The ME Global Chronicle

www.let-me.be

6 - August 2014

1. Colofon / Personalia

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Textual contributions for the October issue need to be supplied in Word by 4th October and sent to: contribute@let-me.be
The next issue will come out on October 15,2014.

Subscribe to this newsletter
We are no association or society, just a bunch of idealists who want to give our best efforts towards recognition of this terrible disease. By trying to help connecting to each other all patients all over the world. Anyone who expresses the wish to receive the Newsletter will be added to the list: that's the only formality and thing to be done. subscribe@let-me.be –
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Picture front page: ***Greg & Linda Crowhurst, Eddy Keuninckx***
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3. Introduction

Dear friends,

You will find plenty of fairly recent ME news from all corners of the world in this August edition of the ME chronicle.

We find that you, our readers, are more and more often thinking along with us and sending in suggestions for articles (via contribute@let-me.be). This is a pleasant development, which will hopefully continue. Because, as we are now repeating time and time again: this magazine is not only for all of us, but by all of us as well.

Another delightful piece of news is that **dr. Jose Montoya** has joined the CFSAC panel. A less pleasant piece of news is the direction the P2P has taken, about which you will find a lot of information in this edition.

We divided the articles into sections to make the magazine better surveyable. Furthermore, we added a new section: **Severe ME**. The Severe ME Awareness Day on 8 August formed the inspiration for this addition. It is a subject that should be better illuminated and we are happy to do our bit.

The news from Denmark, where another young woman is likely to be the victim of the power that psychiatry still holds over ME, is very distressing. Fortunately we also have good news from the United Kingdom. Invest inME has succeeded in collecting the required **£350,000** for the **Rituximab** research. Also, there is a new donation button for the children's fund
Save4Children: http://www.geef.nl/doel/save4children

We will keep you posted on the preparations of what is likely to become the most important event of 2015: the march to Capitol Hill in May.

Please continue turning this magazine into your own magazine. Distribute it amongst your own circle if possible.

We hope you will enjoy and learn from reading this magazine.

Eddy Keuninckx
David Egan
Rob Wijbenga

Next issue will be published towards **15th October**.
Written contributions in Word before **4th October** to contribute@let-me.be

4. Preface

Dear reader,

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

The Summer is coming to a conclusion now and the year is steadily moving forward. The changing of seasons mirrors changes in the lives of people, including those of us in the ME and CFS communities. Inevitable changes in lives, destinies and fortunes, as **Shakespeare** said in his sonnets "each changing place with that which goes before".

Many of the top politicians, senior civil servants, policy makers, medical doctors, medical councils and bodies, research organisations have just arrived back from Summer holidays. Hopefully they are fresh faced, relaxed and rested, and eager for new challenges.

We encourage all persons to contact their governments and all health bodies and research bodies in their own countries and ask them to take a more active interest in ME and CFS, and provide more funding and resources for research , for clinics and for implementation of Canadian (2003) and ICC criteria (2011).

It's up to you the readers to fight for the changes desperately needed in your own countries.

We will continue our exploration of Biomarkers for subgroups. In this issue we will look at 2 highly important Biomarkers for subgroups:

- The RnaseL abnormality
- The low number of natural killer cells and low levels of function and cytotoxicity.

These are unusual findings in any illness and are important factors, and occur in most cases of ME and CFS. In the constant rush and obsession for new knowledge and new facts, and new research, and exciting new developments, we all often lose sight of some really important established scientific facts. The subgroup biomarkers are of great strategic importance and will continue to be over time.

We live in the era of 'doublespeak' as **George Orwell** termed it in his famous book '1984'. This is very apparent and obvious in the ME and CFS world. We have a minority of doctors and patient organisations who support CBT, GET and psychiatric drugs for ME and CFS while dismissing and condemning all standard medical treatments for the complex biological abnormalities found in ME and CFS.

And their hatred of herbs, supplements and healthy nutrition is well known. Some have co-written papers and over-used the words "inconclusive", "not proven", "inconsistent" in relation to biological findings.

Some have slyly mentioned stress and childhood trauma in these studies but forgot to mention them in studies into Cancer, Alzheimers, Heart disease, Diabetes, Strokes, Anti-NMDA receptor encephalitis, Common Variable Immune Deficiency (CVID), Ehlers–Danlos syndrome (EDS), Neurological illnesses, mitochondrial disorders, serious Endocrine disorders, TB, MS, etc..

Yet they fully support the findings for CBT and GET and psychiatric drugs, which have proven useless and ineffective in over 85% of ME and CFS cases.

Strangely, these same doctors claim to support the biological basis of ME and CFS. This is outright hypocrisy. It is the clearest example of 'doublespeak'. And it is this 'doublespeak' which has stopped research progressing in the field and stopped ME and CFS from being taken seriously by government, medical, civil service, academia, press and media and pharmaceutical industry players.

'Doublespeak' is the means by which patients are ridiculed and neglected for years and decades. As a consequence, we have an 'Epidemic of Bogus Treatments' as outlined here at http://www.me-ireland.com/bogus.htm . We need to confront 'doublespeak' wherever we find it and remedy it with relevant scientific and medical facts.

One of the functions of the ME Global Chronicle is to act as a bastion of scientific and medical facts, which will arm patients, carers and doctors worldwide with the truth.

We need truth after suffering over three decades of lies, deception, 'doublespeak' and neglect. Let us sum up with the words of two brilliant minds, **William Shakespeare** and **George Orwell**:

"This above all: to thine own self be true,
And it must follow, as the night the day,
Thou canst not then be false to any man."
William Shakespeare

"In a time of universal deceit - telling the truth is a revolutionary act."
George Orwell

A special thanks to the increasing number of you for your contributions and insights.

The next edition will be due on October 15th 2014

David Egan

5. Grassroot

The Underfinanced ME/CFS Research Field Pt III

The Underfinanced ME/CFS Research Field Pt III: What Can We Do

In two previous articles, published in the March-issue of the ME Global Chronicle (http://let-me.be/request.php?5) and the June-issue (http://let-me.be/request.php?7) we have laid out the facts about the underfinanced ME/CFS research field. Now, on to the question

What Can We Do?

Quite a lot, in fact.

> For one thing, patients need to get organized in patient associations, so that effective advocacy can be carried out.

Advocates for other poorly funded and supported disorders have successfully used advocacy techniques to increase research funding, implement treatment changes and provide support.

Until **Betty Ford** announced she had breast cancer in 1974, breast cancer was mostly a topic discussed behind closed doors. Using techniques pioneered by AIDS activists, breast cancer advocates were able to hugely increase federal research funding. Autism is another disorder that has parlayed strong activism into greatly increased federal funding.

ME/CFS does not have to continue to get low funding.

Small Amounts Add Up If Everyone Provides Them

We also need to come together and start raising the money needed, little by little. Even when it comes to diseases with a decent federal budget, important research efforts are carried out with private funding.

Charities are raising substantial funds for cancer, Alzheimer's and many other diseases. We need to follow their lead. We need to start helping ourselves, by reaching out to our family and friends and ask them to contribute.

It doesn't take much to make a difference. Small pilot studies by non-profits can reap dividends if they strike gold. A small pilot study enabled the Australian ME/CFS research group PHANU to snap up a $800,000 grant. The CFIDS Association of America has been able to translate limited research funding into millions of dollars of federally funded studies.

With federal funding at around 6 dollars per patient a year, we could easily multiply the research budget if we all contributed. If all ME/CFS patients managed to donate 15 dollars, we would have at least tripled the budget right there. If everyone asked two friends or family members to do the same, it would again multiply.

Donate $15 – Multiply the ME/CFS research budget!

Let's all try to fix a donation of at least $15 to biomedical ME/CFS research. Many of us patients have a poor financial situation, but we need to reach out to friends and family. One thing which has been successful for many people is letting friends and family know that donations to ME/CFS research is a good way to celebrate a birthday or Christmas.

Donations are easily made online (via a credit/pay card or PayPal).

Here are a few tips (all gifts are directed towards biomedical ME/CFS research):

Lipkin Microbiome Project

Dr. Lipkin believes 'the action' in ME/CFS is in the gut. Probably for the first time ever, an eager **Dr. Ian Lipkin** is turning to crowdfunding to get a study done. **Dr. Lipkin**'s $1,000,000 Crowdfund effort aims to get at where he very strongly believes 'the action is' in ME/CFS – the gut microbiome. If everyone with ME/CFS in the US donated $1 or if 10% contributed $10, the study would be mostly funded. Find out more about the study here http://bit.ly/1zZn96S.

OMI-MERIT/Open Medicine Foundation

The OMI has almost too many funding opportunities to mention. It's OpenMedNet online bioinformatics program will open soon. Learn more about the OMI here http://bit.ly/1ovP0CY and donate here http://bit.ly/1ovOZPs

Simmaron Research – Redefining ME/CFS

Simmaron recently sponsored 8 immunologists to go to the IACFS/ME conference to produce immune recommendations for the CDC. The only organization given access to the NIH's biobank of XMRV associated samples, Simmaron has a slew of projects underway, and right now there's an opportunity to double your donation to Simmaron through a matching donor offer! http://bit.ly/V70UvL

ME Research UK (MERUK)

MERUK has a variety of projects underway http://bit.ly/1oiofrs including a Vit D3/cardiovascular study, a study on muscle bioenergetics and an autonomic nervous system study by **Dr. Julia Newton**. Donate here http://bit.ly/1nywjhH.

Rituximab Clinical Trials

Norway

Another successful Rituximab trial could break this disease wide open. Two initiatives are raising funds for the multi-site Norwegian Rituximab trial by **Drs Fluge** and **Mella**:

- MEandYou Foundation (PayPal donations) http://bit.ly/1yc9rdT
- ME-forskning, a Norwegian ME Association initiative (donations through VISA and Mastercard) http://bit.ly/1oKnqqe

UK

The UK Rituximab Clinical Trial - This big trial is fully funded! http://bit.ly/1d1jzwq

Workwell Foundation

Help the top ME/CFS exercise physiologists continue their investigations into the core issue in ME/CFS: the post-exertional breakdown. http://bit.ly/1vjUoCQ

The ME Association

The ME Association's Ramsay Research Fund (RRF) is funding research into the post-exertional fatigue present in ME/CFS http://bit.ly/1ovPM2L

Source: Anne Örtegren,
from **Health Rising** (www.cortjohnson.org)

part 1: http://let-me.be/request.php?5, p. 32
part 2: http://let-me.be/request.php?7 , p. 15

Open Letter To Those Without CFS/ME/Fibro

Having CFS means many things change, and a lot of them are invisible. Unlike AIDS and Cancer, most people do not understand even a little about CFS and its effects, and of those that think they know, many are actually mis-informed. In the spirit of informing those who wish to understand …

These are the things that I would like you to understand about me before you judge me…

Please understand that being sick doesn't mean I'm not still a human being. I have to spend most of my day flat on my back in bed and I might not seem like great company, but I'm still me stuck inside this body. I still worry about school and work and my family and friends, and most of the time I'd still like to hear you talk about yours too.

Please understand the difference between "happy" and "healthy". When you've got the flu you probably feel miserable with it, but I've been sick for years. I can't be miserable all the time, in fact I work hard at not being miserable.

So if you're talking to me and I sound happy, it means I'm happy. That's all. I may be tired. I may be in pain. I may be sicker than ever. Please, don't say, "Oh, you're sounding better!". I am not sounding better, I am sounding happy. If you want to comment on that, you're welcome.

Please understand that being able to stand up for five minutes, doesn't necessarily mean that I can stand up for ten minutes, or an hour. It's quite likely that doing that five minutes has exhausted my resources and I'll need to recover – imagine an athlete after a race. They couldn't repeat that feat right away either. With a lot of diseases you're either paralyzed or you can move. With this one it gets more confusing.

Please repeat the above paragraph substituting, "sitting up", "walking", "thinking", "being sociable" and so on … it applies to everything. That's what a fatigue-based illness does to you.

Please understand that chronic illnesses are variable. It's quite possible (for me, it's common) that one day I am able to walk to the park and back, while the next day I'll have trouble getting to the kitchen.

Please don't attack me when I'm ill by saying, "But you did it before!". If you want me to do something, ask if I can and I'll tell you. In a similar vein, I may need to cancel an invitation at the last minute, if this happens please don't take it personally.

Please understand that "getting out and doing things" does not make me feel better, and can often make me seriously worse. CFS may cause secondary depression (wouldn't you get depressed if you were stuck in bed for years on end!?) but it is not caused by depression. Telling me that I need some fresh air and exercise is not appreciated and not correct – if I could do it, I would.

Please understand that if I say I have to sit down/lie down/take these pills now, that I do have to do it right now – it can't be put off or forgotten just because I'm doing something. CFS does not forgive.

Please understand that I can't spend all of my energy trying to get well. With a short-term illness like the flu, you can afford to put life on hold for a week or two while you get well. But part of having a chronic illness is coming to the realization that you have to spend some energy on having a life now. This doesn't mean I'm not trying to get better. It doesn't mean I've given up. It's just how life is when you're dealing with a chronic illness.

If you want to suggest a cure to me, please don't. It's not because I don't appreciate the thought, and it's not because I don't want to get well. It's because I have had almost every single one of my friends suggest one at one point or another.

At first I tried them all, but then I realized that I was using up so much energy trying things that I was making myself sicker, not better. If there was something that cured, or even helped, all people with CFS then we'd know about it.

This is not a drug-company conspiracy, there is worldwide networking (both on and off the Internet) between people with CFS, if something worked we would KNOW.

If after reading that, you still want to suggest a cure, then do it, preferably in writing, but don't expect me to rush out and try it. If I haven't had it suggested before, I'll take what you said and discuss it with my doctor. He's open to new suggestions and is a great guy, and he takes what I say seriously.

Please understand that getting better from an illness like this can be very slow. People with CFS have so many systems in their bodies out of equilibrium, and functioning wrongly, that it may take a long time to sort everything out.

I depend on you – people who are not sick – for many things.

But most importantly, I need you to understand me.

Ricky Buchanan

CFSAC Written/Public Comment
June 17, 2014

In June, **Eileen Holderman** was in Washington and gave testimony before the CFSAC; she just completed her 4 year term as the Patient Advocate on CFSAC.

(Note: Below is her written comment which contains variations/edits from her public comment because HHS imposed severe time restrictions on speakers during the CFSAC Meeting)

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

Welcome to the new Committee Members, especially the new Patient Advocate. I wish all of you the very best going forward. Sometimes it's important to look back to see what stands in the way of moving forward.

For the past 4 years, I served as the Patient Advocate on the CFS Advisory Committee; was Chair of 2 Subcommittees; and was a member of the Leadership Committee.

