



# ME



# GLOBAL

# Colofon / Personalia

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*Textual contributions for the March issue need to be supplied in Word by March, 12<sup>th</sup> and sent to: [contribute@let-me.be](mailto:contribute@let-me.be)*

The next issue will come out on March, 27<sup>th</sup> 2014.



**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."

# Focus On IOM

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We are happy and proud to submit the second issue of the ME Global Chronicle to you.



This month we will be focusing on an event that will be the most important occurrence since years; it will have an impact for many years to come: the contract of the American HHS with the IOM, and especially the hearing of 27 January 2014. We will continue to closely follow this process. Furthermore, we bring you exciting news from several countries, and Rich has written a new review. Moreover, we are slowly but steadily trying to make this magazine into a magazine that caters for all tastes, and have added a poem and a column.

The first issue has been welcomed by many patients, organizations and researchers. Many a person subscribed and encouraged us to continue our efforts. Amongst them **prof. Leonard Jason**, who has beautifully voiced the idea behind this initiative in the words we will include permanently in the colophon. It is simply too beautiful a statement not to read regularly.

We appreciate that this magazine has nothing new to offer for many patients, since many of them are much better informed of what is going on in the ME-world than the editors are, especially in America. However, we would like to remind you that the sharing of information about ME with each other and the world is the most important purpose of this magazine. So do participate...to share information makes it into a shared project.

This magazine has a magnifying glass-function. It offers us the opportunity to try and put aside all our differences in opinions, and to stand up for the rights of all who are inflicted with this terrible disease as well as our friends, families, companions and advocates.

We sincerely thank all of you who contributed information to this issue; who gave us permission to use the information on their website, Facebook wall or blog; and who gave us our so much needed support in expressing their joy and even gratefulness at the appearance of the first issue.

We will regularly observe a few moments of deep silence for thinking of those of us who remain in dark rooms, unseen and unheard, unrecognized by health professionals, 'friends', family and authorities. So that we may continue to hear their faint voices from the shadows.

Please send or keep sending us all the information you think important enough to share with all of us, all around the world, by emailing it to [contribute@let-me.be](mailto:contribute@let-me.be). Do share this magazine with your followers. If they subscribe, they subscribe to something in which they can actually be involved.

**The editors**

# Rich' Reviews: Coenzyme Q Improves Fibromyalgia Pain and Fatigue. Is this treatment worth pursuing?

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Fibromyalgia pain affects a majority of people who have CFS-ME.

**Dr. Mario Cordero**, a professor at the Spain's University of Seville Medical School treated Fibromyalgia patients with high dose Coenzyme Q 10 (300 mg) versus placebo. Taken for 40 days Coenzyme Q was much more effective than placebo for improving pain ( $p < .001$ ). Fatigue and morning tiredness also improved. ( $P < .01$ ).

Coenzyme Q, an anti-oxidant helps support the function of mitochondria, the energy producing factors within our cells. Among people with Fibromyalgia mitochondrial energy production is often reduced, in part due to increased oxidative stress. COQ10 is generally considered to be safe. So except for the cost, there's little reason not to try it.

However, Coenzyme Q tends to be absorbed poorly.

Having some fat in your stomach at the same time you take Coenzyme Q helps improve absorption. For example, take COQ10 with dinner--usually the fattiest meal--or with a fish oil capsule or with a teaspoon of olive oil. Ubiquinol, an improved form of Coenzyme Q is better absorbed than traditional Coenzyme Q (which is called ubiquinone). Other nutrients are potentially relevant to mitochondrial function include: Creatine, Carnitine, Lipoic Acid, NADH (Enada) and Riboflavin (vitamin B2).

**IMPORTANCE:** We are finally beginning to see a few double blind studies of natural treatments for fibromyalgia, chronic fatigue syndrome and other complex health problems. Of course, one single study, such as this, does not prove that a treatment is effective, but it's certainly more encouraging than having no data at all.

Next step, can we create mechanisms that attract investigators to replicate promising findings such as that of Cordero? Would it be useful to survey patients to obtain their anecdotal experience?

**Cordero MD**, et. al. Can Coenzyme Q Improve Clinical and Molecular Parameters in Fibromyalgia? Antioxid Redox Signal. 2013 Apr 6. Abstract available from [www.ncbi.nlm.nih.gov/pubmed/23458405](http://www.ncbi.nlm.nih.gov/pubmed/23458405)

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

[www.DrPodell.org](http://www.DrPodell.org)

# Health Conscious Hares

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Last week my grumpy body rested while my mind ignored its temper tantrums.

It was a week filled with limp arms and legs, my heart had a resting pulse of 86 and beat out my back like a runaway train. My fingers and wrist on my left side became grinding bones of fun and my armpits cried out when lifted. In short, my friend myalgic encephalomyelitis, was extremely peeved.

However, my mind distracted itself easily. The weather outside my window ranged from marble sized golf balls to sleet, hail, snow, rain and wind. Nature threw down a deluxe range of weather conditions and my eyes watched from the safety of my looking glass.

In my front garden some siskins, goldfinches and tits clung to my peanut feeders, anchored in their stormy sea, while more tested my new garden, picking branches on my new blossom tree to cling to. Road testing them in the severe weather conditions.

While, in my back garden, hares feasted on grass hidden by snow. One evening, four hares entered my garden from an adjacent field. Three barged their way in swiftly, while a fourth ran up and down the fence line for a few moments, carefully picking its spot, trusting only its own instincts.

Once safely in, all four stuck to one patch of grass, none straying from it until their bellies were full. Beneath the dusting of white lay a segment of lush green grass, this patch healthier than the anaemic stretch of winter lawn beyond. The four hares tugged at each blade and sucked on the rich juices of my formula one multivitamin, if they continue to feed on this slice of lawn, they won't need to worry about climbing under the fence line, they will be able to jump it.

Our home utilises an eco friendly sewage system, a system that collects all waste water from our house into a tank in the garden. The sediment rests at the bottom of the tank while the water is pumped into one section of lawn, it's very clear to the naked eye which section of lawn is fertilized and which is not. I'm also guessing most of my multivitamin ends up here...

I'm continually cautioned by my GP to maintain my expensive multivitamin and vitamin D supplement, her words warning, should I stop taking either, my body would be a whole lot grumpier. I've no intention of testing her hypothesis but often joke my body simply pees the stuff out, if this is the case, it's good to know the hares are at least benefiting from my supplements. Should they start jumping the fence, I think I'll invite my GP over to see

**Marie Curran**

<http://currankentucky.wordpress.com/2014/02/06/unrequited-love-2/>



## Our FundRaising

We have created a separate strand to our Biomedical Research Fund which will be explicitly used for this UK rituximab trial.

Goal  
£ 350 000

A specific fund-raising thermometer has been created just for this project - see the image on the right. This will be updated with the current figure raised. It includes all donations and pledges of funding.

£ 283 000  
Raised

The total funding requirement for this trial will be refined as we present more details of the project and as the project progresses. An initial target has been set at £350,000 - which is the target based on an initial scoping of the trial functions which estimated a requirement of £300-400,000.

