



ME



GLOBAL

Colofon / Personalia



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Textual contributions for the March issue need to be supplied in Word by April, 17th and sent to: contribute@let-me.be

The next issue will come out on April, 27th 2014.

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

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Picture front page: The international ME community logo, a global outlook (by Eddy Keuninckx – idea David Egan)

Cartoon page 32: Djanko

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Preface



Dear reader.

First of all we wish to thank you for the overwhelming number of responses we received from you, in which you have shown your support and appreciation in reaction to the second issue of this magazine. This is a great stimulus to continue our efforts to gather news and interesting facts.

At the same time we are signaling the need for factual cooperation. If this initiative is to survive, we will need at least one or two fixed co-workers who will take care of one or several recurrent topics in the magazine. The jobs entail, amongst others, gathering news from countries and making an inventory of all important events that will take place in the next few months.

If you know someone who might be fit and willing to do so, kindly refer him/her to us via contribute@let-me.be. This, then, was our cry for help.

A lot of important things happened this month, such as the Stanford-conference on the 19th and the IACFS/ME-conference in San Francisco from 20 until 23 March. Also, there was a hearing in the Danish parliament about **Karina Hansen**, who has been in psychiatric custody since 12 February 2013. We hope to publish significant impressions of all these events in the April-issue. Europeans may be looking forward to the IiME-conference in London on 30 May.

A special fundraising for children with ME, called Savings4Children, has been introduced. It was induced by pediatrician **Dr. Nigel Speight**'s visit to Germany. He flew there to see 14-year-old **Joanne** (see <http://let-me.be/request.php?3>, page 15, A new impending case of **Sophia Mirza**?). This fund will cover the expenses of **Dr. Speight**, which will enable him to make future visits in Western or Northern Europe whenever necessary, to which he kindly agreed. More on page: 13

A special thanks to **Rich Podell, Jeanette Burmeister, Simon McGrath, Anne Örtegren & Anja Olergård, David Egan** and **Russell Fleming** who actively participated by submitting self-written articles.

The next issue will be published around 27 April. News and articles are to be submitted before 12 April.

We do wish you a very beautiful and agreeable month,

The editors

Editorial

Dear Readers

In the third edition of this newsletter we would like to provide you with one thing which is vitally important to all ME and CFS patients worldwide and that one thing is **HOPE**. It's the Spring time of a new year, it's a time of new beginnings, new hopes, new dawns.

Despite many setbacks over the years, we have as a global community overcome great obstacles and made slow but steady progress. The recent scientific findings of **Dr. Lipkin** in New York and his continued work in this area including the new microbiome project, the continuing successes of **Dr. Light** in genetics, the ongoing deep scientific research of the Open Medicine Institute and the new Rituximab trials in Norway and Britain, the new findings of the National Centre for Neuroimmunology and Emerging Diseases in Australia point towards continued progress.

Thanks to the efforts of many such researchers and doctors over the years, we have biomarkers for the illness and for subgroups, some of which are listed here at <http://www.me-ireland.com/structure.htm#8> .

Even the IOM debacle has some positives in the sense that it united the ME and CFS community in opposition to the IOM contract while at the same time the IOM and HHS were informed about how ME and CFS have been misrepresented in numerous IOM reports in the past and the illnesses neglected by the USA government for over 20 years. Other factors involving an insulting name, stigma and prejudice against patients and misappropriation of federal research funds into CFS were also communicated to the IOM and HHS. It certainly provided an opportunity for us to express our grievances. And it put pressure on the IOM and HHS, and let them know that we will not be taken for granted and we will not accept false psychiatric definitions and treatments.

Problems and obstacles still exist. But problems provide us with an ideal opportunity to focus on issues, and to bring greater focus and clarity into our lives, and work together with others and collaborate with others on new more innovative, more multi-faceted, and deeper, insightful and more thorough solutions.

This impels us to work together in smarter, cleverer and more devious ways.

The lack of research funding is a major hurdle to overcome, the NIH has provided \$5 million or less to ME/CFS research for many years, and this is far too low. The same occurs in other countries. We must all as patients work with each other to increase government research funding into ME and CFS in our own countries. We must form a united front on this in our own countries and put aside our differences.

A listing of government research bodies has been kindly put together on the following web page by our Irish comrades at <http://www.me-ireland.com/research2.htm>.

We urge all patients to get together and contact these research bodies and government departments and ministers and start pumping more money into ME and CFS research. Some critical areas for research are included here at <http://www.me-ireland.com/prioritisation.htm>. These measures may include legal cases or court cases to assert our human rights.

We as patients also need to engage with our governments to get the Canadian criteria (2003) and International Consensus criteria (2011) accepted by our own governments and our medical authorities. This is vitally important. The bogus arguments of psychiatrists and psychologists and some nurses must be challenged continuously.

Many of the weaknesses and lies in their agendas have been exposed by **Dr. Malcolm Hooper** and by the ME Action UK (<http://www.meactionuk.org.uk/>) and other organisations (<http://www.me-ireland.com/bogus.htm>) .

As we work together in our countries and between countries on these issues, we will make progress and get justice. This will prevent others suffering the same injustices as **Sophia Mirza, Karina Hansen, Joanne** (Germany), and the many, many who died of the health complications of ME and CFS.

Dr. Enlander recently outlined a new training academy for ME and CFS, where doctors and medical students would be trained to treat ME and CFS patients. This is an excellent idea and we hope it succeeds. There are some ME and CFS clinics which have brought about significant improvements in patients. We need them all to work together and in collaboration with leading doctors, scientists, research trials, big pharma companies, and with patients and advocates to keep refining the diagnostics, treatments and translational medicine resulting from research to improve the medical outcomes for all patients and subgroups in these clinics. With the ultimate aim of building ME clinics around the world using these methodologies, expertise and technologies.

THE POWER IS IN OUR HANDS. LET US ALL UNITE TOGETHER AND WORK TOGETHER TO GET JUSTICE FOR US ALL.

David Egan

WHAT ARE YOU DOING ON 12 MAY?

*mail it to us, and we will let everybody know in the
April-issue of the ME Global Magazine*

[*contribute@let-me.be*](mailto:contribute@let-me.be)

Rich' Reviews: SAME

An effective natural anti-depressant with relatively few side effects: S-Adenosyl Methionine (SAME).



Patients with chronic illness of any kind are vulnerable to depression. Unfortunately, standard anti-depressant medicines don't work for everyone. Side effects can also cause problems, especially for people with CFS-ME—who are especially side effect prone.

S-Adenosyl Methionine (SAME) is a natural product with more than a dozen double blind studies showing benefit for depression. Yet very few physicians in the U.S. know much about it—psychiatrists included. Of course, SAME can't be patented, so there's little commercial incentive to fund physician education. But, it's also a concern that many of SAME's double blind studies have not been of high quality.

Rigorously evaluating SAME's effectiveness is important, because, anecdotally, SAME seems to be effective, seems to interact safely with standard antidepressants, and is definitely less likely than SSRI's to cause sexual dysfunction.

The psychiatry department of the **Massachusetts General Hospital** has now published a double blind study that fairly well proves that SAME really works.

The MGH team enrolled 73 patients with had not improved despite treatment with a Serotonin Reuptake Inhibitor. The investigators continued SSRI treatment but added either SAME (800 mg bid) or placebo for six weeks of treatment.

Using the Hamilton D depression scale, 46 % of patients on SAME improved compared to only 30% with placebo. ($P < .05$) Full remission (HAM- D score < 7) occurred among 35.8% of SAME patients versus only 11.7% of those on placebo. ($P = .03$).

(Bizarrely, the Abstract of the published article mistakenly understates the benefit of SAME. This was corrected later. The actual data in the article is as I stated here.)

Bottom Line:

SAME was much better than placebo for this difficult patient population. The SAME product tested at MGH was from NatureMade, a prominent brand of natural products.

My personal clinical perspective:

Case reports indicate that SAME can trigger a manic phase in persons vulnerable to bipolar disorder—as can most other anti-depressants. SAME can

cause transient initial anxiety, nausea, diarrhea as can SSRI's. But SAmE does not cause sexual dysfunction. There have been no reports of adverse interactions with SSRI's or reports of hyperserotonin syndrome. Increased homocysteine usually does not occur—a theoretical possibility as Methionine is the precursor of homocysteine.

I recommend starting CFS-ME patients at the lowest available dose, 200 mg, to minimize side-effects. As you know CFS-ME patients tend to be very sensitive to side effects.. Increase the dose in increments of 200 or 400 mg as tolerated (usually every 4 to 8 days). Very often we see improvement after 3 or 4 weeks on 800 mg daily or 400 mg bid. However, others require 800 mg bid, as was used at Mass. General.

Please note: SAmE is one of the body's main methyl group donors. SAmE helps the elongation of carbon chains as in the synthesis of serotonin, norepinephrine, dopamine and other compounds. Folic acid, vitamin B12 and B6 are required. (I usually add a B-complex supplement).

Because SAmE plays a key role at many points of metabolism body's it would not be surprising if SAmE might be helpful in other conditions . For example, there is substantial evidence suggesting benefit from SAmE for osteoarthritis.

Key article:

Papakostas et. Al, S-Adenosyl Methionine(SAmE) Augmentation of Serotonin Reuptake Inhibitors for Antidepressant Nonresponders With Major depressive

Disorder: A Double-Blind, Randomized Clinical Trial, Am J Psych 2010;167:942-948.

Correction of Error, Fleisch, S, Travis, M, Ryan, N, Discrepancy in Response and Remission Rates for SAmE treated Patients in a Double-blind Randomized Clinical Trial, Am J Psychiatry 167:12, December 2010.

Papakostas, G, Reply to Fleisch et al. Letter., Am J Psychiatry 167:12, December 2010.

Richard Podell, M.D., MPH, Summit, NJ
www.DrPodell.org

Creating together



As has been stated from the outset, this magazine is not only meant to inform its readers about things worth knowing about ME/CFS and current events surrounding the disease, since many of the readers are far better informed than the editors.

The main and vital goal is to create something in which virtually everybody can participate, as long as respect and openness to other's opinions are shown.

Therefore it is important that patient organizations who receive this magazine show their support by giving it some attention on their fb-wall, website, twitter account and on other social media. We do not request this from you for our own welfare; we do not profit from it.

As this is a joined effort, we would like to ask those who are reading this if they are willing to design a new cover for this magazine.

The present one was designed in a hurry. The January-issue had to be assembled, laid out and published within less than two weeks.

If you have a marvelous idea, or just an idea, or an idea which might become marvelous, please mail it to contribute@let-me.be, taking into account that the size of the picture you send should be (1000 x 1000 pixels) square and its resolution about 100 dpi.