The Leadership Committee helps to set agenda for CFSAC Meetings. About 2 years ago, we managed to get the critical issue of case definition on the agenda.

After, in October, 2012, CFSAC made a recommendation to convene a workshop using only ME/CFS experts (researchers, clinicians, advocates, and patients) to reach a consensus on a research and clinical case definition starting with the Canadian Consensus Criteria (CCC).

Thereafter, in Subcommittee Teleconferences, HHS began to hijack CFSAC's recommendation and impose their will. Committee Members objected to all the changes HHS tried to make to our recommendation.

In my Subcommittee for Education, Patient Care and Quality of Life, HHS began tampering with our recommendation which led to conflict.

In **Jordan Dimitrakoff**'s Subcommittee for Research, which I attended as a guest, similar contention arose when Committee Members sought information about the NIH's Evidence-based Methodology Workshop (EbMW), now named the Pathway to Prevention (P2P).

Many of us asked why another HHS initiative, that in part was to address case definition, was needed - because we just made a recommendation to convene a workshop to address case definition. We expressed concerns about the NIH P2P such as: costs, timelines, the use of non-experts in ME/CFS, no patient input,

and no transparency. Soon after, **Jordan Dimitrakoff** permanently shut down the Research Subcommittee.

Next, 3 CFSAC Members received phone calls from the Designated Federal Official (DFO), who used intimidation tactics and the threat of eviction from the Committee for expressing our views - the very thing we were called upon to do when we took the official pledge to serve.

Then I was removed from the Leadership Committee, which resulted in no patient input into the CFSAC agenda for the past year and a half.

During the May, 2013 CFSAC Meeting, I publicly disclosed that I and 2 fellow Committee Members were threatened. HHS did not take the allegations seriously - but advocates did.

Advocates sent a letter to General Counsel, with over 40 signatures from independent advocates and advocacy organizations, asking for an investigation.

Months later, **Dr. Howard Koh**, Assistant Secretary of Health, sent a letter in reply which the ME community viewed as completely dismissive.

While I don't wish to speak about the personal effects of the threats, I want to talk about it as it applies to how HHS continually dismisses and obstructs the good work and authority of CFSAC.

HHS's mission to silence Committee Members is indicative of how they have operated in secret, with an iron will, and with disdain toward the ME community.

Instead of implementing CFSAC's recommendation for a case definition workshop with ME/CFS experts, HHS embarked on an aggressive campaign to redefine ME/CFS and enlisted the aid of NIH, CDC, HRSA, ARHQ, and The Institute of Medicine (IOM).

HHS did this in spite of mass opposition to their 3 initiatives (IOM, P2P, CDC Multi-site Clinical Study) from the ME community such as:

- 50 ME/CFS researchers and clinicians signed the Expert's Letter urging HHS to refrain from reaching out to groups such as the IOM to redefine ME/CFS using non-experts, because they reached a consensus on a research and clinical case definition called the Canadian Consensus Criteria (CCC). The experts also urged HHS to adopt the CCC in all Government agencies.
- Over 170 advocates wrote a similar letter as the experts to HHS.
- Nearly 10,000 patients, caregivers, advocates, and medical professionals signed 2 petitions stating objections to the HHS/IOM Contract and urged HHS to adopt the CCC.
- Advocates appealed to Congress with calls and meetings on Capitol Hill.
- An advocate-attorney filed a law suit in US District Court against HHS and NIH for non-compliance with a FOIA request pertaining to the IOM Contract. That same attorney filed legal complaints with the Office of the

Inspector General for IOM's organizational conflict of interest and related legal issues.
- Attorney-advocates filed FOIA requests pertaining to the HHS/IOM Contract.
- Advocates participated in radio, TV, and online interviews with the press about HHS's plans to redefine and rename ME/CFS.
- Advocates demonstrated in San Francisco and Washington, DC to protest the HHS/IOM Contract.
- Advocates from the ME/CFS community collaborated with advocates from the Gulf War Illness (GWI) community because of similar concerns with the VA/IOM reports.
- Advocates submitted a position paper, wrote articles, blogs, and opinion posts on Internet forums to protest the HHS/IOM Contract.

HHS has not listened to the 50 ME/CFS expert researchers and clinicians who sent the letter to Secretary Sebelius; nor have they listened to the advocates, patients, caregivers, or stakeholders.

HHS's mission is to control the message - they decide who can speak and who is silenced, who is on the Advisory Committee and who is off the Advisory Committee, what information they will divulge and what information they will hide.

HHS's mission is to redefine ME/CFS with yet another broad, erroneous case definition, which will include countless people who do not have ME/CFS, so they can recommend CBT, GET, and anti-depressants, and so they can bury the scientific, biomedical evidence of ME/CFS.

HHS will then not have to fund research into this biomedical disease or fund clinical trials or pay for long term disability and other Government entitlements.

Once HHS develops their new definition and name for this disabling, neuroimmune disease, they will embark on their next phase of (mis)educating the medical and scientific communities, the press, and the general public. HHS is acting in bad faith toward the ME community.

Last December, during a CFSAC "webinar," I thanked many people in the ME community, especially my fellow Committee Members, the 50 ME/CFS experts, and the advocates.

So, I will end with a special acknowledgement of one advocate, Jeannette Burmeister, whose intelligence, resilience, and courage inspires me and other advocates in our movement to help the 17 million worldwide suffering from ME.

Thank you.

Eileen Holderman

P2P: The Question They Will Not Ask

The most important question about ME/CFS – the question that is the **cornerstone** for every aspect of ME/CFS science – is the question that the P2P Workshop will not ask:

How do ME and CFS differ? Do these illnesses lie along the same continuum of severity or are they entirely separate with common symptoms? What makes them different, what makes them the same? What is lacking in each case definition – do the non-overlapping elements of each case definition identify a subset of the illness or do they encompass the entirety of the population?

Boiled down to its essence, this set of questions is asking whether all the "ME/CFS" definitions represent the same disease or set of related diseases. The failure to ask this question puts the entire effort at risk.

This fundamental question was posed in the 2012 application for the Office of Disease Prevention to hold the P2P meeting (which I obtained through FOIA). It was posed in the 2013 contract between AHRQ and the Oregon Health & Science University for the systematic evidence review (which I obtained through FOIA). It was posed to the P2P Working Group at its January 2014 meeting to refine the questions for the evidence review and Workshop (according to **Dr. Susan Maier** at the January 2014 Institute of Medicine meeting).

And then the question disappeared.

The systematic evidence review protocol does not include it. **Dr. Beth Collins-Sharp** said at the June 2014 CFSAC meeting that the Evidence Practice Center is not considering the question because there is "not enough evidence" in the literature to answer the question. However, she said that the P2P Workshop *could* still consider the question.

But the draft agenda for the Workshop does not include it. Furthermore, every aspect of the P2P Workshop treats "ME/CFS" as a single disease:

- The P2P description of ME/CFS refers to it as a single disorder or illness throughout the meeting webpage.
- The P2P website characterizes the names myalgic encephalomyelitis and chronic fatigue syndrome as synonymous.
- Every section of the Workshop agenda lumps all the populations described by the multiple case definitions together, discussing prevalence, tools, subsets, outcomes, presentation, and diagnosis of this single entity.

A 20 minute presentation on "Case Definition Perspective" is the only lip service paid to this critical issue. This is completely inadequate, if for no other reason than because the presentation is isolated from discussions on the Workshop Key Questions and dependent topics like prevalence and natural history. As a result, it is unlikely to be thoroughly discussed unless one of the Panelists has a particular interest in it.

Why is this problematic? Because both the P2P Workshop and the evidence review are based on the assumption that the full set of "ME/CFS" case definitions describe the same disease. This assumption has been made without proof that it is correct and in the face of data that indicate otherwise, and therein lies the danger of failing to ask the question.

What if the case definitions do not actually describe a single disease? If there are disparate conditions like depression, deconditioning, non-specific chronic fatigue and a neuroimmune disease characterized by PEM encompassed by the full set of "ME/CFS" definitions, then lumping those together as one entity would be unscientific.

The most important part of designing scientific studies is to properly define the study subjects. One would not combine liver cancer and breast cancer patients into a single cohort to investigate cancer pathogenesis. The combination of those two groups would confound the results; such a study would be meaningful only if the two groups were separately defined and then compared to one another to identify similarities or differences. The same is true of the P2P evidence review of diagnostics and treatments: assuming that all "ME/CFS" definitions capture the same disease (or even a set of biologically related diseases) and attempting to compare studies on the combined patients will yield meaningless and confounded results if those definitions actually encompass disparate diseases.

There is a growing body of evidence that underscores the need to ask the fundamental question of whether "ME/CFS" definitions represent the same disease:

- The P2P Workshop is focused on "extreme fatigue" as the defining characteristic of "ME/CFS," but fatigue is a common but ill-defined symptom across many diseases. Further, not all "ME/CFS" definitions require fatigue or define it in the same way. For instance, Oxford requires subjective fatigue, and specifically excludes patients with a physiological explanation for their fatigue. But the ME-ICC does not require fatigue; instead it requires PENE, which is defined to have a physiological basis.
- When FDA asked CFS and ME patients to describe their disease, we did not say "fatigue". Patients told FDA that post-exertional malaise was the most significant symptom: "complete exhaustion, inability to get out of bed to eat, intense physical pain (including muscle soreness), incoherency, blacking out and memory loss, and flu-like symptoms".
- Multiple studies by **Jason**, **Brenu**, **Johnston** and others have demonstrated significant differences in disease severity, functional impairment, levels of immunological markers and patient-reported symptoms among the different case definitions.

- Multiple studies have demonstrated that patients with PEM have impairment in energy metabolism and lowered anaerobic threshold, and have shown that patients with depression, deconditioning and a number of other chronic illnesses do not have this kind of impairment.
- Multiple studies have demonstrated differences in exercise-induced gene expression between Fukuda/CCC patients and both healthy and disease control groups.
- The wide variance in prevalence estimates shines a light on the case definition problem. Prevalence estimates for Oxford and Empirical populations are roughly six times higher than the most commonly accepted estimate for Fukuda. Even Fukuda prevalence estimates vary widely, from 0.07% to 2.6%, underscoring the non-specificity of the criteria. Nacul, et al., found that the prevalence using CCC was only 58% of the Fukuda prevalence. **Vincent**, et al., reported that 36% of Fukuda patients had PEM, representing a smaller population that would be eligible for diagnosis under CCC.
- The work of **Dr. Jason** highlights the danger of definitions that include patients with primary psychiatric illnesses, especially because such patients may respond very differently to treatments like CBT and GET.

By contrast, there have not been any published studies that demonstrate that the set of "ME/CFS" definitions being examined in P2P encompass a single entity or biologically related set of entities. From Oxford to Fukuda to ME-ICC, there are significant differences in the inclusion and exclusion criteria, including differences in the exclusion of primary psychiatric illness. The magnitude of these differences makes the lack of such proof problematic.

Given that treating all "ME/CFS" definitions as a single entity is based on an unproven assumption of the clinical equivalence of these definitions, and given that there is ample proof that these definitions do not represent the same disease or patient population, it is essential that the P2P "ME/CFS" study start by asking this question:

Does the set of "ME/CFS" definitions encompass the same disease, a spectrum of diseases, or separate, discrete conditions and diseases?

The failure to tackle this cornerstone question up-front in both the agenda and the evidence review puts the scientific validity of the entire P2P Workshop at risk. If this question is not explicitly posed, then the non-ME/CFS expert P2P Panel will swallow the assumption of a single disorder without question, if for no other reason than that they do not know the literature well enough to recognize that it is an assumption and not established fact.

July 21st, 2014

Mary Dimmock *and* ***Jennie Spotila***

http://www.occupycfs.com/2014/07/21/p2p-the-question-they-will-not-ask/

Because It’s Time We Became The Strength Of Our True Numbers.

Join an international network of Myalgic Encephalomyelitis patients and advocates empowering each other to fight for health equality.

I wanted to share news about a new platform currently under development, one with a set of tools that will make it easier for advocates from around the world to meet, collaborate, and join campaigns to promote equal access to healthcare, science, and basic human dignity for patients living with ME.

It's called The #MEAction Network. We're not an advocacy organization. Rather, we aim to empower a grassroots movement with tools and resources that help advocates do what they are already doing, better.

Sign up here**:** **http://meactionnetwork.org/**
Follow us on Twitter: **https://twitter.com/MEActNet**
Like us on Facebook: **http://facebook.com/MEActNet**

Jennifer Brea

ME March In May 2015 - We Need You!

In the June ME Global Chronicle, we shared a letter that **Llewellyn King** had sent to a group of thirty patients and patient advocates calling on them to take action in the form of a Mothers March on Washington, D.C. in May 2015 (http://let-me.be/request.php?7).

As we reported last time (http://let-me.be/request.php?7, p.23) there was an immediate flow of ideas on how to achieve the concept that **Llewellyn** had shared. There was agreement that such a March was not just about children but about all the patients affected by this devastating disease.

The group also agreed that the March was not just about mothers but about the fathers, spouses, children and all the others that are affected when a loved one contracts ME. ME can strike anyone, no matter how healthy they are. And once it strikes, it devastates the entire family.

We also talked about the possibility that some could not get to Washington but might want to do their own marches in the U.S. and also in other countries.

To achieve the effect that we want, the March in Washington will need to be fairly large. Achieving that will take time and planning.

Last month, a small group of patient carers and patients started meeting to discuss what will be required. Some examples that we have started to discuss include:

- *Strategy to define goals, key messages to include in communications.*
- *Logistics for the day of the March to include permits, food and transportation.*
- *Communications outreach to this community and to both Congress and the media –before, during and after the event.*
- *Development of needed materials to drive our messages*
- *Fund raising if needed*
- *Recruitment of volunteers*

That last one – recruitment of volunteers – is a big one if we are going to make this happen. We need your ideas, your expertise and your energy. We need the ideas, energy and expertise of your family members, including those who are healthy.

And what do we hope to achieve in this March? For the U.S., initially proposed goals are to:

- Build awareness with Congress, the media and the public about the devastation caused by ME and its impact on the families of patients and our country.
- Inform the public and Congress about what we know about the disease so far, and the need to build on the biomedical research that we have.
- Inform the public and Congress about the failures in research, how abysmal medical care is, and how stigmatized patients are.
- Gain congressional action on specific issues that must change to change the lives of patients

One request for congressional action is a fair share of NIH research funding. Based on economic impact, disease burden and funding for other diseases, we should have $100M, not the $5M we get today.

We could also request a congressional hearing or ask Congress to pass legislation calling for a national plan that requires a strategic plan and monitors progress.