This is a daunting task but not one the charity feels is impossible to achieve. It is less than some funding given recently by the MRC to researchers performing research in other areas connected to ME.

If you feel you can support us in any way - by fundraising, by spreading word of this, by simply letting us know that you support us in this effort then we welcome that support.

ME patients and their carers, when determined, are amongst the most resourceful around. The Let's Do It for ME campaign has energised ME research.

Donations made via the links below will go to the ring-fenced UK rituximab trial fund. As stated in our FAQs page we are confident that the trial will go ahead but realise that it is important to be transparent about what will happen to the donated funds in the unlikely event that the rituximab project does not proceed. In such a case, the funds raised will be transferred to the Invest in ME Biomedical Research Fund to fund other biomedical research into ME projects. This has been stated from the outset.

<http://www.investinme.eu/index.html>



# Training Generation Cure



Dear fans and supporters of The Blue Ribbon,

Dr. Andreas Kogelnik and Ryan Prior, who suffers from Myalgic Encephalomyelitis (ME), headlined a [press briefing](#) in

Washington, D.C., on Jan. 24. The event took place at the venerable National Press Club and was attended by a mixture of reporters and ME patients. Notably present were reporters from The Washington Post and The Christian Science Monitor.

The purpose of the event was to draw attention to the plan developed by Prior and endorsed by **Kogelnik** to embed first- and second-year medical students with specialist clinics. These would include the Open Medicine Institute in Mountain View, Calif., which **Kogelnik** founded to treat ME (known as Chronic Fatigue Syndrome (CFS) in the United States) patients and those with similar perplexing, immune system-related diseases.

The event was organized by nationally syndicated columnist and TV host **Llewellyn King** and his wife, **Linda Gasparello**, also a print and broadcast journalist. It will be [streamed](#) on the Internet by the Blue Ribbon Foundation.

**King** said he had talked to important media outlets that expressed interest but were unable to attend. These included C-SPAN, The New York Times and Reuters.

**King** said there was no instant way to raise media awareness. "The walls of Jericho are not going to fall down overnight," he said. "But every contact with a major news outlet increases awareness; that will lead to more coverage, and coverage will lead to government action."

Yours in the Cause,  
The Blue Ribbon

Click [here](#) to view the groundbreaking press conference at the National Press Club!

<http://www.youtube.com/watch?v=H8Tn0f5ahLA>

# Stormont - M.E. Research Event a Success



**Joan McParland**  
February 5<sup>th</sup>, 2014

More than 90 researchers, health professionals, politicians, civil servants and patients attended yesterday's M.E. in Northern Ireland: practice and research priorities event at Stormont.

Audience members included: representatives from the Health and Social Care Board and Department of Health, Social Services and Public Safety, **Professor Albert Cilia Vincenti** and **Clare Palmer**, Academy of Nutritional Medicine,

**Dr Joe McVeigh**, Lecturer in Physiotherapy, University of Ulster,

**Micheal O'Reilly** and **Declan O'Carroll**, Irish M.E. Trust

**Right Worshipful** the Mayor of Lisburn, Councillor **Margaret Tolerton**.

"A number of new and exciting contacts were made from Queens University Belfast, and some Health Trusts want more information and further discussions with us," reports **Joan McParland** of Newry and Mourne M.E./FMS Support Group, which organised the event.



"I am very grateful to **Dominic Bradley** MLA (SDLP, Newry and Armagh) for hosting the event," she added. A number of other MLAs were also present, including **Mickey Brady** (Sinn Féin, Newry and Armagh), **Danny Kennedy** (UUP, Newry and Armagh), **Roy Beggs** (UUP, East Antrim), **Fearghal McKinney** (SDLP, South Belfast), **Jo-Anne Dobson**, (UUP, Upper Bann), **Kieran McCarthy** (Alliance, Strangford) and **Jim Wells** (DUP, South Down), who took part in a Q&A

session.



Yesterday's programme included presentations from:

**Dr Mark VanNess**, who highlighted his recent findings about the effect of exercise on M.E.,

**Dr Vance Spence** and **Dr Neil Abbot**, ME Research UK, who accepted a **£1,000** donation from **Newry and Mourne M.E./FMS Support Group**, **Dr William Weir**, who talked about the treatment and management of M.E. patient and campaigner **Horace Reid**, who highlighted the desperate need for more research and better health services.



"**Clare Palmer** also compiled an album of contributions from bedbound patients who emailed her their heartbreaking stories and pleas for help," says **Joan**, who gave a presentation speaking movingly from a personal perspective about the daily challenges faced by M.E. patients. "She presented this to **Jim Wells**, Assistant Chair of the Health

Committee, to give to Minister of Health **Edwin Poots**. **Mr Poots** had originally agreed to open the event but was called away at the last minute."

Joined by MLAs and **Prof VanNess**, patients and carers held a silent demonstration outside Stormont after the event, holding up a banner featuring pictures of all the M.E. patients who would have liked to attend but were too ill to do so.



You can see pictures from the event and demonstration on the [M.E. Alliance Northern Ireland](#) Facebook page, and a DVD of the event will be available soon.

<https://www.facebook.com/groups/245412298880729/?fref=ts>

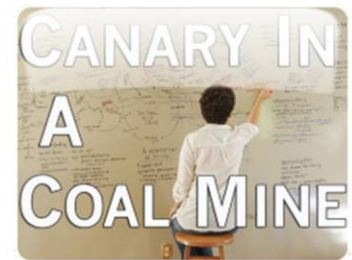
<http://bit.ly/1jwSxRt>

<http://www.imet.ie/>

<http://www.mereseach.org.uk/>

# Canary in a Coalmine

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Project Update:

## ProHealth's 2013 Advocate of the Year

Posted by **Jennifer Brea**

I am completely overwhelmed, embarrassed, humbled and grateful (but mostly embarrassed!) to be named ProHealth's 2013 Advocate of the Year for my work on Canary in a Coal Mine.

<http://www.prohealth.com/library/showarticle.cfm?libid=18613>

It's been a tremendous year in advocacy on so many fronts: Justice for **Karina Hansen**, **Jeanette**, **Jennie**, and **Erica's** excellent coverage of the IOM contract, **Ryan** and **Nicole's** ambitious project to educate a new generation of doctors, petitions in the US and the Netherlands, public letters that have brought together researchers, clinicians, and patient advocates, the launch of Heal Click, crowd-funded research, the list goes on...

I think the charge, for all of us, is to figure out how to learn from this past year and make 2014 another year of growth and progress.

To that end, I plan to use the Advocate of the Year reward to seed a modest project, which I hope in addition to being great fun, will help us to build bridges with other patient communities and learn how to be even more effective whether in our advocacy or in our lives as patients and people.

Cryptic, I know, but stay tuned!

My deepest thanks to **Rich Carson**, **Erica Verillo** (for a lovely article!) and everyone at **ProHealth**. And to our many #MEallies! for being a constant source of support, laughter, and inspiration.