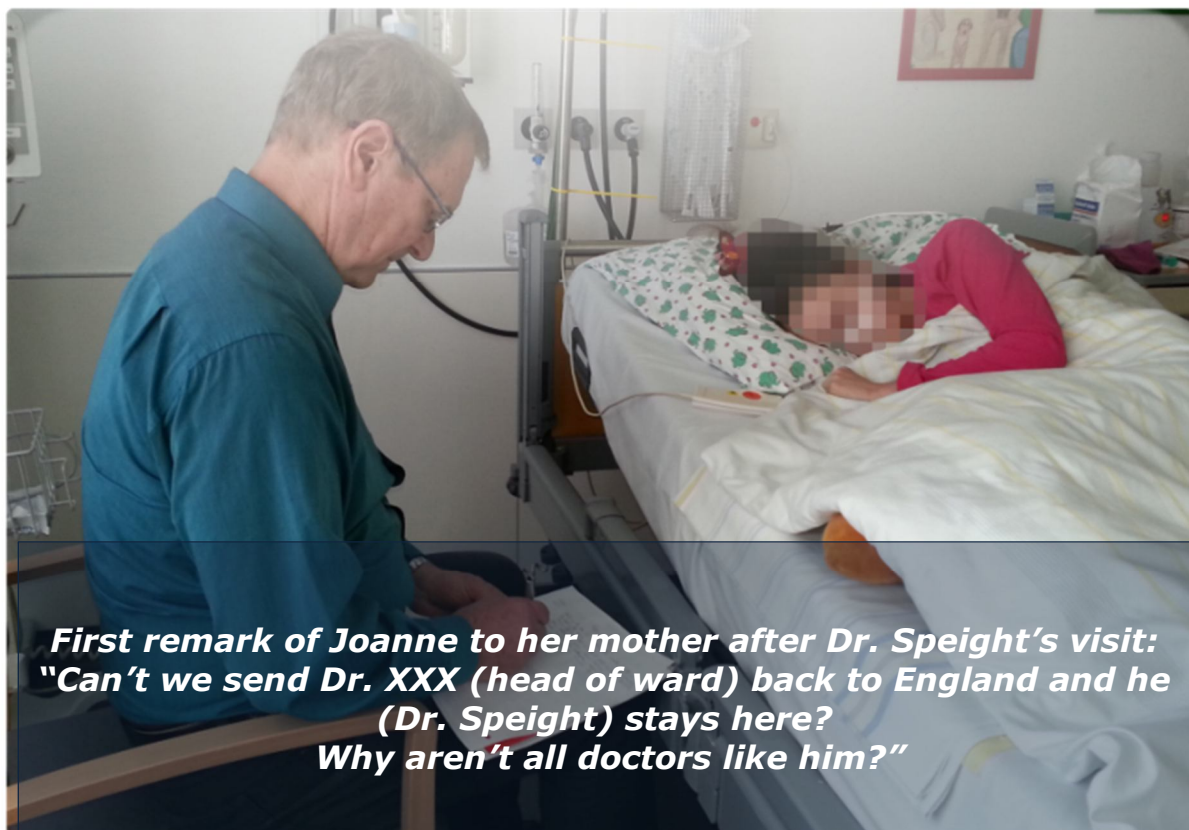
Nigel Speight Visiting Joanne Yet Mother Lost Custody



Unfortunately, we have to give a very depressing update of **Joanne's** case:

- ✚ even though **Nigel Speight** visited **Joanne**, talked to her doctors, nurses, a social worker and her father,
- ✚ even though the court and the professionals received his general letter, signed by more than 20 international experts,
- ✚ even though **Nigel Speight** wrote a second long letter to the court with detailed information on ME/CFS and several case reports very similar to **Joanne's** case,
- ✚ even though he submitted a 13 page medical report to the court
- ✚ the judge decided against **Joanne** and her mother: sole custody is now given to **Joanne's** father who is in the cahoots with the doctors and the child protective services.

The judge ignored **Joanne's** clearly expressed wish that her father should stop visiting her and that she would not want to live with him and that she wants to have her mother back at her bedside.



When asked by **Nigel Speight** who her five favorite people were she immediately named her mother and her (maternal) grandparents. She chose not to mention her father at all. **Joanne** has long stopped to talk to her father when he visited her (which he did not do very often) to show him her dislike. **Joanne** is well aware that it is her father who together with the doctors instigated the court proceedings against her mother who is now only allowed to see her daughter for 30 min a day.

This case is in every aspect absolutely perverse:

- ✚ **Joanne** and her mother have been grossly neglected and abandoned by the health care system. Yet it is the mother who is now accused of having neglected her child, of having put her life at risk and of even having caused the disease – by witchcraft, most probably. If at all, it is the “treatment” regime in the hospital which puts **Joanne’s** life at risk. Yet it is the mother who is accused of putting her daughter’s life at risk by “negatively reinforcing” her and by talking into her negative thoughts that would prevent the “treatment” to be effective.
- ✚ It is the mother who is accused of making her child ill by some as yet undefined ominous “psychodynamics” and of being mentally ill. Yet it are the professionals who obviously fall victim of “psychodynamics” by not being able to recognize the reality of the disease, the detrimental effects of their GET/CBT “treatment” and to cope with their feelings of helplessness towards a severe disease that defies any use of force. It’s the psychodynamics on their side that they seem to believe that creating a scapegoat (mother) would help solving the problems and make the child “healthy” again.
- ✚ The doctors clearly conceded that they had never before treated a case of ME/CFS let alone of severe ME/CFS, yet they dismiss the expert’s advice as “warfare. They declare their treatment regime as evidence based (on the NICE guidelines) and ignore the fact that, according to these very guidelines, for this group of patients CBT and GET are not only inappropriate but potentially harmful.
- ✚ The professionals accuse the mother of preventing her daughter’s age related autonomy. Yet it are the doctors, the social workers and now the court decision that grossly disrespect **Joanne’s** autonomous wishes 24/7. The doctors have not gained informed consent of **Joanne** for their treatment regime. On the contrary: when **Joanne** tells the truth about her symptoms and condition she is accused of telling lies (talked into her head by her mother). When **Joanne** says that the “activation” regime, the sensory overload with sound and light make her worse by the day the pressure on her is even increased. According to the girl’s own report, the nurses even yell at her when she complains about her symptoms. So who is undermining **Joanne’s** autonomy? Who tries to break **Joanne’s** will? Who abuses a totally dependent young girl, whose legs are paralysed, who is unable to feed herself, to sit unaided, to keep her head upright unaided, to turn herself around in bed? Is it indeed the mother?

✚ It is the mother who is accused of brainwashing her child into the illness (by Munchhausen by proxy, by a symbiotic relationship or some kind of ominous psychiatric illness), yet it are the professionals, doctors, nurses, social workers and father who brainwash and traumatize her day by day by not believing her, by claiming that she would only pretend her symptoms and that she could do much more than she does. There are almost 100 short videos in which the girl describes the abuse by doctors, nurses, therapists and weeps bitterly about what is done to her. These videos are heartbreaking and an unequivocal proof of the girl's authentic (and not brainwashed) description of her "treatment", the hostile and outright sadistic behavior of some professionals, the complete disbelief and mockery she has to endure day by day. Again and again she says: "Mummi, I can't go on any longer without you, I feel so bad, I can't go on any longer, you have to come back to me and save me and help me, I can't go on any longer. Please help me!" Or: „When will you get me out of here? They are going to kill me here!"

✚ The girl's human rights are clearly infringed by forcibly severing her relationship to mother and grandparents and thus making her "an emotional orphan". The fact that nobody asked for **Joanne's** informed consent to her "treatment" (CBT/GET are definitely not life-saving measures and therefore need to be agreed upon by a patient who is clearly competent) and that her wishes and statements are overridden systematically might be considered as a severe breach of medical ethics.

There's a slight hope in appealing the court decision. Perhaps the next judge/court hearing will consider **Nigel Speight's** report and letters as well as the biomedical evidence on the detrimental effect of the GET/CBT treatment in severe cases like **Joanne's**.

Should

- a) mother not be given back her parental rights and
- b) should the "treatment" in the hospital go on "until she is healthy again" (as the doctors stated) **the teenager's life is clearly at risk.**

You may help **Joanne** with donating for **Nigel Speight's** trip(s) to **Germany** and for the lawyer's fees. **Joanne's** mother and grandparents are close to bankruptcy and will most probably no longer be able to pay the lawyer pretty soon. Your donation will help to try saving **Joanne's** life, and to save the lives of children who will come to have to live under similar circumstances in the future.



A general fundraising has been set up for this case and future cases in which the intervention of **dr. Speight** might be of influence.

All information at page 13 of this issue of the ME Global Chronicle.

Let's Do This Ourselves

SAVE4CHILDREN



As we reported in the first issue of the ME Global Chronicle (<http://let-me.be/request.php?3>, p.15, A new impending case of **Sophia Mirza**), the 14-year-old German girl **Joanne** has been forcibly enclosed in a neuro-pediatric ward.

In this issue you will read about **Dr. Nigel Speight's** visit to **Joanne** after the mediation of some involved German ME-patients. He also talked to her mother, father, doctors etc., after which he wrote a report and a letter to the judge.

We do not yet know what implications **Dr. Speight's** intervention will have. However, it is quite certain that his visit to Germany has been worthwhile, it makes it more difficult for the authorities involved to have their own way.

Moreover, the case is now being brought under your attention, and you are living all over the world.

We were asked to make an appeal on you to raise money for **Dr. Speight's** travel and stay and the expenses of **Joanne's** mother for a lawyer. However, we came up with a more durable plan, which should also cover future incidents that are similar to **Joanne's** and **Karina Hansen's** case in Denmark.

When asked if he would intervene again, if a similar request came from another Western- or Northern European country, **Dr. Speight** answered in the affirmative.

That is why we decided to open an account to cover expenses of this sort. Costs are still being made for **Joanne's** case, and similar cases will definitely occur in the nearby future as well – we already received a heart-renting appeal for **Dr. Speight** from **Sweden** as a reaction to an interview with **Dr. Speight** (<http://youtu.be/XcRZo1vO53c>).

This project has been named **SAVE4CHILDREN**. It will be an ongoing project; it will not be discontinued until children with ME are no longer taken away from their parent(s) and locked up in psychiatric wards.

Each cent you donate to this fund will go straight to the expenses made by **Dr. Speight** and the indispensable lawyer that parents faced with such a horrendous situation are forced to bring in.

You can transfer your donation to:

IBAN: NL85 INGB 0004 286957 - **BIC-code (SWIFT):** INGBNL2A
ME/cvs Vereniging
Den Bosch

The Netherlands **Please mention: Save4Children**

Fight over Diagnosis Leads to Hearing



Who decides if the cause of an illness is physical or psychological? Should psychiatrists have the right to incarcerate patients and force psychological treatment if they disagree with a physical diagnosis?

A dispute over the cause and treatment of a young woman's illness led to her being forcibly removed from her parent's care on Feb. 12, 2013.

The psychiatrists responsible for this claim she has a mental illness (somatoform illness), while her doctors and parents insist she has a physical neurological illness called ME.

The Danish woman, **Karina Hansen**, is still hospitalized against her will and forced to receive treatments that have been proven to hurt ME patients.



Reporting of Harms Associated with Graded Exercise Therapy and Cognitive Behavioural Therapy in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome:
<http://bit.ly/1gttHhj>

Karina's sister reports that **Karina** is much worse than before she was hospitalized. You can read **Karina's** story here:
<http://www.prohealth.com/library/showArticle.cfm?libid=18739&site=articles>

This heated conflict has now been discussed at an official hearing at the Danish parliament on March 19th in Copenhagen.

<http://bit.ly/1gEGlpb>

The psychiatrists in charge of **Karina** work at The Research Clinic for Functional Disorders and Psychosomatics in Aarhus, Denmark.

<http://funktionellelidelser.dk/en/about-the-clinic/>

This clinic has created so much patient dissatisfaction that 16 patient associations requested that the clinic be investigated. A hearing has now been called and **Karina's** lawyer is scheduled to make a presentation about her case.

Other speakers include doctors who are specialists in conditions this clinic treats with purely psychological methods. These conditions include whiplash, fibromyalgia, IBS, PMS, Chronic Pelvic Pain, etc.

A Danish Justina Pelletier?

Karina Hansen's story has many parallels to the story of American teenager **Justina Pelletier**.