The specific requests will need to be fine tuned over the next 6 months as we see what happens with current efforts

If you are interested and can help with the planning for this March, please send an email to **MarchOnME@gmail.com** and we will contact you.

If you are interested in doing a March in your own city, mail and we will share any materials we have developed.

We can't do this without you!

Political/Legal Developments

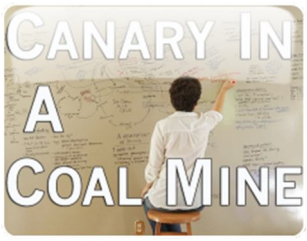
Grassroots movements

A new organisation called ME Action Network, http://meactionnetwork.org/ has been set up by some North American ME activists. The purpose of this organisation is to unify all ME and CFS organisations and advocates in all countries worldwide. They would present a unified front for

- Protesting in individual countries
- Building public awareness about ME in all countries
- Lobbying government and state agencies to implement Canadian (2003) and ICC criteria (2011) and build or set up ME clinics
- Lobbying government and state research bodies for increased research funding into ME
- Crowd-funding for important private research into ME
- Protect the rights of ME patients. This would include protection against the malpractises of psychiatrists
- Crowd-funding for legal cases, involving abuse of the human rights of ME patients.
- International cooperation and assistance between ME patients and ME organisations around the world.
- Education and training of medical doctors and civil servants about ME and CFS, and their biological based diagnostics and treatments in all countries.

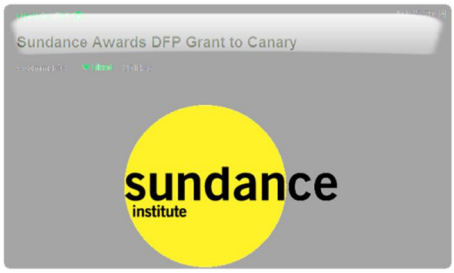
We strongly urge all ME patients, in all countries to join this organisation, ME Action Network, http://meactionnetwork.org/ and build a united front, and work together in this united front.

Canary in a Coalmine



Dear Team Canary,

I'm thrilled to announce that Canary in a Coal Mine has been chosen as a Sundance Institute Documentary Film Program grantee. We are one of 44 projects selected from over 600 applications from 69 countries around the world.



The Sundance Institute is a non-profit organization that provides creative and financial support to filmmakers and independent artists developing original stories for screen and stage. Among its many events, it hosts the Sundance Film Festival each year in Park City, Utah, one of the country's premiere venues for independent film.

With this grant comes the opportunity for a working relationship with Sundance throughout the rest of the production of the film, as well as opportunities to participate in fellowships and workshops with leading filmmakers.

You can read about some of the other projects being supported this cycle. We are in some incredible company! http://on.fb.me/VjoHJj

> We who have been made voiceless and invisible for too long know the power and importance of our story.

To change minds in the larger world, however, we must reach beyond our community to inspire and motivate to action an even wider circle of allies. The support of the Sundance Institute will greatly help our efforts to bring Canary to the widest possible audience.

My thanks to all of you for believing in this film. We still have a very long way to go, but I am amazed at how far we have already come, together.

With gratitude,
Jen

Comment on the announcement on the Sundance website: http://bit.ly/1sVEQjG
Like us on the Sundance Institute's Facebook page: http://on.fb.me/1kBmOUh

Tweet the Sundance Institute to thank them for their support:
https://twitter.com/sundancelabs

6. Science

Rich' Reviews: Neuro-inflammation Might Revolutionize Our Approach to CFS-ME Treatment

Glia cells, including microglia and astrocytes, are immunologically active within the brain. Recent evidence suggests that inflammation induced by glia cells occurs among people with Alzheimer's, Parkinson's disease, major depression, schizophrenia, and perhaps fibromyalgia. Now a research team from **Osaka**, **Japan** reports inflammation within the brain among persons with CFS-ME.

If confirmed, we might quickly consider clinical trials for potential treatments. Several relatively safe medicines have anti-inflammatory effects, cross the blood brain barrier, and are believed to reduce glia associated inflammation. Several natural compounds products have-well proven anti-inflammatory effects using animal models.

The Key Research: **Nakatomi**, **Watanabe** and associates did PET scans on 9 patients with ME/CFS and on 10 healthy controls. None of the patients were depressed and none were on medicines thought likely to affect brain activity.

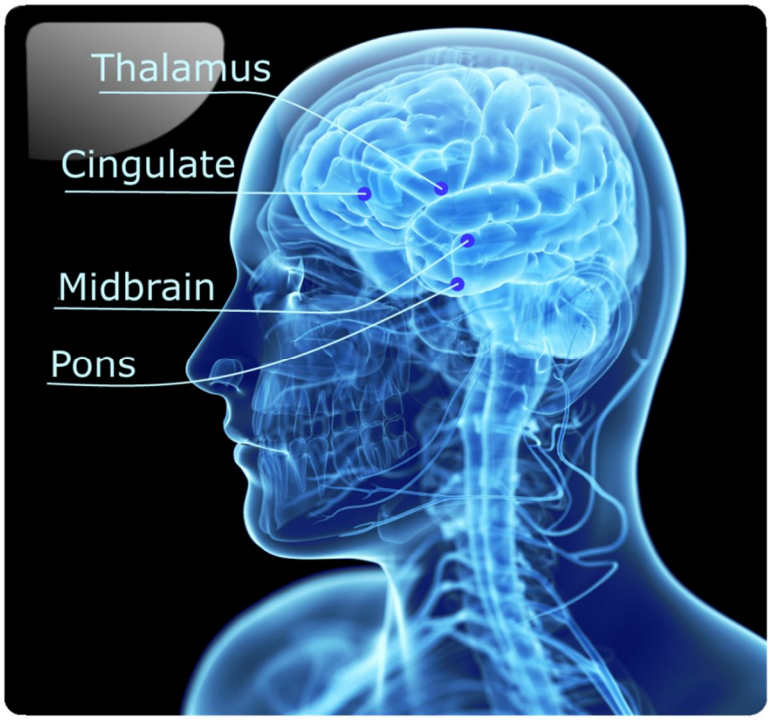
The researchers injected subjects with a tracer that binds to a translocator protein called TSPO. TSPO is expressed in activated microglia and astrocyte cells. Increased levels of TSPO are considered to be valid measures of active neuro-inflammation.

Although the number of subjects was small, patients with CFS/ME compared to healthy controls had much higher levels of inflammation in multiple areas of the brain. The degree of inflammation correlated with the severity of clinical symptoms including fatigue, pain and cognitive impairment.

This chart lists the percent increase in TSPO activity for CFS-ME patients compared to healthy controls and the statistical P values for these differences.

Brain Region	**Increase in Activity For CFS/ME to control In %**	**P Value**
Midbrain	47	0.0001
Pons	45	0.0021
Thalamus	66	0.0013
Cinglulate	199	0.0353

Of course, these findings need to be confirmed. But, if neuro-inflammation is present, (in an ideal world) we should be just a short step away from clinical trials testing whether relatively safe anti-inflammatory compounds can help CFS-ME patients.



Fortunately, there are several reasonably safe and available medicines that might be tested (were funding available). Thus, Minocycline and/or Doxycycline have well-documented anti-inflammatory effects in animals. Both penetrate the blood brain barrier.

Limited clinical trials suggest that Minocycline or Doxycycline improves rheumatoid arthritis symptoms and certain dental disorders. (**Garrido-Mesa**, **N**, **Zarzuelo**, **A**, **Galvez**, **J**, Monocyline: far beyond an antibiotic, Br J Pharmacol 2013; 169:337-52)

Low dose Naltrexone (LDN) is believed to inhibit microglia inflammation. In a double blind study **Mackey** and **Younger** from the Pain Medicine group at Stanford Medical School have reported benefit from LDN for treating Fibromyalgia pain. (**Younger J**, **Parkitny L**, **McLain D.**,
The use of low-dose naltrexone (LDN) as a novel anti-inflammatory treatment for chronic pain, Clin Rheumatol. 2014 Apr; 33(4):451-9.)

Natural products that might inhibit microglia inflammation include Curcumin, Reishi Mushroom, Panex Ginseng, and Stinging Nettle. (**Dong Kug Choi**, **Sushruta Koppula**, **Kyoungho Suk**, Inhibitors of Microglial Neurotoxicity: Focus on Natural Products Molecules 2011, 16, 1021-1043)

At this point we don't know if the brain inflammation in CFS-ME is a useful part of the body's healing response and/or a cause of harm that we should want to suppress. Using the model of autoimmune diseases we might guess that the benefits of suppressing inflammation with relatively safe drugs such as Minocycline would outweigh the risks.

I hope but am not optimistic that the CFS-ME community will soon gain the scientific and political influence required to obtain funding to test these plausible hypotheses. More likely specialists in Alzheimer's, Parkinson's, depression and schizophrenia will pursue these leads first and we might then hitch a ride on the backs of their progress.

Key Article: **Nakatomi, Y, et al**., Neuroinflammatoin in Patients with Chronic Fatigue Syndrome/Myalgic Encephalomyelitis: An 11C-®-PK11195 PET Study, J Nucl Med, published online: March 24, 2014. Doi: 10.2967/jnumed. 113:131045

Richard Podell, **M.D., MPH**, Summit, NJ
http://www.DrPodell.org

Science to Patients

A new milestone: 150.000 views!

A couple of numbers:

- The seventh and final lecture of **Professor Julia Newton** from the University of Newcastle was sent to 570 patient organizations and patients and more than 80 scientists around the world on 5 August 2014. It is the project's 49th lecture.
- On 8 August 2014 all lectures combined had been viewed more than 150,000 times.
- 660 people subscribed to the YouTube channel. This is one and a half times the number of members of the Dutch ME/cfs Association that produces, subtitles and broadcasts all webinars via: http://bit.ly/1sn1pAA
- The project has been subsidized by the Dutch government up until the end of 2014. Financial reserves will allow the project to continue for another two years, but the Association is already trying to find other means to continue this project for an even longer period of time.
- Scientists and researchers from **The Netherlands** and **Belgium** are working together more and more often with colleagues from other countries. A connection has been made between the Dutch cardiologist **Dr Visser**, who gave lectures for the project (http://bit.ly/1nBYnAS), and **Professor Julia Newton**, since their researches overlap. **Dr Visser** has also been brought into contact with other scientists. We hope to be able to provide more information on this topic later this year.
- In September 2013 the project's coordinator began sending out an international newsletter. As from January 2014 this newsletter has been professionalized, which resulted in the first edition of the ME Global Chronicle (http://let-me.be/request.php?3)
- The five editions of the magazine that have been published so far, had, besides having been sent to over 730 addresses over the world, been downloaded 6,000 times on 8 August.
- At the end of 2014 lectures by **Professor Alan Light** and **Professor Lucinda Bateman** will be recorded in Salt Lake City. These will be broadcast from March 2014.
- Furthermore, lectures will be recorded with two speakers of the Iime conference of 2015 in London. The recordings will take place around the time of the conference.
- The lectures, the transcripts of the lectures and the transcripts of the chat sessions can be downloaded via: http://www.me-cvsvereniging.nl/english-page

Program from 1 September:

Prof. Dr Leonard Jason

http://www.youtube.com/user/WetenschapvMEcvsVer

Week 36 #1 & #2
2 September webinar 50: Introduction / experience with ME
2 September webinar 51: Criteria and diagnosis, part 1

Chat: Fri. 5 Sept. Global chat (in English) from 5:00-5:45 PM CET

Week 37 #3
9 September webinar 52: Criteria and diagnosis, part 2

Week 39 #4
23 September webinar 53: ME versus psychiatric disorders

Chat: Fri. 26 Sept. Global chat (in English) from 5:00-5:45 PM CET

Week 41 #5
7 October webinar 54: Treating ME / managing techniques

Week 43 #6
21 October webinar 55: Symptoms of ME and treatments

Chat: Fri. 24 October. Global chat (in English) from 5:00-5:45 PM CET

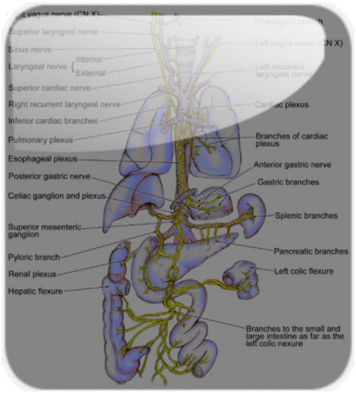
Week 45 #7
4 November webinar 56: Population and social impact

Week 47 #8
18 November webinar 57: Future/teaching about ME

Chat: Fri. 21 Nov. Global chat (in English) from 5:00-5:45 PM CET

Find your local time e.g. on http://www.timeanddate.com/worldclock/

A Look at the Vagus Nerve and Tumour Necrosis Factor



We hear much about the connection between the nervous and immune systems in relation to ME/CFS and recently the possible role of the vagus nerve has been mentioned. ME/CFS patients have also been shown to have high levels of the pro-inflammatory cytokine TNF as well as other cytokines (1) (2).
Could the functioning of the vagus nerve be involved?

A recent article in the New York Times Magazine describes the work of **Kevin Tracey** MD. http://www.nytimes.com/2014/05/25/magazine/can-the-nervous-system-be-hacked.html?_r=0 (NYTM)

Tracey is president of the Feinstein Institute for Medical Research and has concentrated on identifying the connection between the brain and the immune system through the vagus nerve, which has been called the most important nerve in the body.

He is also prominent in the research in bioelectronic medicine which has been described as having the potential to revolutionize medicine by eventually replacing drug treatment.
http://support.northshorelij.com/page.aspx?pid=833

As described in this article, in 1998 the connection between the immune and nervous systems was still considered impossible. Nevertheless, **Dr Tracey** was convinced that there was an interface between the two, particularly the vagus nerve and TNF which was known to trigger inflammation.

He tested this hypothesis on rats. After administering electrical stimulation to the vagus nerve he injected the rats with a bacterial toxin known to promote the production of TNF. He found that the electrical stimulation to the vagus nerve had blocked the expected inflammation by 75%. This finding was published in Nature (3).

'…**Tracey** spent 11 years mapping the neural pathways of tumour necrosis factor inflammation, charting a route from the vagus nerve to the spleen to the bloodstream and eventually to the mitochondria inside cells. We now know more about this electrical circuit to treat (inflammation) than is known about some clinically approved drugs," he says.'

'His work seemed to indicate that electricity delivered to the vagus nerve in just the right intensity and at precise intervals could reproduce a drug's therapeutic in this case, anti-inflammatory –reaction.'

"The list of T.N.F. diseases is long," **Tracey** said.

