they claim to have proof of evidence for it. Professor Olav Mella at Bergen university recently said on the Norwegian TV2 News: *What the collected findings in the now published study shows, is that ME is a disease of the blood, not in the patients' heads.*

I think one of the most important consequences of our findings is that more people start to realize that this is a real physical disease. And the positive findings in this study is that this is an illness that is reversible and that the patients can have a normal, healthy life.



The conclusion should be obvious:
As every other human being, ME-sufferers and their families know their bodies and their minds best, and they are fully capable of reading and understanding scientific articles on ME. It is essential that they are heard. When ME-sufferers and their carers now find that science finally confirms and describes what they have seen all along, then it is most probably this science that will find the answers.

Not listening to ME-sufferers and their carers – is the biggest misconception of them all!

By **Hanne R.**

Source: http://bit.ly/2p1q5DZ
From the site of ME-foreldrene (http://bit.ly/2ohVHAb)
Submitted by ***Stine Aasheim***

Act And Join A Global Chain

"I was well and I had so many dreams. but when you get sick like I did you expect that there will be help, that even if there is no treatments there will be care....."
https://www.youtube.com/watch?v=GolQjX7P4Qc

Join the #millionsmissing global protests next month.

But, what can you do until then?
Sign and please share these global petitions in need of help (see list below).
To get governments around the world to listen.
To start much needed change.
ME patients around the world just want a chance to get their lives back.

Thank you!

- Netherlands: https://meisgeensolk.petities.nl/?locale=en
  Anyone can sign, anonymous if you want, don't forget to click on confirmation link in your email after you sign.

- USA: http://bit.ly/2oyirh0
  Anyone can sign.

- UK: https://petition.parliament.uk/petitions/190618
  UK signatures only.

- Germany: http://bit.ly/2oycalC
  Anyone can sign.

Kindly let us know if some are missing as all the Millions Missing should have a voice… (**The Editors**)

ICD 11 – The Long And Winding Road To A New Biomedical Classification

- ICD is the WHO's international coding system for afflictions
- The current version of the ICD is the ICD 10 from 1990
- A newer version is currently in development: the ICD 11, which will be presented as a concept by the Who to its members in May 2018.
- On April 4th, a preliminary ('frozen') version of the ICD 11 has been released.
- Currently (in the ICD 10), ME has been coded as G93.3: Benign Myalgic Encephalomyelitis; a physical illness.
- All codes are due to change, but there are lingering suspicions that, in terms of ME, the BPS bloc is trying to get the ICD 11 classifications recognized as somatoform disorders. It is therefore important to keep a watchful eye on the code ME to be assigned in the ICD 11.
- Commentary on the 'frozen' ICD 11 version of April 4th can still be submitted until May 31st. Below we'll explain how.
- If you deem this info to be important (which it is, just very hard to follow as a patient), for the most recent developments follow the website https://dxrevisionwatch.com, on which outsider commentary will be published within a few days. You can compare the comments with your own on this site.
- ICD stands for International Classification of Diseases. It is a coding system employed by the World Health Organization (WHO) in identifying diseases and afflictions. This code is continuously being adapted to be in accordance with the rapid progress in the healthcare sector, but the latest base version, the ICD 10, dates back to 1990.
- In the ICD 10, ME is classified by the code G93.3, which, among others, encompasses 'benign' Myalgic Encephalomyelitis. The codes are being used e.g. in acknowledged and insured treatment. That's where the bug is hiding. On one hand, clinicians - among which those in accordance with the BPS model - posit that the coding has no inherent qualitative value; on the other hand, they're attempting to get ME (for which new labels are continuously being invented, from LOK to UPS and from MUPS to BSD; bodily stress disorder, a newfound name conceived by Danish psychiatrist Per Fink classified in the ICD (thus also in the next ICD 11) as a somatoform disorder.

- Right this moment, a revision of the ICD is on its way: the ICD 11. It's going to be an arduous, tiresome journey, but important to keep an eye on. The WHO intends to present the conceptual version to its members in May 2018. A second concept version will follow later in 2018.

Hence the hard planning as it's laid out now:

- On April 4th, a so-called 'frozen version' (beta draft) has been published for field research. Its deadline was set at December 30th, 2016.

- Propositions for any points to be addressed in the 2018 concept version are to be submitted before May 31st

- Commentaries on propositions in the beta draft are preferably submitted during the upcoming weeks. Should a deadline be set, it will be mentioned at the header of the source of this article (https://dxrevisionwatch.com). The same goes for any changes in this version pertaining to the current G93.3 coding. Should you be interested in the whole process, make sure to click that link on a regular basis.

- Propositions submitted after the end of May, e.g. by member states, will be included in the yearly update of the conceptual version of 2018, thus in 2019.

- Before presenting the concept version somewhere in 2018, the WHO will not yet petition the member states for permission. This is because implementation takes years; e.g. in the US it approximately takes six years according to the CDC.

- An ICD-12 may never be necessary due to the updating system having become so advanced to where scientific advancements that can affect the classification are directly registered.

Summary: ME Centraal (https://www.facebook.com/MECentraal/)
English translation: **Jelle Bouwhuis**
Source: https://dxrevisionwatch.com

Special thanks to ME patients **Suzy Chapman** and **Mary Dimmock**

ICD-11: A call to action

For the most newsworthy information, including the commentary on the frozen version of the ICD-10 published on April 4th, head to https://dxrevisionwatch.com before you take action yourself.

For example, you could read up on **Mary Dimmock** and **Suzy Chapman**'s intervention, who are already making a proposition to the ICD system. You can support this proposition or leave your own commentary.

You have 2 options:

- Agree to the submitted proposition by **Mary Dimmock** and **Suzy Chapman**.
- Make your own proposition or submit a commentary. **Mary** and Suzy advise putting the text in a text file first before submitting, as it will be no longer possible to make edits or delete it after submission.

- You must register by clicking this link: http://bit.ly/2n7Kdj4. You will be asked which patient group you associate with. Should this not be applicable, you can fill in Race to Solve ME/CFS.

You'll be asked for:

- A username, for which you can use your email address.
- A password and confirmation thereof (optional: adding an existing social media account, such as Facebook)-> press [Enter]

On the next screen, you'll be presented with a few questions (in English), and some optional questions as well. Enter the [CAPTCHA code] below and press [Enter].

Now you're registered.

Next, this link: http://bit.ly/2p5sAVJ will send you to the input of **Mary Dimmock** and **Suzy Chapman**. On that page, scroll all the way down (if you're willing, you could read their entire contribution, but it's not necessary).

There you're given the option to reply, agree or disagree or mark it as spam. If you click Agree, you can add your own argumentation as to why. That is recommended as those posts will not get lost.

Done!

Unrest (Canary In A Coalmine)

Canary in a Coal Mine is now "UNREST"

In just over a month, my TED talk (http://bit.ly/2opOOk8) has been translated into **18 languages** and has been viewed over **1,100,000 times**. This has been thanks in large part to how much you have shared and spread this talk and its message about the reality of Myalgic Encephalomyelitis (ME).

Unrest makes headlines in Denmark - March 18, 2017


8 DANMARK

Film retter skarp kritik mod sundhedsvæsnet

Politisk uro om

S vil ansætte flere i Skat

Politiken

Unrest made major headlines at its international premiere at CPH:DOX in Copenhagen. Major articles in Politiken, Weekendavisen and Information discussed the film, the controversy over the treatment of ME in Denmark, and the **Karina Hansen** case.

Weekendavisen

Information

The past few months have been amazing. After our world premiere at Sundance in January, **we brought *Unrest* to SxSW** in Austin, Texas, where health, technology, and entertainment communities converged around the film. We rounded out March with multiple sold-out screenings at CPH:DOX in **Copenhagen, Denmark, where the film made its international premiere**. And in just a few weeks, we'll have our **Canadian premiere at HotDocs** in Toronto!

Now, we're entering an even wider phase of our festival release. We're going to be bringing *Unrest* to dozens of film festivals (http://bit.ly/2oej7XX)around the world, from North Carolina to Arkansas, Vancouver to Zagreb. This is our first opportunity to engage local media, regional audiences, and communities of medical professionals. It's thrilling to see the film getting out in the world, to witness the impact we're already beginning to make. And there's so much more to come!

SXSW

We had four beautiful, emotional screenings at SxSW, attended by filmmakers, patients, doctors, health tech innovators, and members of the local Austin community.

There was incredible enthusiasm to support patients and mobilize for change. We were blown away by the audience members who approached us after screenings to share their experiences: the young man who talked about caregiving for his girlfriend as she battled cancer, the sister of an ME patient moved to tears by seeing her experience reflected, the woman who'd been following the film's journey since our initial Kickstarter campaign.

SxSW reminded us of the universality of the story we're telling, and helped lay the groundwork for future screenings with medical schools and the scientific community.

CPH:DOX

Immediately after our SXSW screenings, *Unrest* made its international and European premiere in Copenhagen, Denmark, at CPH:DOX, one of the leading festivals for documentary film in the world

Omar and I attended the festival — It was my first time traveling internationally since I got sick — and had the opportunity to meet **Ketty Hansen**, mother of **Karina Hansen**, a young Danish ME patient who three years ago was forcibly removed from her home by police in order to undergo psychiatric treatment for her ME.

In the 24 hours before our premiere, articles about *Unrest*, ME, and **Karina Hansen** appeared in three different major Danish newspapers (http://bit.ly/2pjhiwK): *Politiken*, *Weekendavisen,* and *Information*.

We also appeared on the popular Danish television program DR2 Dagen (http://bit.ly/2p5haBd), discussing her experience with ME and the making of the film. This is a major reset of the conversation in Denmark, one we hope will reverberate throughout Scandinavia.

After the screenings, we spoke with doctors who pledged to become allies and bring this film to medical school campuses. Patients and caregivers spoke of feeling seen and represented. We felt a clear sense of community transcending language, culture, or country.

Upcoming Screenings

The list of festivals we'll be screening at is ever-growing. In the coming days, weeks, and months, we'll be screening the film at the RiverRun International Film Festival in North Carolina, the Ashland Independent Film Festival in Oregon, the Florida Film Festival (Jen's hometown festival!), and many more. Each of these festivals provides new audiences, new visibility, and new opportunities to shape the narrative around ME patients, chronic illness, and invisible disabilities. Here's what North Carolina's *Triad City Beat* had to say about *Unrest* in their preview coverage of RiverRun (http://bit.ly/2oekt5b):

***Brea** knits together a global community in a way that is beautiful and empowering. Her voice lifts a film that is both charged with urgency and slowed down to the speed of a disease that freezes lives in place while the world seems to pass by. "Sickness doesn't terrify me, and death doesn't terrify me," **Brea** says. "What terrifies me is that you can disappear because someone's telling the wrong story about you."*

We'll also be screening at Hot Docs (http://bit.ly/2nP6KWd) in Toronto next month. Hot Docs is North America's largest documentary film festival, conference, and market, and we're honored to be making our Canadian premiere there. Soon after, we'll head west to DOXA (http://bit.ly/2pmZnCC) in Vancouver. We're keeping busy!

For a full list of upcoming screenings, visit our website (http://bit.ly/2nPhdBb) or our Facebook events page (http://bit.ly/2oedybZ).

We're so excited for all that's to come. Thank you for everything you've done to support this journey. We could never have done it without you - and this is only the beginning!

Jen

See also: http://bit.ly/2ojHncg

Sharing Is Empowering: Share Your Experiences With GET!

If you have been harmed by Graded Exercise Therapy, here is a chance to get your story out there https://goo.gl/Ygu2Pq

People with ME know that graded exercise therapy is very unpopular amongst patients and most of us have us have heard horror stories. However, this isn't what the general public expect when they hear about it.

The name does not match our experience:

- Graded sounds gentle
- Exercise, that's good for everyone, right?
- Therapy has connotations of healing in a supportive environment

Personal stories can be a useful tool for making a heartfelt connection with the general public, especially for a topic like this which is counterintuitive.

For ME Awareness month (May) and Millions Missing we want to share your experiences of graded exercise therapy. We will post your story here (https://goo.gl/Ygu2Pq) and share in various places online.

If you or someone you know has a graded exercise therapy story to tell: Email GETpetition@gmail.com your story in a couple of paragraphs.

Points to consider

If you've already written a suitable blog post about GET, the most energy efficient solution is to simply send us the link and we'll repost it (perhaps you want to add a bio paragraph to promote your blog?).

If you are writing something new, these are some pointers:

- Concrete examples of how your health and limitations changed are helpful (or perhaps there was no difference?)
- How did you feel after GET?
- Did it stop you doing certain activities?
- How long did the impact last?
- How did medical staff respond? Were you allowed to stop the treatment without consequences?

Imagining that the person reading knows nothing about ME these points could help you explain.

Do you have pictures you are comfortable sharing? Visible before and after GET changes would be particularly poignant.

Your story will be shared widely. Do you want to use a pseudonym or do you want to use your real name (plus contact details)? Please make this very clear.

Please also ask people you know who have a powerful story to contribute. We are particularly interested in hearing about children who have done graded exercise therapy.