Both girls were forcibly hospitalized in February last year and both sets of parents were accused of mistreating their daughter by following medical advice from experts in the girls' respective diseases.



Justina has mitochondrial disease. In both cases, the psychiatrists in charge refused to agree to a second opinion. And in both cases, the human rights of the patient and the parents have been completely ignored.

Justina's story will have been told on the **Dr. Phil show** on March 17th. <http://exm.nr/OnHY9B>

Karina's case will have been discussed at the open hearing in the Danish parliament on March 19th. The hearing was to be streamed live and later posted on Youtube.

The hearing was in Danish, but an English language statement about the hearing was to be released within a week from this source.

Rebecca Hansen

ME Association, Denmark

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The Strange Case of NIH and an Elusive Disease



The federal government has a mostly open dialogue with those it serves and those who serve it. This happens pretty well across government agencies, from the Pentagon to the Department of Transportation to the Department of Agriculture.

So it is troubling that the National Institutes of Health, an arm of the Department of Health and Human Services, appears to have no communication with a critical but ignored patient cohort: those suffering from Myalgic Encephalomyelitis, also known as Chronic Fatigue Syndrome, and often referred to only as ME/CFS. NIH does not appear to hear the cries of the petitioners at its door; it seems to be interested only in classifying and defining the disease.

According to the Centers for Disease Control, ME/CFS afflicts 1 million people in the United States, and 17 million people around the world. While those numbers of victims are disputed, their suffering is not; they are ill in a terrible way.

ME/CFS takes healthy -- often athletic -- people and casts them into a shadow world of physical incapacity, mental fog, loneliness and relentless dependence on others. The suffering is measured in years and decades. Suicide is common.

It is a disease of the immune system, but what triggers it is unknown. Physicians who treat ME/CFS have told me that they would rather have cancer than this disease. One epidemiologist said, "**With cancer, you are cured or you die. ME/CFS just goes on and on. You live the life of a zombie.**"

From a physician devoted to treating and researching ME/CFS, this is not only a terrible admission, but also a de facto indictment of the national effort to find a cure, or even a therapy, for alleviating the suffering.

One of the problems affecting ME/CFS treatment is diagnosis. There are no biological labels, known as markers, that enable doctors to easily identify ME/CFS; it cannot be picked up in a blood tests or a urine sample. It is a ghostly manifestation, and doctors fall back on what is known as wastebasket diagnosis. In its simplest form, this means testing for a lot of diseases and if it does not turn out to be one of them, it could be ME/CFS.

But one case definition has satisfied the ME/CFS community in recent years, and it is endorsed by specialists in the field. Established in 2001, it is called the **Canadian Consensus Criteria**.

Yet, incomprehensibly, the NIH is spending some of the paltry \$6 million devoted to ME/CFS, on a study to come up with a new case definition for the disease; something that no one wants and which could do real harm.

To do this work, the NIH selected the Institute of Medicine (IOM), which has no expertise in ME/CFS and which had drawn opprobrium with its clumsy attempt to do a case definition of Gulf War Syndrome.

The NIH, which has failed to explain itself in plain English, has ignited incandescent rage in the patient community and from patient advocates. In a unique outpouring of objection, 50 of the world's top doctors and clinicians wrote to Secretary of Health and Human Services Kathleen Sibelius, pleading with her not to muddy the waters and to stay with the definition which is working well. The NIH went ahead with the IOM contract.

So lacking is government support, moral as well as financial, that the research community, including dedicated physicians such as **Andreas Kogelnik** of Mountain View, Calif., **Daniel Peterson** of Incline Village, Nev., and **Derek Enlander** of New York City, feel they have to raise funds privately to continue their work. Even celebrity virus hunter **Ian Lipkin** of Columbia University has abandoned hope of getting his seminal work funded by the NIH and has joined the researchers who have had to hold out begging bowls to the public to do their research.

Judging by social media, the entire patient community is in a state of metaphorical war with the NIH.

There is a cry from and on behalf of the pitiable sick for action, sympathy and even courtesy from the bureaucrats in Bethesda, where the NIH is headquartered. **The Hippocratic Oath says, "first do no harm"**. When people are in pain and despair, inaction is palpable harm.

A congressional hearing is needed to investigate decision-making in the NIH, find out about its budget request to the Office of Management and Budget, and to demand that it listen to those who suffer and those who are trying to help them.

Llewellyn King is executive producer and host of "**White House Chronicle**" on PBS. He is the creator and co-host of ME/CFS Alert on YouTube. His e-mail is lking@kingpublishing.com.

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Web Site: <http://whchronicle.com>



CFSAC Meeting December 2013: Webinar from Hell

Jeannette Burmeister

There is no way to sugar coat this. The December 2013 CFSAC webinar was a colossal middle-finger salute to the patient community. The sheer number of glitches, the unmistakable indifference exhibited by CFSAC's Designated Federal Officer (DFO), **Dr. Nancy Lee**, to the many patient concerns raised in advance and during the meeting, and the mind-boggling degree of incompetence in running and mishandling the meeting outraged the community.

One of the most objectionable parts of the meeting was the DFO making a strong point to accuse some advocates of "much vitriol and personal attacks in emails and in blogs around the IOM study." She talked about some unnamed advocates apologizing for "the vitriolic behavior of another advocate" whom she also didn't name.

Maybe the most appalling statement the DFO made was to call for the advocacy community to "call out and reel in," in the future, those advocates whose comments and opinions she doesn't approve of.

Ms. Eileen Holderman, the patient advocate on CFSAC, who has reported having been threatened (together with two other CFSAC members) by the DFO, swiftly called out the DFO for indicting the advocacy community with her comments. **Dr. Marshall**, CFSAC's Chair, tried to shut **Ms. Holderman** down citing time constraints, but **Ms. Holderman** insisted that she "could not let [the DFO's statement] stand" and the Chair relented by giving her one minute.

Ms. Holderman pointed out that most, if not all, of the discourse around the IOM "study" had been civil and constructive and called the DFO's accusation unfair.

Being one of the advocates who has been very vocal about the IOM "study," I can firmly say that I stand by everything I wrote. I can also say with certainty that I have not seen any vitriolic behavior on the part of other advocates nor have I seen personal attacks on anybody.

In fact, the patient community, even those of its members who don't agree on many issues, seems to be pretty much in agreement that advocates have behaved nothing but professionally.

I don't know if it's more amusing or disturbing to see government officials whining when their position, competence, expertise, action or anything else related to their official capacity is criticized, especially in a field where patients have been harmed by government agencies for decades, as pointed out by **Ms. Holderman**.

It's bad enough that the government is not listening to, but, in fact, is harming, patients—the latest and maybe the worst example being the shoving down our throats of the IOM “study”—but it's adding insult to injury to be accused of being vitriolic just as a result of appropriately expressing criticism.

Not that the ad-hominem-attack charge is a new tactic at all. HHS took a page out of **Simon Wessely's** playbook of unsubstantiated death-threat accusations.

Should there be any doubt, advocacy is politics and politics, if it's to be effective, is not always pretty. Imagine a U.S. president whining about attacks from the other side of the aisle. A pretty ridiculous thought, no?

ME patients are fighting for their lives. The kid gloves came off a long time ago, maybe when the CDC misappropriated funds for our disease in the 1990s? It's unfortunate that a member of the administration would feel the need to use the power of her position and the platform it bestows—CFSAC meetings she tightly controls—to call people out who are availing themselves of their **First Amendment rights**, whether it's due to being overly sensitive or using a tactical ploy.

This should be obvious, but since it's apparently not, let's be very clear. If you are a government official and your work is being criticized, even if harshly (with very few exceptions, such as comparisons to Nazi Germany), that is not an inappropriate or personal attack.

Everything that has to do with official government business—as opposed to the private life, the appearance, the personal choices, such as religion, etc. of government employees—is most definitely fair game. The DFO's comments at the meeting in that regard were quite frankly contemptible and reprehensible and one can only hope that they were not blessed by her superiors.

But they were not off-the-cuff statements. Rather, they were clearly prepared well in advance, as the DFO was anxious to read them at the end of the session. Trying to split the patient community by inciting attacks on inconvenient advocates is inexcusable and pretty much as low as it gets.

By the way, I don't know this for sure, but I have a feeling that those inconvenient advocates might be even more resolved in their will to continue fighting the good fight as a result of the DFO's shameful comments.

If they were easily intimidated, they probably wouldn't have taken a strong stance on the IOM issue in the first place.

Like I said, just a hunch. So, it remains to be seen if this attempt by HHS to quiet some advocates will be successful and if other advocates will be complicit in it.

For the full article:

<http://thoughtsaboutme.com/2014/03/11/cfsac-meeting-december-2013-webinar-from-hell/>

ME & CFS Mortality Study



DePaul University's Center for Community Research is currently recruiting respondents for a study on myalgic encephalomyelitis (ME) and chronic fatigue syndrome (CFS) mortality.

They are looking to recruit surviving family members, friends, and/or caregivers of individuals who had been diagnosed with ME or CFS and are now deceased. Principal investigator is **Abby Brown, M.A.**

Their intention is to document the experience of these deceased individuals, and the experience of their family and friends, to improve our knowledge of ME and CFS and to help those individuals who are currently suffering from the illness.

There has been almost no research done on ME and CFS mortality in the U.S. or internationally since it is not generally recognized that people die as a direct result of having ME or CFS.

We believe the information we will obtain in this study has the potential to change the perception of this disease from "just being tired" or at worst not too serious to the reality of its life-altering disability for those who suffer from it.



The medical community and relevant government agencies need to be informed of the frequency and circumstances of deaths resulting from having ME and CFS. The purpose of this study is to document the severity and consequences of ME and CFS.

It will run until **9 October 2014**.

The study will have two phases: phase 1 will involve a confidential online study. At the end of **phase 1**, participants can choose to identify themselves and volunteer for **phase 2** which will consist of an in-person or phone interview.

If you meet the criteria for the study (knew someone well who was diagnosed with ME or CFS and is now deceased, and you are at least 18 years old), please use this link to access the study:

<https://redcap.is.depaul.edu/surveys/?s=DHxuYxScEn>

Contact by telephone at 773-325-1164 or by email at DePaulMECFSResearch@gmail.com with any questions you may have or to receive a copy of the questionnaire by postal mail.

Everybody is requested to forward the flyer below to as many as possible.

ME and CFS Mortality Study

RESEARCH PARTICIPANTS NEEDED

Were you familiar with someone who had been diagnosed with myalgic encephalomyelitis (ME) or chronic fatigue syndrome (CFS) and has since passed away?

Researchers at DePaul University are looking to investigate issues related to ME and CFS mortality by hearing directly from surviving family members, friends, and/or caregivers of individuals who had ME or CFS and are now deceased.

Participation in this study is voluntary. We understand that this is a sensitive topic and that it might be emotionally difficult for some individuals to participate.

However, we believe the information we will obtain from this study has the potential to lead to a better understanding of ME and CFS mortality.

The medical community and relevant government agencies need to be informed of the frequency and circumstances of deaths resulting from or associated with having ME or CFS. The purpose of this study is to document the severity and consequences of ME and CFS.

If you know someone who passed away after being sick with ME or CFS, please participate in this important survey. If you can distribute this request for study participants to all whom you know in the ME and CFS communities, please do so.

This research can help to make the disease(s) of ME and CFS less invisible for patients and their loved ones.

Participants will be asked to complete a confidential online survey and will be given the opportunity to volunteer for an additional in-person or phone interview. The online survey portion is expected to take up to 1 hour of a participant's time. Participants must be at least 18 years old.