> In one of his papers he states: '… the idea is revolutionary'. The 'potential (of using a nerve-stimulating medical device to treat inflammatory diseases) emerged from a breakthrough in neurophysiology revealing that electrical signals transmitted in the vagus nerve suppress inflammation.

The potential therapeutic implications of this concept are far-reaching, because inflammation is a participant in many disease syndromes, including Alzheimer's and other neurodegenerative brain diseases, as well as inflammatory bowel disease, congestive heart failure, atherosclerosis, and diabetes.' (4)

Rheumatoid arthritis, which was chosen to study the electrical treatment the inflammtory process is '… like brake failure in a car barreling down a mountain, the neural control exerted by the vagus nerve fails and the production of TNF goes out of control.

Very recent insights have revealed that it may be possible to restore the vagus nerve signals that are missing in these patients and reestablish safe levels of TNF.' (4)

Some early success with an implanted electrode in bringing about remission in arthritis was reported (4).

However, a report after publication of the NYTM article revealed that 'The protocol was terminated early (prior to complete enrollment) after interim analysis proved data to be statistically insignificant.'
http://www.clinicaltrials.gov/ct2/show/NCT00859859?term=Tracey

Various bioenergetics methods have already been in use, but as reported by NYTM, one of the challenges is to discover the discrepancies between baseline signals in a healthy person and those produced by someone with a particular disease.

GlaxoSmith-Kline has devoted funds for the research into bioelectronic medicine. The article also discusses the implications of implanted electronic devices in the body and the potential for hacking.

Even if this trial of bioelectronic treatment has not succeeded, the connection between the vagus nerve and TNF is of interest.

In ME/CFS the question is complicated further if the vagus nerve itself turns out to be inflamed, as hypothesised by **Dr. Michael VanElzakker**.

He states: 'The vagus nerve infection hypothesis of CFS contends that CFS symptoms are a pathologically exaggerated version of normal sickness behavior that can occur when sensory vagal ganglia or paraganglia are themselves infected with any virus or bacteria..

Drawing upon relevant findings from the neuropathic pain literature, I explain how pathogen-activated glial cells can bombard the sensory vagus nerve with proinflammatory cytokines and other neuroexcitatory substances, initiating an exaggerated and intractable sickness behavior signal.' (5)

Perhaps these hypotheses may lead to yet another avenue of research for the mechanisms of ME/CFS and a treatment for it.

Susanna Agardy

References:

1.**Patarca R**, **Klimas NG**, **Lugtendorf S**, **Antoni M**, **Fletcher MA** Dysregulated expression of tumor necrosis factor in chronic fatigue syndrome: interrelations with cellular sources and patterns of soluble immune mediator expression. Clin Infect Dis. 1994 Jan; 18 Suppl 1:S147-53.

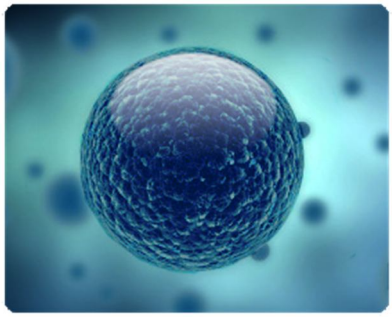
2.**Moss RB**, **Mercandetti A**, **Vojdani A** TNF-alpha and chronic fatigue syndrome. J Clin Immunol. 1999 Sep;19(5):314-6

3.**Borovikova LV**, **Ivanova S**, **Zhang M**, **Yang H**, **Botchkina GI**, **Watkins**, **LR**, **Wang HR**, **Abumrad N**, **John W**. **Eaton JW**, **Tracey KJ** Vagus nerve stimulation attenuates the systemic inflammatory response to endotoxin Nature 405, 458-462 (25 May 2000) | doi:10.1038/35013070; Received 12 January 2000; Accepted 3 March 20

4.**Andersson U**, **Tracey KJ**, New Approach to Rheumatoid Arthritis: Treating Inflammation with Computerized Nerve Stimulation. Cerebrum 2012 Mar-Apr; 2012: 3. Published online Mar 21, 2012. PMCID: PMC3574800A

5.**VanElzakker MB**, Chronic fatigue syndrome from vagus nerve infection: A psychoneuroimmunological hypothesis Med Hypotheses. 2013 Sep; 81(3):414-23. doi: 10.1016/j.mehy.2013.05.034. Epub 2013 Jun 19.

Biomarkers



Defects in the 2-5a synthetase / RnaseL anti-viral pathway & PKR pathway

This biomarker can identify ME & CFS subgroups. The 2-5a synthetase / RnaseL anti-viral pathway is involved in anti-viral activity inside cell. Activation of the pathway typically occurs in response to a viral infection.

The 2-5a synthetase / RnaseL anti-viral pathway destroys viruses through producing RnaseL which destroys virus RNA and human RNA, and activating Interferon beta. If the virus cannot be totally destroyed, then the cell undergoes apoptosis (self-destruction).

In normal conditions, this will result in viral destruction or viral and human cell destruction, with strong immune system response to the viral infection, followed by patient recovery after a few days or weeks. However in ME and CFS something very strange happens.

There is a RnaseL abnormality in ME and CFS which was first identified in 1994 by **Robert J. Suhadolnik** and his research team in a trial of the drug **Ampligen**. Thirteen of the 15 patients studied normal levels. As their symptoms improved, their RNase L activity returned towards normal. Both human RNA and viral RNA (if present) were being destroyed at a high rate.

In the 2-5a synthetase / RnaseL anti-viral pathway an unusual form of RNase-L has been found in ME patients - 37 kDa RnaseL. There is cleavage of the normal 80 kDa form of RnaseL into 37 kDa RnaseL by Elastase, cathepsin-G and m-calpain.

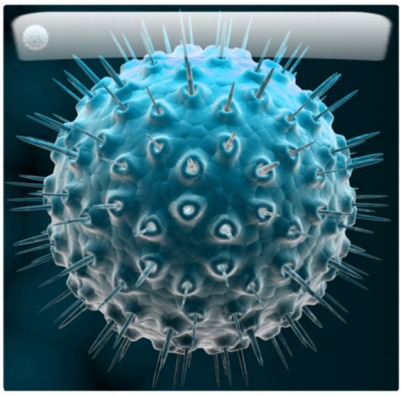
The ratio of 37 kDa to the normal 80 kDa form of RnaseL is high in ME patients, and is a diagnostic biomarker for subgroups. 37 kDa RNase-L can be six times as destructive as the 80 kDa RnaseL.

This fact is important as 37 kDa can be 1,500 times above normal levels in seriously ill ME patients. The 37 kDa RnaseL destroys human messenger RNA, disrupts the PKR pathway, disrupts protein synthesis, and disrupts ion channels throughout the body, and keeps the immune system abnormally activated.

Disrupting protein synthesis in the cells, impairs the liver and the body's detoxification system and leads to a build up of toxins and free radicals.

Also, increased (abnormal) immune activation increases the level of free radicals produced and oxidative stress in the body. Most studies reveal very high levels of oxidative stress in ME patients, which points to significant ongoing damage over time.

The large increase in free radicals disrupts mitochondria and the Krebs cycle, causing great fatigue and continuing damage to the cells, internal organs and the body, which is cumulative over time. This impairs the body's ability to recover. All of this makes the patient very ill and can be devastating to the patient over a number years.



Many scientific researchers, including **Suhadolnik**, **De Meirleir**, **Nijs**, **Lebleu**, **De Becker**, **Knox**, **Peterson**, **Cheney**, **Reichenbach**, **Roen G**, **Metzger**, **McCahen**, **Gaughan** and **McGregor** have confirmed this in ME & CFS subgroups.

Many research papers are listed here at http://bit.ly/1r6DhTf

The following medical and scientific book:
"Chronic Fatigue Syndrome: A Biological Approach" By **Patrick Englebienne** and **Dr. Kenny De Meirleir** provides a detailed analysis of these biological abnormalities.

The following information provides a good guide of the biomarkers. Some of these biomarker tests can be carried out at http://www.redlabs.be

- Ratio of 37 kDa RnaseL to 80 kDa form of RnaseL. This measures the cleavage of the 80 kDa form of RnaseL into 37 kDa RnaseL. An important diagnostic bio-marker. The ratio of the 37 kDa to 80 kDa RNase-L is reported to correspond to a patient's clinical status. The ratio of 37 kDa to the normal 80 kDa form of RNase-L is high in CFS patients.

- Upregulation of RNase L enzyme activity. This can be 1,500 times above normal levels in seriously ill CFS patients.

- The levels of STAT1-alpha protein. Deviation from normal levels. Another important bio-marker.

- Low levels of p53 protein. Deviation from normal levels. Another important bio-marker.

- Increased NF-Kb levels and activity. Another important bio-marker.
- CD19 B-cell counts
- Elevated levels or over-active human luekocyte elastase - research findings suggest that elastase plays a key role in the cleavage of RnaseL, STAT1-alpha and p53 proteins and Actin and in arterial stiffness, and blood circulation problems. Tests carried out by Dr. Kenny De Meirleir seem to confirm that elastase is the main culprit in CFS
- The cleavage of RnaseL leads to the presence of RnaseL fragments. 3 RnaseL fragments have been found to be significant: Fragment 1, an ankyrin binding repeat domain which is known to interact with various transport proteins. It is is capable of NF-kappaB mimicry. This may be interrupting the ion channels in the body. "these results show that upon pathological cleavage of RNase L, fragments containing the ankyrin domain are released, which could be capable of interacting with selected members of the human ABC superfamily, preventing their interaction with the normal cognate ankyrin protein and hence impairing their proper cellular function. This interaction constitutes a common physiological mechanism explaining numerous and currently unexplained symptoms experienced by patients with CFIDS, which are otherwise totally unrelated." Fragment 2, the 2-5A binding fragment that has catalytic activity and thus is able to degrade RNA ; Fragment 3, shares homology with chain A of Cdk6 (Cyclin dependent kinase). It of Cdk6 chain A mimicry ;
- Cell Apoptosis (cell death) increases initially in CFS and then is inhibited when the levels of Rnase L related fragments reach a certain point ;
- Elevated levels or over-active protease levels. Elevated levels or over-active other proteolytic enzyme levels
- Abnormal cleavage of Actin
- Elevated levels or over-active calpain levels;
- Abnormal caspase activity and disrupted cell apoptic process
- PKR activity and levels. Deviation from normal levels
- Ion channel interruption and dysfunction affecting many other body parts.
- Elastase, cathepsin-G and m-calpain are responsible for fragmenting RnaseL. Test for high concentrations and activity levels of these.

David Egan

The science of Olive Leaf

The fruit thereof shall be for meat, and the leaf thereof for medicine (Ezekiel 47:12)

The olive leaf has been used as a medicine in Mediterranean countries and some Middle Eastern countries for thousands of years.

These ancient cultures used it to treat fevers caused by viral and bacteria infections, malaria infections, reduce blood sugar, improve energy levels, and for poultices for wounds, skin rashes and boils. It was held in high esteem by the ancient Greek, Egyptian and Israelite populations.

The Egyptians used it for mummification of royalty, it is referred to as the 'tree of life' in some Israelite scriptures, and winners in the ancient Greek Olympic games were crowned with a wreath of olive leaves. It is still used in traditional Italian medicine to treat viral infections and fevers.

The first account of olive leaf 's medicinal use in modern times was in 1843 when **Daniel Hanbury** reported a bitter substance from olive leaf tea was the agent responsible for healing malaria and associated fevers. This was officially reported in the 1854 Pharmaceutical Journal of Provincial Transactions (pp. 363-354), where **Hanbury** stated that olive leaf was an effective remedy for malaria and fevers during numerous outbreaks.

This journal also included an olive leaf recipe and dosing instructions for treating malaria and fevers (caused by viruses, bacteria, parasites). Throughout the 19th century and early 20th century, British doctors and civil servants recommended olive leaf brews for treatment of malaria and other microbial infections which British people got while working in tropical countries of the British empire. It was found to be very effective then, and was certainly a lot more effective than medicines at the time.

In 1969, **Upjohn Pharmaceuticals** isolated oleuropein and calcium elenolate from olive leaves and tested them against all known viruses. They inactivated or destroyed all of these viruses. They were also effective against many bacteria, fungii and parasites. This surprised the researchers. However it was not possible to isolate the active ingredients from the olive leaves and patent them, and make a new drug.

And the olive leaves could not be patented as they were a natural food. So the company could not commercialise it's findings. These scientific findings were forgotten about until the mid 1990's when there was a renewed interest in olive leaves and olive leaf extract. This was stimulated by its effectiveness in reducing viral loads in many AIDS patients.

Since the mid 1990s' Olive leaves and Olive leaf extract have been found to:

- have strong anti-viral, anti-bacterial, anti-parasite, anti-fungal properties
- modulate the immune system
- reduce blood pressure and blood sugar
- act as a strong antioxidant
- protects heart and cardiovascular system
- anti-inflammatory

Continuing scientific experiments with olive leaves and olive leaf extract shows a wide range of health benefits for several illnesses.

From the perspective of ME and CFS patients, any drug / herb / supplement which does the above is bound to benefit some ME and CFS patients and subgroups. **Dr. James Privatera** in the USA regularly gives olive leaves and olive leaf extract to his ME/CFS patients, and many have improved significantly.

Dr. Morton Walker in his book, 'Olive Leaf Extract' mentions a wealthy Wall street investment banker who got 'Chronic Fatigue Syndrome' and he went to the top medical doctors and hospitals in the USA and abroad, desperately looking for a cure. They all failed him.

The "expert opinions" of these doctors / experts were no good to him. In the end, when he was almost suicidal, it was his Italian mother who advised him to take olive leaf brews, every day, as they were found to be effective for fevers and infections for thousands of years in Italy.

He did this and after 12 months he was completely cured. He still takes a maintenance dose to ensure he remains in good health.

Considering Olive leaf's benefits, it is certainly better than taking nothing and waiting for some miracle drug to be invented in the future. There has been too much waiting around for too long in the ME and CFS communities.

Here is an excellent video about Olive leaf presented by a well known American medical doctor, **Dr. Richard Becker** http://bit.ly/1vQvmLR

Some research papers on olive leaves and olive leaf extract:

- Research findings - viruses http://bit.ly/1rd8F2s
- Research findings – bacteria http://bit.ly/1t2sMwJ
- Research findings – Lyme http://bit.ly/1oA2pjg
- Research findings – Candida http://bit.ly/1oOhacv
- Research findings - immune system http://bit.ly/1oUR78K
- Research findings – antioxidant http://bit.ly/VrG1M8
- Research findings - heart http://bit.ly/1oOhlob

Methylation

Griffith University,
Gold Coast, **Australia**

An Abstract

Objective: Methylation is known to regulate biological processes and alterations in methylation patterns have been associated with a variety of diseases.