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

# The ME and CFS Documentary Project

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## Project Update:

We're gearing up for shooting days 32-40, which will be an aggressive 9-day push through 4 states: Georgia, Massachusetts, Rhode Island, and New York (bringing our total number of states filmed in to 10). We have some exciting shoots scheduled, including:

- 1.) **Wilhelmina Jenkins**, a patient and former physicist who appeared on the Oprah show to talk about ME/CFS in 1998
- 2.) **Marian Sonnenfield**, a former doctor with ME/CFS who appeared on the PBS NewsHour in 1992
- 3.) **Roger King**, who published the novel "Love and Fatigue in America" in 2012. He is a former international economist who did development work for the United Nations, among others. He has suffered from the illness since 1991.
- 4.) **Hillary Johnson**, the correspondent for Vanity Fair and Rolling Stone who literally "wrote the book" on ME/CFS, "Osler's Web," the 720-page investigative masterpiece that uncovered entrenched political interests against "CFS" at the CDC and NIH.
- 5.) **Dr. Derek Enlander**, who recently received a \$1 million grant to establish the New York ME/CFS Center at Mt. Sinai Hospital in Manhattan. Spanning genomics, cardiology, pulmonology, internal medicine, and immunology, the Center represents the kind of complex, interdisciplinary research required for this disease in the 21st century.

We'll start tomorrow in Atlanta (February 18<sup>th</sup>, 2014).

# Massachusetts CFIDS/ME & FM Association

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Links to the video-recording of the Fall 2013 Lecture by **Dr. Anthony Komaroff** are now available on our home page.

**Dr. Komaroff** discussed "CFS Research: Recent Progress and Challenges" and took many questions from the audience.

**Dr. Anthony Komaroff's** 2013 lecture "CFS Research: Recent Progress and Challenges" (56 minutes)

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

**Dr. Komaroff's** 2013 lecture Questions & Answers (37 minutes)

<http://bit.ly/1dThx5a>

The video-recording of the Spring 2013 lecture, "The Science of Sleep," presented by **Dr. Jo Solet** is also available.

<http://bit.ly/1dThNB8>

Also, you can sign up for our monthly newsletter at

[www.masscfids.org](http://www.masscfids.org)

to get other announcements like this directly.



Almost every seat was taken at Wednesday's Exercise and M.E./CFS: the evidence event (<http://bit.ly/1kCR2EP>) in Bristol this week.

Along with our CEO **Sonya Chowdhury**, attendees included patients, carers and professionals including the ME Association's **Charles Shepherd**; specialist physiotherapist **Pete Gladwell** (Bristol M.E./CFS service), **Dr Phil Hammond** and occupational therapist **Anne Johnson** (Bath M.E./CFS service) and **Andrew Douglass** (Somerset M.E./CFS Service).

The event began with a screening of a new 30-minute version of the moving M.E. documentary, *Voices from the shadows* (<http://bit.ly/AuKXMT>), introduced by **Natalie Boulton**, who made the film with her son **Josh**. This shorter version, edited down from the hour-long original, was made after **Dr Montoya**, Stanford Medical School, suggested it, with the intention of showing it to medical students.

After the film, **Prof Mark VanNess** (<http://bit.ly/NDGisd>) spoke about the work he and his team are doing at the fatigue laboratory in the Health, Exercise, and Sport Sciences Department, University of the Pacific, California.

Working with people who have mild to moderate M.E., they are finding objective, rather than self-reported or subjective, evidence for the kind of fatigue that is specific to M.E.

Using cardiopulmonary exercise testing, Prof VanNess has proven that people with M.E.:

- ✚ experience significant post-exertional malaise, though he prefers to call it post-exertional amplification of symptoms
- ✚ have significantly impaired ability to generate energy from aerobic activity.

The key is that subjects are tested over two days.

People with M.E. and healthy controls, all volunteers, spend 10 minutes on the treadmill on the first day, and then again 24 hours later.

Results show that on the second day the metabolic function of people with M.E. has dropped by around 25%, such a marked decrease that, **Prof VanNess** told us:

"exercise physiologists protested that the machine must not be calibrated properly".

As a result of the data he has gathered, **Prof VanNess** has concluded that therapeutic interventions for people with M.E. should avoid aerobic exercise.



Instead, they should be offered anaerobic activity, intended to retrain the short-term (anaerobic) energy system to increase range of motion and improve functional strength.

“Crucially”, he said, “the ratio of activity to rest should be one to three, and physical therapists should be trained and experienced in this type of physical therapy”.

**Prof VanNess** and his colleagues wrote an article for the CFIDS Chronicle (<http://bit.ly/1dJf88g>), which explains these findings in more detail. He has also published numerous papers in peer-reviewed journals on his topic, including:

- ✚ Post-exertional malaise in women with CFS (2010) (<http://bit.ly/1dJfsnA>)

- ✚ Conceptual model for physical therapist management of CFS/M.E. (2010) (<http://bit.ly/1eVgT74>)

After a break, retired consultant paediatrician **Dr Nigel Speight** spoke about his management approach for M.E. in children and young people, and how important it is that the whole family be believed and supported.

He told the audience that, during the past 12 months, he had worked with five cases of children with M.E. where the families are being subjected to the threat of child protection proceeding.

The parents from some of those families were in the audience.

**Erinna Bowman**, part of the CURE-ME (<http://bit.ly/1aWg5zk>) team at the London School of Hygiene and Tropical Medicine, gave the last presentation of the evening, about the UK M.E./CFS Biobank (<http://bit.ly/1eR1o1p>) co-funded by Action for M.E.

“The biobank has been designed as an open resource for the best researchers around the world,” she said, describing the work the team are doing, being almost half-way to the their target of collecting samples from 500 donors.

After the presentations, **Sue Waddle**, ME Research UK (<http://bit.ly/1hdDCi8>), chaired a Q&A session.

# ME / CFS Research Newcastle

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The last few weeks have been occupied with some serious grant writing. We have submitted a large grant to the MRC and another to a scheme called NIHR EME. So we have our fingers tightly crossed that there will come off.

Getting the funding to 'do' the research takes an awful lot of time. So although both of these grants are outline applications they have taken lots of meetings, discussion and write and rewrites of the content. Even for outlines a full costing is required, and this means you need to know exactly what you would like to do if you are successful so that you can accurately cost the application.

Otherwise if you get the costs wrong you might not have enough funding to actually do the project if you are successful. So fingers crossed for these .. Will be great if we are successful.

One of the current MRC projects is coming to an end soon and we are just recruiting the last few participants. We need at this stage to also include some non-CFS people who we can use as a comparator group. We need to be sure that they match our CFS group as near as possible - so that can be a bit difficult sometimes to get absolutely right.

The Action for ME funded sleep studies are now finished and the analysis is complete. The first draft of the paper has been written for submission for publication in a scientific journal and we had a group meeting to finalize this before we ended it off. It's really important that the work we do is not done in isolation and that the findings are disseminated to both the people who have taken part and also clinicians who see patients. It's only that way that the research can change how we manage patients. Next step for these studies is a small intervention study (funded by ME association) where we are going to look at whether treating sleep problems improves fatigue.

A few months ago one of the team working on the muscle studies came to see me because after completing their PhD they moved to a lab working on skin cells. They thought that the novel studies of mitochondrial they were doing in skin could easily be done in muscle cells too. They knew that we had muscle cells in the lab from CFS patients and wanted to see whether I thought it would be a good idea to look at them too. I found a small amount of funding for them to perform these pilot studies and they emailed two weeks ago to say that they were very excited about the results. Just last week we had a meeting to look at the results on So more of that soon.