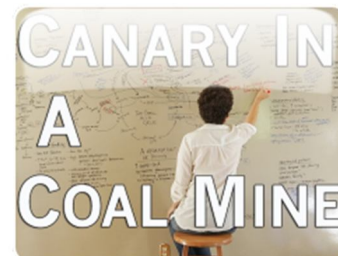
DePaul University has published many studies of ME and CFS and is a well respected source of information about the disease.

If you are interested in participating, please use this link to access the survey: <https://redcap.is.depaul.edu/surveys/?s=DHxuYxScEn>

You can contact **Abby Brown** at 773-325-1164 or at DePaulMECFSResearch@gmail.com with any questions.

DePaul University, Center for Community Research
990 West Fullerton Avenue, Suite 3100
Chicago, IL 60614

Canary in a Coalmine



Project Update:

Announcing **Thrive Show**,

A Google Hangout series about living well with chronic illness.



I'm thrilled to announce a new project from my bed. It's called **Thrive Show**, and it's a Google Hangout series about living well with chronic illness. If you'd like to help support this new endeavor, please take a minute to like us on Facebook or Google Plus, follow us on Twitter, or share this information with a friend or loved one living with a chronic illness.

Follow us at:

<http://j.mp/thriveshow>

<http://fb.com/thriveshow>

http://twitter.com/thrive_show

<http://thriveshow.org/>

One in five Americans now lives with a chronic illness, rates of autoimmune illness have quadrupled in the last fifty years, and neuroimmune diseases are striking more people at younger ages. While the endpoints of this process may be different – Myalgic Encephalomyelitis for one person, Parkinson's for another – a common set of causes may be increasing our risk.

This project is about breaking down boundaries between disease spaces and increasing the scope of what patients might learn from one another. It may be difficult to ever know or prove with certainty the contribution of our altered food supply, microbial environment, or chemical exposure to this silent epidemic.

What is becoming increasingly clear, however, is that while our diseases are diagnosed with biomarkers that tell us how we are different, many of the underlying mechanisms that contribute to disease are the same.

So too are some of the questions we face: How and whether to become parents? How to love and accept a new body? How to become better advocates for ourselves? How to explain to others an illness that may be difficult to see or understand?

Thank you for joining me on this new journey and check out our amazing lineup of guests, below.

Warmly,

Jen



Eva Hagberg: "It's All in Your Head"

Join us on **Thursday, March 27th at 3pm ET** for our first live Google Hangout: an interactive conversation with **Eva Hagberg**, author of the bestselling Kindle Single, *It's All in Your Head*.

For five years, **Eva** struggled to find a doctor who would take her symptoms seriously. They told her she was stressed, depressed, or struggling with an unresolved trauma. In fact, she had two masses in her brain and a rare heart condition, Wolff-Parkinson-White.

We'll talk to **Eva** about writing about illness, gender & medical care, misdiagnosis, and how living with these conditions has helped her learn how to live a fuller life.

You can read more about **Eva** here:

<http://www.thriveshow.org/eva-hagberg/>

And RSVP at her Google Plus event page here:

<http://bit.ly/NUBvIH>

Upcoming shows:

<http://www.thriveshow.org/tag/upcoming-shows/>

- ✚ Join us on **Wednesday, April 2nd at 2pm ET** for an interactive conversation with **Donna Jackson Nakazawa**, author of *The Autoimmune Epidemic* and *The Last Best Cure*.

- ✚ Join us on **Tuesday, April 22nd at 3pm ET** for an interactive conversation with **Emily Deans, M.D.**, an Instructor in psychiatry at Harvard Medical School. She's on the hunt for evolutionary solutions to the general and mental health problems of the 21st century. She blogs at *Evolutionary Psychiatry*.

- ✚ Join us on **Wednesday, May 1st ET at 2PM** ET for an interactive conversation with **Toni Bernhard**, author of *How to Be Sick* and *How to Wake Up*.



<http://www.canaryinacoalminefilm.com/>

Wind Up Clock

I am one out of 1 million Americans waiting for decades in a medical “no man’s land” for solutions to a debilitating disease with no known cause, NO approved treatment and none in the pipeline. We have no designated specialists, and no cure in sight.



We feel abandoned by our government who funds research on our disease at a rate less than that of male pattern baldness, we feel failed by the researchers and drug companies who can’t seem to make progress fast enough, and we feel ostracized by the medical profession who throws us around like hot potatoes hoping someone else will handle us.

If we are fortunate we have a support system and receive disability, but many struggle alone with no finances and no one to help them, some of whom are completely bedbound. We are so determined to return to the healthy active lives we once knew that some of us will try whatever we can to get well.

When I was in graduate school my professor of Auditory Neuroscience and Psychoacoustics lectured us about sound pressure. In teaching us the mathematical equation for sound traveling through the acoustic system, he made sure we understood that if one looked at only the first part of the equation it would appear that an acoustic signal actually gained energy as it passed through the middle ear.

However, this increase only compensates for the loss of energy that eventually occurs when the sound enters the fluid filled inner ear. The net amount is actually a slight loss in energy, and if you see the entire equation this is clear. In order to make this point he taught us,

“There ain’t no such thing as a free lunch” (TANSTAAFL),

meaning that even if something seems like it is free, there is always a cost, no matter how indirect or hidden.

While I didn’t retain much of my hearing science knowledge, I remembered TANSTAAFL, and ME/CFS reminds me of this every single day. It’s as though I am an old fashioned wind up clock ticking along and then running down. As I run out of energy my tick tock sound gets slower and slower.

I sit on the table for various intervals, until someone randomly walks by, sees me and decides to rewind my mechanism. I may be mid-way between fully wound and fully spent; sometimes they rewind me all the way, and other times just a few rotations.

I never know how much energy I really have. I just keep tick-tock-ing at whatever level I am capable given the amount of energy at any one time.

I worry. I worry that if I stop ticking I'll suffer a slow, progression of this awful disease that forces me to stop moving. It's not because I want to stop moving, or because I'd rather sit around than be active. Nothing could be farther from true.

But every time I feel well enough to move, and I get out there and do the things I love, at a much reduced level than before the disease I am left feeling a relapse of symptoms for days, weeks or months. This is not motivational, but fortunately I was an athlete before becoming sick, and I am a determined person.

I do all the good things I can to stay in control of my symptoms as best I can. I avoid foods and drinks that my body doesn't tolerate, and I take only the few medicines and supplements I really need. I insure ample good quality sleep, drink plenty of water, get regular massage, meditate, walk, do yoga, advocate, and I paint.

Although this practice gets me close to maintaining some sort of balance between staying somewhat active and being too sick to move, unfortunately none of this is enough to create what could even loosely resemble a full life.

I am unable to work, unable to travel without relapsing, unable to participate in sports at a level I would like, and socializing is minimized. So, to quote a famous movie, "I'm not dead yet", but I'm not really living either.

I'm occupying no man's land with the rest of my fellow patients, and none of us wants to be here.



Claudia Goodell

<http://www.occupycfs.com/2014/02/24/guest-post-wind-up-clock/>

The ME and CFS Documentary Project



Project Update:

THE BLUE RIBBON is a film exposing the hidden story of ME/CFS. It features interviews with top researchers, doctors, and activists.

Trailer <http://youtu.be/G-O5ZAuvOcQ>

We plan to travel through 10 cities across North America interviewing activists, patients, researchers, and doctors. We'll produce a feature-length film documentary for release on Netflix, Hulu, iTunes, and Amazon Video on Demand.

Yet even more than that, we plan to equip people in towns and cities across the world to stage screenings of the film in movie theaters, schools, hospitals, churches, and community organizations. It's a tragic fact of this illness that most patients are far too ill to protest in the streets in order to get society to hear our voices.

However, we can tell this story through a documentary film, widely distributed through grassroots organizing. We can tell the story, together, and help build bridges between communities of faith, politics, science, and the arts. True change will happen person by person, one community at a time.

The Blue Ribbon Northeast Tour

Barnstorming Massachusetts and New York

The journey began at Hartsfield-Jackson International Airport on February 19th in Atlanta, GA. The first day of filming began near Amherst, Massachusetts with novelist **Roger King**. **King** is a former world-roving economist who was commissioned by various UN agencies to advise on agricultural output in developing nations.

After accepting a post in the early 1990s as a university professor in Spokane, Washington, he experienced a collapse while exercising and was soon diagnosed with "ME disease."

In 2012, he published *Love and Fatigue in America*, a novel which explores his two-decade struggle with the disease. A frequent sufferer of tropical diseases in his former adventurous life, he described ME/CFS as akin to "having malaria for 20 years."

Next stop was to film **Hillary Johnson**. In the mid-1980s, journalist **Hillary Johnson** was an in-demand magazine writer filing stories with such storied publications as *Rolling Stone*, *Vanity Fair*, *Life*, and the *Wall Street Journal*.

But something profoundly new happened when she published a story in Rolling Stone on a strange new disease that would soon become known as "chronic fatigue syndrome." **Johnson** recalled receiving shopping bags full of reader mail, telling the most devastating of stories.

She soon embarked on a nearly decade-long pursuit of the deeper story behind the new disease, investigating the CDC and NIH. Her book *Osler's Web* is the classic work on ME/CFS, and notable for uncovering a scandal in which the CDC misappropriated millions of dollars earmarked for vitally needed CFS research.



Derek Enlander, MD is a respected Manhattan doctor treating a cohort of 3,000 ME/CFS and fibromyalgia patients, one of the largest practices in the world devoted to this disease.

He was recently the recipient of a **\$1 million grant** to establish the ME/CFS Center at nearby Mt. Sinai Hospital.

Combining research as diverse as genomics, immunology, and exercise physiology, the Center is the first of its kind at a major teaching hospital

anywhere in the world.

Enlander is also founder of the new Academy of ME/CFS Physicians, an organization that plans to help train a new generation of ME/CFS experts.

To be continued...

WHAT ARE YOU DOING ON 12 MAY?

*mail it to us, and we will let everybody know in the
April-issue of the ME Global Magazine*

contribute@let-me.be

Standing Up for Patients: An Interview with Dr. Derek Enlander



Gabby Klein considers the efforts **Dr. Enlander** has gone to to ensure that the reality of ME/CFS is presented to the world at large, and gives us an insight into his opinions on some current issues, including an update on the formation of an academy for ME and CFS physicians, announced recently at the Institute of Medicine (IOM) meeting during his presentation...

You can read the complete Phoenix Rising article [HERE](http://bit.ly/1ncwzIY): <http://bit.ly/1ncwzIY>

What follows are selected extracts from the actual interview:

*You were one of the 50 experts who signed the open letter to **Secretary Sebelius** urging her to cancel the contract with the IOM and to adopt the CCC (Canadian Consensus Criteria) now.*

Why did this group feel the need to take such a strong stand against an HHS action?: "This group of experts considered it important to make a comment regarding whether we need to restate the criteria of ME or CFS. In hindsight, the letter seems if anything even more prescient, given makeup of the IOM group they have tasked to define the disease."

Why did your group specifically ask for the CCC to be adopted as opposed to the ICC (International Consensus Criteria)?: "The CCC is the recognized criteria used by most of the experts to diagnose and treat the disease. There are some who favor the newer ICC, but my feeling is that while those may be more specific, actually they are more in need of refinement than the Canadian Consensus. But there is no need, definitely no need, for a million dollars to be spent on whatever refinement is necessary."