Chronic fatigue syndrome/Myalgic Encephalomyelitis (CFS/ME) is an unexplained disorder associated with immunological and molecular changes.

CD4+T cells specifically, regulatory T cells (Tregs) have been implicated in CFS/ME patients where significant increases in Tregs have been observed in these patients. Therefore the objective of this study was to examine methylation in CD4+T cells from CFS/ME patients.

Methods: The study comprised twenty-five CFS/ME participants and eighteen controls aged between 25-60 years. A volume of 20 ml whole blood was collected from each participant and peripheral blood mononuclear cells were isolated via density gradient centrifugation.

A negative isolation kit was used to isolate the CD4+T cells using the Illumina Infinium 450 K Human methylation array system. Data analysis was performed using Genome studio and Partek Enrichment software.

Results: 120 CpGs were observed to be differentially methylated in the CFS/ME patients in comparison to the controls. Pf these 70 were associated with known genes. The majority of the differential methylated regions in the CFS/ME were hypomethylated. Additionally, most of the genes with differentially methylated regions in the CFS/ME patients were responsible for apoptosis, cell development, cell function and metabolic activity.

Conclusion: The present study demonstrates that epigenetic changes in CD4+T cells may have a potential role in the immunological changes observed in CFSA/ME patients.

Authors: **Ekua Brenu**, **Donald Staines** and **Sonya Marshall-Gradisnik**
Source: http://bit.ly/1sYorL3

7. Research

OMI Launches Novel Bioinformatics-Healthcare Research Platform

The Open Medicine Institute (OMI) rolled out its novel OpenMedNet platform designed to improve healthcare on July 9. 2014.

This integrated healthcare model represents a new approach that many experts believe will improve the outlook for patients especially those suffering from prevalent but complex diseases such as Autism, Chronic Fatigue Syndrome, Lyme, certain cancers and others that have evaded characterization.

In May 2013, the Open Medicine Foundation was awarded a competitive grant from the VMware Foundation that included financial and consulting support for further development of the OpenMedNet system – a novel software platform that incorporates leading-edge technology for the study and clinical management of disease.

The goal was to expand the OpenMedNet architecture to develop a data capture and analytic system able to optimize large amounts of information from patients, healthy volunteers, physicians, researchers and caregivers to help diagnose and treat difficult medical conditions.

"OMI is extremely grateful for the support of the many contributors to the project, including VMware, EMC and Extreme Networks, and subject matter experts at the VARs, including HPM Networks and Kovarus," said **Andreas Kogelnik**, MD, PhD, Founder OMI.

"What started out as significant recognition from the VMware Foundation, became an incredibly broad project that was overseen to the last detail by a group of highly skilled people collaborating to solve major scientific and technical challenges."

A Better Understanding of Lung Cancer – First Application

The Open Medicine Institute is pleased to announce its new partnership with the Addario Lung Cancer Medical Institute (ALCMI) and the initiation of two key studies that will be supported by the advanced OpenMedNet platform. In both, the data capture, sharing and analytics will be processed using the newly-debuted system.

The first study focuses on inherited lung cancer mutations and the second will characterize genomic markers associated with lung cancer in young people.

The recently launched “INHERIT” study includes data optimization and exchange via a patient registry and biobank utilizing the OpenMedNet platform.

The upcoming genomics study will seek for the first time to identify the genomic profiles associated with unexpected early cancers found in young people.

Both studies will combine clinical and genomic data to provide new insights into lung cancer.

For more information, please visit: http://www.openmedicineinstitute.org.

Griffith - NCNED

CFS/ME Specialised Clinic

The CFS/ME specialised clinic has been launched! This clinic is dedicated to providing health services to patients with CFS/ME.

The clinic team will work in conjunction with patients existing GPs to manage their illness and provide the best health outcomes.

We strongly believe that the provision of invidualised care through an integrated, dedicated specialised clinic is currently the most suitable model of care and management that provides the safest possible approach to improving the health of those with CFS/ME.

The consultation with the clinician will involve assessment of clinical history, physical examination and differential diagnosis. As CFS/ME is a multifaceted illness, patients may be referred to other specialists for further investigation. Once the clinician is satisfied with their initial assessment, they will explore possible management plans specific to each individuals needs and symptoms.

All patients require a formal letter from their GP or specialised clinician to make an appointment at the CFS/ME clinic. CFS/ME patients will be able to contact reception after September 8th 2014 to organise a consultation. Further information can be found on our NCNED website for the clinic after September 8th 2014. If you have already provided your name to be on our waiting list prior to today, you will be contacted. If your name is not already on our waiting list, please contact reception on September 8th 2014.

CliniHelp Launch

This message is to provide you with an update regarding developments at NCNED.
We have developed an application that will enable you to:

- Track your symptoms on a weekly basis
- Download monthly health reports to email or print
- Share these monthly reports with your physician

(http://bit.ly/1oM949a) This app is also designed for Chronic Fatigue Syndrome, Multiple Sclerosis and Rheumatoid Arthritis patients.

This app is available in the app store for Australia, United States, United Kingdom and Europe. It will be available in Canada shortly. Please make sure you have updated your software to the latest IOS 7. We hope this application can create sustained improvements in health and care for you.

NCNED in the Media

Below are a number of links to recent media outlets featuring NCNED: http://ab.co/XhgkzH - http://bit.ly/1AdCa4Q - http://bit.ly/1kBd1gN - http://ab.co/1sVazmI - http://bit.ly/1yvyUiJ

NSU/INIM

Nova Southeastern University to Build $80 Million Research Facility

On Thursday, Feb. 13, Nova Southeastern University (NSU) broke ground on a revolutionary Center for Collaborative Research (CCR) that will house an IBM supercomputer, one of Florida's largest wet labs, the NSU Technology Incubator and some of the world's most accomplished researchers.

NSU is classified as a research university with "high research activity" by the Carnegie Foundation for the Advancement of Teaching. More than 200 research projects are currently underway at NSU, including studies on cardiovascular disease, anti-cancer therapies, chronic fatigue syndrome, autism, coral reef restoration, stem cells and wildlife DNA forensics, among other subjects.

The center will also house NSU's Institute for Neuro-Immune Medicine

http://bit.ly/1yhcPEy

Members of **dr. Nancy Klimas**' INIM-team are:

- **Mary Ann Fletcher**, PhD is bringing her Diagnostic Immunology to the Institute, joining the faculty as the Schemel Professor of Medicine, and bringing her outstanding team.
- **Mariana Morris**, PhD joined the Institute faculty and launched the NSU Gulf War Illness Consortium, a DoD funded effort to find effect treatment for veterans suffering fro Gulf War Illness.
- **Gordon Broderick**, PhD, and **Travis Craddock**, PhD, joined our faculty to create the institute's Computational Biology program.
- **Paula Waziry**, PhD joined the faculty to develop a better understanding of just what latent viruses do to the cells they infect
- **Lubov Nathanson**, PhD (a founding faculty member of the institute) is putting the final touches on the nanostring we will use to complete our dynamic modeling work.
- **Irma Rey**, MD, Medical Education Director, has developed an on site training program for the Allergy Immunology Fellowship at larkin.
- **Maria Vera**, MD joined the clinical team to expand its services in Kendall and also work with the informatics team as it develops web based platforms to help with both our clincial and research missions.
- **Nancy Klimas, MD, Director of the** Insitute is working to develop a philanthropically funded translational medicine program to move research to clincial trials faster.

8. ME And Children

False Allegations of Child Abuse

False Allegations of Child Abuse in Cases of Childhood Myalgic Encephalomyelitis

By **Jane Colby**
Executive Director of Tymes Trust
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http://www.tymestrust.org

This peer reviewed paper was commissioned and published by the journal "Argument and Critique." http://bit.ly/1oKEoEV

Abstract

There is no cure for ME (Myalgic Encephalomyelitis). In its absence, management regimes are prescribed, typically based on cognitive behavioural therapy (CBT) and graded exercise therapy (GET).

In the case of children this may involve the application of Child Protection powers to enforce treatment.

NICE confirms that patients may withdraw from treatment without effects on future care, but parents who decline, or withdraw children from, management regimes, which may have worsened their illness, can find themselves facing investigation for child abuse or neglect, or have their child forcibly confined to a psychiatric unit.

Tymes Trust has advised 121 families facing suspicion/investigation. To date, none of these families has been found to be at fault.

Subsuming ME under the heterogeneous term Chronic Fatigue Syndrome (CFS) has confounded research and treatment and led to disbelief over its severity and chronicity.

As evidence points to persistent viral infection, recommendations have been made to separate ME from CFS.

International consensus criteria for ME emphasise post-exertional deterioration as distinct from fatigue.

If the child with ME deteriorates under management regimes, re-diagnosis with a psychiatric condition can mask treatment failure and lead to blame attaching to the parent.

A more constructive redeployment of resources away from Child Protection investigations into appropriate practical support for these seriously unwell children, should be developed.

New Danish "Karina case" in North Jutland?

The ME Association, Denmark, is posting this for the parents of a severely-ill ME patient. Their daughter is 23 and has been hospitalized after the involvement of the Board of Health.

The mother is threatened with charges of neglect and the daughter may be given a state-appointed legal guardian. Here is their story. For now they request that their identities remain anonymous.

"There have recently been online rumors that a new "Karina case" was on the way in North Jutland. (Denmark)

Our adult daughter, 23, has asked us to use social media to tell about what is happening to her right now. In order to protect our daughter, who is currently hospitalized, we have chosen to make the case public, but to keep our identity anonymous for now.

Our daughter suffers for the neurological disease, ME, (Myalgic Encephalomyelitis) which has the World Health Code of G93.3. She received the diagnosis from **Dr. Valerius**, Hvidorve Hospital, and from **Dr. Henrik Isager**, who is the leading expert in ME in Denmark.

Since 2011, our daughter had been tube fed, with a nutritional mixture that her doctor ordered for her. But she was having problems tolerating this and was losing weight. Both our daughter and we in the family became increasingly concerned about her weight loss and she decided to allow herself to be admitted to hospital on July 18, 2014.

Her intolerance to the tube-feeding resulted in a lot of weight loss over time. Our daughter has always been aware of her situation and the risks and consequences of it.

But because of previous traumatic hospital stays, and the fear that something similar would happen again, she did not want to go the hospital again. Instead, she had chosen to be treated at home in a quiet, safe environment that would not risk a further deterioration of her underlying disease, ME.

Our daughter recently accepted that the current hospitalization was to take place and that it would be at the same ward of the same hospital where she had been treated very badly before. But she was not happy about it.

The homecare workers and the country had for some time, behind our daughter's back, had contact with the Board of Health about our daughter. In June 2014, after a home visit, her doctor made a referral for hospitalization because of anorexia.

This was also without our daughter's knowledge. An assessment from a different doctor in September 2013 stated that it would be atypical for an anorexic patient to be bedridden for several years and that our daughter would like to eat, but that the problem lay elsewhere.

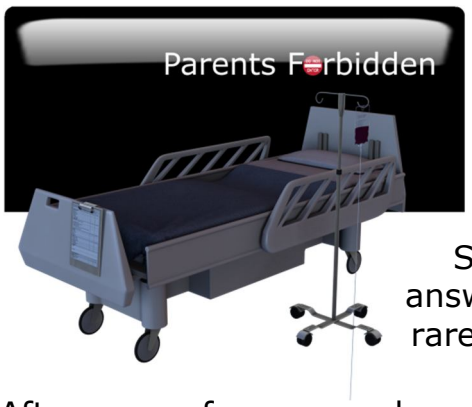
The current status is that our daughter is now in the hospital to be "fattened up" and when she achieves a better nutritional state, she has been told that she will be treated by psychiatrists and with physical rehabilitation.

Despite repeated requests to receive copies of her full journals, she has only received an edited version from the first 2 days.

The Danish hospital system is not designed for patients with the special needs that ME patients have - they are very busy and often remind us how their normally do things.

The mother is hired as a nurse and caregiver for the daughter and was therefore hospitalized with her. But after a week at the hospital, the parents were verbally expelled from the hospital on the grounds that they obstructed the staff in carrying out their work.

The goal, from our side, has been to create a tolerable environment for our daughter with the calm needed for her to be able to tolerate the tube feeding, as that is the most important thing right now. And to prevent that this hospitalization become yet another traumatic experience for her.



Our daughter now has a guard with her 24 hours a day. She is not even allowed to go to the bathroom unguarded. The guard will even wake her up and tell her, for example, that now she must wash herself.

She is forced to use her very limited energy to answer questions from the staff - body language is rarely accepted.

After a few days of a ban on visiting, the parents are now allowed to visit her 30 min. a day, but a nurse must be present at all times. Our daughter has also now been allowed to have her mobile phone.

The father has been verbally advised to try to bring the mother's employment (as their daughter's caregiver) to an end and was told that the mother will be charged with mistreating their daughter.The father was also verbally informed that his daughter will be legally incapacitated.

The court of Aalborg just sent a letter informing the parents of an impending court date where it will be requested that a legal guardian be given to their daughter.

We are very concerned about our daughter and pray that she will soon be nutritionally better and that the stress of the hospitalization does not mean a permanent deterioration of her ME illness. At present, she is extremely exhausted and has lost more weight since she has been at the hospital.

It is has been necessary to decrease the amount of tube feeding due to adverse changes in the blood tests and the reactions of her body due to the stresses that she is exposed to.

Further developments for our daughter and for us are hard to predict. We have followed the case of **Karina Hansen** - and we can already see many similarities!

For more information please contact

Rebecca Hansen,
ME Association, Denmark,
icerebel62@hotmail.com

Joanne – 9 Months In Hospital Against Her Will

The unbearable situation of Joanne, 14 year old girl from Germany with severe ME, continues. You may have read about her plight in the former issues of The Global Chronicle.

She is now incarcerated in hospital for 9 months, and she says – if she is able to speak at all – that she has never been that bad and that she wants to go home "before it is too late".

She never recovered from the general anaesthetic they gave her to make a lumbar puncture and an MRI three months ago. Four weeks ago, they gave her another high dosage of immunoglobulin to which she reacted very badly. **Joanne** said that this was like a bomb to her body.

She got unbearable headaches and a stiff neck, fever and increased sickness as well as an increase of all her other neurological symptoms – most probably a sign of aseptic meningitis. Yet again they disregarded **Joanne**'s complaints and did not reduce the dosage or stop the treatment.

In spite of this negative reaction and the lack of any improvement they are just now (while this article is published) repeating the immunoglobulin treatment for a third time. We all wonder how she will react and whether this will make her even worse.