**Prof. Julia Newton**

# An Interview with Michael VanElzakker Ph.d



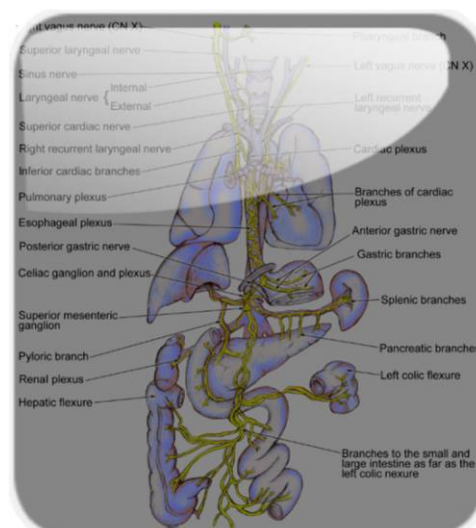
**Michael VanElzakker's** Vagus Nerve Infection Hypothesis (VNIH) for Chronic Fatigue Syndrome may be the most intriguing hypothesis to come along in the last twenty years.

**VanElzakker** is a neuroscientist mostly focused on posttraumatic stress disorder (PTSD), which he considers to be very different from CFS and a separate arm of his research interests (although there are many interesting overlaps between the views of CFS and PTSD within our culture). A sick friend prompted his interest in this disorder

There are a lot of technical problems that will require pilot testing. Most PET scans are done of the brain. VE would like to do one further down in the vagus nerve area. One of the big problems is that PET scans cost thousands of dollars per hour. It's difficult to convince funding agencies to give money to pilot test a method.

There's interest because of this hypothesis, but most imaging of the vagus nerve thus far has been at the level of the brain, trying to understand the mechanism of vagus nerve stimulation for epilepsy or depression. We're trying to image it farther down.

It is possible to radiolabel antibodies so that they pick up clusters of infection in the body. But there are several problems to this with regards to the VNIH of CFS. One is that antibodies are specific, but CFS could be caused by a number of different pathogens.



So, we could flood someone's body with radiolabeled antibodies against HHV-6, but maybe in that specific case, their symptoms are caused by HHV-4 (Epstein-Barr).

Another problem is that some of the pathogens that might be most likely to cause CFS are found in the vast majority of humans. So, radiolabeled antibodies against HHV-1 would find a signal in most people, but only cause CFS if the viruses are in a vagus (para)ganglion.

And the vagus nerve is so highly branched, that could be all over the trunk. Another problem is that antibodies cannot always get inside ganglia, which are immunoprivileged. But despite all of that, I still think it's a research program that is worth pursuing.

The response to VE's hypothesis has been very positive; he is working on putting a study together to test his hypothesis. The week the paper came out, **Anthony Komaroff** contacted me, we've been in contact since.

The paper is already being taught at some universities and medical schools, so hopefully it will at least get young scientists to start thinking about CFS. I hope people start to think about new CFS findings through the lens of this hypothesis because in my experience, it explains a lot of phenomenology.



Even if the hypothesis doesn't turn out to be accurate, or is only partially accurate, I hope that it gets us closer to effective treatments that are actually attacking the root causes of CFS symptoms and not just helping people cope with them.

On the record, I've put together a really great team to pursue the VNIH and **Dr. Komaroff** is part of it. There are a lot of technical issues but we're hoping to use functional imaging to gain enough preliminary data that we can pursue it further.

**VanElzakker** will be at the **IACFSME** conference with a poster presentation of his hypothesis.

- See more at:

<http://simmaronresearch.com/2014/02/>

<http://bit.ly/1hpUt12>

# News from...Holland

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The three large patient organizations in the Netherlands initiate collective campaigns more and more frequently. Hopefully, the individual organizations' strong points will be exploited optimally in 2014.

The project Science to Patients was viewed for the **100,000th** time on January 31st. The webinars of pediatrician **Dr. Nigel Speight** have come to an end. His final chat session was on February 14th; it was available to all English speakers and turned out to become a very vivid question & answer session.

The transcripts of the webinars and the Q&A sessions of **Dr. Speight** have been sent to you last week.

The first two webinars of **Dr. Charles Shepherd** are now online:

35. Introduction / Experience with ME

<http://youtu.be/2M8DFFF8-u8>

36. What is the difference between ME and CFS?

<http://youtu.be/EIYwZIFzKCg>

International chat sessions will be held with him as well, presumably on March 14th, April 10th and May 15th.

For more information you can visit

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

There you will also find the webinars that have already been broadcast and their transcripts.

Questions to **Dr. Shepherd** can now be posed via [wvp@me-cvsvereniging.nl](mailto:wvp@me-cvsvereniging.nl)



# News from...Belgium



This year there will be elections in Belgium for the:  
European parliament  
Federal Government  
Flemish, French / German and Brussels Communities

Indeed, politics are complicated in this country. If you suffer from an unknown/complicated illness, it's even worse. Responsibilities are distributed between the different decision makers and the assignment of a budget for a proper research can take years. Therefore it's important that the different governments are kept under pressure by all means.

We do have several groups that organise events, petitions and participate in meetings to discuss a vision of ME/CFS, fibromyalgia and other illnesses. Luckily, and as far as I know, they don't interfere with each other's actions, which is good. They should continue in doing so. But because the situation is so complicated here in Belgium, it's even more important to have a global consensus on how to approach this disease.

We encourage the Belgian ME/CFS advocates to continue in what they are doing: stand up for themselves, but especially stand up for those who can no longer so.

In "The Me Global Chronicle #1" we already reported about the HHS-IOM contract and the criteria for re-defining the illness of M.E. / CFS. Neither the impact nor the outcome of this contract can be foreseen. But for a small country like Belgium, that has so many decision makers, it will be huge. So let's hope that some common sense will be used instead of personal (financial) interests. This disease deserves proper funding, proper research and proper treatment.

Eddy Keuninckx



# News from Ireland...

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Here in Ireland a team of Irish ME patients are working on an ME clinic proposal for presentation to the Irish government and the national health authority the HSE.

The proposal is at [www.me-ireland.com](http://www.me-ireland.com) .

It covers most of the issues concerning ME, such as diagnostic and treatment criteria using best international practises, a biomarkers section, research findings, the top ME and CFS clinics in the world, doctor training programmes, lectures by ME experts, a research section, etc. Also a cost benefit analysis was devised for the ME clinics, showing how an investment in improving the health of ill people and recoveries would economically and financially benefit the Irish economy and government

I have made several adjustments to our ME clinic proposal to make it as accurate and factual as possible. Its been very difficult and tough work, and has been ongoing for a few years now.

There are many in Ireland who feel so hopeless and down that they cannot believe in anything, they don't believe in ME clinics, ME diagnostic and treatment criteria, ME research, ME medicines, ME improvements, etc., they have lost all hope.