A specific hashtag for this is #MissingMoreGET

So, we can share on social media with various combos of #MissingMoreGET and #MillionsMissing #MEawarenesssmonth #stopGET #May12 etc

To get updates when Missing More posts are published, follow us on:

Twitter: @stopGETteam / @MEActNetUK

Facebook: www.facebook.com/stopGET orwww.facebook.com/MEActNetUK

22nd April 2017
By **StopMAGENTAteam**

ME/CFS Alert

Series of interviews with ME-researchers, clinicians and patient advocates by **Llewellyn King** and **Deborah Waroff**

Three new videos since last issue of the MEGC:

March 29, 2017
https://youtu.be/cOEed2Gu-l4
#86: Interview with **Charmian Proskauer**, president of the Massachusetts CFIDS/ME & FM Association to discuss their work, and **Charmian**'s husbands diagnosis.

April 12, 2017
https://youtu.be/eU5wcOwO-Bo
#87: Interview with **Dr. Alan Gurwitt**, a pioneer ME/CFS psychiatrist, explains the distinctions between ME/CFS and psychiatric illnesses and talks about his own diagnosis.

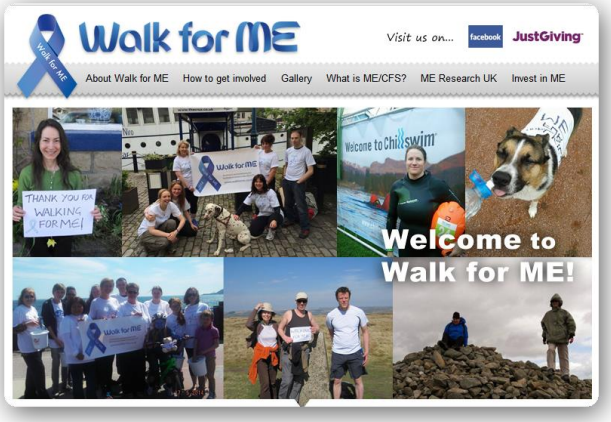
The pediatric primer mentioned:
https://www.masscfids.org/pediatric

April 23, 2017
https://youtu.be/guxRunBPmv4
#88: Interview with **Leah Williams**, ME/CFS advocate and mother of two children who have both been diagnosed with ME/CFS. Leah shares her experience, and advice for parents.

Please help support this program: https://www.gofundme.com/MECFSAlert

Walk for ME 2017

The original idea behind Walk for ME was that friends, family and loved ones of an ME sufferer do a sponsored walk on their behalf: hence the name Walk for ME or Walk for me. However, as well as walks we have had healthy friends and families of ME sufferers do swims, rides and runs! It is hoped that as many friends and loved ones as possible will do a sponsored walk or other fun event during ME Awareness Week which runs from 8th May to 14th of May.



A significant number of people with ME/CFS are bed-bound, house-bound or can only walk short distances. One of the tragedies of ME/CFS is that it is effectively an invisible illness as so many are too ill to work, raise awareness of the illness or raise money for research. We hope Walk for ME can help address all these issues by raising awareness and vital funds for research into ME.

We hope this will be a fun but poignant event. Family and friends can choose to walk any distance they choose; it could be 1 mile, 5 miles, or 10 miles or whatever feels appropriate. Alternatively, they can choose to swim, do a run or go for a ride. The whole idea is that the friend or family member is doing something that their loved one would love to be able to do but can't.

Please do get your friends and family involved there is more info on our website at http://www.walkforme.co.uk

It is less than two weeks until ME Awarenesss week and we just wanted to thank all the amazing people doing events as part of Walk for ME 2017 and all those who have donated so generously. The team target has reached £9,840 and an incredible £3,762 has already been raised with every penny going to biomedical research into ME.

You can find out more about the events people are doing at our events page https://www.facebook.com/events/223650654748426/

There's still lots of time to get involved so please do contact us for more info or visit our website at http://www.walkforme.co.uk

Source*:* https://www.facebook.com/WalkforMEUK/

8. Karina Hansen, Save4Children

Karina Hansen at Home

Karina Hansen and Save4Children

Karina Hansen is the second child the fund Save4Children is focusing on, since German **Joanne** did return home in July 2015. Inquiries with her mother didn't result into information about her present state, so we presume **Joanne**'s still free.

Karina is home as well, but her freedom is still being threatened by 'her' psychiatrist **Nils Balle Christensen** of Aarhus as ME-patient and -activist **Bente Stenfalk** so aptly describes in the article preceding this appeal. As long she's not completely out of danger, she will remain our main focus, both from the aspect of information and from trying to help her and her parents with legal procedures to get her unhelpful guardian off her case.

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

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

Once **Karina** is in save haven by being relieved of her guardian and thus being completely independent, we suggest we'll consider requests of **Dr. Nigel Speight** to financially support cases of British children with ME being threatened with enforced custodial placements.

Since last issue one gift of € 250,= has been received. Please continue to donate via https://let-me.be/page.php?11 as the effects of your donations are obvious, helping to give back already two young ME-patients their freedom instead of an uncertain institutionalized life at the hands of 'caregivers' who only care for their own career and wages.

Karina Hansen Slowly Getting Better

Karina's parents let us know they're very happy to have **Karina** back home again, and **Karina** is getting a little bit better day by day. Thinking of the coercion she has been exposed to and her flashback-reactions to this, **Karina** is improving a little every day. Her parents are very happy to be able to tell the good news that **Karina** for the first time has had a full week without flashbacks.

One family member of **Karina** said that there is a big difference between the day **Karina** came home heavily medicated tand now when **Karina** is under less medication. Now she's able to smile and she looks alive and interested, in contrast to the day she came home with all muscles completely stiff and looking like a living dead. **Karina** is still not talking, but she is following and understanding conversations and is able to write down answers.

The day when **Liselott Blixt**, Chairman of the Danish Health Committee, doctor **Stig Gerdes** and I visited **Karina** and her parents, **Karina**'s cat jumped on **Karina**'s lap and **Karina** smiled the most beautiful smile and it made us all very happy. **Liselott Blixt** and **Stig Gerdes** talked and joked with **Karina**, and it was a very bright day.

We can rightfully feel hope by now. If **Karina** is left in peace for a long time I am sure she will become her old self again one day, and maybe she can finish her highschool. Now all she needs is complete peace to recover mentally.

Every day **Karina** takes small walks in the city of Holstebro with one of her parents. She is able to walk some hundred meters without resting now. But they also walk with her wheelchair. **Karina** enjoys it so much when her cat is following them on their walk.

In March **Jennifer Brea**s film "Unrest" was shown with great success in three cinemas in Copenhagen. Nearly all seats were sold, and **Karina**'s mother**, Liselott Blix**t and **Stig Gerdes** were present at the first release. Three newspapers wrote about ME after the premieres, of which two in an informative way and one from a psychiatric point of view. In the film, **Karina**'s parents tell how awful it was when **Karina** was taken away from them and how they were kept in abeyance about their daughter. **Karina** is seen very shortly in the film but she was not able to say anything to the filming crew.

Next step is to visit a psychiatrist and try to get rid of the guardian which is no easy process. The whole Danish system is against such a step. The psychiatrists, the municipality and the guardian wanted **Karina** to live in another institution far away from her family where she could be activated. But I'm rather sure that if the parents had not taken **Karina** home again, **Karina** would have suffered a lot more from flashbacks and then 'the system' would have medicated her heavily to get rid of the flashback-reactions. That is what institutions do to patients who suffer from angry outbursts even if the they do not last longer than a few minutes.

The guardian does not step back of his own will which would be the only right thing to do, so we have to try and remove him via legal procedures. If we did not get help from **Save4Children** we could not proceed this guardian-case in court. We are very grateful to **Save4Children** and all of you who donated money for **Karina**'s sake. Without the help from all of you we could not have done anything which would have been a pity because what has happened to **Karina** should never have happened and should not happen again to others.

This sad case has had other consequences too. When **Karina** came home she had no GP. Nobody dared to be her GP. **Dr. Stig Gerdes** helped **Karina** to take a little less antipsychotics so she could slowly get off medication (she isn't yet, she has to get off very slowly not to get worse). **Dr. Stig Gerdes** requested access to **Karina**'s files at Hammel Neurocenter and subsequently the Board of Health withdrew **Stig Gerdes**' authorization to work as a doctor and sent him word that as he wasn't allowed to practice anymore he wasn't allowed access to **Karina**'s files. Actually, he should have cooperated with psychiatrist **Nils Balle Christensen**. However, **Christensen** WAS NOT **Karina**'s psychiatrist at that moment as he had left **Karina** under the care of the psychiatrist at the Risskov Hospital which had recommended **Karina** to get rid of her medication as fast as possible. So **Stig Gerdes** had done nothing else than follow up the recommendation of the new psychiatrist. When the Board of Health came to know this, they reacted that this did not affected their decision!

A couple of journalists followed this case 'at a distance' and read all we sent them. They did agree it's a very serious case, but said presently they don't have time to write or film about it.

This case has become nothing less than a case about democracy and human rights which is known to journalists and politicians, who just want the case to 'disappear'. Yet parents of young people with ME, the Danish ME-association and the Danish Civil Rights Movement don't want the **Karina**-case to be forgotten before the court has decided in her favour.

Let us all keep talking about **Karina**'s case and help her through the legal procedure to become a completely free and independent young lady.

Bente Stenfalk, Vice-President of the Danish Civil Rights Movement
April 24, 2017
Edited by MEGC

9. Science

A Mediterranean Diet Might Help Cognition

(***Dr. Rich Podell*** *submitted this adapted version of an article we published earlier, but thinks it important enough to share this revised article once more. It's up to you to judge.* ***The editors****)*

Again, the "hook" to CFS is that since there is strong evidence that Mediterranean diet reduces cardiovascular risk and no known health negatives, and since there is moderate evidence that Mediterranean diet is better than standard American Heart Association type low fat diet for cognitive health, it's a reasonable choice for our patients to try--even though we have no studies of applying it to our group of diseases.

SUBJECT OF STUDY: Mediterranean diet—a style of eating that emphasizes eating "good fats"—mainly from olive oil and/or nuts---encourages eating fruits, vegetables, and whole grain cereals. Also, moderate portions of wine. Minimize red meat (high in saturated fat). Minimize high sugar junk foods.

SUMMARY: Known to powerfully lower heart attack rates, this diet may also prevent mild cognitive impairment. If so, would this diet be worth trying for patients with "brain fog" due to ME/CFS or Fibromyalgia?

When patients ask me, Doctor, what they should eat, they almost always already have a specific diet in mind: organic, gluten free, allergy elimination, and lately, most often of late a Paleolithic**/**cave man type diet. These all have their used; but their best bet most often is the *Mediterranean Diet*.

Much research suggests that this relatively high-fat diet markedly reduces the risk of heart attacks and stroke. Two recent studies, PREDIMED and the Mind Diet, suggest that this style of eating might also help prevent the mild cognitive impairment (MCI), frequently associated with aging. MCI sometimes though not always progresses on to full Alzheimer's dementia.

The PREDIMED study

For a long-term diet study, Spanish researchers recruited 7,000 middle aged and older men and women who tended to have heart disease risk factors such as high blood pressure, high cholesterol or diabetes.

Each volunteer agreed to be randomly assigned to either a high fat Mediterranean style diet with-- the main fat source being either olive oil or walnuts-- versus a diet modeled on the American Heart Association's low fat recommendations.

Key Finding: *After 5 years, the rate of heart attacks was about 25% lower among those on the Mediterranean diet compared to those eating an American Heart Association style relatively low fat diet. The rate of stroke was also reduced. (*http://www.nejm.org/doi/full/10.1056/nejmoa1200303#t=article*]*

The Mediterranean Diet might also reduce the mild cognitive impairment that often occurs as we age.

Mild Cognitive Impairment (MCI) is estimated to affect 10 to 15% of older Americans.

The Barcelona branch of the PREDIMED study selected 447 of their subjects to take a battery of cognitive skill tests at the start of the study. Most, but not all of them, returned for repeat cognitive testing after about four years on their assigned diets.

The initial scores on nine detailed cognitive tests were about the same for subjects in each of the two diet groups.

*But at follow-up, the Mediterranean Diet group scored significantly higher than the low-fat-diet group for four of the nine cognitive tests—including the two that were the most challenging and complex**.** The Mediterranean Diet group also outperformed the low-fat-diet group on the other five test scores, though the differences for these tests were not statistically significant.*

These results suggest that the Mediterranean Diet helps prevent mild cognitive impairment (MCI)
(http://jamanetwork.com/journals/jamainternalmedicine/fullarticle/2293082)

Study Strengths: The cognitive test arm of the PREDIMED study was well designed. Its 4 year's long follow up is a major strength.

Study Weaknesses: The 447 patients involved in the cognitive arm of the study are "small potatoes" compared to the 7,000 followed by the full PREDIMED study. Also after 4 years about 100 of the original 447 subjects were not willing to come back for repeat cognitive testing.

While these results are encouraging, they don't yet fully prove that the Mediterranean Diet keeps cognition strong.

At this time, the Barcelona PREDIMED report *is the only well designed long term direct intervention controlled study where formal cognitive testing was done both before and after adopting the Mediterranean Diet. Fortunately, other indirect studies also lead toward an optimistic conclusion.*

The MIND DIET results also support the Mediterranean Diet.

Dr. Martha Morris and her team at Chicago's Rush University Medical Center monitored self-chosen diets for 960 people who were in their 70's and 80's. Formal cognitive testing was done at the start of the study and periodically over the next 4.5 years. Each person's actual eating choices were matched against an "ideal" Mediterranean Diet and also against a fairly similar diet that **Dr. Morris** named the "MIND diet".