Do you believe that ME as defined by the CCC and CFS as defined by the Fukuda are one and the same? Is one the subset of the other? Does CFS exist? "There is a lot of debate into this question, and it's both complicated and difficult to answer. In the right hands, Fukuda can properly diagnose ME. However, the right hands are few and far between, and at this point in time it seems more likely that a physician lacking experience with the disease can apply the Fukuda criteria inappropriately, resulting in a CFS diagnosis in a case where the patient is not suffering from Ramsay ME or CCC ME/CFS."

"There are some who consider ME to be a subset of CFS, but as ME predates CFS, and arguably is the reason CFS was initially created... I try to leave this to others. There is no reason to not diagnose and treat patients with CFS but not ME, but it is helpful and important to understand the difference. I have always

been interested in focusing on ME rather than semantics, even as the nomenclature has changed over time."

*You have mentioned **Dr. Ramsey's** work in your comment to the IoM. Do you have personal connection with **Dr. Ramsay** and his work?:* "**Ramsay** was the most prominent, perhaps the father figure, in the original definition of ME. I have always considered him to be extremely important in our understanding of the history of the disease. Unfortunately, **Dr. Ramsay** died about 25 years ago, just prior to my interest in the disease, so I never had the opportunity to meet him."

How is your research study at Mt. Sinai Medical Center in New York progressing? Do you have any news that you can share with our viewers?: "The pilot phase of the multisystem research on the effects of exercise on ME/CFS patients is complete. It's difficult to estimate when we will see the results published, but we hope to do so very soon. Hopefully this can go a long way towards confirming or denying the conclusions of the PACE Trial with regards to Graded Exercise Therapy."

What is your view on the issue of properly naming this disease?: "I'm not really interested in the semantics - I am much more interested in proper diagnosis and effective treatments. There is lively debate, and aspects of this are important, but at times it tends to overshadow issues that I consider more important. For all intents and purposes we could call this **Ramsay's Disease.**"

"We have other entities such as Cushing's disease, Addison's, Grave's disease, etc., named after founding figures. With this instance we would perhaps discard the term CFS that has produced immense discontent, and reduce the semantics surrounding inflammation, neurological signs and symptoms... Including the fruitless debate we have previously seen about "Myalgic Encephalomyelitis" vs. "Myalgic Encephalopathy". Details are important, but the debates become unhelpful."

Do you feel that we currently have testable biomarkers for the disease?: "Yes, although not as many as we should have considering how much time has passed without proper recognition. I believe that the strongest candidates thus far proposed are the immune system markers including, NK cells, cytokine abnormalities, and T-cell abnormalities. We are also exploring newer factors related to post-exertional malaise."

"We are actively proposing a new research project pointed towards testable biomarkers and new treatment methods using Ampligen, Vistide and GcMaf. Government funding in this area is notoriously sparse. More government funding has been provided for itch research centers at Temple Medical School and elsewhere than for research in ME/CFS."

"We need to raise funds, and we need the help of patients and other interested people."

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

Huge crowdfunding appeal for Lipkin study



Dr Ian Lipkin, the famed virus hunter, is appealing directly to patients to fund his new ME/CFS study to the tune of more than one million dollars. He wants to look at the gut microbiome, a vast ecosystem of bacteria, viruses and fungi that he believes could be driving ME/CFS - and a group of patients have just launched a crowdfunding campaign for this at <http://www.microbediscovery.org/>.

Dr Lipkin is already running the world's largest biomedical ME/CFS study to look for pathogens and immune dysfunction, a collaboration with key clinicians and researchers including **Dr Dan Peterson** and **Professor Carlos Montoya**. To date, the study has found no clear signs of pathogens. What has shown up clearly, though, is a strong signal of immune activation through cytokines - as **Lipkin** revealed last September (<http://bit.ly/1rsRTK7>). And this immune activation could directly lead to ME/CFS symptoms including fatigue and cognitive problems.

Smoking gun

For **Lipkin**, the immune activation is a smoking gun and he now wants to track down who or what pulled the trigger. He thinks the gut is a good place to look (though he hasn't completely ruled out pathogens yet). There are at least one trillion microbes in the gut microbiome - and more immune cells in the gut than anywhere else in the body, making it a great place to hunt for microbes that might be triggering immune activation. Particularly in an illness where many people have gut problems.

Microbiome Medicine

The microbiome is an exploding area of research, linking microbiome changes to many diseases, including Inflammatory Bowel Disease and Diabetes. The best illustration of the importance of the microbiome is the "Superbug" Clostridium Difficile (C. diff). C. diff lives peacefully in most of our guts, but can show its dark side by taking over if other bacteria in the microbiome are wiped out - eg by antibiotics - leading to bloody diarrhoea and even deaths.

The bug is highly-resistant to antibiotics, but met its match when doctors used to faecal transplants (effectively a microbiome transplant) to restore the microbiome to health, putting C. diff back its box and restoring health.

The C. diff example shows how a normally-harmless bug can take over causing serious disease, and how a simple treatment was able to restore health. The situation in ME/CFS may not be as clear-cut as this, but it does show how problems in the microbiome can lead to illness, and how treatment is feasible without developing new drugs.

The Microbiome study

The study, which will cost at \$1.27 million, will use cutting-edge techniques to discover what microbes make up the microbiomes of 100 patients (meeting both Canadian and Fukuda criteria) and 100 carefully-matched controls. Sophisticated statistical analysis will be used to see if there are differences between patients and controls - this first requirement for showing a role for the microbiome in the illness. Crucially, the study will also look to see if changes in the microbiome are matched by changes in cytokines (indicating immune activation) which would provide evidence that the microbiome is playing a direct role in the illness.

Gut microbes that are consistently associated with immune are candidates for causing ME/CFS. More work would be needed to establish a causal role for these candidate microbes, and part of this the study is developing sophisticated antibody tests which could be used to check the findings hold up in larger samples. If some of these candidate microbes prove to play a causal role in ME/CFS, **Dr Lipkin** says it could lead swiftly to clinical trials of carefully-designed restriction diets, probiotics or drugs.

A Stellar Scientist

Dr W Ian Lipkin, featured in the [New York Times](#), was described by Discovery magazine as the world's foremost virus hunter, and was a consultant for the movie [Contagion](#). He's part of the World Health Organization (WHO) diagnostic discovery and surveillance programme designed to catch pandemics as they arise -. and is Director, [Center for Infection and Immunity](#) at Columbia University: the world's largest and most advanced academic centre in microbe discovery, identification and diagnosis.

Crowdfunding: patients can make this happen

Dr Lipkin has tried to raise funds through normal channels for the microbe discovery project, but has recently been turned down by the NIH (National Institute of Health). Step forward **Vanessa Li**, a patient who was frustrated that such an important and promising project could be lost - and saw that patients could come together to crowdfund it.

Together with a few other patients and endorsement from **Dr Lipkin**, a Crowdfunding campaign was born: **The Microbe Discovery project**.

There are 1 million CFS patients in the US alone, a similar number in Europe and nearly 20 million globally. The Rituximab campaign raised \$430,000 in 90 days, mainly from Norway, a tiny country with around 20,000 patients. Patients around the world, together with our friends, families and supporters can

raise the \$1.27 million dollars, and we can do it quickly.

This is our chance to make cutting-edge research happen. Please go to microbediscovery.org to find out more, to donate and to spread the word.

Together, we can do this.

Simon McGrath

<http://nyti.ms/1gloLQt>

<http://bit.ly/1jpPEWw>

<http://bit.ly/1pv9CN4>

The Underfinanced ME/CFS Research Field - Pt 1: The Facts

In federal budgets around the world, biomedical research into ME/CFS has been allocated either ridiculously small amounts of money, or no money at all.

Take the world's largest medical research funder; the National Institutes of Health in the US. The NIH theoretically distributes funding for disorders based on parameters such as the number of patients affected, illness severity and societal costs in the form of health care and lost productivity.

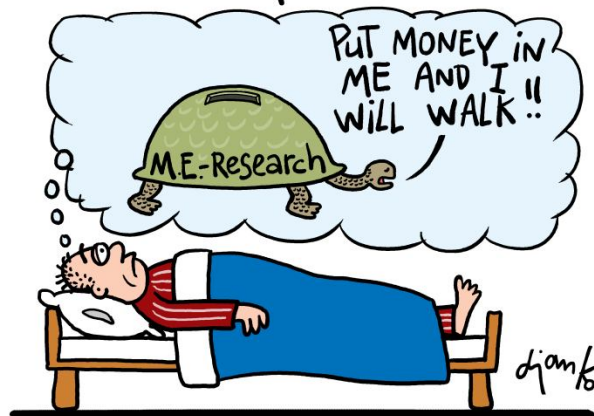


**Anne Örtegren,
Sweden**

NIH Plays Favourites

But the US government plays favourites – showering some disorders with cash, modestly funding others and virtually ignoring others. How it actually allocates funds is not clear, but need is clearly not its only driver. Let's look at different disease groups.

TOO LITTLE MONEY FOR M.E.-RESEARCH



The NIH allots around \$5,450 million per year to cancer, \$800 million to obesity, \$230 million to arthritis, \$150 million to Parkinson's disease, and \$130 million to epilepsy. The figure for chronic fatigue syndrome is \$6 million per year.

And per person afflicted? In 2013 cancer research received \$4,400 in funding per cancer patient. Compare that to the \$150 per patient prostate cancer and Parkinson's Disease

research receives yearly, the \$85 per patient for Alzheimer's research and the \$45 per patient for Hepatitis B.

Finally compare that to the funding for ME/CFS research: \$6 per patient per year!

Based on prevalence, suffering and societal costs, the funding for ME/CFS in the US is about 20-30 times smaller than it should be. For instance, MS prevalence is about half that of chronic fatigue syndrome yet MS' NIH budget (\$120 million) is 20 times higher than that of ME/CFS. Both ME/CFS and asthma cost the US economy around \$20 billion per year in economic losses, yet asthma gets 40 times as much NIH funding (\$250 million/year).

Among the 233 disease categories the NIH lists, chronic fatigue syndrome – at \$6 million per year – is 218th in funding.

Not Alone

ME/CFS is not alone at the bottom. In fact, all of its so-called allied disorders such as fibromyalgia (FM), irritable bowel syndrome (IBS) and interstitial cystitis get short shrift at the NIH. Fibromyalgia gets about \$2 per patient per year in research support and TMJ less than \$1 per patient per year. Interstitial cystitis gets about \$18 per patient per year in funding.

These are all complex disorders that primarily effect women and have low death rates and are relatively new on the research scene. NIH seems to have trouble funding these types of disorders.

Consequences

With such scarce funding it's no wonder there are no biomarkers or effective treatments for ME/CFS. In fact, the opposite would have been more surprising!

In the past 25 years biomedical ME/CFS research has come up with a number of interesting findings and launched several possible theories. There has been no lack of promising leads and exciting possibilities. But all too often successful initial pilot studies have not been followed by larger studies or independent confirmation.

When we hear that "there has been no proof of a biomedical cause for ME/CFS" and "in spite of decades of research, there is no cure for ME/CFS", we should perhaps answer: "First, let's spend as much money on biomedical research for ME/CFS as we do with other diseases, for a decade or two. Then, let's resume this discussion."

Even with its low level of funding, the USA is still the world's leader in biomedical ME/CFS research and many countries devote no money at all to this area. In some countries the government claims to be promoting ME/CFS research, but is in fact only funding research on the much broader, Oxford criteria defined "chronic fatigue". This research is not exploring biomedical issues in ME/CFS, but trying out various psychosocial approaches to chronic fatigue, and is of very little help to patients with actual, Canadian Criteria defined ME/CFS.

This deplorable situation must change. Increased funding for ME/CFS research is absolutely necessary if ME/CFS patients are to have a chance of one day getting better and returning to functional lives.