For many years nothing has been done and hope has been lost. Most ME and CFS patients have lost jobs, careers, educational opportunities, partners, relationships, homes, etc.. Most have suffered stigma, prejudice and social isolation by friends, family and acquaintances. Some patients have been victims of crime and abuse by criminals and nasty people.

They are regularly denied justice under the law as there is still a lot of prejudice and discrimination in society and it's institutions. In Ireland, the poor have no rights and are downtrodden. Many people in Ireland are very narrow minded and they like to target the disabled, the ill, and the unemployed, and belittle, mock, abuse and harass them.

I and some others are trying to restore hope and we will meet the Irish government this month to put the proposal to them. We have enough information to build a strong case. We have a good team, very committed and determined. We will restore hope to the Irish patients and Irish people.

We urge other peoples and nations to view our ME clinic proposal at [www.me-ireland.com](http://www.me-ireland.com) and use it to assist them in their efforts in their countries.

**David Egan**

# News from...Denmark

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A British doctor who specializes in the devastating disease myalgic encephalomyelitis (ME) has joined an international bid to free a young ME patient who was incarcerated in a Danish hospital a year ago.

**Dr. Nigel Speight** wants to examine **Karina Hansen**, a sane but sick woman aged 25 who was forcibly removed from her home in Denmark on February 12 last year, and provide a second opinion as soon as her state-appointed guardian gives the go-ahead.

If he gains access, **Dr. Speight** believes he will be able to rescue the young woman from the hospital's mental ward, where she is being held against her will and the will of her parents.



A group known as Justice for **Karina Hansen** (J4KH) has been petitioning for the young woman's release from Hammel Neuro Center since May last year.

Their most recent campaign was launched last Thursday, in the form of an open letter from her parents, **Per** and **Ketty Hansen**, to the man appointed by the Danish health authorities as **Hansen's** guardian.

In terms of the World Health Organization's (WHO) A Declaration on the Promotion of Patients Rights in Europe (March 1994), that states patients "should have the possibility of obtaining a second opinion," they have asked that **Dr. Speight** be allowed to see her and give a second opinion.

The ME Association in Denmark has undertaken to pay his travel costs. J4KH reported on their Facebook page that the guardian had acknowledged receipt of the letter and undertaken to discuss the matter with "those in charge of her care." The group has also launched a new change.org petition that already has more than 2,400 supporters.

The bedridden **Hansen** was taken from her home in Holstebro County last February, by five policemen who forced their way into the house; they were accompanied by two doctors, two social workers and a locksmith. **Hansen** called for help, but none of the family members could get past the police.

She also phoned her sister, **Janni**, asking for help, saying she did not know where she was being taken. The following day she phoned her mother from her cell phone asking how she could "get out of here." She said she could not "take this."

They later discovered that she made a total of 43 calls and sent seven text messages before her phone battery went flat.

The last call was to the police. The **Hansens** have asked for transcripts of the calls, but have received nothing. They have asked that her phone be recharged, but she has to do it herself and cannot get out of bed.

The **Hansens** said they were not given any reasons for the action and received no official paperwork relating to it. All they found was a note on the floor with a telephone number and message to say they would be contacted daily by a doctor.

This did not happen, and they have not been permitted to visit their daughter because they do not support her treatment.

Her sister, **Janni** has seen her briefly and is very concerned about her condition.

The **Hansens** have taken legal action, but the court system is slow and drawn out.

More:

<http://bit.ly/1oI418E>

# Danish public hearing about functional disorders...

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The Danish Parliamentary Health and Prevention Committee has invited to a public hearing about functional disorders on the 19th of March 2014 from 9 am to noon CET in the parliament building of Christiansborg, Copenhagen.

The committee has invited a number of experts to debate the following two general themes:

- Introduction to functional disorders and the key issues.
- Functional disorders and diagnoses.

There will be the following presentations:

- Introduction to functional disorders by **Professor Per Fink** from The Research Clinic for Functional Disorders, leader of the Research Clinic and the "father" of the TERM-model [www.funktionellelidelser.dk](http://www.funktionellelidelser.dk).

Together with **psychiatrist Nils Balle Christensen** responsible for the incarceration of the ME-sick **Karina Hansen** at Hammel Neurocenter and for re-diagnosing her with the controversial psychiatric diagnosis **PAWS**, Pervasive Arousal Withdrawal Syndrome [www.facebook.com/JusticeForKarinaHansen](https://www.facebook.com/JusticeForKarinaHansen).

- Challenges in the diagnosis of functional disorders by **MD Stig Gerdes** who works actively for patients who get squashed in "the system"
- Legal issues related to functional disorders by **Kjeld Parsberg, lawyer** of Karina Hansen
- Whiplash and functional disorders by chiropractor, lecturer and **PhD Lars Uhrenholt**
- ME ( Myalgic Encephalopathy ) + possibly fibromyalgia and functional disorders by specialist **MD Henrik Isager**, author of the book "Blind Spots" [www.kirkusreviews.com/book-reviews/henrik-isager/blind-spots/](http://www.kirkusreviews.com/book-reviews/henrik-isager/blind-spots/).
- Irritable bowel syndrome and functional disorders by professor and consultant **Peter Bytzer**



The last three speakers will talk briefly about the location of the respective diagnoses whiplash, ME, and Irritable Bowel Syndrome in the WHO classification ICD-10. Plus:

- Brief information about how many people have the diagnosis in Denmark , and how many are disabled
- Short of physical/anatomical characteristics of the disease,
- Investigation and treatment, and prevention - based on recent research from home and abroad .

After the presentations of each topic there will be a possibility for MPs to aks questions. If time permits, there will be opened up for questions from the audience.

The hearing will be broadcast by TV-parliament.

<http://www.ft.dk/webTV/Direkte.aspx>

Invitation to the public hearing about functional disorders:

<http://bit.ly/NesBPU>

**Helle Rasmussen**

# News from... USA

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## Mount Sinai, New York

**Dr Enlander** received **\$1,000,000** from one of his patients allowing him to set up an ME center at Mount Sinai Medical Center , Icahn Research Building, Madison Avenue/ 98th Street, New York.

The name for the center is the **Mount Sinai ME CFS Center** , New York. This is the first ME CFS center that has been set up by a major medical school in the world.

The ME CFS Center is a multidisciplinary clinical and research Center, with specialists in clinical diagnosis of ME CFS, immunology, genetics, Pulmonary physiology , virology and RNA/DNA radical research. Two conferences have been held by the center last one being a few months ago in November.

These conferences showed cutting edge research and clinical diagnosis of the disease. International and American patients are seen daily for diagnosis and treatment.

Skype and telephone consults are now routinely available, appointments for these can be made at

212-794-2000

or by email [mecfsOFFICE@enlander.com](mailto:mecfsOFFICE@enlander.com)

## OMI, Mountain View, California



The Open Medicine Foundation met their goal of raising over \$150,000 for a study into the benefits of using B12 and Folate supplementation for a simple and inexpensive treatment to reduce fatigue and cognitive issues in ME/CFS patients with certain gene mutations (including MTHFR), one found in many ME/CFS patients.