Key Finding: *Persons whose diets most closely matched the Mediterranean and MIND-style diets had substantially less cognitive decline over 4.5 years compared to those whose food choices tended away from the Mediterranean/MIND diet way of eating.*

Impressively, those who most closely followed the MIND/Mediterranean pattern had only about half the risk of developing full Alzheimer's dementia compared those whose diets least reflected this healthful diet style.

[https://www.rush.edu/news/press-releases/new-mind-diet-may-significantly-protect-against-alzheimers-disease]

Takeaway and recommendation: Not only does this diet have other significant health benefits, but for people concerned about cognition, this is the one diet that has the most data to support it. My main caution is that the Barcelona study is the only well-long term study of the Mediterranean Diet that did cognitive testing both before and after the diet. It would be good to have additional controlled studies.

We don't know if the Mediterranean Diet would help the "brain fog" of ME/CFS or Fibromyalgia. Still, the diet is safe and most likely protective of cardiovascular health. So, of all the diets proposed for people with ME/CFS or FM, a 3 to 6-month trial of a Mediterranean style diet might well be considered.

Practical issues: How to Start a Mediterranean Style Diet

The diet used in the PREDIMED study recommended what most Americans would view as enormous intakes of olive oil—4 tablespoons each day either added to food or taken down straight. Nor do we know for sure which elements of the Med Diet are most important for health: olive oil versus vs fish vs whole grains vs. wine vs. low red meat fat vs. drastically reducing sugary junk.

Here are the specific diet recommendations from the PREDIMED Mediterranean Diet study:

Food Type Recommendation	How Much Recommended for Eating Each Day
Olive oil	>4 Tbs./day
Tree nuts and peanuts	>3 servings/week
Fresh fruit	>3 servings/day
Vegetables	>2 servings/day
Fish (especially fatty fish)	>3 servings/week
Legumes	>3 servings/week
Sofrito sauce (This is a blend of tomato, onion, garlic, aromatic herbs, and olive oil)	>2 servings/week
White meat	Instead of red meat
Wine with meals	>7 glasses/week
Foods To Not Eat Much	
Soda	<1 drink/day
Commercial bakery goods, sweets, and pastries	<3 servings/week
Spread fats	<1 serving/day
Red and processed meats	<1 serving/day

Richard Podell, **M.D.**, **MPH**

More Evidence For Altered Metabolism In ME/CFS

Metabolism is the process of converting food and drink into energy to keep our body's cells alive. Disturbances in metabolism results in too much or not enough of the substances needed for these vital chemical reactions. This can affect the function of organs- including the brain – and even the ability of the mitochondria to produce energy. Mass spectrometry is a sensitive technique used to analyze the metabolites and chemicals in a sample.

In a paper published this month in Scientific Reports, the research team led by **Professors Kataoka** and **Watanabe** at RIKEN Center for Life Science Technologies in Kobe Japan provides strong evidence for altered metabolism in ME/CFS.

The title is "Index markers of chronic fatigue syndrome with dysfunction of TCA and urea cycles" (http://www.nature.com/articles/srep34990).

The study included Japanese adults ages 20-60 years including 67 ME/CFS patients and 66 healthy controls. A total of 47 ME/CFS patients and 46 healthy controls were assigned to the training set, while 20 CFS patients and 20 healthy controls were used in the validation set. A fasting blood sample was collected from these individuals and the plasma analyzed by capillary electrophoresis time-of-flight mass spectroscopy (CE-TOFMS).

The chemicals of glycolysis, the TCA cycle, the urea cycle and glutamine metabolism were analyzed. The TCA cycle and the urea cycle were abnormal in ME/CFS.

- In the TCA cycle the amount of citrate, isocitrate and malate were significantly lower in ME/CFS patients.
- In the urea cycle citrulline was (highly) significantly lower in ME/CFS while ornithine was significantly higher in ME/CFS patients.
- There were no differences in glycolysis and glutamine metabolism between healthy and ME/CFS.

In analyzing the differences, the researchers were able to distinguish between ME/CFS and healthy controls.

The TCA cycle (also known as the Krebs cycle) occurs in the mitochondria where through a series of chemical reactions energy is produced in the form of ATP. The results from this study indicate that ME/CFS patients have a deficiency in ATP production.

The urea cycle produces urea – which is excreted – from ammonia (NH3) which is toxic if not metabolized by the body. The urea cycle is an essential detoxification projects that takes place predominately in the liver. Problems in the urea cycle result in the build up of toxic chemicals that can affect the function of the liver as well as other cells and organs.

The Bateman Horne Center of Excellence is working with the team at RIKEN to confirm these results. We sent several hundred samples to Japan last month and testing is currently underway. Should these results be confirmed, these metabolite markers could be developed into a clinical diagnostic tool as well as guide potential therapeutic interventions.

This week (7.29.17) the BHC sent 100 patient samples off to Japan! There, **Professors Watanabe** and **Kataoka** and the team at RIKEN (http://bit.ly/2opxnQG) will conduct cutting-edge metabolomics (an approach that looks for differences in metabolic profiles) to discern any differences in ME/CFS that could lead us to a biomarker! https://youtu.be/9_eFqi20BQ4

Source: https://batemanhornecenter.org/whats-buzz-october/

Scientists Discover Biological Evidence Of "Atypical" Chronic Fatigue Syndrome

Defining subgroups may help clinicians identify and treat the complex, debilitating disease also known as myalgic encephalomyelitis or ME/CFS

NEW YORK (April 4, 2017)—Scientists at the Center for Infection and Immunity (CII) (http://bit.ly/2opyPlW) at Columbia University's Mailman School of Public Health are the first to report immune signatures differentiating two subgroups of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS): "classical" and "atypical."

This complex, debilitating disease is characterized by symptoms ranging from extreme fatigue after exertion to difficulty concentrating, headaches, and muscle pain.

Typically, symptoms of ME/CFS begin suddenly following a flu-like infection, but a subset of cases classified by the investigators as "atypical" follows a different disease course, either from triggers preceding symptoms by months or years, or accompanied by the later development of additional serious illnesses.

To uncover evidence of these disease types, first author **Mady Hornig**, **MD**, (http://bit.ly/2oXPY41) director of translational research at CII and associate professor of Epidemiology at Mailman, and colleagues used immunoassays to measure levels of 51 immune biomarkers in cerebrospinal fluid samples taken from 32 cases of classical and 27 cases of atypical ME/CFS.

All study participants were diagnosed using the same standard criteria, but atypical cases either had prior histories of viral encephalitis, illness after foreign travel or blood transfusion, or later developed a concurrent malady—seizure disorders, multiple sclerosis-like demyelinating disorders, Gulf War Illness, or a range of cancers—at rates much higher than seen in the general population.

Their analysis revealed lower levels of immune molecules in individuals with atypical ME/CFS than those with a classical presentation and course of illness, including dramatically lower levels of interleukin 7 (IL7), a protein linked to viral infections, and interleukin 17A (IL 17A) and chemokine (C-X-C motif) ligand 9 (CXCL9), inflammatory molecules implicated in a variety of neurological disorders.

"We now have biological evidence that the triggers for ME/CFS may involve distinct pathways to disease, or, in some cases, predispose individuals to the later development of serious comorbidities," says **Hornig**.

"Importantly, our results suggest that these early biomarker profiles may be detectable soon after diagnosis of ME/CFS, laying a foundation for better understanding of and treatments for this complex and poorly understood illness."

"Early identification of patients who meet the usual clinical criteria when first diagnosed but then go on to develop atypical features would help clinicians like myself identify and treat these complex cases and even prevent fatal outcomes," says co-author **Daniel L. Peterson**, **MD**, principal clinician at Sierra Internal Medicine in Incline Village, NV.

Subgroups

The new study builds on earlier research by **Hornig** and collaborators that found robust evidence of distinct stages in ME/CFS. A pair of 2015 publications based on analyses of blood (http://bit.ly/1JP7byf) and cerebrospinal fluid (http://bit.ly/1M7IUcT) showed differences in the immune signatures of ME/CFS patients who had the disease for three years or less as compared with those who had been ill for more than three years.

The researchers reported that patients were flush with cytokines and chemokines until around the three-year mark—suggesting an over-activated immune response in that phase of the illness; thereafter the immune system showed evidence of "exhaustion," and levels of immune molecules dropped.

In the new study, both subsets of ME/CFS patients showed signs of an unbalanced or dysregulated immune system within the central nervous system, with immune markers different than those seen in healthy individuals.

However, the dampened immune profiles previously observed after the three-year mark were only observed in individuals with the classical form of the disease, not in those with atypical ME/CFS. Among subjects in the atypical group, levels of cytokines and chemokines were more likely to remain steady or increase.

According to **Hornig**, instead of the immune exhaustion seen in later phases of classical ME/CFS, atypical patients may be experiencing a "smoldering inflammatory process" in which the immune system is still working to recover, although she acknowledges that much work remains to be done to confirm this hypothesis.

Alternatively, these findings could suggest a pathway to disease in atypical individuals that involves biomarkers not captured in the 51-molecule assay, potentially even involving non-immune-related processes. Atypical individuals may also have genetic susceptibilities that lead their immune systems to respond differently than in classical cases.

Ongoing studies at CII are exploring other subgroups, including patients with allergic disorders, high levels of cognitive dysfunction, and gastrointestinal disturbances.

"Multiple biological pathways are likely involved in the pathogenesis of ME/CFS, with a range of clinical subtypes relating to variability in the types of environmental triggers, genetic and epigenetic vulnerability, as well as comorbidity patterns," says senior author **Ian Lipkin**, **MD**, **director of CII** (http://bit.ly/2nZykwd). "Shedding light on these pathways may help us to identify the various agents that precipitate disease as well as to design more precise, targeted treatments."

The study was supported by the Chronic Fatigue Initiative/Hutchins Family Foundation and the Edward P. Evans Foundation. Additional authors include **Meredith L. Eddy**, **Xiaoyu Che**, and **Joy Ukaigwe** at the Columbia University Mailman School of Public Health; and **C. Gunnar Gottschalk** at Sierra Internal Medicine. The authors declare no conflicts of interest."

Dr. Ian Lipkin, **Dr. Mady Hornig** and the scientists at the Center for Infection and Immunity at Columbia University Mailman School of Public Health need help to fund an exceptionally comprehensive and robust study for ME/CFS. Please read about this monster of a study (http://bit.ly/2gPHGYm) and consider making a donation.

Source: http://bit.ly/2n7pNus (press release)

An Update On ME/CFS Research

By **OMF Scientific Advisory Board Director Ronald W. Davis**, **PhD**

OMF shared a research update by Open Medicine Foundation's Scientific Advisory Board director, **Ronald W. Davis**, **PhD**, produced by **Ashley** (**Davis**) **Haugen** at the Stanford Genome Technology Center (SGTC):
https://youtu.be/sGBXXlQO49g broadcast on Febr, 21, 2017

Transcript: http://bit.ly/2opyJuP

The Center has made significant breakthroughs towards understanding the molecular mechanisms of the disease and is now in a position to test chemical compounds for treatment.

In a follow-up video **Dr. Davis** answered questions which the first video arouses. As the OMF put it: We thank you for all your great questions. We have chosen several of them for **Dr. Davis** to answer in this video, produced by **Ashley** (**Davis**) **Haugen**.
https://youtu.be/jXL2xzxCXBw broadcast on March 7, 2017

Transcript: http://bit.ly/2nUr9WI

OMF is helping fund the work of **Dr. Davis**' CFS Research Center team at the SGTC. So far, their breakthroughs have been achieved by doing one experiment at a time, week-by-week. At this point, the team is ready to ramp up the project in order to carry out multiple parallel investigations to get answers as fast as possible.

Submitted by **Marilyn Simon-Gersuk**

An Immunosignature Assay For Rituximab Therapy?

In many cases, the drugs used to treat various diseases are effective in only a proportion of patients. It can therefore be valuable to identify these individuals, so that those unlikely to benefit can be spared unnecessary treatments and potential side-effects. Rituximab is an antibody that attacks B-lymphocytes, a type of white blood cell. The drug has been used to treat some cancers and autoimmune disorders, and a scientific report in 2011, by **Øystein Fluge** and **Olav Mella** of the Haukeland University Hospital in Bergen, suggested that the symptoms of ME/CFS could be improved by treatment with rituximab (http://bit.ly/2ojs3fL).

The results of their study showed "lasting improvements in self-reported fatigue" over 12 months of follow-up in 67% of ME/CFS patients on rituximab, compared with a response rate of 13% among those on placebo. Rituximab was also associated with significant improvements in some quality-of-life measurements, and there were no serious adverse events. The investigators subsequently reported promising results in another group of ME/CFS patients (http://bit.ly/1H46lj7), in a study designed to explore the effects of rituximab over a longer period. They are now working on a randomized, placebo-controlled trial of the drug at five centres in Norway.

The Norwegian team has also been keen to collaborate with researchers around the globe, and has established contacts with the group led by **Prof. David Patrick** at the School of Population and Public Health, University of British Columbia. In 2015, **Prof. Patrick** received a grant from ME Research UK to help examine the post-exercise fatigue and malaise of ME/CFS patients using newly available gene sequencing technologies (http://bit.ly/2opGOzH), and this work is well underway. Another of his group's specialities, however, is the development of immunosignatures (http://bit.ly/2opC654). An immunosignature uses an array of chemical compounds called peptides to give information about the antibodies present in an individual's blood.