Keep following this series to find out "Why it takes 20 Years to Get 1 Year's Research Done" and "What can we do?"



Source: Health Rising
www.cortjohnson.org

News from...Australia



We want to make a difference. We have chosen to support Change for ME, an Australian organization that helps sufferers of neuro-immune illnesses such as Myalgic Encephalomyelitis (ME), Chronic Fatigue Syndrome (CFS), Lyme Disease, Multiple Chemical Sensitivity and Fibromyalgia.

We feel that there is very little awareness of these illnesses and very little support made available to sufferers. An old school friend of Trish's suffers from ME and until her diagnosis, we were totally unaware of the extent of suffering caused by ME.

We feel that our lives are the antithesis of that of a ME sufferer. We are indeed lucky to be in good health and have to have the capacity to train hard. Whilst many ME sufferers do not leave their houses for months on end, we are able to spend many hours outdoors each week during our training, enjoying the joys of nature.

We wanted our training to be purposeful and not solely directed to fulfilling personal goals. We took on the 3 Peaks Challenge in order to fund raise for change for ME. We chose the 3 Peaks Challenge because it is an event that requires a huge commitment to training.

Now that the 3 Peaks ride is done and dusted, **Suzanne** and **Trish** would like to thank you for supporting the ride by donating to Change for ME.



"We are pleased and proud to announce that so far the amount raised for Change ME is **\$10,717.**"

Ann Single, the Secretary for Change for ME, who some of you would have met at the fund raising party, says that some of the money raised will buy an EMR/EMF meter to lend out."

"It can cost \$100-\$200 for people to hire these machines, making it prohibitive for many. Thus, ME sufferers will now have **free access** to this machine."

"Riding the 3 Peaks was truly a wonderful experience for us. Not only did we go through the hard grind of all the training, but we also shared some great moments, not just with each other but with the riders from **Cams Cycle Coaching**, who we trained with."

"We will not easily forget standing at the finish line waiting for the riders to come in and cheering them as they rode past the finish line.

Thank you for your generosity.

Trish Wright and **Suzanne Scott**

News from...Belgium



As I already reported last issue of the ME Global Chronicle, there will be elections in Belgium. Most of the political parties are using the CFS-dossier to gain votes. So they've put it now on the political agenda.

On March 19th, the commission of health had a public hearing on CFS. The president for this hearing was **Maya Detiège**.

Several (open) letters and 18.000, were sent to politicians. The representative of the Flemish Patients Platform, **Mark van Impe**, had the chance to express the needs of the ME/CFS/Fibromyalgia patients. He had a text prepared in collaboration with all the concerned associations in Flandres. I was also there and to my idea he did a good job.

Will it change something for the ME/CFS patients? We are not sure about that. But from what we know at this moment, it's going the same way as it goes in the USA, Netherlands and so on.

When we take for example the implementation of the "new" pain centres. The previous "Centres Of Reference" (ran by psychiatrists) were shut down because they had no results. They noticed this after 10 years. **Hello!**

The new "Pain Centres" will be run by psychiatrists. **Hello!**

The experts in the health commission, are psychiatrists from the obsolete "Centres Of Reference". **Hello!**

Gasthuisberg, the biggest hospital in Belgium, is constructing a whole new building for the psychiatric patients. One of the new "Pain Centres" will be hosted here. **Hello!**

If one has to fly over the cuckoo's nest it will be M.E.

The lambs aren't silent anymore, some of the strongest of them will stand up (or sit down) for the whole community, worldwide, as this is a global injustice. Oath of Hippocrates "...**never do harm to anyone...**"

I'm not crazy, I'm mad. They can put my straitjacket on now...

Eddy H. Keuninckx

News from...Denmark



[EQ-5D Scores for Danish ME/CFS patients 2013-2014](#)

PhD Fellow Michael Falk Hvidberg (<http://bit.ly/1obSPjw>) from Aalborg University, Danish Center for Healthcare Improvements (<http://bit.ly/1gC6PNm>) is behind this new Danish report:

Danske ME/CFS-patienters helbredsrelaterede livskvalitet (EQ-5D) og livstilfredshed 2013-2014 (<http://bit.ly/1fAO2RP>)

The title, translated:

Danish ME/CFS patients' health-related quality of life (EQ-5D) and life satisfaction from 2013 to 2014.

EQ-5D™ (<http://bit.ly/1fMwoPO>) is a standardized instrument for use as a measure of health outcome, - it provides a simple descriptive profile and a single index value for health status.

The ME Association in Denmark (<http://bit.ly/1nuq7xg>) has taken the initiative to launch this Danish study in collaboration with the author, PhD Fellow Michael Falk Hvidberg from Aalborg University, who are working with the quality of life of chronic diseases.

The ME Association distributed a questionnaire to the members and 94 participated in the study. Data collection occurred from ult. 2013 to early 2014.

The study shows ME/CFS patients have the lowest quality of life compared to 21 diseases. In fact, quality of life for ME/CFS patients is significantly lower for 17 of the 20 diseases. This is regardless of whether you look upon the average or median.

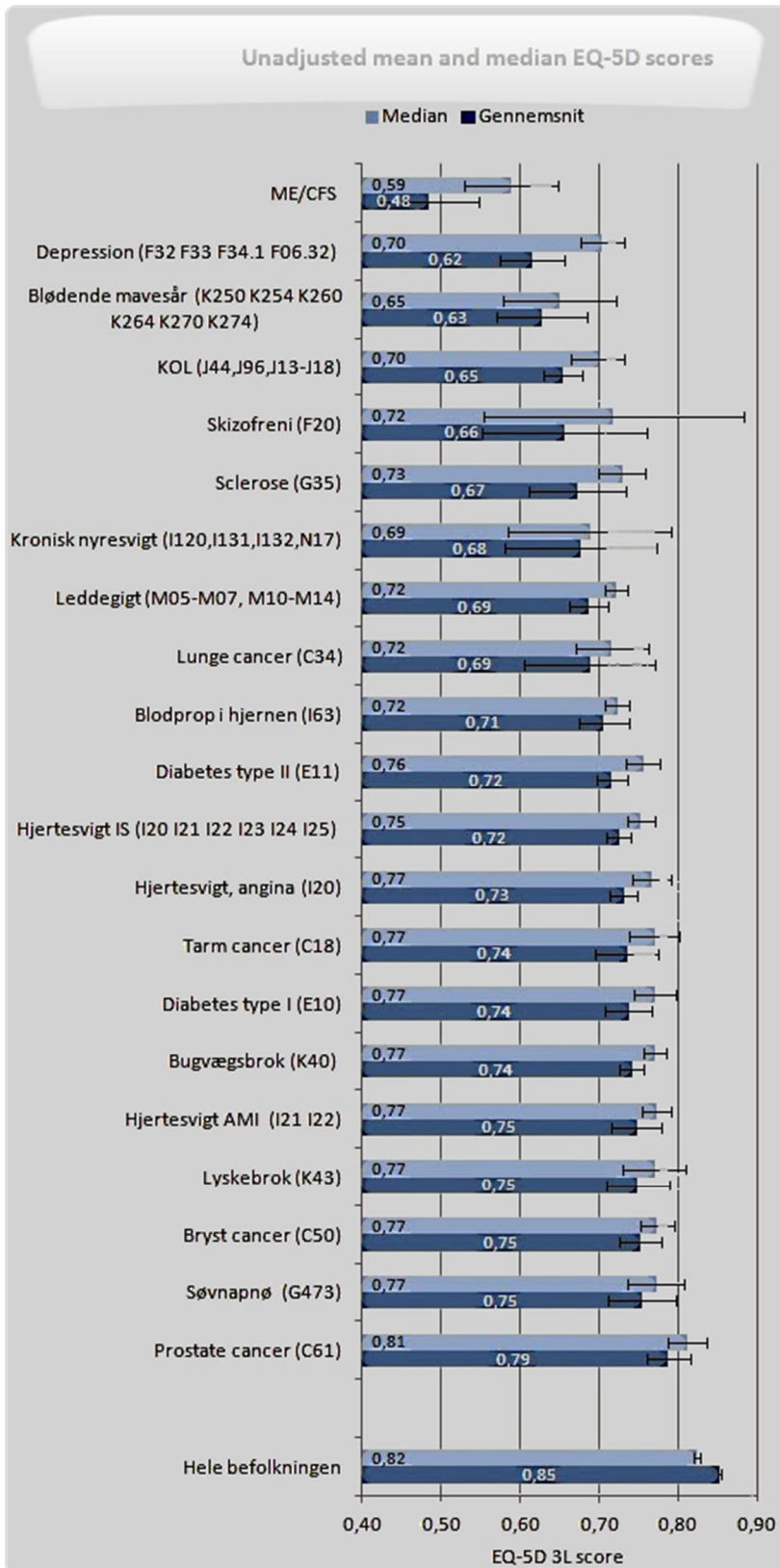


Figure 1 from page 8 in the report. EQ-5d-based quality of life and disease.

Thanks to **PhD Fellow Michael Falk Hvidberg** from Aalborg University and the ME association in Denmark for this report.

Further reading:

Comparison of Euroqol EQ-5D and SF-36 in patients with chronic fatigue syndrome (<http://bit.ly/NjOTzl>)

Health-related quality of life in patients with chronic fatigue syndrome: An international study (<http://bit.ly/1d9O6Ia>)

Health status in patients with chronic fatigue syndrome and in general population and disease comparison groups (<http://bit.ly/1gpYqM9>)

News from...Holland



Dutch Petition

After an intense political lobby we succeeded in preventing our civil initiative from being declared inadmissible. Partly thanks to the help of our lawyer the initiative has been removed from the agenda. This means that the classification of the initiative as a settled subject has been prevented.

The secretary of the health department, **Edith Schippers**, was overactive when she untimely published the letter 'Reaction to the civilian's initiative Recognize ME'. This was a mistake on her behalf, as the commission of the Health Department was not entitled to ask **Schippers** for a response of this kind.

The ultimate amount of signatures (**55.600**) is even higher than formerly mentioned, and they were found to be valid according to a sample survey.

Our lawyer has been approached by the registrar of the Public Health commission with a missive, which reads that the commission wishes to talk with the initiators of the civilian's initiative Erken ME (Recognize ME) with the mediation of the lawyer. This conversation will take place coming April or May.

To be continued...

Group ME Den Haag

Trooper Daan

A new season of the Dutch series **Bikkels** (Troopers) started on 2 March. This season the program focuses on youngsters who provide some form of informal, unpaid care to a chronically ill parent.

The episode broadcasted on Sunday 9 March featured trooper **Daan**, who, together with his brother, does a great deal of housekeeping for his divorced mother, who is unable to perform these tasks herself, because she is too severely stricken with ME. A number of applications for assistance were rejected: she was told the children would be better off if they moved to foster parents. Ironically, foster parents are paid some €**540.-** per month for a child they are fostering, whilst if the mother of **Daan** would be given this amount, she could easily pay for all the help she would need...

Daan is a very funny and bright young man of 11, who loves to play chess and admires his idol, the Swedish football player **Zlatan Ibrahimovic**, whose autobiography he has devoured several times. His profession is psychologist. I would say: philosopher.

<http://villa-achterwerk.nl/kijk-op-tv/bikkels/daan.html>

(Dutch spoken, no subtitles)

News from...Malta



News from The Times of Malta, 4 March 2014 read:

"A working committee set up eight months ago to develop a strategy for treating the debilitating illnesses ME and fibromyalgia will soon be submitting its report to the Health Ministry, a government spokesman has said. The government announced last week that myalgic encephalomyelitis (ME) and fibromyalgia were going to be officially recognised as chronic diseases.