**Dr. Andy Kogelnik** and **Dr. David Kaufman** of the Open Medicine Institute will lead the study.

# Children with ME as test subjects – an ethical warning (Norway)

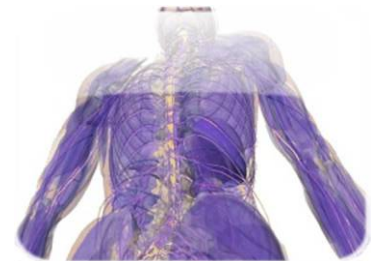
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We are several ME-moms (and -dads) who for a long time have been concerned about the way our children are met at the National center of ME/CFS expertise (Department of Pediatrics, the Oslo University Hospital). To redefine a serious physical illness as psychosomatic is a serious matter, an opinion we have expressed earlier (please use google translate to read).

We are not only concerned about the attitude toward our children's disease at the University Hospital. The so-called "treatment" our children are offered in line with their "sustained arousal theory", is of great concern to us as well. Not only trials with graded exercise, cognitive treatment (including the highly controversial "Lightning Process"), but also trials of potential "stress-reducing" drugs. The medication now in question is Clonidine. Clonidine is a medical drug that blocks the sympathetic nervous system's adrenergic activity and is considered to reduce bodily distress. The hypothesis is that "patients with CFS have enhanced sympathetic activity and that sympatho-inhibition by clonidine would improve symptoms and function."

In line with this theory, the scientists have for a long time been giving other types of blood pressure reducing drugs (beta blockers) to several children suffering from ME, with little or no positive effects as far as we have observed. We also have reason to believe that there has been a lack of follow-up of these children, since none of them, to our knowledge, have been summoned for medical follow-up after starting on this medication. This alone is of medical concern as far as we can see.



Regarding Clonidine – how could the scientists choose to use children when they were testing this drug, knowing that this drug has potential serious side effects (which are also the case for beta-blockers) and is generally not recommended for children at all?

"Not recommended for children and adolescents. Serious side effects, even lethal, are observed when clonidine is combined with methylphenidate for children with the unapproved indication ADHD. [...]"

(Excerpt from The Norwegian Pharmaceutical Product Compendium 2011, my translation and highlighting.)

The fact that a drug trial is performed primarily on children without testing on adults with the same diagnosis is a highly uncommon medical practice as far as we know, a practice we consider both irresponsible and unethical. (Declaration of Helsinki) This is the reason why for instance rituximab, another, – and

considerably more promising, drug now being tested on ME-patients, has to await testing on children until results are available from the testing on adults.

We have also seen speculations raised in the Norwegian medical community whether Clonidine should be used in the treatment of ME at all. The blogger SerendipityCat quotes the neuropharmacologist **Sturla Molden** (University of Oslo) who writes that this drug actually can give the opposite results from the expected by increasing an auto-immune process in the body, and that this medical trial is in his opinion is highly unethical and valueless, as discussed here (please use google translate to read).



The hypothesis that ME-patients should have a sustained bodily arousal is also highly speculative and controversial, in our opinion. Research done including «pure» ME-patients selected by strict criteria (ICC) has shown that these patients have substantial biomedical changes in their bodies. Such changes have been described by several medical experts, including **prof. Anthony Komaroff** (The Physical Basis of CFS) and, recently by **prof. Ian Lipkin** and co-workers (only preliminary results), who in a large examination of specimens from several hundreds of ME-patients have discovered interesting findings suggestive of a continuous stimulation of the immune system leading to an overactive immune response.

One of the major concerns in ME-research in general, and not the least in this Norwegian trial from The Oslo University Hospital, is the use of non-strict criteria in diagnosing ME;

«In agreement with clinical guidelines,<sup>2,32</sup> we applied a broad case definition requiring 3 months of unexplained disabling, chronic/relapsing fatigue of new onset [...]. We did not require that patients meet any other accompanying symptom criteria.»

This means that the research team probably included patients with several stress-related conditions in addition to those suffering from ME. This is of concern not only ethically, but also makes the interpretation of the results difficult. This fact has also been noted by the medical press, commenting upon the Norwegian trial (the clonidine trial in News Daily). See also a discussion about diagnostic confusion by the Norwegian author **Jørgen Jelstad**: Diagnoseforvirringen (in Norwegian).

Despite mainly “negative” findings, the Norwegian scientists have now published the results of the Clonidine trial and an additional trial (in Norwegian) where they examined the effect of Graded Exercise (GET). Despite the chance of a highly diverse mix of patients, they have not been able to confirm their hypothesis of “sustained arousal”. (Fortunately, we must say).

The fact that a highly speculative hypothesis has lead to drug testing directly on children, as we have been witnessing in this trial, is, in our opinion, frightening and alarming and we therefore find it important to shout out a warning!

By Frustrated ME mum, MD, PhD

Share by using this url: <http://wp.me/p3VLNe-cM>

# P2P: “Patients to Purgatory” or the Jury Model Stood on its Head (USA)



*"They don't know. They don't know anything." - **Susan Maier**  
about the P2P panel members*

On January 27, 2014, the Institute of Medicine (“IOM”) held its first out of five meetings relating to the development of diagnostic criteria for ME/CFS. It was a two-day meeting, with half of the first day being open to the public. Several government officials gave reports during the open part of the meeting.

**Susan Maier**, Deputy Director of the Office of Women’s Health of the Department of Health and Human Services, gave the NIH report on the so-called Pathways to Prevention (“P2P”) program currently underway relating to ME/CFS research—parallel to the IOM effort—which will culminate in about 12 months in a workshop in which an appointed panel will (1) receive the report of an evidence-based review/report by the Oregon Health and Science University (“OHSU”) (under a task order from NIH), (2) listen to presentations of the government and experts and (3) then deliberate and write a report of recommendations to the NIH within 24 hours of the end of the workshop.

In response to a question from an IOM committee member, **Susan Maier** described the workshop as based on the “jury model” that requires the exclusion of any clinician or researcher who has any experience with ME/CFS. Here is what she said:

“It’s a jury model. You have the defense, you have the prosecution; they both know the case really well. They know the details, they know what’s going on, they know all the nuance, they know what’s going on in media. Your jury is sequestered. **They don’t know. They don’t know anything.** ... The jury hears the evidence. And they make their decisions based on the evidence. That’s essentially the difference between the workshop speakers, the evidence report and the panelists.” [emphasis added]

Deep breath! So, NIH really believes that designing the P2P workshop to be analogous to a jury trial is a valid method. Experts and government officials with varying points of view will present their views at the workshop, which **Susan Maier** likened to the prosecution and defense in a trial. Then the P2P panel, made up—by design—of those with no expertise or prior research or opinions on ME/CFS AT ALL, will take the evidence report of OHSU and the comments of the presenters—the “prosecution” and the “defense”—and deliberate and issue their recommendations in writing within 24 hours (!)



I must say, when I heard **Susan Maier** give that explanation, with a completely straight face and an obvious expectation of everybody to consider this approach sane, I just about fell off my chair. I found myself shaking my head violently. I even uttered the word “Noooo!” under my breath.