Prof. David Patrick acquired some samples from the Norwegian team with which to develop an immunosignature capable of distinguishing ME/CFS patients likely to respond to rituximab treatment from those who will not. This issue is important because rituximab is associated with potentially serious side-effects and requires clinical monitoring, and it is also an expensive drug. The preliminary results were promising (200 peptides differentiated responders from non-responders 92% of the time) (http://bit.ly/2oR8min), so ME Research UK has awarded Prof. Patrick a grant to see if the results can be confirmed in a blinded study using a larger number of samples from all 152 patients taking part in the Norwegian randomized trial. If the immunosignature pattern for the clinical response to rituximab is found to be sufficiently sensitive and specific, it may represent a useful biomarker for ME/CFS patients' responses, helping to predict those who will and those who will not benefit from rituximab treatment.

Source: http://bit.ly/2oBA3IE

CNS Findings In Chronic Fatigue Syndrome

CNS findings in chronic fatigue syndrome and a neuropathological case report

In this mini review and case report, **Kimberly Ferrero**, **Mitchell Silver**, **Alan Cocchetto**, **Eliezer Masliah**, **Dianne Langford** addressed central nervous system (CNS) involvement of CFS and present neuropathological autopsy findings from a patient who died with a prior diagnosis of CFS.

CFS is classified as a neurological disorder and increasing evidence supports CFS as a disease of the nervous and immune systems.

In the central nervous system (CNS), CFS may be triggered by exposure to radionuclides, viral or microbial infection, seizure, trauma, genetic mutations and/or other factors.

What are the new findings?

Neuropathological autopsy findings from a patient who died with a prior diagnosis of CFS report focal areas of white matter loss, neurite beading, and neuritic pathology of axons in the white matter with axonal spheroids.

Atypical neurons displaying aberrant sprouting processes in response to injury are observed throughout cortical gray and white matter. Abundant amyloid deposits identical to AD plaques with accompanying intracellular granular structures are observed as well.

Neuro fibrillary tangles are also present in the white matter of the frontal cortex, thalamus and basal ganglia. How might these results change the focus of research or clinical practice?

Taken together, these neuropathological findings warrant further studies into CNS disease associated with CFS.

Source: Journal of Investigative Medicine, April 6, 2017

Study Offers Hope To Patients Suffering From Chronic Fatigue Syndrome

A new study looking at epigenetic changes in patients with Chronic Fatigue Syndrome (CFS) is the first to identify differences in sensitivity to a specific hormone found in the body.

The study is the first to identify epigenetic differences among CFS patients in sensitivity to glucocorticoids, a type of hormone that plays a role in the immune system and is used to treat immune system disorders.

"Hopefully these results will offer CFS patients some hope," says lead author **Wilfred de Vega**, a PhD student in Associate **Professor Patrick McGowan**'s (http://bit.ly/2pmG6kA) lab at University of Toronto Scarborough.

Epigenetics, which is **McGowan**'s area of expertise, looks at changes in gene function. An epigenetic change doesn't change the gene itself, rather it influences how and when a gene is turned off. Epigenetic changes can be caused by environmental triggers like toxins, stress, nutrition or infections.

McGowan and **de Vega** compared immune cells in CFS patients to a control group first by looking at epigenetic differences across the entire genome. Then they tested patient immune response to glucocorticoids, in this case a version of cortisol, which has anti-inflammatory properties.

"When we tested immune response, we found two different sub-groups of CFS patients," says **de Vega**. "There are some that are hypersensitive to the drug, and others that have a regular response, one that you would typically find in non-CFS patients."

CFS, or Myalgic Encephalomyelitis (ME), is a chronic disease characterized by debilitating fatigue that cannot be resolved with rest. It affects the brain and multiple body systems, but its cause is not understood. It's thought to affect millions across North America.

McGowan, who runs one of the few labs in Canada doing active research on the disease, says historically CFS been treated as a psychiatric illness because medical doctors simply didn't know how to treat patients. He likens it to fibromyalgia, a disease that that is now recognized as a biological disorder.

“The patient response to this work has been eye-opening,” says **de Vega**, adding he’s received personal emails from patients who are looking for information.

The study (http://bit.ly/2mHvfjk) , which is published in the journal *BMC Medical Genomics*, found there’s a lot of differences across the genome in CFS patients, including more than 12,000 sites related to cellular metabolism or other metabolic processes that are epigenetically different. They also found 13 specific sites that indicate a sensitivity to glucocorticoids.

In the past glucocorticoids were used as a therapy for CFS but many patients suffered terrible side effects. **McGowan** says being able to identify which patients would respond positively to the treatment would signify a major advance.

“For years, they have felt largely ignored and not taken seriously, so they’re happy to know there’s active research happening here in Canada.”

The hope, adds **McGowan**, is that by finding different epigenetic marks in CFS patients there’s an opportunity to develop treatments that can alter those marks.

“If you can identify specific epigenetic changes in the immune system of CFS patients, you can then start to develop ways of testing drugs already in use or develop new therapies."

Don Campbell

Source: http://ose.utsc.utoronto.ca/ose/story.php?id=9360
University of Toronto
Submitted by **Allison Haynes May**

The Gut Microbiome In Myalgic Encephalomyelitis

A study by **Maureen Hanson** & **Ludovic Gileautaux** (Cornell University, USA)

Gastrointestinal disturbance is a symptom often reported by ME patients. Our research group undertook a study of the bacterial gut microbiome by comparing faecal samples of 48 ME patients and 39 controls. A conclusion that can be drawn is that ME cases have reduced bacterial diversity in comparison to healthy controls. Such reduced diversity has been observed in other diseases such as Clostridium difficile infection, inflammatory bowel disease and necrotizing enterocolitis. The reduced abundances of Bifidobacterium and Faecalibacterium species in patients have also been reported in inflammatory bowel disease and other conditions. Yet a harmful bacterium could be present in ME patients and go undetected by ribosomal DNA sequencing.

When the intestinal lining is inflamed, bacteria can translocate into the bloodstream through loosened intestinal tight junctions leading to a 'leaky gut'. The immune system then detects the presence of bacteria or bacterial components in the blood and mounts an immune response to counter this apparent invasion. There can be collateral damage from the immune system's attack on perceived threats. ME patients often have symptoms of chronic inflammation such as muscle and joint pain and swollen lymph nodes.

The abnormal gut microbiome in ME patients likely contributes to their chronic inflammation and ensuing symptoms. While digestion most often comes to mind when considering intestinal bacterial species, there is increasing evidence that the gut microbiome affects the risk of colorectal cancer, obesity and abnormal mental function. Metabolites and proteins from the gut enter the bloodstream in healthy as well as diseased individuals, and some can affect the central nervous system and brain.

Prospects for treatment

Oral prebiotics and probiotics are being investigated for restoration of bacterial diversity and resolution of gastrointestinal diseases. Prebiotics are substances thought to improve growth of beneficial species, while probiotic supplements contain microbes known to be present in healthy guts.

Because pure cultures of many gut microbes cannot be obtained, researchers have turned to faecal transplants, i.e. introduction of faecal material from healthy human donors into recipients. This treatment has cured some individuals with severe gastrointestinal dysfunction from Clostridium difficile infection. Promising reports have appeared about improvements in ulcerative colitis, Crohn's disease and autism. Whether this process can also help patients with other types of intestinal diseases and ME is less clear.

With regard to ME, anecdotal reports from patients who have tried faecal transplantation indicate some reduction in symptoms, but not complete recovery nor persistent improvement in their conditions. One study of faecal transplantation indicated that 42/60 ME patients had a favourable response. The results are sufficiently promising to suggest that a clinical trial of faecal transplants in ME would be worthwhile.

While these gut abnormalities may be a response to some other inciting factor, rather than the basal cause of disease, learning how to ameliorate them could have clinical benefits for patients and help promote recovery, perhaps in conjunction with other treatments.

Source: April 2017 © Biochemical Society
http://www.biochemist.org/bio/03902/0010/039020010.pdf

Gut Bacteria In ME/CFS May Influence Disease Severity

"Much like IBS, ME/CFS may involve a breakdown in the bidirectional communication between the brain and the gut mediated by bacteria, their metabolites, and the molecules they influence. By identifying the specific bacteria involved, we are one step closer to more accurate diagnosis and targeted therapies." ~ Ian Lipkin, director of CII and John Snow Professor of Epidemiology at Columbia's Mailman School.

Anticipated work from the CII teams' early investigative research into ME/CFS is starting to be published. The new study in the journal *Microbiome* from Drs Ian Lipkin and Mady Horning at Columbia University Center for Infection and Immunity (CII) finds abnormal levels of certain types of bacteria in the gut microbiome of ME/CFS patients. It also found disturbances in bacterial metabolic pathways that, in combination with the changes in bacteria, may influence disease severity.

The CII team collaborated with some of the top clinicians in the field, including Klimas, Peterson, Montoya, Bateman and Levine, to ensure they had rigorously-diagnosed patients. Harvard Professor Tony Komaroff was part of the team too. The open access paper is titled 'Fecal metagenomic profiles in subgroups of patients with myalgic encephalomyelitis/chronic fatigue syndrome' (http://bit.ly/2pkVSgp).

Researchers took fecal and blood samples from 50 patients and 50 healthy controls. They analysed cytokines in the blood, as they did in their original cytokine study (http://bit.ly/18vqYbM) and they applied metagenomics (http://go.nature.com/2qhx2NA) to the fecal samples. Metagenomics is a new field that combines remarkable technology for sequencing huge amounts of DNA with a kind of sophisticated genetic detective work to not only identify which bacteria are present, but also which bacterial metabolic pathways are active too. ME/CFS patients differed from controls in both.

Additionally, the authors state that their findings indicate that features unique to ME/CFS may be masked by disturbances arising from irritable bowel syndrome. They recommend that for more accurate results, microbiome studies should factor in whether or not ME/CFS patients have irritable bowel syndrome, IBS, which is very common among ME/CFS patients. This may help gain insight for the development of therapeutic strategies for both ME/CFS subgroups.

Some types of bacteria were strongly linked with ME/CFS cases whether or not they had IBS, while other bacteria were linked with those ME/CFS patients who also have IBS.

This complex research paper is not easy reading, the research team analyzed a lot of data and highlighted many bacteria and metabolic pathways, but here are some interesting things:

- Levels of distinct intestinal bacterial species—Faecalibacterium, Roseburia, Dorea, Coprococcus, Clostridium, Ruminococcus, Coprobacillus—were strongly associated with ME/CFS; their combined relative abundance appears to predict if someone has the illness.
- Increased abundance of the Alistipes group of bacteria, and decreased Faecalibacterium were the top biomarkers of ME/CFS with IBS.
- Enrichment in the pathway for vitamin B6 (http://bit.ly/2qhBhZF) biosynthesis and salvage (i.e. recycling B6) was the strongest predictor of ME/CFS, regardless of whether or not patients had IBS. Vitamin B6 helps the body use and store both proteins and carbohydrate, as well as help form the haemoglobin that carries oxygen round the body. There is some evidence B6 is low in patients, but this could be down to changes in the body rather than in gut bacteria.
- No changes were observed in immune markers which may reflect the lack of participants who had been ill for a short time; earlier research suggests immune changes may only be evident when comparing short and long duration cases

Bacterial types and metabolic data combined correlate with symptom severity

An intriguing finding was from analysis that combined data on changes in metabolic pathways with data on bacterial types. In ME/CFS subgroups, symptom severity measures, including pain and fatigue, correlated with the abundance of distinct bacterial types and metabolic pathways.

"Individuals with ME/CFS have a distinct mix of gut bacteria and related metabolic disturbances that may influence the severity of their disease," says co-lead investigator Dorottya Nagy-Szakal, postdoctoral research scientist at CII.

It is important to note that it is not clear if dysbiosis is contributing to metabolism changes. The researchers state "more work is needed to assess the relationship between the bacterial metabolic pathways identified by using gene content, bacterial metatranscriptomics, and metabolome in ME/CFS" and they concluded with:

"Our results confirm and extend previous work indicating intestinal dysbiosis in ME/CFS. We further demonstrate that patterns of dysbiosis vary with IBS co-morbidity. Future prospective studies should consider more detailed exploration of IBS subtypes, associated GI symptoms, and their relationship to ME/CFS dysbiosis. The identification of ME/CFS networks—characterized by specific profiles that integrate microbiota, metabolic pathways, and plasma immune molecules—may enable more accurate diagnosis and lead to insights that inform the development of specific therapeutic strategies."

April 26, 2017

Source: http://bit.ly/2q5ZVx1

10. Severe ME

The Care Needs Of People With Severe ME

On Tuesday April 25, 2017 Greg Crowhurst announced: "I am delighted to announce that the 25% Group and Stonebird have published a new Care Guide, which you can download, as a Word document, here :http://bit.ly/2oHEccQ"

Taken from the new Care Guide: the basic principles behind Severe ME-aware care:

- Never define the person by their behaviour.
- Acknowledge the serious and severe physical illness underlying the person's symptom experience.
- Adhere to a strictly defined definition of ME (The International Consensus Criteria).
- Honour the WHO classification of ME as a neurological disease and respond appropriately and equally as in any other recognised neurological disease.
- Treat the person with respect on all levels; respect for the way interaction occurs, the physical and the cognitive limitations enforced on the person by their severely disabling multi-system dysfunction.
- Honour what the person says regarding their physical and cognitive needs.
- Listen to the person and to only interact at the correct time in the correct way. We call this the MOMENT approach, honouring the severe illness the person has whilst maximising the opportunity to engage safely in order to help, not harm them, when undertaking all care needs.
- Understand any hypersensitivity issues (chemical, drug, touch, noise, light, movement, motion, food); never ignore, undermine, negate or belittle them, recognising the danger of the ordinary environment as real, not just perceived.