Ever since the second course of immunoglobulin, **Joanne** suffers from bouts of uncontrollable trembling and horrible shaking of her hands and feet. Though this is clearly a sign of neurological damage nurses and doctors declare this as the beginning of voluntary movement (**Joanne** is paralysed from hip downwards and can only move her arms and head).

This misinterpretation of neurological symptoms as a success (of symptoms that are worsened or even caused by the "treatment") permeates the entire mindset of the nurses and doctors: they seem to systematically ignore the suffering, to belittle even alarming symptoms as an expression of an alleged psychological disturbance and eventually declare these symptoms as a sign of improvement.

They seem to simply close their eyes to the reality of **Joanne**'s unimaginable suffering. And what they do to her mother is just as cruel.

Joanne's father topped the cruelties in requesting the judge to enforce by penalty mother's ban from the premises of the hospital except for her visiting times. That means: when mother is near her daughter's bed outside of the permitted visiting time because she is undergoing a life-threatening medical intervention under general anaesthetic or when she is waiting for a doctor to talk to she might be punished with a fine up to 25.000€ alternatively imprisonment.

This man has sole custody of **Joanne** while her loving and caring mother might never get back her parental rights. There seems to be more than one reason why **Joanne** recently said to her father that she would deny him the right to call himself her father. Not only does he fight against her mother, he supports all the "therapies" of the doctors and accuses **Joanne** that it would be her fault that she'd not get better.

Joanne's mother contacted the ethics committee of the hospital because the consistent disregarding of **Joanne**'s statements that she would refuse all the "treatments" is definitely a violation of medical ethics. **Joanne**'s mother had written down her declared wishes and **Joanne** had signed the declarations. **Dr. Nigel Speight** contacted the ethics committee several times but got only an inconclusive and evasive answer.

The ethics committee had contacted the doctors of the ward but it is unclear whether they had any influence at all.

Another internationally renowned ME specialist visited **Joanne** and talked to one of the doctors of the ward. May be it was her influence that they stopped all "treatments" and now constantly ask **Joanne** whether she would want this or that. But her constant refusal is only regarded as a sign of a somehow psychologically motivated resistance and not as of lack of energy and as a sign of severe ME.

Even though the doctors of the ward concede that the consulting psychiatrists cannot confirm any psychological or psychiatric disturbance (!) the doctors insist that the lack of progress must be a function of either **Joanne**'s "psyche" or her mother's "bad influence" or a combination of both.

The nurses and doctors persist in disbelieving in the genuineness of her disability and talk to her of their determination not to let her free until she has responded to their "treatments" and until she is "completely healthy" again. And that they would "protect" her – alluding to the alleged "bad influence" of her mother.

This is tantamount to a death sentence since **Joanne** will never experience the slightest improvement under the distressing conditions and the cruel "treatment" by nurses and doctors alike. Joanne once said: "I am not treated as a patient nor as a human being nor as a living thing but as an object. I cannot stay here! I am not an object to … (doctor´s name) use! They owe me freedom!"

Joanne and her mother are in constant fear that the next day might be her last. Since the temporary suspension of all "therapies" that imposed even more physical strain and sensory overload did not make her better they now conclude that "rest" would be the wrong treatment and they cannot risk that "rest" makes her worse.

Consequently, they announced they'd resume all "therapies" like schooling, aggressive physiotherapy, deliberate exposure to noise of other children on the ward, driving her around etc.

Moreover, they threaten to put her again under general anaesthetic for a gastroscopy and even the placement of a peg tube. They do not realize that **Joanne**'s constant sickness and throwing up is a sign of her severe ME and the fact that they made her much worse and that neither a gastroscopy nor a peg tube would help with this.

All these measures – a new course of high dosage immunoglobulin treatment, the resuming of all kinds of "therapies" and another general anaesthetic – are considered by **Joanne** and her mother as a constant death threat. According to **Dr. Nigel Speight**'s assessment her condition is so bad that anything that makes her worse might be indeed her end.

And the still impending court decision on mother's appeal to her removal of parental rights is another sword of Damocles hanging over their heads. The only chance for **Joanne** to survive is going home and being gently cared for by her dedicated mother.

The precondition for this would be that her mother gets back custody – and that the fatherwould agree to her going home to mother. Her dedicated lawyer is still fighting by writing excellent letters to the court and the ethics committee. We hope that the court hearing will bring a turn for the better.

A new judge has been appointed, but he immediately ordered a psychologist to test mother's ability to educate – 90% of these "certificates" result in a negative assessment.

So we would be most grateful for any donation to the **Save4Children** fund – which will at present be solely used to support **Joanne** and her mother. **Dr. Nigel Speight**'s travelling costs are now covered – thanks to your invaluable support, but **Joanne**'s mother has no means to pay for the lawyer's bills.

THANK YOU for your support!

Editor's note: The German author of this report wants to stay anonymous. She is well familiar with this case.

Save4children

To Donate: http://bit.ly/1qwwmz0
See also p.74

9. Severe ME

Final Stages

Dear Friends and Family,

This is a post I've been putting off for quite awhile. But I no longer have the luxury of putting it off anymore – not if I want it to get written.

My personal journey with ME is near its end.

A long time ago, after months of deliberation, I made the decision that if my digestive issues ever got to the point where I could no longer get or keep food down naturally, I would not seek life sustaining measures, but would allow the illness to play itself out naturally.

I am at that point, and have been for awhile now.

Let me preface this by saying that none of this is a judgment on those severe ME patients who choose to take advantage of technology like nasogastric tubes, hydration IVs, etc in order to remain alive as long as possible.

I believe this is a highly personal decision, and what's right for me may not be right for the next person (and vice versa).

For me, this decision was made based on the knowledge of what ME often turns into for those who accept life sustaining measures.

As bad as things are in my current situation, they could get even worse.

ME truly can become a living death – except with much, much more suffering – a large portion of which is untreatable.

This is difficult not only for the patient, but for loved ones who have to stand back and watch the process, longing to reach out and help but knowing their very presence only increases their loved one's suffering a hundred fold.

I have already experienced much of this.

I cannot personally justify enabling it to continue and worsen via medical technology – not in my specific case.

That said, each person must decide for him/herself when enough is enough, and where their individual priorities lie in terms of life and the quality it holds for themselves and those around them.

Right now, my body is literally starving itself to death.

Even my best efforts to get food down have been met with frequent vomiting, rapid weight loss, and clear disease progression.

The fight to get food down is exhausting. It involves closely monitoring nausea levels every single waking moment, waiting for the one minute window I may receive each day where my nausea subsides just enough that I think getting two or three bites down might be feasible.

Even then, I nearly always lose the food anyway. The excess weight ME once placed on my body is coming off extremely fast.

Just one example: I have dropped over an entire ring size just since the end of May. You don't lose a whole ring size just from dropping a few pounds. It takes a significant amount of weight loss to make that happen.

> Everything I own is loose on me. In fact, the other night I was shocked when able to pull my wedding ring off for the first time in years!

Because the food battle has become so exhausting and completely pointless, the decision has been made to stop trying to force feed a stomach that clearly can't handle it anymore.

Ironically enough, stopping all food has actually lessened my nausea significantly.

Still, all it takes is one bite for things to skyrocket again and my food to come flying out, totally undigested, either the same day or the one following.

So no food for me. At this point, I have already begun experiencing some hypoglycemic symptoms. Also, my resting heart rate has shot up to 120 bpm. Several other new symptoms have also developed. Needless to say, it won't be long now.

The biggest issue I am currently facing in all of this is a complete lack of medical care. My most recent post explains some of how this happened.

Much more has happened since then, and I fully intend to write a post specifically about that as soon as I'm able, but for now, the basic situation is the same. No care.

I am in the process of trying hard to get back into hospice care for this last leg of my journey, and will let you guys know how that turns out.

My biggest fear at this point is that my husband and I will be forced to go through this completely alone.

Among other things, a hypoglycemic coma is almost certain (assuming my heart holds out that long), and it terrifies me to think of my husband having to deal with that alone, with no doctor or nurses overseeing the situation.

This should not be happening in today's society!

But it is. And people need to know it happens, often to the very sickest among us. But more on that in a later post.

For now, I simply felt the need to update everyone on how this disease has progressed, where I'm at with it, and how it is most likely to play out in the near future.

Should something happen before I get a chance to write future posts, my mom (who works in the medical field) has promised to take over this blog for me.

She will write a post updating everyone on the situation, and has my full confidence in being capable of answering any comments or questions left on posts in the future. I appreciate her taking on this responsibility.

My deepest love and gratitude goes out to everyone who has been so supportive of this blog.

Several of you have become good friends, and writing this blog has given me a sense of purpose – something we all need in life.

I hope and pray this post finds everyone doing as well as possible. I'll keep working at adding new posts as long as I'm able, so keep your eyes peeled!

Edited to add:
Please check out my subsequent post, Clarification (http://bit.ly/1ykBJVq), for a bit more explanation of the history behind my digestive issues and various treatments tried and failed.

Thank you

Moore

House And Bedbound Does Not Describe Severe ME

When you look with honest eyes and open heart at the plight of people with Severe ME; the ones who represent most fully what ME is, with their tormented bodies, widespread cognitive dysfunction, crushing muscle dysfunction, untreatable multi-layered pain, shaking spasms, transient paralysis, acute noise sensitivity, light sensitivity, touch, motion and chemical sensitivity, complex gut issues and difficulties swallowing and eating, the pretense that the disease is manageable and treatable psychologically is shocking.

The medical neglect and the isolation of the most ill is a tragedy and a travesty. People with Severe M.E. are not being investigated adequately, not being properly medically treated, not being represented accurately or portrayed fairly.

In order to survive, cope with the profound challenges that living in an increasingly hostile environment creates, patients become more and more isolated from the world, invisible even, left to suffer for decades on end without proper treatment or tests.

The term "house and bed bound" is often used in context of Severe ME, as if that describes severity. "House and bed bound" is a blanket term that:

- does not identify what is going on medically at a physiological level in Severe ME.
- does not describe the severity of symptoms each person experiences individually and differently.
- does not convey the complex multi- system dysfunction people experience.

Neither does "house and bed bound" convey:

- the endemic medical neglect
- the government responses that, against all the evidence, buy into psychological treatment pathways;
- the charities, practitioners, medical establishment, who willingly collude with psychiatry;
- the inadequate, inaccurate portrayal and focus on fatigue;
- the poor identification criteria;
- the lack of medical identity;
- the disinterest of neurology;
- the misunderstanding of M.E. deliberately compromised through immersion in a sea of loosely defined and under-investigated conditions;
- the complete lack of biomedical input and proper medical investigation that people with ME experience, time and again.

Nor does the label stop psychiatry from callously perpetuating the misinterpretation and misrepresentation of ME as a mental health condition.

People who live with Severe ME, sooner or later come to know personally, those who die, directly or indirectly, as a result of this medical neglect. Their numbers, sadly, mount up over the years.

What inspires us about those wonderful people, sadly no longer with us, was their determination to be themselves, despite everything. What angers us is how badly they were let down by society, government and the medical establishment: the wasted lives, lost too soon.

What grieves us is the unmet global need for much, much better treatment and acknowledgment of the full reality of this devastating physical illness,the need for much better medical support and understanding, for responsive services that actually reflect understanding of the house and bed bound reality.

There is little real hope of adequate or honest provision, all the time the psychiatric lobby entrenches itself further and further into mainstream ideology, misdirecting funding and research, leaving people unsafe, without adequate recognition and little or no power to get things changed.

When you are very severely affected you live on the edge and the others live there with you. You do not know who might be next to die. You do not know if it will be you.

You just keep going and keep going, one moment at a time, hoping to improve for no real reason, for little or nothing is being done.
There are no cohesive, reliable, complete explanations, the medical profession as a whole does not want to know. You hope you will not be harmed; much as you try to avoid mistreatment, inevitably it still finds you.

The longer you live with Severe ME or live with someone who has Severe ME, their health deteriorating into unfathomable levels of suffering, too vast to describe, the more clearly you see the truth.

You see very clearly that :

- People are being medically ignored and fobbed off by the medical establishment.
- Current research does not generally involve people with complex hypersensitivities, too difficult to deal with, excludes the most severely affected, the ones with the full range of symptom experience.
- Medical professionals do not have the first clue how to deal with those who are profoundly noise, light, chemical, touch, movement sensitive and paralysed; they do not know how to communicate safely with people who are harmed if approached or touched wrongly or spoken to loudly or in the wrong way.
- Psychiatry is rapidly increasing in power and expanding its influence.

On Severe ME Understanding and Remembrance Day, August 8th, Severe ME sufferers, desperate to be "seen, heard and recognised" mounted an "ME Cover-Up" Campaign to highlight the whole-scale neglect of M.E. Enormously ill people, at great effort, took and sent in photographs of themselves covered up with a sheet. Some of the slogans they held up were heartbreaking : "Out of sight, out of mind", "Severe ME, invisible, ignored", "21 years of agony and no Consultant", "Living behind the lies", "Twenty years sick, stop the cover up!".

Their powerful images can be viewed here :
http://stonebird.co.uk/archive/aug8/

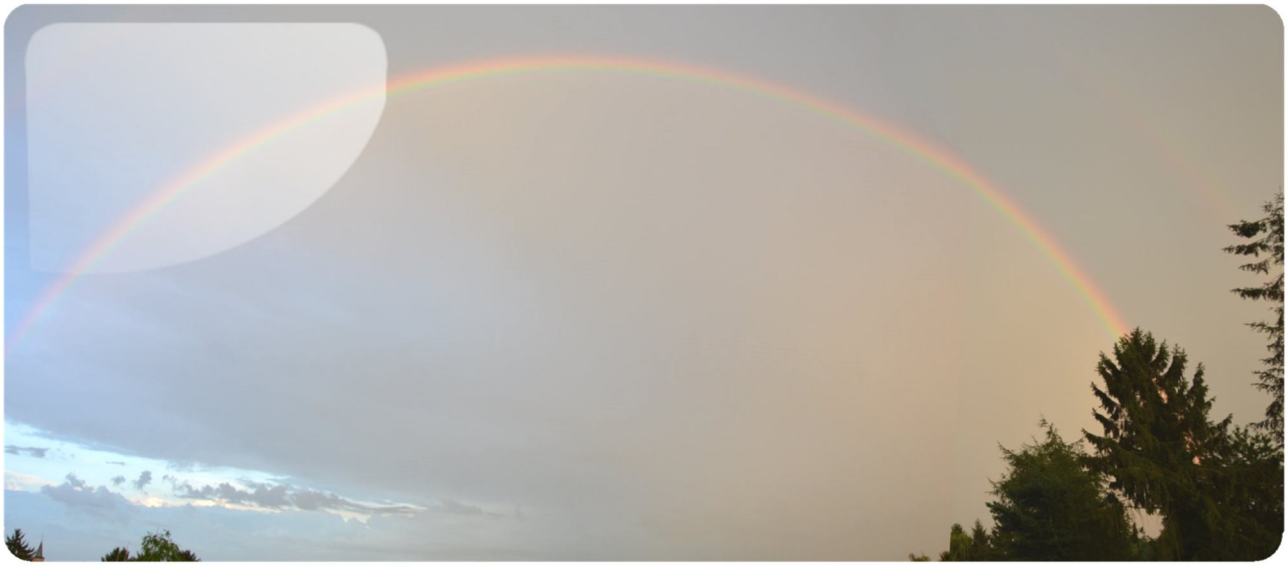
Perhaps the most moving picture was the one a fourteen year, old sent-in, wrapped in a sheet. What is the future for the children, we have to ask?