I find it hard to capture in words the absurdity of this approach for what Susan Maier described as “focus[ing on the] improve[ment] of science.” Let me add: the improvement of science for an incredibly complex disease, not that I am advocating this model for any other disease. The jury in the American justice system exists in order to assess the facts, not develop or interpret the law. The law is given to the jurors by the judge, who also serves as an impartial screener of the evidence presented by the parties for bias, relevance and many other factors. The outcomes of jury trials do not have any precedential value for future trials or the law.

In the P2P process, the jury model is stood on its head entirely. There is no judge to explain to the P2P panel of non-ME/CFS experts what the “law” is or to screen the evidence presented by the OHSU or the presenters at the workshop. Rather the panel is supposed to determine and confirm what the “law” is from what undoubtedly (or maybe hopefully) will be an abundance of highly technical information presented by OHSU in its evidence review.

This all happens in in an incredibly abbreviated period of time. As Susan Maier said, “**We have a enough content for a five-day meeting. We have to cram it into two days.**” (emphasis added) Even juries in a trial get to deliberate for several days or even weeks and don’t have to write a detailed report in that time.

The powers that be within NIH dragged their feet for 30 years—ignored us, harmed us, tried to sweep us under the rug—and now they can’t spare three additional days on a quality workshop? Not that even five days would be sufficient for a complex disease such as ME/CFS.

According to **Susan Maier**, the “goal of P2P is ... to review the evidence.” This evidence will then be applied to all future government-sponsored research of ME/CFS. This is like asking a jury in a murder trial to listen to the evidence as presented by the prosecution and defense, unfiltered and unclarified by rulings or instructions from the judge, and to develop, within 24 hours, a set of definitions and criteria for what constitutes first degree murder, second degree murder, manslaughter and negligent homicide. These will then be applied in all future murder trials.

This is the opposite of the scientific method! And talk about giving the jury model a bad name!

**Albert Einstein** and **Clarence Darrow** would turn over in their graves.

**Jeannette Burmeister**

<http://bit.ly/1gc6Dph>

# The IOM attempt to define ME/CFS

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Stigma and Prejudice. These two words have been the defining characteristics of ME and CFS for the last 26 years, since the official invention of 'Chronic Fatigue Syndrome' or CFS in 1988. The current IOM meeting in the USA to define ME/CFS represents another important milestone in this long running saga. It remains to be seen if important issues of scientific and medical negligence, errors, omissions, deceptions, misdirections, and criminal misconduct in the past will be addressed or remedied by the IOM and it's senior partner the Department of Health and Human Services (HHS).

The insulting and derogatory name 'Chronic Fatigue Syndrome' or CFS and its suggestion of being merely tired has trivialized the illness and destroyed millions of lives worldwide. It was constructed in 1988 and re-defined in 1994 to describe an ME type epidemic in Lake Tahoe, Nevada. Strangely, the biomarkers from the Lake Tahoe and Lyndonville outbreaks and other clusters were deliberately omitted from the CFS definition in 1988 and again in 1994.

Thus the very basis of the illness was deliberately ignored in the two definitions. So many scientific research findings were ruled to be "inconclusive", biomarkers alleged to be "inconclusive" and no biomarker would be accepted for CFS. The very basis of science itself was undermined by the poor quality CDC criteria. The vagueness and lack of clarity of the CDC criteria enabled psychiatrists to hijack the term CFS and claim it as psychiatric. The Oxford criteria for CFS developed in 1991 in Britain took full advantage of the deficiencies in the CDC 1988 criteria and enabled some unscrupulous psychiatrists to convert CFS into a psychiatric illness.

In September 2013, the Institute of Medicine was contracted by the US Department of Health (HHS) to develop a definition for ME/CFS. This was done in secret, with no consultation with patients, advocates or CFS organizations in the USA. This appeared sinister and created uproar in the CFS community in the USA and abroad. The US Department of Health (HHS) cancelled the contract as a result of this uproar. However a few weeks later, they renewed the contract with the IOM much to the surprise of many patients and organizations.

This provoked a furious backlash from patients throughout America and the world. **A letter was drawn up by CFS advocates and signed by 50 of the top ME doctors and scientists in the world, asking the US Secretary of Health, Kathleen Sebelius to immediately cancel the IOM contract and adopt the Canadian criteria (2003).**

The support of these 50 medical doctors and scientists was a radical new development, unprecedented in the history of CFS or ME. Another letter was drawn up and signed by 171 patients and advocates from across the USA and the world and sent to the US Secretary of Health, Kathleen Sebelius concurring with the aforementioned letter signed by the top 50 ME doctor and scientists.

There was optimism in the global ME and CFS community that the Secretary would take this matter seriously and engage with patients and work on a solution to this impasse. Intriguingly, Secretary Sebelius chose to ignore them and force through the IOM contract. The IOM proceeded forward against the wishes of most patients, organizations and the top ME doctors and scientists.

The IOM were reminded they were guilty of conflicts of interest and bias as a result of prior studies into Gulf War Syndrome where CFS and ME were mentioned as being part of Gulf War Illness and classified as somatoform disorders and psychiatric illnesses. I for one informed the IOM that it's official and legal position on ME and CFS was clearly and consistently stated in IOM studies from 2000 to 2013. This created obvious institutional conflict of interest.

**David Egan** directly engaged the IOM about this in several letters and also pointed out that the scientific evidence into ME and CFS was deliberately ignored and omitted by the IOM in studies between 2000 and 2013. He also submitted a list of those ME and CFS patients who died of medical neglect and

the health complications caused by the illness. The Office of the Inspector General wrote back in late December claiming that there was no conflict of interest and that the original contract had been changed from a fixed service contract between HHS and IOM to a task order contract between NIH and IOM.



Despite this, organizational conflict of interest persisted, but the Office of Inspector General has chosen to ignore it.

**Jeanette Burmeister**, an ME patient and lawyer, also pointed out the obvious conflicts of interest to the IOM and HHS and also to the Office of the Inspector General for Health services in Washington DC. , and has issued legal proceedings in court for documents under the Freedom of Information Act in the USA. This may form the basis for future legal actions. Ultimately, we as ME and CFS patients will have to fight for our human rights as we have been let down, lied to, and neglected for too long by government bodies.

The first IOM meeting to define ME/CFS was held in the Keck center in Washington DC on January 27<sup>th</sup>, 2014, and was broadcast over the Internet to an international audience. It included a few well known ME and CFS doctors such as **Klimas**, **Bateman**, **Lerner**, **Chung**, and the well known **Nancy Lee** of the CFSAC.

The only useful information provided at this meeting was from patients and advocates towards the end of the meeting.

**Mary Schweitzer** provided a great description and analysis of the illness, and its effects on her for many years. She clearly stated that ME is a biological and physical illness and mentioned the need for more thorough diagnostics to identify the various infections and immune dysfunctions commonly found in most CFS patients. She also expressed disappointment with the FDA and the need for treatments such as Ampligen and other anti-viral and immune system modulators which desperately need to be legalized and made more available for patients. Gabby Klein emphasised the point that ME is a biological, neurological and immune system illness.

**Susan Kreutzer** echoed these sentiments while reinforcing again the fact ME and CFS are not psychiatric illnesses, and that proper diagnostics and treatments are desperately required.

**Jeannette Burmeister** reminded the IOM that conflicts of interest still exist and that legal proceedings had been initiated.