- Understand and comprehend that the person with Severe ME is not experiencing the world the same way as a well person and cannot fit into the demands and obligations imposed on them by others, easily or at all. A flexible, knowledgeable, sensitive, compassionate, non-judgmental, person-centred not goal oriented approach at all times is critical. Being aware of the after impact of any interaction is essential; that even something once achieved cannot necessarily be achieved or tolerated again or regularly or increased.
- Recognise the irrelevance, unhelpful and dangerous nature of a psychosocial response and interpretation of Severe ME, a physical disease. Psychiatry has no right to first hand intervention in this disease which requires a biomedical response and care pathway .

It is vital to ensure that that you never put any overt or covert pressure, demand or expectation to improve, upon the person with Severe ME, nor any underlying belief that is in opposition to the truth and severity of the disease and very real lack of valid treatment and cure.

Adapted from "Severe ME : Notes for Carers"

By **Greg Crowhurst**
http://stonebird.co.uk/Notes/index.html

Article produced by Stonebird & the 25% ME Group Source: http://bit.ly/2oHEccQ

11. News from

Australia

UNSW school of medicine responds:
CBT/GET training trial for chronic fatigue syndrome

Prof Rodney Phillips, Dean of Medicine at the University of New South Wales (UNSW) denies that **Prof Lloyd**'s trial would cause harm to participants and refuses to stop the trial or amend it in any way. The university says the people who are protesting harbour 'resentment against the notion that CFS may have psychological causes', while there is no evidence for their argument.

The letter from **Prof Phillips** was in response to the petition (http://bit.ly/2ohM98s)protesting a trial of a training module of graded exercise therapy (CBT) and cognitive behaviour therapy (GET) for health professionals. The petition was sent to UNSW's Vice Chancellor **Prof Ian Jacobs**; the Mason Foundation; the federal health minister and the National Health and Medical Research Council (NHMRC). It asked them to stop UNSW's trial of an education module for health profess-sionals (http://bit.ly/2ohM98s) which treats chronic fatigue syndrome patients with GET/CBT, despite the evidence showing these therapies have no benefit and often cause permanent harm.

The trial registration (http://bit.ly/2ck77DT) says "despite GET and CBT being widely acknowledged as best-practice interventions for CFS, the great majority of patients in Australia are not receiving these appropriate evidence-based interventions. Recent studies have demonstrated that the reason for this documented gap between research and practice is largely due to practicing health professionals lacking the knowledge and skills to provide appropriate care."

The letter from UNSW explains that the dean believes chronic fatigue syndrome (CFS) to be a subjective diagnosis of exclusion; going against researchers at ANU, Melbourne University, Griffith University and overseas at Stanford University and other leading universities, who use the Canadian or International Consensus criteria and have made significant medical progress. The World Health Organisation also classify it as neurological, not psychological.

"This is a difficult, and often controversial, clinical syndrome featuring disabling subjective fatigue," said **Prof Phillips**.

"The diagnosis is made after careful exclusion of alternative medical and psychiatric explanations for the fatigue state. The controversy typically relates to the validity of the illness as a separable diagnostic entity, and also whether the illness has a purely 'psychological' basis. I do not propose getting into those arguments here."

It appears that UNSW do not have a clear grasp of the illness in the group of people they are aiming to treat.

"Since listing the trial on the register, the study investigators and the UNSW HREC have been receiving correspondence from critics requesting the trial not go ahead. This response essentially reflects resentment against the notion that CFS may have psychological causes."

It poses an international risk, as UNSW plan to "disseminate the treatment to other centers nationally and internationally", according to information the University provided to the National Health and Medical Research Council (http://bit.ly/2oKxrKO).

"The scientific evidence base for CBT and GET patients with CFS both individually and combined is very strong," argued **Prof Phillips**.

Submitted by **Sasha Nimmo**

Abridged by **MEGC**
Source: http://bit.ly/2nATeSJ

Belgium

On the 7th next June, Linda Tannenbaum, who is the CEO of the Open Medicine Foundation (OMF - http://bit.ly/MXG66I), will land in Belgium. This organization makes attempts at offering quick solutions to ME and related chronic complex illnesses.

The OMF has arranged a team of researchers that, within various subdivided areas of research, seeks to find a cause of these diseases. Among the constituents of this team are three Nobel Prize laureates and several other globally accredited scientists. (https://www.omf.ngo/scientific-advisory-board).

The complete calendar for Linda's tour can be found here:http://bit.ly/2nH5O4y

On June 7th, the WUCB is to organize a patients' meeting where Linda will provide a speech. We deem this visit very important for Belgium and secretly hope that at least some persons from the medical world will be present. But of course, political people are always welcome, seeing as they're the ones who have to draft the healthcare policy. And last but not least, anyone who feels they've been affected, heavily or not so heavily, by anything involving the illness is also very much welcome.

The press has also been invited. We're hoping for high attendance. Alert us at wucb.provincieantwerpen@yahoo.com if you're going to attend the event.

Event commences at: 15:00 and ends at 18:00
Entry fee: €7,-
Location: Cultuurcentrum Merksem, Nieuwdreef 135, 2170 Merksem.
Contact: wucb.provincieantwerpen@yahoo.com

The WUCB newsletter can be read here (only in Dutch):http://bit.ly/2pCWtJ4

On May 12th, we're going to make the day, an Awareness Day. We will do this together, with the rest of the world. We hope many of us will congregate on social media. https://www.facebook.com/MEBelgium

Practically anyone can help by:

- lighting up buildings and town squares with blue lights;
- lighting up their own yard;
- sticking a poster on their window (http://millionsmissing.be) or
- placing a blue light at the window;
- posting or share an image/film to Facebook, Twitter etc., do so for ME using the hashtag #MillionsMissing.
- Take a picture of it and send it to info@millionsmissing.be

Canada

The M.E. documentary "Unrest" will be shown at the Toronto HotDocs Festival, April 29, May 1 and 5, and also at the Vancouver DOXA festival, May 12 and 13.

The Vancouver showing is being sponsored by the ME/FM Society of B.C. (province of British Columbia), and will correspond with May 12th, world-wide M.E. Awareness Day!

You can download the PDF of the new M.E. Definition booklet by **Dr. Byron Hyde**. http://bit.ly/2oe1Iii

Here is a summary of Canadian patient **Allison Haynes May**:

Dr. Byron Hyde's Nightingale Research Foundation website is undergoing some renovations, but he has made available his 23-page booklet "The Nightingale Research Foundation Definition of Myalgic Encephalomyelitis (M.E.)", which he presented in 2016 in Barcelona, and at the IACFS/ME Conference in Fort Lauderdale, Florida (USA), and at Cornell University (USA). To order a paper copy by mail, see the instructions in the PDF on the "inside front cover "page.

This booklet discusses many areas of interest and importance, all relating to a better understanding of M.E.. These include the following.

1) **Dr. Hyde**'s conclusion, supported by the work of Dr. John Chia in California, USA, that M.E. is caused by a polio-like enterovirus (EV).

2) The similarities between polio and M.E. (the history of epidemics, the symptoms, and at the level of the EV genome).

3) The clear differences between: a) Primary Post-EV M.E., b) Secondary Sporadic M.E., and c) Chronic Fatigue Syndrome (CFS).

4) Clear explanations as to why "CFS" is merely a symptom or group of symptoms that may indicate various pathologies. If a Doctor diagnoses CFS, he/she has failed to properly diagnose the patient. More information on this can be found in Dr. Hyde's book "Missed Diagnoses", available for purchase online at hulu.com.

5) How **Dr. Hyde** diagnoses M.E., that is to say, with these 3 main criteria:
   a) clinical history of the patient,
   b) proof of EV infection at onset from gastric biopsy or from gastro-intestinal-tract biopsy in chronic patients,
   c) HMPAO brain SPECT (Single Photon Emission Computed Tomography) scan, demonstrating significant hypoperfusion (lack of blood circulation) in at least the left temporal lobe and cingulate gyri, employing "Segami Oasis Neurogram" software.

He goes on to elaborate on the above (5 a, b, and c) as follows:

- 5a) describes the typical clinical history and symptoms of M.E.
- 5b) explains EV testing and shows illustrations from microscope slides of active EV infection in an M.E. patient. The EV infection causes the hypoperfusion in the brain.
- 5c) includes photos from actual SPECTs of M.E. patients, and illustrates and explains how the damaged areas of the brain correspond to the type and severity of M.E. symptoms. (Other types of brain scans, or SPECTs without the proper software, are unable to adequately demonstrate this damage to the brain.)

6) Also discussed is the history of M.E. outbreaks, and the mistakes made (for example, the Lake Tahoe epidemic being mis-labelled as Epstein-Barr Virus, when EBV has a 40-day incubation period so cannot occur in outbreaks), and the other prejudices and conflicts of interest (committed by the NIH, the New England Journal of Medicine, the UK psychiatric lobby, among others) that have left a shameful history of neglect and abuse of M.E.-sufferers world-wide.

7) To end on an optimistic note, I will quote **Dr. Hyde**: "At the August 2016 Europic meeting on picornaviruses in Switzerland, several new anti-enteroviral medications were discussed. Although at an early stage, some have shown success in animal models. Help may yet be on the way for chronically disabled M.E. patients." I will also add that **Dr. Hyde** believes that the development of a new enterovirus immunization will be the key to preventing further cases of M.E., as well as polio, type 1 diabetes, and the millions of childhood deaths occurring yearly, worldwide, due to EV diarrhea and pneumonia.

I highly recommend this booklet and hope that the information therein will be seen by all those who are working on M.E. research, from whatever angle they may be approaching the disease. If M.E. is indeed caused by an enterovirus, the logical next step is to develop anti-enteroviral drugs.... just as with AIDS, the HIV retrovirus was identified, and then anti-retroviral drugs were developed, and became a very effective treatment for those living with HIV.

In the words of a friend living with both HIV and M.E., and obviously receiving treatment for the HIV but not the M.E., "HIV is a walk in the park!" We can only hope to receive such treatment for M.E. in the near future. I am 57 and have been disabled by M.E. since age 30. I would certainly appreciate having a chance at improvement in my lifetime. Sincere thanks to **Dr. Hyde** for all his dedicated work since the 1980's and for this excellent latest publication.

Allison Haynes May, Ottawa, Canada.

"At 30 Years old I live in fear for my future because so little is done and no treatments are available."… One week later - **Justin** Was dead

A mother says goodbye to her son - unbearable, intolerable.

Dear **Minister Philpott**:
I wanted to take a few minutes to tell you about my son, **Justin Noble**. **Justin** was 31 years old when he passed away on October 13, 2016. Two years prior to that, my son was a hockey player, went to the gym regularly, loved sport fishing, enjoyed a good job, had a fiancee and, in general, was leading a life to its fullest.

Then the symptoms began and as time went on, having run through the usual specialists here in Vancouver, e.g., Immunologist, Cardiologist, Rheumatologist, Neuromuscular specialists... ...the list goes on and on; we kept coming up against a wall. His life was being spent more and more in a dark room.

Being in a desperate situation with no help from the Canadian medical system, I took my son to the University of Nevada to be tested by a Belgian doctor who was affiliated with the University. After much testing and an in-depth study of his symptoms, my son was diagnosed with Myalgic Encephalomyelitis which, as you know, to this day, has no cure. Researchers are working in the U.S. but Canada has turned its back on this disease by its lack of funding for research.

As an advocate not only for himself, in his dark room, **Justin** helped many, many people through online conversations and encouragement. His name was known to those he came in contact with and, it was for this reason, that **Dr. Ron Davis** and his CFS Team at the Genome Technology Center at Stanford University, with the help of the Open Medicine Foundation, have honoured **Justin**'s name through an Internship for their ongoing research into ME.

My son had asked that in lieu of flowers, donations were requested to be made to the Open Medicine Foundation - as we have no Canadian equivalent.

Minister Philpott, I would be shocked if you do not see the irony of what is happening. My son, Canadian born, would have been so proud to be helping other Canadians in this struggle. Why do we continue to turn our backs on something so very important?

My son is only one of thousands and thousands who suffered (and continue to suffer) from this debilitating disease. When are we going to give some of these people hope for their future? I read a poem at **Justin**'s Memorial Service which was written by a dear, former work colleague of mine. It hit me so hard that I just knew I had to stand up and read it for those in attendance. I've attached it to this letter.

Please, **Minister Philpott**. Please provide the necessary funding that this disease needs to not only save lives but also provide help for those who are struggling each day with very little hope of returning to their active lives.

Thank you for taking the time to read my letter and attached poem.
Sincerely,

Susan C. Noble Richmond B.C., February 22, 2017

Source: Millions Missing Canada
http://bit.ly/2paHDgQ

Germany

Dear fellow patients,

May is just around the corner. May is the ME awareness month. German ME patients urgently need international support for our petition which is addressed to German Health minister, science minister and healthcare provider. Let`s get 5000 signatures!