Activist **Kevin Drake**, an ME sufferer, said: "The recognition is good, but now what? Recognition is only the tip of the iceberg and recognition without appropriate and timely follow-up action is even worse." He insisted on the need to set up a specialised unit for neuro-immune diseases in hospital, train medical practitioners to diagnose the illness and start "a proper regiment of treatment".

The working committee was set up in July with the participation of NGOs and ME and fibromyalgia sufferers. The ME Sufferers Malta spokesperson added: "It is unfortunate that we were not invited to participate in the committee.

(<http://bit.ly/1geHZbu>)

Is this news that pink... It stands to be seen. As another ME Sufferer Malta, **Rebecca Sultana** wrote in the same newspaper on 9 March:

"ME Sufferers Malta has been fighting for recognition since 2006, so we were thrilled to learn that ME (Myalgic Encephalomyelitis) was finally and, at long last, added to the list of chronic diseases last week.

Recognition is the first step forward in the right direction, but to make a difference, it then must translate into an effective plan of action. Saying that ME patients are "entitled to full healthcare services and patients will now be prescribed for medications within the government's formulary, as determined by the clinical judgment of their consultant" is utter nonsense.

Unless the Minister for Health seriously intends to get international ME experts to Malta to guide and train local medical practitioners regarding what ME is, how to diagnose it accurately and how to offer an adequate treatment regimen, the situation can only get worse.

No one locally is competent enough in the field of ME and there are no ME specialists or consultants. Ask anyone suffering from this dreadful disease. Only a couple of doctors understandably feel confident to diagnose the disease, let alone how many are prepared to treat it or even know where to begin. That brings us to the second point: medication. What medication? Medication based on what? Will medication keep being prescribed on a trial-and-error basis?

The only way forward to treat ME patients successfully is to get advice from renowned experts abroad. Otherwise, the Health Ministry's statement is just a ruse to deceive the public into thinking that, unlike the previous government, it is paying more than just lip service to address such a serious and critical problem.

ME is a degenerative disease. Patients need to be diagnosed and treated fast. Delay can allow the condition to become extremely severe and, in some cases, the patient becomes too weak to respond to treatment. For a few it is already too late.

The Health Ministry must stop dragging its feet, wasting more time (and lives) and start to use its resources productively. If not, ME patients and their families can only regard its 'plans' as a cruel and distasteful ploy to cover up the fact that the ministry is no closer to devising an effective strategy to finally begin treating people with ME."

Time(s) will tell what will be the final outcome.....

Source:

<https://www.facebook.com/groups/118672358164231>

fb ME Sufferers Malta

News from...Northern Ireland



Canadian ME Criteria in Northern Ireland..?
Why Northern Ireland should lead the way

Northern Ireland is in a unique situation, in that it can independently choose to adopt the CCC for ME/CFS. This move would give local doctors the best means to accurately identify patients with ME and this could potentially lead to better prospects for patient recovery and hopefully an earlier return to a productive life.

Newry & Mourne ME/Fibromyalgia Support Group have already been pro-active in bringing some of the foremost researchers in ME to Northern Ireland to speak to medical professionals. The most recent being the presentation by **Dr Mark VanNess** in Stormont for which two Continuous Professional Development points were awarded by the Royal College of Physicians in London. It is hoped that more presentations of this nature will follow.

Current NICE guidelines recommend that ME patients should have Graded Exercise Therapy (GET) to help them recover. GET is now known to be harmful for ME patients. Adopting the CCC would allow Northern Ireland to take the lead in developing a more sympathetic and paced approach to the treatment of ME.

The fact that currently there are no specialist ME or FMS clinics in Northern Ireland, leaves open the possibility of creating a brand new ME and FMS Clinic that could become a centre of excellence, perhaps even leading the way for ME and FMS treatments globally! The new clinic could adopt a fresh perspective and up-to-date outlook, with diagnostics and treatment options based on the very latest biomedical research.

Perhaps, the new Centre of Excellence for Public Health at Queen's University Belfast, could collaborate with international researchers to bring the biomedical study of ME and FMS to Northern Ireland?

Northern Ireland has a chance to lead the way:

by fully adopting the CCC; by promoting the understanding of ME and FMS as physical illnesses; and perhaps even by creating an ME and FMS Centre of Clinical Excellence.

Collection of signatures in progress.

[Help ME/CFS Circle](#)

Please email to: newrymournemefms@live.co.uk
Newry and Mourne ME and Fibromyalgia Support Group
Thanks to **Jan van Roijen** (Help ME Circle) for the survey

News from...Norway



In Norway, the ME mums (ME-mammaene) is about to become a concept, at least in some circles. And we who are ME mums are proud of the job we do. It is one of the world's toughest jobs: Taking care of seriously ill children, while balancing the interests of a health care and support services that surprisingly often seem to be trying to make our children sicker.

Not on purpose, of course, but good will doesn't help much. It is our children and we caretakers who must cope with the consequences of the «help». Therefore, we follow the research at home and abroad closely, and we have taken some very important initiatives through our letters to the health authorities.

Our letters are crucial. We know that when your GP refers to «a letter that someone who calls themselves the ME mums has written», and says that the letter has made him think. And for the first time he may give clear advice that is consistent with our experience of the illness – as it manifests itself in our children!

The feeling is good; our children are finally heard and their condition understood! The letters can be found here.

<http://fryvil.com/2013/10/16/me-mammaenes-brev/>

(Please use translate google to read them, although it translates a bit strange.)

One of the letters requests the authorities to consider whether the Oslo University Hospital's CFS/ME team for Children and Youths is guilty of duty violations, and this led to a large spread in one of the largest papers in Norway, VG. They have written about our kids before too. Thank you, VG!

The fact that mothers engage themselves strongly when their children suffers from ME and seek together online is hardly a coincidence. In most cases where children

ME-mammass betrouerser



are severely and prolonged ill, it is probably still the mother who ends up cutting down on paid work or apply for "Attendance Allowance"*. And if the parents doesn't live together, still most children live with their mother. Therefore the mother is nearest, and sees the child or children the most.

We need to learn and understand as much as possible of this disease that steals years of our children's lives. We feel very alone at times, and are therefore looking for someone who understands and with whom we can communicate. And when we are more at home – and at home it must be still and quiet – and less out at work and in the community, we also develop unmet social needs.

I think that's why, suddenly, social media provide an important social arena for a lot of us. We have found each other through word of mouth, and it must be that way. But once we have found each other, most of us experience tremendous support simply by learning that there are more people with similar experiences and challenges.

We would very much like to have healthy children and be working full time! The ME moms are no secret sect boiling soup on imaginary symptoms and trying to milk the system of support we do not need. We share experiences, ups and downs. We help each other where the society/system does not have anything to offer.

Thus we see that ME affects our children in similar ways, and we can benefit from each other's experience. And the support and benefits we do manage to get, is most needed.

"The one who wears the shoe, knows best where the shoe pinches!"

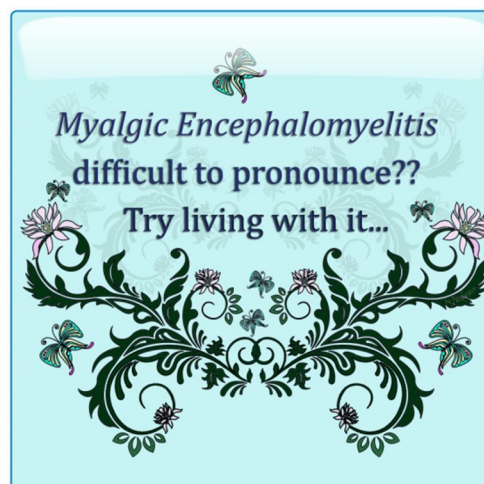
Our shoes are painful to walk in, they both hug and kipper. But we go on. Walking for our children, and we do not give up .

Here you can read more about the immensely valuable support of the ME moms:
<http://fryvil.com/2014/01/12/the-support-of-fellowship/>

*Attendance Allowance – compensation of income when you need to stay at home with seriously ill children. (Not all who really need it get it.)

Written by **@fryvil**

Go directly to this page:
<http://wp.me/P3VLNe-6S>



News from...Scotland



ME Research UK / CFS Research "£1 million of Biomedical Research"

ME Research UK has awarded **£1 million** in grants to scientific researchers. To mark the occasion, we've produced a 32-page booklet – "£1 million of Biomedical Research".

It is written in a clear, simple style, and describes some of the 35 projects (and 55 published scientific papers) we've helped to fund, classified into subject areas, such as circulation, muscle, diagnosis etc. This being printed and copies will be available soon – if you are not already on the mailing list for free copies of our publications, send an email to: <mailto:mmeruk@pkavs.org.uk> with your address.

"Breakthrough" magazine <http://bit.ly/1kCPjNs>

The spring 2014 issue of "Breakthrough" magazine will be published in April, and the electronic version will be available on our website shortly thereafter. This issue contains coverage of ME Research UK-funded research on the brain (laser-evoked potentials and cerebral blood flow), the impaired movement of the eyes, weakness in the upper limbs, and much more...

Publication – Upper arm muscle recovery <http://bit.ly/1fCxaKw>

Dr Kelly Ickmans is an ME Research UK Fellow at Vrije Universiteit Brussel, Brussels, and has produced a scientific paper showing that muscle recovery is significantly slower in ME/CFS patients with widespread pain than healthy people.

Publication – Immune responses to HSP60 <http://bit.ly/NoiveS>

The scientific journal PloS ONE has published a report by **Prof. Jonas Blomberg** and colleagues at the University of Uppsala, who are funded by ME Research UK and others. Their paper describes the identification of antibodies to heat shock protein 60 (HSP60), one of a number of "stress proteins" produced when cells undergo physiological stresses (e.g. excessive heat, disease, or infection).

Useful Information on ME/CFS <http://bit.ly/1mdKIEk>

A number of overviews, guidelines and reports have been written on the disease over the years, and this is a list of those we have found most useful.

ME Research UK-funded studies <http://bit.ly/1g3fAFj>

The details of studies we are funding or have funded can be seen at the link above.

Weekly research updates

Every Friday, we produce a weekly round-up of all ME/CFS-related scientific publications in the past week, with links to the relevant publications or commentaries. Have a look on our website next Friday!

Helping ME Research UK

a) Walk for ME 2014 <http://bit.ly/1hsy5j1>

The idea behind Walk for ME is that friends and family of an ME sufferer do a sponsored walk (or stroll or dawdle) on their behalf, raising money for a charity at the same time. People can walk during anytime. But we're urging our friends to join around ME Awareness week (11–17th May 2014). Signing up is easy at the link above.

b) Buy from Amazon <http://amzn.to/1eb56l9>

You can help us greatly by ordering your gifts from Amazon, through this link . And you can also buy a present for ME Research UK via our Amazon wish-list.



ME Research UK is a Scottish Charitable Incorporated Organisation (charity number SC036942) funding biomedical research into ME/CFS and related illnesses.

Our principal aim is to commission and fund high-quality scientific (biomedical) investigation into the causes, consequences and treatment of ME/CFS, but we also have a mission to "Energise ME Research" <http://www.mereseach.org.uk/>

News from...Sweden



Seminar on ME/CFS for Swedish Parliament

On Oct 16, 2013, there was a seminar on ME/CFS for the Swedish Parliament. Also present were members from the Swedish national ME/CFS patient organization (RME), and researchers and physicians.