Exceptionally bleak, if things do not change.

Greg & **Linda Crowhurst**
August 2014

What It's Like To Live With Severe ME

August 8 was Severe ME Awareness Day, dedicated to those who suffer the worst effects of Myalgic Encephalomyelitis. ***Naomi Whittingham****, one of the main characters of the film Voices from the Shadows, described life with severe ME in an article which she posted on the fb wall of the Telegraph and immediately afterwards was published in the newspaper. Within 24 hours it was liked by over 5,000 persons.*



Ordinarily, illness is measured in days or weeks; and for the unfortunate months or even years. Then there are those of us for whom illness, pain and suffering is measured in decades. This is my twenty-fifth year of being ill: a quarter of a century spent mostly in housebound, bed-bound isolation.

I have had ME since the age of twelve, after catching a routine virus from which I never recovered. Within months I was unable to move, speak or open my eyes.

I had to be spoonfed. Constant, agonising headaches forced me to lie in a dark and silent room. I was so ill that my family and doctor feared I could die at any moment.

ME affects around 250,000 people in the UK, with 25% so severely affected that they are house or bed bound. It is now widely recognised as a neurological condition although some doctors still mistakenly believe the cause to be psychological, or that it can be cured by exercise.

ME involves every bodily system and symptoms include flu-like malaise, severe pain, muscle weakness, cognitive dysfunction and acute sensitivity to sensory stimulation.

After spending my early teenage years in a death-like state, I began to slowly improve. At 37, I remain in a wheelchair most of the time and dependent on full-time care from my mother, now 63, but I consider myself fortunate.

If you met me during a better spell in the day, you might not realise there was much wrong with me. You wouldn't see the collapse into bed afterwards; the desperate need to lie in silence to prevent an escalation of symptoms such as pain, muscle jerking and vomiting.

In the twenty-five years of my illness I have watched my peers become teenagers and then adults. My journey to maturity has been marked by very different rites of passage: I have had to learn to feed myself again, to speak, to sit up.

I have had to re-build self-belief from the shattering effects of having a misunderstood illness. It is destroying enough to experience the collapse of every bodily system; it brings one close to ruin when the cause is suggested as lack of motivation or a wish to escape life.

I have never driven a car or made a journey unaccompanied; I have never had a job or a boyfriend or a home of my own. I will never have the children I would love. For many women this last would be a devastating blow. Swamped by so many other losses, I barely register it.

Chronic illness is a bereavement: a lengthy grieving for shattered dreams. Despite this, I am not a tragic figure. Decades of intense suffering have given me a deep appreciation of life, of the simple pleasure of a sunset or spring flowers.

I have a wide network of friends with ME and those of us who are well enough communicate through email and Facebook.

Recently someone asked me what I would do if I were well for a day. The possibilities for that one, cherished day not confined to bed or a wheelchair are too numerous to comprehend.

Getting out of bed unaided, stepping out into the garden, making a cup of tea, styling my hair, shopping, going to the sea for the first time in years: basic, spontaneous activities which most people take for granted.

For me and thousands of others locked in this prison, the only prospect of release lies in quality biomedical research, of which there is far too little.

There are promising developments in the study of viruses and immune abnormalities, and the hope of identifying diagnostic biomarkers and eventually drug treatments.

But lack of funding means that progress is slow and in the meantime lives are wasted.

I will never get my youth back; but progress in understanding ME is urgently needed, before future generations lose theirs.

Naomi Whittingham

Voices from the Shadows, an award-winning documentary, tells the story of several severe ME sufferers, including Naomi and Sophia Mirza, who died aged 32. http://www.voicesfromtheshadowsfilm.co.uk

10. Column - Clown

I sometimes feel like a clown.
A clown with ME (myalgic encephalomyelitis). An invisible and often very misunderstood illness.'The illness that makes you feel tired, right?', I'm often asked.

No, sorry, you're wrong. So wrong! I'm not just feeling tired. I'm exhausted, in pain and very vulnerable to infections.ME is a debilitating illness that not only affects your energy level, but also your whole immune and nervous system.

Always! Every minute of every hour of every day. It feels very much like running on an empty battery. A battery you're never able to fully charge. Not even after resting for a whole day, week, month or year. **Never!** '

But you look so good!' I'm often told. Yes, you're probably right, but that's why it's called an invisible illness. And don't forget that you only get to see me on my 'good' days. The days on which I actually manage to get out of bed, shower, get dressed, stand up straight and smile.

The days on which I do my best to enjoy life to the max, despite my illness.
The days on which I take all those fun pictures you get to see on my Facebook-wall. Not to show off how great my life is, but mostly to remind myself that my life is still very much worth living for. And of course to share these precious moments with my dear family and friends.

Anyway, while looking at these pictures or seeing me in real life, please don't judge and think there's nothing wrong with me. Just because I'm smiling. The smiles aren't fake, but neither is my illness. Despite all the smiles, I'm still ill, I'm still exhausted and I'm still in pain. And on all the days you don't get to see me, I'm just surviving and resting to recover to the state I was in before. Still ill, but 'better'.

In between I often feel very frustrated because my body is never able to keep up with my mind. In between I'm home feeling lonely, sometimes not even able to take care of myself. In between I'm fighting to recover just enough to be able to have another fun day. In between I'm just hanging in there. Sometimes in my hammock, but mostly in my bed.

Now I don't want you to feel sorry for me. Please don't!!! I just need you to respect the fact that I'm doing the best I can, even if I'm not doing what you think you would do in my case. Be glad you're not! I for one am very glad if you're not !

Muzzly - A Dutch ME-patient http://youtu.be/IOflARSgNnE

11. News from

Belgium

New governmental initiative:

What is "new"?
The former multidisciplinary diagnostic centers for CFS, that have not been successful, will be replaced by...

- multidisciplinary diagnostic centers for CFS where the GP will be playing a central role, for which the latter will be compensated.
- The former Graded Exercise Therapy GET (which is harmful) and Cognitive Behavioral Therapy will now be given by therapists from the patient's environment.

What is lacking?

- A good working therapy.
- A thorough research on what CFS actually is
- An exhaustive information flow in benefit of the therapists, who are now forced to find information by themselves. Because of this, there is no uniform treatment.
- ...

This means that nothing has actually changed: we can hardly call this a new initiative.

Much work is still to be done
(see also http://bit.ly/1rLSogF).

The "Flemish Patient Platform" (VPP) will be organizing two identical info sessions about the new statute for "people with a chronic disorder" on 25 September from 14:00 until 16:00 hrs and on 20 October from 19:00 until 21:00 hrs.

These will be held at:
Groenveldstraat 15,3001 Heverlee (016/23.05.06).

The subscription is free of costs, please register via:
an.decock@vlaamsepatientenplatform.be, mentioning "Lid van **WUCB**".

For more information, please look at http://bit.ly/XvymOJ

Eddy H. Keuninckx

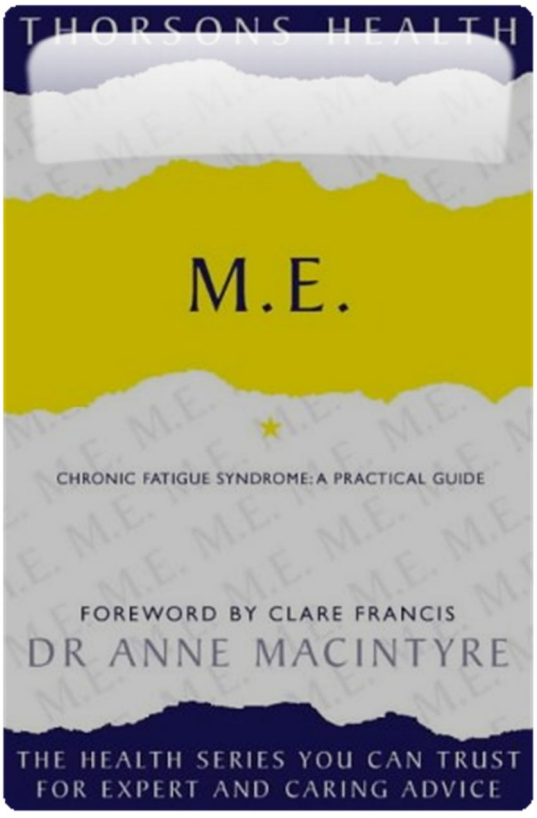
Northern Ireland

We are delighted to announce a very positive outcome in our search for a worthy patron for
Newry & Mourne ME/Fibromyalgia Support Group.

Dr. Anne MacIntyre, is not only an authority on the illness and longtime campaigner but also a sufferer and has kindly agreed to take on this role.

See link to her book below, although written in 1999, still one of the most informative sources of practical living with M.E.

Used copies can be bought on Amazon at a very cheap rate and also borrowed from our free member's group library.



http://youtu.be/yhJrECO2Wb8

The Netherlands

Research **Dr Visser**

The Dutch cardiologist **Dr Visser**, who gave seven short lectures for the project Science for Patients (http://bit.ly/1nBYnAS), is currently preparing for a research project that he hopes to conduct in cooperation with the Belgian **professors Jo Nijs** and **Mira Meeus**.

The goal of the research is to explore whether patients with Myalgic Encephalitis (ME)/ Chronic Fatigue Syndrome (cfs) show a relationship between the cerebral blood supply, pain reduction and the autonomic parameters during rest, and during and after exertion.

Patients with ME/cfs experience pain differently: they feel more pain in the muscles and joints during and after exertion. This is an abnormal reaction, since it is exactly the opposite for healthy people.

Furthermore, the blood flow to the brain has a lower quality than that of healthy people. The causes of these defects are actually largely unknown. In this investigation we are seeking to find a correlation between the altered experience of pain and the reduced blood supply to the brain.

Also, the involuntary (autonomic) nervous system of ME/cfs patients has changed contrary to that of healthy people. We wish to correlate these defects with the altered pain experience and the altered blood supply to the brain as well.

Recently, **Dr Visser** posted an appeal to research 15 healthy test persons via the channels of the ME/cfs Association (http://www.me-cvsvereniging.nl). He intents to do a preliminary research among 15 patients (selected according to the Fukuda and CCC criteria) and 15 healthy people, after which a similar larger follow-up cohort study will be conducted.

The aim is to finish the entire project within a single year.

An ethical commission approved the research, on condition that a maximum of 150 people will be participating.

Sweden

The Swedish National Society for ME Patients, RME, is arranging a seminar about children and youngsters with ME/CFS on Wednesday 12th November in Stockholm.

The speakers will be:

- **Dr. Peter Rowe**, Johns Hopkins Children's Center, USA, talking about orthostatic intolerance
- **Dr. Nigel Speight** talking about diagnosis and management as well as child abuse by the medical profession and other authorities due to misdiagnosis in cases of ME/CFS
- **Dr. Amolak Bansal** who will talk about the immune, viral and endocrine interface in ME/CFS
- 14-year old **Natalie** will also be speaking about her situation as an ME/CFS sufferer

RME's main target group are medical and educational professionals, politicians and media.

The general public is welcome if there are any vacant seats after 20th September, which is the last date for registration.

For registration and other details visit http://www.rme.nu/seminarium-2014

For more information about the seminar please contact info@rme.nu

Box 11037

404 21 GÖTEBORG

United Kingdom

ME Research UK

Vitamin D and vascular function

Given the possibility of links between vitamin D insufficiency and ME/CFS, ME Research UK awarded funding to the Institute of Cardiovascular Research in Dundee to examine vitamin D levels and vascular function in two ME/CFS populations.

The results of these preliminary studies have now been published in the International Journal of Cardiology http://bit.ly/1sfVQUA, and show significant associations between circulating serum vitamin D levels and markers of inflammation, oxidative stress, endothelial function.

Subsequently, we funded a clinical trial in Dundee to test whether high-dose vitamin D supplementation might be a relatively simple, effective way of contributing to reducing risk of cardiovascular disease in ME/CFS patients, and the results of this larger study will be published shortly.

"Breakthrough" magazine

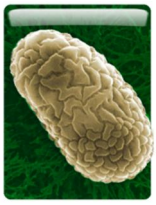
Our Autumn 2014 "Breakthrough" magazine will go out free in the post to friends and supporters shortly. The contents of this issue include:

- Raising the curtain on severely affected ME/CFS patients
- Vitamin D and vascular function
- Abnormal visual attention in ME/CFS
- Widespread neuroinflammation
- Information on ME/CFS – what's out there?
- IACFS/ME conference 2014
- Plus research "bites" on NHS provision for severely ill patients, post-mortem brain and tissue bank, a rational basis for diagnosis, orthostasis & heart abnormalities, ME/CFS and 'market failure', movement restrictions in young patients, low nerve proteins and more

If you would like to receive a free hard copy in the post, please email us with your address. The electronic version should be publically available in the Autumn. http://bit.ly/1oHZELa

Plaque unveiled at University of Newcastle

At a recent site visit to Newcastle University Medical School, the trustees of ME Research UK heard about progress of the research studies, and unveiled a plaque marking the charity's latest award – a Programme Grant to **Prof Julia Newton** to advance biomedical research into ME/CFS. http://bit.ly/1kJVzV1.



There were a number of presentations from researchers engaged in work funded by ME Research UK, including studies into abnormalities in muscle cells of ME/CFS patients, and using spectrophotometry of cultured cell samples to examine the complexes of the mitochondrial electron transport chain.

ME/CFS is more than a meme

http://bit.ly/1pZ7aTW

A meme is "an idea, behaviour or style that spreads from person to person within a culture."

On 18th June 2014, a comment appeared on the website of the British Medical Journal entitled "Is Chronic Fatigue Syndrome a meme?", suggesting that 'chronic fatigue syndrome' fits the model of a meme-mediated syndrome – a "dysfunctional culturally-transmitted idea-infection".

The 'rapid response' from ME Research UK was published on the BMJ website, and it pointed out that "ME/CFS is much more than a meme; it is very real, it should be taken as seriously as any other medical condition, and patients should be treated with respect."