Please sign and share our petition. Thank you very much for your support!
http://bit.ly/2oycalC

Here you can read **Regina Clos`** (http://bit.ly/2oC7lt1) translation of the relevant part of our petition: Petition to recognize ME in Germany

ME or "CFS" patients ask for:

- Recognition of the WHO Code G93.3
- Funding of Biomedical research on ME ("CFS")
- No more discrimination by our health system

Myalgic Encephalomyelitis? - Never heard!

Myalgic Encephalomyelitis (ME) is the most common and the most devastating disease your doctor has never heard about. Many doctors believe that this disease exists only in the minds of the patients. However, already in 1969 the WHO classified ME as an organic disease under the diagnostic code G93.3.

In Germany, ME is being played down and incorrectly labelled as "Chronic Fatigue Syndrome". These names are the result of an unprecedented campaign of trivializing and psycho-pathologizing ME, which began shortly after the WHO classified ME as an organic disease.

In particular, we call for:

- An official acknowledgement of BMG (Federal Department for Health), the G-BA (determines the benefits catalogue of the Statutory Health Insurance), the Bundesärztekammer (German Medical Association), the GKV (Statutory Health Insurance), the MDS (medical advisory service of the German association of statutory health insurance funds), the AWMF (committee of the scientific medical expert associations) and the DRV (German federal pension fund) to classify ME (and "CFS") under the key G93.3 as determined by the WHO.
- An official acknowledgement of all the institutions listed above to bring into line their future actions with regard to the disease ME or "CFS" with Article 2 (2) and Article 3 (2 u. 3) of the Basic Law of the Federal Republic of Germany [Article 2 (2) "Every person shall have the right to life and physical integrity. ... ". Article 3 (2) "Men and women shall have equal rights. The state shall promote the actual implementation of equal rights for women and men and take steps to eliminate disadvantages that now exist." Article 3 (3) "No person shall be disfavoured because of disability."].

- The deletion of all references to "CFS" and ME in the AWMF guideline on p3 without substitution.
- A new version of a guideline of the AWMF for Myalgic encephalomyelitis based on the International Consensus Criteria of 2011 and the International Consensus primer of 2012.
- The deletion of the chapter "Chronic Fatigue Syndrome (CFS)" and all references to "CFS" and ME in other chapters including the deletion of patient letters from DEGAM guideline no. 2 "tiredness" without substitution.
- A new version of a medical guideline on Myalgic Encephalomyelitis based on the International Consensus Criteria of 2011, and the International Consensus primers 2012.
- The development of patient letters based on the International Consensus Criteria of 2011 and the International Consensus primers 2012.
- Forwarding of information (new guidelines and patient information, see above) to all doctor's offices for general medicine, internal medicine, neurology, infectious diseases, immunology, allergology, rheumatology, cardiology, haematology, endocrinology, environmental medicine, sports medicine, physiotherapy, osteopathy, psychiatric and otolaryngology.
- Information and education campaigns on the disease for doctors, hospitals, emergency rooms, rehabilitation clinics, public health offices, school boards, social services departments, health insurances, pension insurances, disability insurances, medical consultants, job centers and the social association VdK.
- Medical Training on Myalgic Encephalomyelitis based on international biomedical research.
- The establishment of the subject in the curricula of medical schools.
- The deletion of all references to "CFS" and ME and G.93.3 from the DRV "Guidelines for the sociomedical assessment of people with mental disorders" without substitution.
- A nationwide awareness campaign on ME based on the International Consensus Criteria of 2011 and the International Consensus primers 2012 (print and digital media).
- The withdrawal of the deficiently researched RKI report "Erkenntnisstand zum Chronic Fatigue Syndrome (CFS)"
- The establishment of a research budget for biomedical research into ME. The size of the budget should be equivalent to diseases of comparable prevalence and comparable level of disability (eg MS).

We ask for your signature!

http://bit.ly/2oycalC

Submitted by **Katharina Voss**

Ireland

HOPE

OpenMedicine Foundation

THE END ME/CFS WORLDWIDE TOUR 2017

OMF in Ireland!

Join Team OMF & Irish ME/CFS Association
As We Welcome Guest Speakers

Linda Tannenbaum & **Dr. Ros Vallings**

CEO/President, OMF

New Zealand Expert

Sunday, May 28, 2017

2:30—5:00 PM

The Maldron Hotel Dublin Airport

Open Medicine Foundation® (OMF) is the leading research organization working to end ME/CFS and related chronic complex diseases. OMF's **End ME/CFS Worldwide** Tour is delivering **HOPE** to parents, patients, caregivers and friends.

Presentation will include an update on OMF's revolutionary research and what OMF and others are doing to increase awareness, education and support. Following the presentation will be question and answers. All are welcome!

Price: €5 at the door

For more info: **openmedicinefoundation.org | info@irishmecfs.org**

Italy

Video project for ME Awareness day

For the ME/CFS Awareness Day on May 12th the Italian ME/CFS Association wanted to produce a video-collage of patients (and doctors) telling how many years they are ill and what caused their illness.

They therefore asedk all patients if they were able to make a self-reported video of 15-20 seconds, in which they say a few sentences about the effect of the disease on them.

The video (along with ones name and location) - or even just a selfie with overwritten information, had to be sent by April 25 at admin@cfsitalia.it.

All the videos (and photos) will then be assembled together, fragmented by any video of doctors, blue flakes and cards with the symptoms of the malady, to make one single awareness video.

The slogan was: 'Join the crowd. You can shoot as you like. Also, lying in pajamas. We try to give a concrete face to our common suffering. Join the crowd!'

Municipal Palace of Pordenone lit up in blue on May 12, 2017

Good news: the mayor of Pordenone welcomed the request of the CFS Italian Association to illuminate the Pordenone Municipal Palace blue for ME/CFS, purple for Fibromyalgia and Green for MCS and Lyme on May 12, the World Awareness-day, which this year marks its 25th anniversary. We will be there from 9.30 pm as required.

The event, which is held worldwide, is promoted globally by Action CIND, or Action Chronic Immunological and Neurological Diseases, a Canadian nonprofit organisation committed to people suffering from immunological and neurological diseases.

Interview with the president of the CFS Italian Assocation (2014)

now available with English subtitles:
https://youtu.be/FyIcVRbS8Ek
Doctor Giada Da Ros, president of the CFS Italian Association, is interviewed on CFSME. She is referred to as "doctor", but in the sense of iuris doctor, she is not a physician. She is mentioned of having links to the Cancer Reference Center of Aviano, but only because her association has its headquarters there.

New-Zealand

A Sense of Belonging - being part of our global community

Something very powerful happens when new members attend our Support Groups for the first time. For many, it is their first experience of being amongst those who understand their condition and comprehend the bewilderment that accompanies a changing physicality and life.

All of us have been there. We know the emotional devastation of not knowing where to turn for help or worse, of reaching out to find there is no one there.

Within our Support Groups, or when I field inquiries on our public help line, I am always struck and saddened by the shared commentary. A shared commentary of being in a dark place, a vacuum from which there seems no escape.

Within this dark place, it can be difficult to find the things we need:

- clinically valid information on ME/CFS/Fibromyalgia
- knowledgeable non-harming medical practitioners
- validation (being believed, being heard)
- wider community awareness
- support (emotional, physical, social, spiritual, financial, medical)

For most, attending a Support Group for the first time is a profound experience. A light switches on in that dark place. At long last here is validation, support, empathy, acceptance and support in a safe and supportive environment amongst those whose stories echo our own. At last here is a sense of belonging, of being part of something bigger than ourselves – of community.

The need to belong, to be part of a community and something larger than ourselves is inherent in every human. And we do belong – not only to our regional support groups or to our national organisations - we belong to the ME/CFS global community. Our community is huge, there are literally hundreds of thousands of us throughout the world. Each one of us is intertwined through those global connections.

That connectivity manifests in many ways, including when we as individuals, wherever in the world we may be, read this publication with its articles from the many global ME/CFS contributors. It manifests every day through the thousands of men and women throughout the world working towards a common aim - to give those with ME/CFS a better life - to find the switch that turns on the light in that dark place. From every piece of research, every dollar raised, every national organisation, every support group meeting it all comes back to this central point – we as individuals are part of something bigger than ourselves.

From out here in the periphery, out here amongst the multitude of support groups and national organisations throughout the world, we watch and we wait. We are always there - a silent presence, silent witnesses, silent cheerleaders - as our scientists strive to find the way forward - to find the switch that turns on the light in that dark place.

Each one of us is part of this international matrix. It is the glue that binds us together and make us part of something bigger - part of a truly global community.

Sandra Forsyth

Vice Chair, WellMe
Wellington, New Zealand
April 2017

http://anzmes.org.nz/

Northern Ireland

Millions Missing & 12th May

This year is the 25th Anniversary of International May 12th Awareness for ME and Fibro and other neuroimmune related illnesses.
We welcome and encourage anyone who is at all able, to join us for this important day.

Details confirmed so far: SATURDAY 13th MAY. 3pm-6pm Newry City Hall will be lit up purple and blue to mark this event.

Newry Lord Mayor, **Gillian Fitzpatrick** will read out the Newry, Mourne and Down Council official proclamation for May International ME and Fibro awareness, at 4PM.

Followed by light refreshments.
Invitations have been sent to all Councillors (40) in NM&D District Council.

Over 100 pairs of empty shoes from patients, too ill to attend, will be displayed on the footpath area, directly outside the City Hall.

Leaflets about our campaign for adequate, specialist NHS services for Northern Ireland will be available to the public.

An information stall and Millions Missing posters will also be on display.

Submitted by **Joan McParland**

Norway

12th May is approaching, and then the ME association will mark the day all over the country.

Our association is also becoming larger and larger. The last count was 4016 members and even more signed up when we could announce we visited the Prime Minister's office the other day and conveyed our concerns to one of her advisers.

The ME association is concerned with many issues, but especially with the lack of research, the way ME-patients are approached and the lack of updated understanding of the disease itself.

In May, at the headquarters of NAV, the association has sent letters to the Directorate of Health that they should revise the supervisor and we still have meetings with parliamentarians.

ME patients now need to be taken seriously, and in that case, public players should cease to be angry because patients disagree with their views.

Also, they must stop recommending unregistered treatments or recommending "alternative" treatment methods. Getting more knowledge about the disease is to be preferred over just seeing. It is also very surprising that several players in the health sector today recommend so-called "alternative" treatment plans for the ill.

One should not believe but know when it comes to health.

Olav Osland
Source: website of ME Foreningen Norway http://bit.ly/2oPjUiq

Poland

Screening of Unrest in Krakow

In Krakow there’s a screening of the movie 'Unrest'on Saturday April 29 at 15.00 PM at the Off Camera Film Festival.

In the movie **Jen Brea**, a patient with ME / CFS talks about how in an instant from a strong, independent woman, traveling the world she turned into a very sick and helpless patient. She made the documentary with significant help of her husband, as she was convinced all over the world there were much more people like her, for whom there’s no medical help

If you have family / friends / friends in Krakow, this is a great opportunity to raise awareness about the illness amonstg yourselves!

Location: MOS (Małopolski Ogród Sztuka) - Rajska 12 street - small room - tickets for 15 PLN

Http://www.offcamera.com/festiwal/filmy/unrest

Source: Millions Missing Poland
https://www.facebook.com/MillionsMissingPoland/

South Africa

We are holding a virtual event on 12 May. I have done a radio interview on April 26th which they want to air for awareness on 12 May.

We are working towards TV news coverage of the day, am still trying for a physical event, but not sure yet.

Here is the official link for outside South Africa to the TV program we had, don't know if you can/want to use it:
https://www.youtube.com/watch?v=aNIk-pwwwkg&feature=youtu.be

The one of the two facebook versions has gone viral, we are on 66 000 views.

BBC Radio OS contacted me and I did a brief live interview on 31st March with them on invisible illnesses - here is the link:
http://www.bbc.co.uk/programmes/p04xj4hn

45 minutes into this video an interview of BBC Worldwide Service with THE ME CFS Foundation South Africa.

Thank you, BBC OC! Unfortunately, they ran late and we only got about 7 mins instead of the planned 15 mins.

Submitted by **Retha Viviers**

Sweden

Careful with treatments

An article in the Swedish local newspaper Borås Tidning

Sometimes recommends treatments that lack scientific support. It is time for the hospital to release old performances and acquire new knowledge of ME / CFS, the writers consider.

Last week Borås Tidning reported about **Susanne** who despite being ill is unable to receive any medical treatment. She suffers from the ME/CFS disease, classified as neurological by the WHO.

But **Måns Thörnqvist**, chief physician at the neurologist reception at Säs, "does not share that perception". Instead of the mitigating treatment recommended by international ME/CFS experts, **Thörnqvist** believes that patients should be treated with GET and cognitive behavioral therapy (CBT) at the healthcare centers.

Contrary to what **Thörnqvist** claims, there is no scientific support for his treatment recommendations. They can also be harmful to ME/CFS patients. Most of the members of the National Association for ME patients (RME) treated with therapy called for physical exertion have worsened by it. In many cases, the deterioration has become permanent. CBT and physical activity is certainly an effective treatment in many diagnoses, but in ME/CFS it is the opposite - typical of ME/CFS is that one is less assessable. The deterioration is measurable and scientifically proven.