Some voices from the seminar:

Dr. Dan Peterson, Simmaron Research/Sierra Internal Medicine, USA:

I encourage the Swedish health care system to open a Center of Excellence for ME/CFS patients where they can be treated by [biomedical] experts. The disease is incurable, but the quality of life for the patients can be improved if they receive this kind of help.

In the US we have had the same discussion as in Sweden of whether ME/CFS is a psychological or physiological disease. I am happy to say that we are past that stage and agree that it is a physiological disease.

Dr. Olof Zachrisson, Gottfries Clinic, Mölndal, Sweden:

The patients fall between the cracks in today's health care system and need access to qualified care units. Primary care physicians would also benefit greatly from these clinics.

ME/CFS is a physiological disease. Its causes are unknown, but evidence points to infection induced autoimmunity.

Now we move forward with research concerning whether the secretion of the cerebrospinal fluid is blocked or disrupted in any way through an autoimmune mechanism.

Pernilla Zethreus, former party secretary and congress woman, ME/CFS patient, Stockholm, Sweden:

Those of us who experience [ME/CFS] with our own flesh and blood are aware of the physical limitations, the feeling of infection, the weighty, fatigued sensation. But also the desire and anticipation before an activity, despite the fact that we know our symptoms will flare up as a result.

The seminar concluded with a roundtable discussion and Q&A session with six health care politicians representing different political parties: **Barbro Westerholm, Sven Britton, Stig Nyman, Eva Olofsson, Agneta Luttröpp,** and **Finn Bengtsson**.

It was suggested that ME/CFS treatment centers be established at all university hospitals (which are government funded in Sweden) and also that they participate in teaching both doctors and nurses. **Finn Bengtsson** underlined that this would be reasonable considering that ME/CFS is quite common (approximately 40 000 patients in Sweden). The panel unanimously agreed.

An emphasis was put on the fact that the government as well as the administration has several options to act on a federal level. In research bills (proposed every four years to the Parliament by the administration; translator's note) individual diseases can be earmarked for funding -- cancer, diabetes, and neurodegenerative diseases were specifically allocated money in the research bill of 2008, for example.

There is legal room for funding a National Center of Excellence which will in turn coordinate a national network of competence.

It was restated that primary care providers are not suited for handling a complex neuroimmunological disease such as ME/CFS, and that it is very costly to have patients drift around the health care system as the case is now.

Government funded specialist clinics for ME/CFS will require an initial cost, but will also save substantial amounts of money in the long run.

Finally, the plan to continue the cooperation between politicians and the Swedish national ME/CFS patient organization (RME) was confirmed, including creating ME/CFS clinics at the teaching hospitals and a national center of excellence.

A video recording of the roundtable discussion, in Swedish, is found here:
<http://www.youtube.com/watch?v=74ibQzaUV60&feature=youtu.be>

(Separate videos of lectures by doctors and patients from earlier in the day are also found on YouTube.)

From the Swedish newsletter, Text **Anne Örtegren**
Translation **Anja Olergård**

WHAT ARE YOU DOING ON 12 MAY?

*mail it to us, and we will let everybody know in the
April-issue of the ME Global Magazine*

contribute@let-me.be

News from San Francisco



19 March 2014, California Conference Season: Stanford Presents – Advances in Clinical Care and Translational Research

There were hundreds of attendees. They needed to move them to a bigger room because the regular room was standing-room only. The conference was super-intense. There were few breaks and even lunch had the Voices from the Shadows screening and the journalism talk.

There is, not surprisingly, frustration that there is not more funding to do research.

Prof. José Montoya opened this one day conference. He was walking through a case of a scientist who got a severe case of ME/CFS starting in 2006. It started with digestive problems. Other illnesses were ruled out. He/she had a high level of HHV-6A DNA in his/her blood and cerebrospinal fluid. He/she improved after going on valcyte in 2009. But he/she just had a recent and major relapse. Talking about the valcyte research he said it's not only an antiviral, it is also an immunomodulator.

Montoya says there are a lot of additional symptoms including gastrointestinal, cardiovascular/autonomic, neurological, etc. The illness involves several organs/systems, is chronic and fluctuating. He did a shout-out to patients who are bedbound.

Seeing these patients makes him realize that curing ME/CFS is urgent... Why did Stanford get involved in CFS? In response to the suffering experienced in solitude by millions of patients who have patiently waited for an answer from the medical and scientific research communities. "Our goal is for healthcare providers worldwide to acknowledge that CFS and Chronic Lyme Disease are real diseases; thus, validating patients and fully integrating them back into mainstream".

Next was **Elizabeth R. Unger**, MD, PhD who ran through some statistics and issues of agreement (PEM or relapse is characteristic, sleep problems, difficulty with memory or concentration, muscle and joint pain, dizziness, can be accompanied by other co-morbid conditions such as fibro, IBS, TMJ, MCS, etc.

Key symptoms of the illness –sleep, pain and fatigue- definitely interact) and disagreement (duration of fatigue, number of symptoms required, medical/psychiatric illnesses to be excluded).

Jarred Younger, MD talked about cytokine fluctuations. He tested patients 25 days in a row and had them track their symptoms. Leptin was generally correlated with fatigue. Microglia are easily activated when exposed to different stimuli, such as infections, chronic stress etc. They are also activated more easily with aging. Leptin also lowers the threshold for microglia.

Younger listed a lot of meds (such as minocycline, naltrexone) that work on microglia. He also mentioned a lot of herbs (primarily Chinese) that have potential but haven't been studied.

Lunch and Learn "Media Portrayal of ME/CFS" – featured **Natalie Boulton**, **David Tuller** and **Erin Allday**, journalist of the SF Chronicle.

After lunch there were talks from **Mehdi Sikhri** on cardiovascular aging in CFS, **Michael Zeineh**, MD, PhD on MRI findings in ME/CFS, **Marcie Zinn**, PhD & **Mark Zinn**, MM, PC on quantitative EEG studies suggesting subcortical pathology in ME/CFS.

Anthony L. Komaroff, MD, talked on the evidence of CNS involvement in CFS: there's neuroendocrine dysfunction, information processing impairments are not explained by concomitant psychiatric diseases, there's autonomic dysfunction, there are MRI findings, areas of reduced signal are found in Spect, and there's an increased lactate in CFS.

Dr Komaroff thinks the evidence shows that something has activated several different parts of the immune system. What has activated it is unclear. He walked through the many potential infectious agents linked to CFS.

Jose G. Montoya, MD, FACP, FIDSA talked on circulating cytokines in ME/CFS patients revealing a novel inflammatory and autoimmune profile. Conclusions: As disease lasts longer, the immune system loses its capacity to suppress inflammatory T cell responses; progressive increase of cytokines and decrease of anti-inflammatory cytokine with disease duration. Data open doors for treatment with anti-inflammatory agents to treat other inflammatory diseases.

W. Ian Lipkin, MD talked on microbial diagnostics and discovery in ME/CFS. **Dr Lipkin** doesn't think it's feasible to do many tissue biopsies since we should see antibodies to the viruses (e.g. enteroviruses) if they are present in the blood analysis.

The number of bacteria in the body outnumber human cells 10 to 1. Hundreds of people studying the microbiome have learned that the bacteria in our digestive system are not inert.

He thinks the microbiome is the area that makes the most sense to focus on. It's hard to get funding.



All credits to **Phoenix Rising**, who granted us permission to use this material

Sign These Petitions



Stop the HHS-IOM contract and accept the CCC definition of M.E.:

<http://bit.ly/1ghbG8v>



Fybromyalgie/Spasmofilie/CFS/ME/Erkenning/Recognition:

<http://bit.ly/1bYxIJW>

<http://on.fb.me/1gc6aDo>



Madame Onkelinx ministre de la santé.: la reconnaissance de la fibromyalgie comme HANDICAP à plus de 8 points:

<http://bit.ly/1beruL4>



We ask you to allow Karina Hansen to have the right to a second opinion from a leading ME expert **Dr Nigel Speight**:

<http://chn.ge/1itY00i>



Northern Ireland has a chance to lead the way:

- ✚ by fully adopting the CCC;
- ✚ by promoting the understanding of ME and FMS as physical illnesses;
- ✚ and perhaps even by creating an ME and FMS Centre of Clinical Excellence.

Let's make change together,

Newry and Mourne ME and Fibromyalgia

<http://bit.ly/1dzrbX3>

Major fundraisings



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: \$3,403.00 Goal: \$20,000.00

Info: <http://www.gofundme.com/5yhjdo>



Ian Lipkin study.

The initial target has been set at \$1 million.

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 has now reached £288,000.

The goal is £ 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 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



Lovely initiative from a lovely 17 year young lady with two younger sisters with ME: around 12 May she is going to cut off her so beloved dreadlocks.

She's asking sponsors for this act of bravery, and wants to raise £1000 for Invest in ME.

Go to: <https://www.justgiving.com/keishasdreads> and donate.



This project has been named **SAVE4CHILDREN**. It will be an ongoing project; it will not be discontinued until children with ME are no longer taken away from their parent(s) and locked up in psychiatric wards.

You can transfer your donation to:

IBAN: NL85 INGB 0004 286957 - BIC-code (SWIFT): INGBNL2A

ME/cvs Vereniging

Den Bosch - The Netherlands

Please mention: Save4Children

Each cent you donate to this fund will go straight to the expenses made by **Dr. Speight** and the indispensable lawyer that parents faced with such a horrendous situation are forced to bring in.



Worth reading & watching



Webinars with **dr. Nigel Speight**

During January and February one interview and six short webinars with **dr. Nigel Speight** were broadcast. They are all to be found on

<http://www.me-cvsvereniging.nl/english-page>

On 1/24, 1/31 & 2/14 chatsessions were held with **dr. Speight**. If you did not receive the transcripts of those q&a's yet, please mail to wvp@me-cvsvereniging.nl with your request.

Questions to **dr. Charles Shepherd**, **prof. Julia Newton** and **prof. Leonard Jason** can also be made known already.



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/1I73rRM>



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



CFS in short, no need to read:

<http://bit.ly/1peYFPH>



Released on 16 March by **Llewellyn King**

ME/cfs Alert, episode #57 in the series. Featuring **Ryan Prior** talking about his Blue Ribbon-plan to have medical students intern with M.E. doctors.

http://youtu.be/eoj_0uXp68I



Jet Wacky Hijinks Spero has just self-published her first ever ebook - a poetry anthology
<http://amzn.to/1peZNCO>



Dr. Charles Shepherd on Triggers of ME:
<http://youtu.be/vN66ZbKxKyQ>



"I'm ill, crippled by osteoporosis, paralysed by ME at times, and I no longer even have a GP. That's how bad it's become for me. I would rather suffer alone until the end, than subject myself to further abuse and medical negligence. I've been yelled at, thrown out, treated like scum. I've been spoken to like I'm from another planet....."

Pixi in Severe ME - **Greg Crowhurst**

A book one absolutely should have read, at least glanced through. To be ordered via <http://bit.ly/1g4GCLB>



Mom Needs To Lie Down:
The years and lives slept away by ME/CFS
Canadian documentary explaining ME/CFS:

<http://youtu.be/EvrU-ciEFcM>

Gateway



Dancing of fingers
My mind travels deep
Falling and spinning
Like Alice once did

Moving through e-mails
From people I miss
Letters and fables
Sent with a kiss

Traveling through Facebook
I meet up with friends
Discover new stories
Pictures and gems

At the strike of a clock
My web ravel's up
Hurtling me back
To the edge of the earth.

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<http://currankentucky.wordpress.com/2014/02/03/the-long-and-winding-road/>

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."