Thanks to **Dr. Neil Abbot**, Research & Operations Director ME Research UK

12. Vote For…

http://bit.ly/1r1Xo59

With the start of the month of August 2014, birth was given to a new global petition. It is a strong and urgent appeal on the WHO to recognize the implications and implementation of the ICD 10 G93.3 on ME:

"We as concerned and compassionate global citizens ask the World Health Organisation to make sure that the member states comply to the ICD10 G93.3 Myalgic Encephalomyelitis classified as a neurological disease.

Under heavy pressure of multinational insurance companies and also in the interest of governmental organisations, the definition of - and guidelines for this widely spread neurological disease have gone astray and are heavily corrupted.

Scientific research in this debilitating disease is seriously hampered by this attitude. In several countries this attitude has directed researchers in the wrong way, subsidised by the same governments.

One government, the **Norwegian**, has recently issued apologies and say they feel remorse about neglecting their citizens with Myalgic Encephalomyelitis. All WHO member governments should follow this example and improve this dire situation as soon as possible."

http://bit.ly/1r1Xo59

13. Major Fundraising

Llewellyn King is raising funds

to be able to continue his 100% free and very important and useful interviews with well known scientists researching ME/cfs
Raised: $4,815.00 Goal: $20,000.00
Info: http://www.gofundme.com/5yhjdo

Ian Lipkin study. Raised: **$111,446**
The growing total of the appeal was much-helped by recent donations of **$25,000** from a business man who has a daughter with ME/CFS, and another recent gift of **$10,000**. However, small gifts are the lifeblood of the appeal so please give whatever you can – even a dollar will help. We also love it when people raise money as a group, eg a recent Zionsville Fellowship Church fundraiser raised more than $900. http://bit.ly/XynrE8

Tour of the microbiome study HQ

Recently a member of our (tiny!) team was in New York and had the privilege of visiting the Center of Infection and Immunity (CII) where **Dr. Lipkin** and his 60-strong team will conduct the crowdfunded microbiome study. Read the photo blog (http://bit.ly/1rTHs0t).

Why we give

"Seeing my daughter deteriorate from a bright, well-meaning teenager into what can only be described as a wreck of a human being breaks my heart… "Not only must I hold my daughter's hand as she mourns the losses of losing the prime years of her life to being in bed; being unable to have a family or any life of her own; and having no career—I must also let go of the hopes and dreams I had for her as a child. "However you may personally feel about the microbiome, **Dr. Lipkin** is a world-class researcher of whom, simply, we have far too few in this disease." As any ME patient will know, time is something we cannot buy back and the more and the sooner any research is done into this illness, the better. "We must find ways to speed up research. Even if it means crowdfunding one dollar at a time. Lily and other donors on why they have given to the appeal – we'd love to hear your stories too (just email us) info@microbediscovery.org.

There are still a few tickets left (£5 each) for **Dr Lipkin**'s talk about studying infection and his work on ME/CFS on **September 3rd**. Contact **Action for ME** (http://bit.ly/VDfL1v) for tickets (thanks to the ME Association too, who have helped organise this event).
If you can't make it, you can see **Ian Lipkin**'s recent talk at the Stanford Symposium in March – check out video number 5, or read the transcript at the ME/CFS forums Wiki (http://bit.ly/1tlukII).

Can you help with Facebook?

We have a small group of willing but sick volunteers running the appeal and we would love to get help from anyone with Facebook or other social media skills. Please email us if you can help info@microbediscovery.org
Info: http://phoenixrising.me/archives/21929
http://www.microbediscovery.org/

Raising Funds for the UK Rituximab Trial

Info: http://bit.ly/1jVGHng
Thanks to an amazing effort across many countries the Biomedical Research Fund for the IiME/UCL UK rituximab clinical trial is now funded for **£350,500**. The goal was **£350,000**.
To donate: http://bit.ly/1dc1wmS

Grand Opening of the "Step Up for M.E." Store!

http://theblueribbon.storenvy.com/

Support The Norwegian ME Association's fundraising for biomedical research into Myalgic Encephalomyelitis! We would very much appreciate your help! Donations can be a made on our website:
http://me-forskning.no/donations/
Or you can wire transfer a donation to our bank account:
1503.32.04334 - IBAN NO67 1503 3204 334 - BIC DNBANOKKXXX

If you wish to donate to **Dr. Enlander**'s ongoing and future research.
Please contact: cfsconference@gmail.com

A fund called **Save4Children** has been initiated in March 2014. We would very much appreciate your financial help with this project.

You can donate any amount through http://www.geef.nl/doel/save4children

Donations made to this fund will initially be used to provide individual support for children with ME whose illness is being dangerously mismanaged. The funds will be allocated on occasions when **Dr. Speight** needs to travel to give appropriate assistance, or a lawyer is needed, and families can prove they are not able to afford this (see article on Joanne, p. 50).

Later on other experts may be invited to plead similar cases, all over the world.

If there's any such case known to you, please let us know through

info@let-me.be

Till so far **€ 1311,38** has been donated. **Dr. Speight** had to travel twice to Germany to see **Joanne**, her mother and authorities. His covered expenses were € 1150,06. Bank charges over this period were € 14,48. Current balance is € 146,84

We would like to thank the generous givers till so far.

14. Worth Reading & Watching

Evolving Science
Don't tell us you never stuck upon the high quality fb-wall Evolving Science from Belgian ME-patient **Linda**. You missed a lot, but still can make up for it by clicking right now
http://on.fb.me/QEG4T0

Examining case definition criteria for chronic fatigue syndrome and myalgic encephalomyelitis
Leonard A. Jason, **Madison Sunnquist**, **Abigail Brown**, **Meredyth Evans**, **Suzanne D. Vernon**, **Jacob D. Furst** & **Valerie Simonis**
http://bit.ly/1l73rRM

Poems from Conflicted Hearts:
Poems of Kentuckycurran. **Tayen Lane** Publishing / Smooth Stones Press
Published March 1st, 2014
eBook: $4.99 (Amazon, Barnes & Noble, iTunes & Tayen Lane).
To request a review copy, schedule a contributor interview, or obtain more information regarding publishing an excerpt, please send an email to info@tayenlane.com

Science to Patients

Prof. dr. Julia Newton
on ME and the future

http://www.youtube.com/playlist?list=UUPZtpMdUGvQblEJ3IfgYQ8Q

High time to join forces, all over the world:
Need a reason?
Almost 53,000 views
Watch this: http://youtu.be/IOflARSgNnE

Llewellyn King, ME/cfs Alert,
produced by **Llewellyn King** and **Deborah Waroff**:

Two new videos of Llewellyn King & Deborah Waroff:

Episode 64: http://bit.ly/1sISHgt
Llewellyn King: Call for action

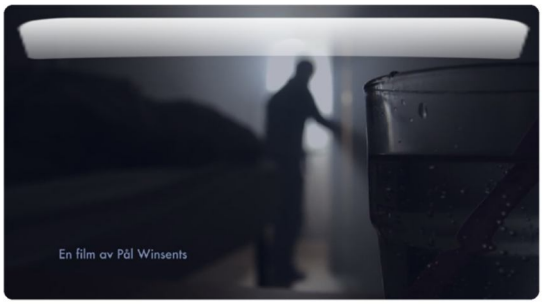
Episode 65 http://bit.ly/1uvG74M
Interview **Deborah Waroff** with **prof. Jose Montoya**,
The Stanford University Medical Center
August 10, 2014

Solve ME/CFS Initiative
Leveraging patient-centered research to cure ME/CFS
FORMERLY KNOWN AS THE CFIDS ASSOCIATION OF AMERICA

http://solvecfs.org/solvecfs-biobank/eligibility/
To participate in a global biobank for ME/CFS-research

A Good Practice Guide to Education for Children with ME for GPs, Schools and Families is also available online:
http://www.tymestrust.org/pdfs/gpguidev2.pdf

Source: www.tymestrust.org



Norwegian docu **Sykt Morkt** (**Sick Darkness**)
Trailer with English subtitles
http://www.syktmorkt.no/

A small group of us have created a series of short videos mostly showing the errors in the PACE trial reports. The latest two have just been released, concerning the claims that CBT promotes recovery in people with ME/CFS.

6: ME Recovery Song http://youtu.be/QbKTBMyZfX0
7: How's That Recovery? http://youtu.be/d_7J5ELjArU

The complete set can be found here:
http://www.youtube.com/user/MEAnalysis/videos

I hope that there is something there that interests you.

Graham McPhee

Appeal from **Rich Podell**, see article on page 8 in issue #5.

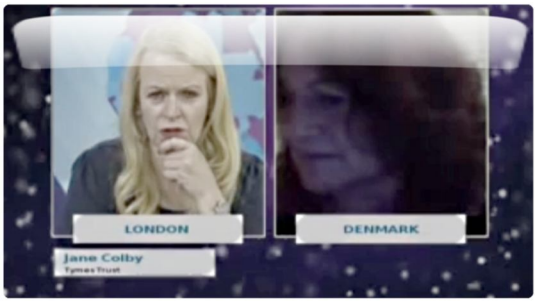
I'd appreciate hearing from others who have used Valcyte or other anti-viral drugs. Please share your experience with our readers. Do you agree or disagree? Is Valcyte is ready to be used for CFS-ME?

Kindly mail to: podell2@gmail.com

Here's the video from **Prof. Martin Palls** talk in Copenhagen on March 5th 2014 about the NO/ONOO- cycle, a New Disease Paradigm (2h 20 min) http://youtu.be/6A7r1gemjto

Martin L. Pall's
home page The Tenth Pardigm
http://www.thetenthparadigm.org/index.html

Thanks to
Helle Rasmussen



Interview **Sonia Poulton** with **Rebecca Hansen** and **Jane Colby**, amongst others on **Karina Hansen** and the psychomatisation of ME, and on ME and CFS:

http://youtu.be/n9vKpmelKeE

Dysautonomia Youth Network of America, Inc.
Promoting Awareness, Support, Research and Recovery
"A Ray of Hope"

Awareness Series informational brochures, of the Dysautonomia Youth Network of America (DYNA):
http://www.dynainc.org/resources/brochure

The DYNA Awareness Series Brochures are designed to provide youth and young adult patients diagnosed with a dysautonomia condition (and their physicians, caregivers, families and communities) with a better understanding of the conditions. They are an invaluable resource for distribution within the network of people with whom dysautonomia patients live and interact.

By making these brochures available within your community you can improve the overall awareness, support, and understanding that all patients with dysautonomia receive.
Thanks to **Sheila Mitchell**

"What comes as a surprise to many medical practitioners is that even at this level of illness severity, blood tests and other so called standard investigations, reveal very little about the illness to the 'average' doctor, and nothing whatsoever to the ME skeptic. This is a medical tragedy writ large."

Taken from:
Severe ME
Featuring "Justice to **Karina Hansen**", p.180 –
Greg Crowhurst
To be ordered via http://bit.ly/1wwcDlN

M.E. Facebook groups

Severe ME Chat & Support http://on.fb.me/1t6a6x3
Severe ME/CFS: A Guide to Living http://on.fb.me/1pQYFYX
The M.E Chat Room http://on.fb.me/1sITnCy

CanaryChat http://on.fb.me/VpY7hR
help, support and camaraderie for people with chemical sensitivity and their friends

Invisible Diseases
Support Chronic Fatigue Syndrome, ME, Fibro & Lyme and associated diseases
http://on.fb.me/1l8t32q

August 2014 issue of ***the newsletter of Invest in ME***:
http://bit.ly/1oQ1fPU

to subscribe: http://bit.ly/1BjOkL7

All the presentations during the one-day Stanford Conference on March 19, 2014:

http://mecfs.stanford.edu/2014SymposiumVideo.html

Video 1:
Epidemiology of ME/CFS, What Have We Learned? - **Elizabeth R. Unger**, **MD**, **PhD**

Video 2:
Daily Fluctuations of Cytokines in ME/CFS Patients - **Jarred Younger**, **MD**
Gene Expression Findings in ME/CFS - **Amit Kaushal**, **MD**, **PhD**

Video 3:
Lunch and Learn "Media Portrayal of ME/CFS" - Moderator: **Phil Bronstein**
Panel: **Natalie Boulton**, **David Tuller**, **Erin Allday**

Video 4:
"Cardiovascular Aging in CFS" - **Mehdi Skhiri**, **MD**
MRI Findings in ME/CFS - **Michael Zeineh**, **MD**, **PhD**
EEG/LORETA Studies Suggest Cortical Pathology in ME/CFS - **Marcie Zinn**, **PhD**, **Mark Zinn**, **MM**

Video 5:
Approach to the Medical Care of a ME/CFS Patient: Medical Interview and Diagnostic Pitfalls - **Anthony L. Komaroff**, **MD**
Microbial Diagnostics and Discovery in ME/CFS - **W. Ian Lipkin**, **MD**
Closing Remarks - **Jose G. Montoya**, **MD**

15. Poem - The Invitation

It doesn't interest me what you do for a living.
I want to know what you ache for
and if you dare to dream of meeting your heart's longing.

It doesn't interest me how old you are.
I want to know if you will risk looking like a fool
for love
for your dream
for the adventure of being alive.

It doesn't interest me what planets are squaring your moon...
I want to know if you have touched the centre of your own sorrow
if you have been opened by life's betrayals
or have become shrivelled and closed
from fear of further pain.

I want to know if you can sit with pain
mine or your own
without moving to hide it
or fade it
or fix it.

I want to know if you can be with joy
mine or your own
if you can dance with wildness
and let the ecstasy fill you to the tips of your fingers and toes
without cautioning us
to be careful
to be realistic
to remember the limitations of being human.

It doesn't interest me if the story you are telling me
is true.
I want to know if you can
disappoint another
to be true to yourself.
If you can bear the accusation of betrayal
and not betray your own soul.
If you can be faithless
and therefore trustworthy.

I want to know if you can see Beauty
even when it is not pretty
every day.
And if you can source your own life from its presence.

I want to know if you can live with failure
yours and mine
and still stand at the edge of the lake
and shout to the silver of the full moon,
“Yes.”

It doesn’t interest me
to know where you live or how much money you have.
I want to know if you can get up
after the night of grief and despair
weary and bruised to the bone
and do what needs to be done
to feed the children.

It doesn’t interest me who you know
or how you came to be here.
I want to know if you will stand
in the centre of the fire
with me
and not shrink back.

It doesn’t interest me where or what or with whom
you have studied.
I want to know what sustains you
from the inside
when all else falls away.

I want to know if you can be alone
with yourself
and if you truly like the company you keep
in the empty moments.

Oriah Mountain Dreamer

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."