Thörnqvist's view is based on the so-called PACE study of 2011 which reported that CBT and training improved patients. The study spread all over the world but has been the subject of an international scandal since a couple of years as it was found that the researchers exaggerated the 'positive' results by 400 percent. They have used among other things wide criteria by which patients would be excluded in the study and changed the definition of post-improvement for more favourable outcomes.

Following a court process, the researchers were forced to discard the material and an independent analysis showed no effect beyond the expected placebo effect.

Source: http://www.bt.se/debatt/sas-bor-ta-till-sig-ny-kunskap/

The Netherlands

Earth without art is just "eh..."

Dutch ME patient **Anil van der Zee** has set up a beautiful and potentially self-proliferating international project. **Anil** used to be a professional ballet dancer - which was once the spirit of his life - until he was struck by the CMV (cytomegalovirus, HHV 5) beyond recovery. His health deteriorated to the point where the screening of **Ryan Prior**'s ME documentary "Forgotten Plague" he organized in Amsterdam, including the speech by **David Tuller** in February 2016 couldn't be attended by him, despite living within throwing distance of the venue.

During recent months, he has appealed to his ever impressed circle of friends and artists to put together a broad ME awareness program. You can join in on this yourself by liking, sharing, or posting an artistic form of expression yourself.
Read more information on his website, particularly designed for this purpose: http://anilvanderzee.com/undauer-nl/

In this blog, you will find information about **Anil** himself and extensive info about ME, including the most promising current developments in the field of science pertaining to ME. Want to know how to aid him in this project?
Then click this link: http://anilvanderzee.com/undauer-nl/#hoe. **Anil** implores everyone to share this info to as many places as possible. There should not be a language barrier; the site is available in English, German, French and Spanish:
http://anilvanderzee.com/undauer-en/
http://anilvanderzee.com/undauer-de/
http://anilvanderzee.com/undauer-fr/
http://anilvanderzee.com/undauer-es/

Any donations will go to the following five projects:
The Open Medicine Foundation, info: https://www.omf.ngo (**Ron Davis et al.**)
The Microbiome Discovery Project, info: http://microbediscovery.org (**Lipkin, Hornig et al.**)

Invest in ME, info: https://www.facebook.com/groups/5804522506/ (including annual conference day in London, where peak international researchers in ME gather, including the three days prior)

The Norwegian rituximab trail , info at: http://me-forskning.no/donations/ (**Mella** & **Fluge**)

The Blue Ribbon Foundation, info: http://theblueribbonfoundation.org/ (**Ryan Prior**, director of the ME documentary "Forgotten Plague")

This will be a continuing project, starting right now

The Dutch ME/CFS association has compiled a second survey; this time with treatment as its main subject. Questions are already being asked about judgments by family doctors and specialists, about the occasionally imposed CBT and/or GET, and about bio-medical treatments.

The first survey in 2016, titled "Zorg voor ME" ("Care for ME", which surveyed patients about their care in the Netherlands) managed to draw the attention of the press and policy makers, partially thanks to the large number of participants (629, which were in accordance with the IOM criteria of 2015, based on certain questionnaires).

Millions Missing Holland-day will take place this spring, on May 12th, just like in other European countries.
No initiative of placing down empty shoes at various locations this time, but instead, attempts to light up a building in blue lights in each of the 12 provinces in the Netherlands.
For more info > see section Events

Dream or Donate/KissMEGoodbye
http://nl.dreamordonate.com/dromen/kissmegoodbyebynienke/
Fundraiser #kissMEgoodbye
For OMF research.

Valentine's Day 2017, start of action
A day of love. A day to kiss.

Nienke (9 years) misses her mother in many aspects of life due to ME and thanks to her idea an action has been started to raise funds for the Open Medicine Foundation (OMF's end ME/CFS project).
To kiss ME goodbye forever.

What started as an action with kiss-selfies as a challenge is taking on more and more shapes. For example, there has been a market sales day. A facebook webshop will be opened. And there are plans to keep an auction of art objects in the autumn. Preparations are already in progress.

#kissMEgoodbye is committed to all ME patients around the world.
For example, we have instructions (memes) in 10 languages. We hope that the support for this challenge will be increasing, as ripples on water so that more money can be donated to the OMF project.

Help 17,000,000 people pass for research. Help **Nienke** achieve her dream of getting ME out of the world. Learn how to help the Open Medicine Foundation to achieve the ultimate goal; treatments for all ME patients.

http://www.kissmegoodbye.nl http://www.kissmegoodbyeomf.com
Facebook: http://bit.ly/2l0WZ1H
Https://twitter.com/KMGchallenge

#KissMEgoodbye

A better kiss does not exist.

This action is supported by the OMF via **Linda Tannenbaum**

United Kingdom

Debate in Parliament the absence of an effective policy for the treatment of M.E

Sign this petition:
https://petition.parliament.uk/petitions/190618

ME (Myalgic Encephalomyelitis) a physical, neurological illness, but remains untreated except with psychotherapy - a failed policy based on the views of discredited psychiatrists who deny that ME exists. A non-psychiatric policy of ME research and treatment would end this ongoing medical scandal.

- **At 10,000 signatures...**
  At 10,000 signatures, government will respond to this petition

- **At 100,000 signatures...**
  At 100,000 signatures, this petition will be considered for debate in Parliament

As yet over 6.600 persons have signed. The petition runs until September 22, 2017. Only British citizens can vote

Submitted by **Jo Best**

NHS prescription charges survey
In August last year I wrote about the Prescription Charges Coalition campaign (http://bit.ly/2oi4Rg2) to make prescription charges fairer for those with long term conditions. There's now a survey to help with the campaign.

The NHS prescription charge in England is going up to £8.60 per item on April 1st. If you pay for your prescriptions, or if you did before you became exempt, click the link below to complete the survey which closes on 30 April 2017:

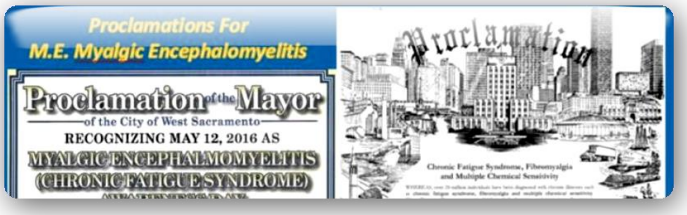
- Take the prescription Charges Coalition 2017 Survey (http://bit.ly/2llIwBI)
- Find out more about the Prescription Charges Coalition (http://bit.ly/2llIwBI)
- Find out about saving money on your NHS health costs in England (http://bit.ly/2oeh0DB)

Written and submitted by **Emily Beardall**

12. 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

12th May – ME Awareness Day



A new Facebook page has recently been created to gather all the proclamations recognizing May 12 Awareness Day and May Awareness month for M.E. and similar diseases. The page is looking for more proclamations and hoping more people will submit proclamations to their city and state governments.

FB page - Proclamations For M.E. Myalgic Encephalomyelitis:
https://www.facebook.com/groups/184652382049781/?ref=br_rs

Submitted by ***Colleen Steckel***

May 12, 2017
25th Anniversary of awareness day for

- ME - Myalgic Encephalomyelitis
- FM - Fibromyalgia
- GWI - Gulf War Illness
- MCS - Multiple Chemical Sensitivity
- CLD - Chronic Lyme Disease
- Mold/Biotoxin Illness

How It All Began
May 12 - International Awareness Day for C.I.N.D.'s (Complex Immunological and Neurological Diseases) and the organization behind it, RESCIND, Inc. were started in 1992 by ME/CFS patient and advocate extraordinaire Thomas Hennessy, Jr. Tom died on Sept. 9, 2013. May12.org continues Tom's work fighting for patient rights.

The Florence Nightingale Connection
May 12th was chosen to memorialize the birth date of Florence Nightingale, the English army nurse who inspired the founding of the International Red Cross. Nightingale contracted a paralyzing, CIND-like illness in her mid-thirties and became chronically ill. She spent the last 50 years of her life virtually bedridden, and despite being severely debilitated she started the world's first school of nursing.
(Taken with permission from http://www.may12.org/history.aspx)

In Europe, the first Millions Missing-day of 2017 will coincide with ME awareness day, i.e. on May 12, 2017.

More info elsewhere in this issue and on the wall of MM http://millionsmissing.org/

For American citizens: here are some steps to get a local or state proclamation of May 12th, 2017 as Myalgic Encephalomyelitis, Fibromyalgia, Chronic Lyme, and Multiple Chemical Sensitivity Awareness Day

1. Find the person to contact - Google "[name of state or city] proclamation"
If no links is found then:

- For City proclamations contact the City Clerk
- For State proclamations contact the Governor's office assistance line and ask to be connected with the person who handles proclamations.

2. They will ask you to submit wording. The following wording is one option:
Proclamation of May 12th, 2017 as Myalgic Encephalomyelitis, Fibromyalgia, Chronic Lyme, and Multiple Chemical Sensitivity Awareness Day

WHEREAS, Myalgic Encephalomyelitis [ME], Fibromyalgia [FM], Chronic Lyme disease, and Multiple Chemical Sensitivity [MCS] are all Complex Immunological and Neurological Diseases [CIND]; and

WHEREAS, Myalgic Encephalomyelitis (commonly known as ME/CFS) is extremely difficult to diagnose, is debilitating in its severity and is characterized by severe exacerbation of systemic illness following any forms of exertion, is understood to be an inability to properly generate energy within cells and which prevents most sufferers from working, studying, or otherwise living a normal and functional life; and

WHEREAS, ME can be as impairing as multiple sclerosis, late-stage AIDS, and chemotherapy cancer treatments and there is no known effective treatment and no cure; and

WHEREAS, Chronic Lyme disease can be a similarly severely disabling disease with a post-sepsis like outcome, which needs accurate and valid Lyme testing, and is often misdiagnosed as ME, CFS, FM, or multiple sclerosis; and

WHEREAS, Fibromyalgia is a disease characterized by severe pain in muscles, ligaments and tendons which can prevent sufferers from working or engaging in any physical activity; and

WHEREAS, Multiple Chemical Sensitivity can cause an allergic-like reaction in individuals when exposed to a number of different pollutants such as chemicals, perfumes and other environmental triggers; and

WHEREAS, some forms of these diseases can leave patients homebound and/or bedbound resulting in social isolation, stress on the families of those impacted, financial hardship; and suicide or death; and

WHEREAS, 25 years ago staunch advocate Thomas Hennessy, Jr., an ME and Lyme patient, chose May 12th as International Awareness Day for these illnesses to commemorate the birth of the famous nurse, **Florence Nightingale**, who suffered from an ME/CFS-like illness; and

WHEREAS, these diseases affect millions of individuals in the U.S. and impact people of all ages, races, and backgrounds, including individuals living in Washington, North Carolina; and

WHEREAS, increased awareness and education for Complex Immunological and Neurological Diseases can help patients get diagnosed earlier, foster support for individuals and families coping with these life-altering conditions, and receive proper treatment and compassionate care.

NOW, THEREFORE, I, XXXXXX, of the City of XXXXXX, do hereby proclaim May 12, 2017, as "**Myalgic Encephalomyelitis, Fibromyalgia, Chronic Lyme, and Multiple Chemical Sensitivity Awareness Day"** in XXXXXX and commend its observance to all citizens.

Examples of other proclamations can be found at FB page:
Proclamations For M.E. Myalgic Encephalomyelitis
https://www.facebook.com/groups/184652382049781/

Note: Most proclamations will only use some of the wording offered. Unfortunately, we don't always get a say in the final wording.

3. You may be invited to attend a signing by the mayor or governor. If you are not up to attending, then they will usually mail you the signed proclamation and they sometimes notify the local newspaper or post it online.

Submitted by **Colleen Steckel**

HERE I STAND - *a benefit + awareness show*
Saturday, May 13th, 2017 @ 7:30pm
Marpole United Church (1296 West 67th Ave. Vancouver, BC, Canada)

Join award-winning singer **Jacqueline Ko** and friends for a journey across the musical spectrum in support of a great cause! In Mariposa's fifth annual charity benefit show, **Jacqueline** performs alongside pianist **Angus Kellett** and guests to explore music ranging from pop to Puccini, from Offenbach's *The Tales of Hoffmann* to the hit musical *Hamilton*. This one-night-only concert event has something for everyone, so you won't want to miss the uplifting new show from the singer that critics rave "knows exactly what to do with an absolutely gorgeous voice" (Review Vancouver)!

In honour of the International Awareness Day for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome & Fibromyalgia (ME/CFS & FM), a portion of every ticket sale will benefit the ME/FM Society of BC. The evening will include a reception, as well as a charity raffle contest with over $2,000 in prizes.

$25 general | $20 students, seniors and disability benefit | $15 for groups of 4+
Get your tickets at http://hereistandconcert.brownpapertickets.com/,
at 1-800-838-3006 or at the door. To learn more, or to make special seating arrangements due to health or mobility concerns, please call 778-918-9498

Jacqueline Ko, *soprano*
Angus Kellett, *piano*

Also featuring: **Daniel Amaya**, **Ian Backstrom**, **Russell Cripps**, **Courtney Dugan**, **Carolin Ford**, **Robin Hahn**, **Stephanie Ko**, **Brittony LeFever**, **Melissa Ratcliff**, **Roan Shankaruk**, **Mark Wolf**

The story behind the show:
Vancouver performer **Jacqueline Ko** has lived with the systemic neuroimmune disease Myalgic Encephalomyelitis (ME), sometimes referred to as Chronic Fatigue Syndrome (CFS), since age six. Despite the challenges of her illness, which left her bedbound for years, she has managed to become a multi-award-winning singer and found a critically acclaimed opera and musical theatre company. She is committed to using her passion for music to help others, and since 2009 her benefit performances have raised over $38,000 in support of ME & FM treatment, education and research. Her story is featured in the new book *Lighting Up a Hidden World: CFS and ME*

By **Valerie Free**.

Learn more: http://operamariposa.com/
Invite your friends to the Facebook event: http://bit.ly/2oLKPuJ
Can't come to the show? You can show your support with a donation:
http://bit.ly/2oyUMQN

Conference Schedule For IIMEC12 - 2nd June 2017

08:55 Chair - **Dr Ian Gibson**:
Welcome to #IIMEC12

- **Professor Ian Charles**: Keynote Speech - A Centre of Excellence for ME
- **Dr Vicky Whittemore**: Keynote Speech - NIH Research into ME
- **Prof Sonya Marshall-Gradisnik** and **Prof. Donald Staines**: Dysregulation of Transient Receptor Potential (TRP) ion channels and calcium in natural killer cells in CFS/ME patients
- **Prof Nancy Klimas**: Genetic Signature Study
- Plenary Session - **Dr Ian Gibson**

Refreshment Break

- **Dr Jakob Theorell**: Studies of NK cells and cytotoxic T-cells in ME-patients from one Swedish and one Norwegian cohort
- **Dr Jo Cambridge**: Immunoregulation in patients with ME
- **Prof Simon Carding**: Gut Microbiota in ME
- Student Panel: Q & A for Students Researching ME
- Plenary Session - **Dr Ian Gibson**

Lunch

- **Ass Prof Mady Hornig**: Gut-metabolome-immune disturbances in ME/CFS subsets
- **Prof Olav Mella**: Update on the clinical trials RituxME and CycloME
- **Dr Øystein Fluge**: Metabolic Profiling in ME/CFS
- Plenary Session - **Dr Ian Gibson**
- *Refreshment Break* **Professor Warren Tate**
- **Professor Ron Davis**
- Plenary Session - **Dr Ian Gibson**

Millions Missing Day across the world

Australia

Sydney

There will be a #MillionsMissing event in Sydney on Friday the 12th of May, on the steps at the Town Hall. Most previous #MillionsMissing events have used empty pairs of shoes to represent sufferers of ME/CFS who are missing from work/study/social/sports settings. To give our #MillionsMissingSydney a special Sydney-esque flavour we plan to use thongs to represent those who are missing. So come along if you can and bring a bag with some pairs of thongs!
This event will last for an hour or so, though we don't expect to be standing all the time.

Belgium

Diest at the Demer river

During the evening of May 12th the fountains on the Kaai in Diest will be lit blue. Possibly other buildings/monuments will be coloured blue as well on the occasion of international ME-Awareness day. One could also light up blue one's own garden or place a blue light behind one's windows.

Denmark

Nyhavn

May 12, from 11 am till 14 pm: demonstration

France
No activity known yet

Great Britain & Ireland
UK's May Protests at: Birmingham, Dublin, Edinburgh, Newcastle upon Tyne, Isle of Man, London & Newry

-Edinburgh ***(Scotland)***
Scottish Parliament
12 May from 12 Noon until 2pm
https://www.facebook.com/groups/175392066302063/

-Newcastle upon Tyne
Two bridges will be lit up in blue. Supporters are invited to meet at one of the bridges at 8:30 PM.

-Isle of Man
Legislative Buildings
12 May from 12 noon until 2pm
https://www.facebook.com/events/809510442557970/

-Birmingham
Birmingham Cathedral
12 May from 1pm until 5pm
https://www.facebook.com/groups/419273485132072/

-London
Department of Health
12 May from 12 noon until 2pm
https://www.facebook.com/events/414470832248176/

-Newry ***(Northern Ireland)***
Newry City Hall
13 May from 3pm until 6pm
https://www.facebook.com/MillionsMissingNewry17/

-Dublin ***(Ireland)***
Leinster House
11 May from 11am until 3pm
https://www.facebook.com/events/133532340510944/

Holland
In the Netherlands, they managed to light up the night blue for ME:
-*Zwolle* Central station's pedestrian tunnel, with exposition & event
-*Barendrecht* building Nedelko
-*Heemstede* Townhall
-Heemstede Mill
-*Eindhoven* Evoluon
-*Lelystad* Library and Blue Pillar statue of Lely after whom the city was called

On May 12th from 15.00 tot 18.00 pm #MillionsMissingHolland is present at the south of the central station of Zwolle, capitol of one of the twelve province with an exposition of part of the 1000 shoes which were exposed at the Plein in The Hague on September 27, 2016

The pedestrian tunnel underneath the station will be lit up in blie, thanks to #ProRail. Prorail will also pay attention to the action with press releases and via the social media with the hashtag #prorail en #millionsmissing.

Iceland

Reykjavik

On Friday, May 12, 2017, Iceland will participate in the Millions Missing Global Million Missing Program (Millions Missing) for the first time.

ME patients will gather at the Asturvöller Place in Reykjavik from 11:00 am till 14:00 pm

This participation marks a milestone in the awareness of ME / CFS (chronic fatigue) in Iceland and is the first of two events this year. September 28th there will also be a conference about ME in Iceland.

We urge everyone to meet and show solidarity.

Italy

Pordenone

The Pordenone Municipal Palace will be lit up blue for ME/CFS, purple for Fibromyalgia and green for MCS and Lyme on May 12, the World Awareness-day, which this year marks its 25th anniversary. We will be there from 9.30 pm as required.

Also thanks to ***Helle Rasmussen*** *for collecting data of events on* http://bit.ly/2pkovug

South Africa

A virtual event is planned on 12 May. A radio interview has been recorded on April 26th which is to be aired for awareness on 12 May.

They are working towards TV news coverage of the day, and still trying for a physical event, but not sure yet.

13. Poem - Hope

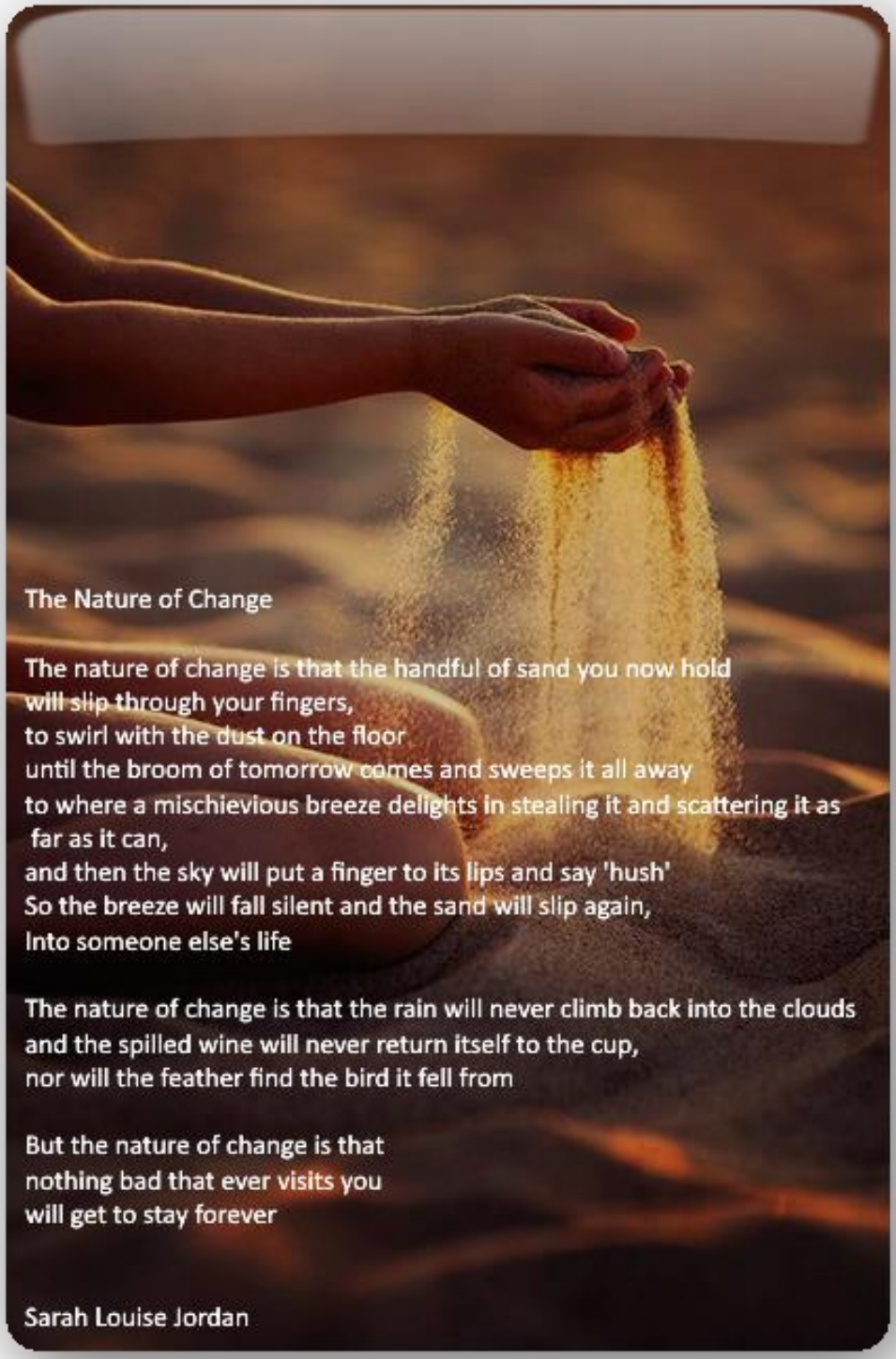
Hope is the thing with feathers
That perches in the soul
And sings the tune without the words
And never stops at all

And sweetest in the Gale is heard
And sore must be the storm
That could abash the little Bird
That kept so many warm

I've heard it in the chillest land
And on the strangest Sea
Yet never in Extremity,
It asked a crumb of me

Emily Dickinson

14. Poem – The Nature Of Change



https://www.inkinstrangeplaces.com/home/2017/4/4/change

15. Column

Not minding the illness too much

This is a remark that is heard frequently by ME patients. Most often directly from their general surroundings, but also in revalidation centers or from physicians. Something more hurtful to say, no matter how well-intentioned, is unfathomable for someone afflicted with a condition for which any help is lacking and any prospect of recovery is non-existent.

Jason was living the time of his life. He was enjoying the fruits of his career. It had been a busy time and this holiday proved to be a great drift-away from his daily life. He watched the sea's waves from a high rock which he had just climbed atop of, enjoying the wind flutter through his hair and the sunshine onto his face. The fresh air and the sea's scent were doing him good. This is exactly what he needed.

He hesitated briefly before making that dive. He didn't scale that rock for nothing, but the altitude made him shake a little. **Jason** was an experienced swimmer and diving was his favorite sport. The adrenaline at the moment superseded his fears. He made the dive.

Grasping for air, he surfaced from the water. With an arm's strength, he was just able to reach the inlet of the rock. He managed to drag himself onto the shore and screamed in pain. The waves had flung him onto an underwater rock-something he did not foresee.

Swimming the entire track back just by arm power was not feasible. And that he knew. His entire life seemed to have changed with that one accident. From a successful life which allowed him to do anything to a life of survival. One of hopefully being able to return ashore, back to his former lifestyle. Nothing else was more important. Everything that was once more significant, vanished in a heartbeat into obscurity.

Not minding the illness too much.

The life of ME patients is also one that shifted dramatically between days. From a regular life to one focused on survival. A life without aid, where one is seemingly absent from the picture; where all strategies are being considered in the hopes of finding the way back. Back to the world which we were once part of.

How odd is it that you're meticulously trying to follow all scientific advancements out of hope? To keep yourself busy with the road back to the past?

We need to prove that we're unable to actually swim back ashore. We mustn't talk about the pain and should accept the situation as it is.

Would people tell **Jason** that he should just "accept" the situation and be done with it? Or would they say it's logical for him to resolve his case with everything at his disposal?

Those still able to at least swim would swim with all their strength, occasionally enjoying the view. Those whose legs had been debilitated, are those who, on a daily basis, are trying to conceive new strategies to return to their former glory, to gain some control. A struggle that is usually invisible, because it shouldn't even have been there.

How odd is it that we focus on our illness when everything has been taken away from us? It's all about returning ourselves to the former lives we lived which we loved living so much.

Dear society, dear physicians. I strive to once again enthusiastically contribute as my part in society. Hence why I'm looking into the possibilities of returning ashore ASAP. So I can get back to getting tired after work and then reveling in my well-deserved vacation time. But for the time being, I'm confined from the outside world on that rock, hoping for more. Grasping every straw. Trying every therapy that was offered.

Jason emerged in a state of intense pain, and had no faith in getting off that rock on his own and returning to shore. Fortunately, the sweet water puddle in the rock's inlet would keep him alive for the time being.

His life was suddenly all about surviving. He wanted to give up anything for it. Would anyone notice him? Would any help arrive? A salt tear precipitated across his cheek. The memories of his former life were evoked. He would fight to the bitter end, hoping to stay alive, forever.

Rosa

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

16. 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."