Overall there was a strong forthright and consistent message delivered by ME and CFS patients to the IOM and HHS.

One has to wonder what actions will result from this? The Gulf War Illness debacle started out well at the IOM and ended in disaster with psychiatrists inventing and taking over 'multi symptom illness' and one well known CFS advocate supporting this nonsense.

Hidden agendas have always existed, and one must expose and shine light on them. For over 20 years, the patients have been ignored and neglected and important scientific and medical evidence dismissed, are we going to see a sudden change in direction, a new honesty, transparency and accountability?

**David Egan**

# How "Chronic Fatigue Syndrome" Obscures A Serious Illness

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An abstract of a beautiful and transparant survey article by the New York Times-journalist **David Tuller**.

Read the full article on  
<http://bit.ly/1gNshlz>

Ten years ago, **Jeannette Burmeister** was working full throttle, logging 80-hour weeks as an attorney specializing in international commercial and employment law at the San Francisco area offices of a major law firm. So when she developed a sinus infection over the Christmas holidays in 2005, she assumed she'd bounce right back. But she didn't. The illness persisted; Burmeister then began suffering from profound lapses of energy, crippling problems with concentration and memory, and severe sleep disorders, among other symptoms.

In recent months, her blog has doggedly tracked the creation of a new, federally commissioned panel charged with reviewing and updating the diagnostic criteria for the disease. The Department of Health and Human Services announced in September that it had requested the Institute of Medicine, an independent, highly regarded affiliate of the National Academy of Sciences, to conduct the study. At a public hearing in Washington, D.C., on Monday, Jan. 27, **Burmeister** told the members of the panel why she thinks their project stinks.

The recent round of activity involving case definitions began in fall 2012, when the Chronic Fatigue Syndrome Advisory Committee — a body created under the auspices of the Department of Health and Human Services to provide guidance on the issue — recommended that the agency convene a workshop to nail down definitive case definitions for both clinical care and research.

The 2012 recommendation of the Chronic Fatigue Syndrome Advisory Committee to the Department of Health and Human Services included two key elements: that the workshop to develop the research and clinical case definitions should be for stakeholders in the ME/CFS field, specifically doctors, researchers, and patients, and that it should adopt the Canadian criteria as the starting point for making adjustments.

**Mary Ann Fletcher**, a member of the Chronic Fatigue Syndrome Advisory Committee who strongly supported the recommendation for a committee of experts, said she was totally baffled by the health department's action. "***This was not ever our recommendation, so I really can't explain why they took us there,***" said **Fletcher**, a professor at Nova Southeastern University in Fort Lauderdale and a leader in immunology research related to ME/CFS.

The protest letter of last fall from several dozen leading experts in the ME/CFS field to **Secretary Sebelius**, in addition to registering overall objections to the IOM effort, also identified the Canadian criteria as the appropriate basis for further refinements. In her response to the experts' letter, **Sebelius** wrote that the IOM approach "was determined to be the most appropriate response" to the Chronic Fatigue Syndrome Advisory Committee's recommendation. She also noted that the Canadian criteria would be considered, along with others.

Many people with ME/CFS are especially concerned because of an IOM report produced last year under a contract with the Veterans Administration on treatments for **Gulf War Illness** — now renamed "**chronic multisymptom illness**." By focusing extensively on stress-related factors and recommending cognitive behavior therapy and antidepressants as the key forms of treatment, the report caused controversy and drew complaints from veterans.

Under the Freedom of Information Act, **Burmeister** has requested documents relating to the IOM project and the institute's contract with the Department of Health and Human Services, hoping they would shed light on the federal agency's decisions and intentions. So far she has not received them, which is not unusual; federal agencies often take years before producing actual documents in response to such requests. Undaunted, **Burmeister** this month filed a lawsuit against the department charging it with violating the Freedom of Information Act.

Source: <http://www.buzzfeed.com/davidtuller/chronic-fatigue-syndrome>



# Sign These Petitions

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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/1itYO0i>

# 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: \$3,313.00      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://bit.ly/MhhQLT>



## **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 £285,000.

The goal is £ 350,000.

To donate: <http://bit.ly/1dc1wmS>

## **HealClick: Patient Matcher**

Matching patients to help them share

**Joey** and cofounders **Cari Allshouse** and **Beth Mazur** turned this vision into **HealClick**, a website that uses patient-matching to make sense of all the treatment reviews shared online. "First, patients use our tracking system to share basic biographical info, conditions, symptom ratings, and treatment ratings. Then we match them up by how much they have in common! Now they can see treatment reviews from their best patient matches."

All this data will be used for medical research after we make it anonymous.

<http://bit.ly/1d6zY22>



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

# Worth reading & watching

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## ***A Sudden Illness - How my life changed***

<http://www.cfids-cab.org/MESA/Hillenbrand.html>

A beautiful article on how **mrs. Laura Hillenbrand** fell suddenly ill, her long path towards recognition and how it changed her life.

## ***ME/cfs Alert/White House Chronicle***

**Mr. Llewellyn King** has again produced some very interesting episodes of ME/cfs Alert, being Episode 54 (<http://youtu.be/qPMq46Rb0G8>), **prof. Andy Kogelnik** addressing an audience in Washington during the presentation of **Ryan Prior's** Blue Ribbon Project, and Episodes 55 (<http://youtu.be/sbHtPVXVAIY>) & 56 (<http://youtu.be/ap5dzdXuDBc>) ,

**Llewellyn** interviewing **Andy Kogelnik** on different topics, amongst others about the present state of affairs re. recognition of ME/cfs, and the diversity of researches going on.

**Llewellyn** is also host of the tv-program **The White House Chronicles**, with co-host **Linda Gasparello** and which is broadcast on PBS. He recently took an interview from **Mary Dimmock**, ME/cfs-activist who formerly worked within the pharmaceutical industry: <http://bit.ly/1jME97Q>

He also shed light on the HHS/IOM contract in his beautiful column Getting a seat at the table

<http://www.whchronicle.com/2013/10/getting-a-seat-at-the-table/>

Moreover **Llewellyn King** is looking for funds to be able to continue his series with ME/cfs Alert which are very informative with many outstanding scientists. (> funding)

## ***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](mailto: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.

## **Twelve reasons why you should choose to live with severe ME**

- ✚ you are a beautiful person
- ✚ your life is precious
- ✚ giving in and choosing death means the culture of death and denial wins
- ✚ there is always hope of a better moment
- ✚ there is always hope of a biomedical breakthrough
- ✚ It is not your fault that you are ill and you should not blame and punish yourself because you are struggling to cope
- ✚ suicide and euthanasia cause massive harm in the impact on other people emotionally, mentally, even lead to more suicide and death
- ✚ there is always something you can change however small that might make a difference
- ✚ the illness is huge but you are bigger than it
- ✚ you can rethink the way you are living and make different positive choices to accommodate your difficult reality. Even small things can make a big difference
- ✚ feeling you want to kill yourself is not the same as actually doing it
- ✚ you can be kinder to yourself and validate how amazing you are to be living in such difficult circumstances, not hurt yourself more

From: Severe ME (Featuring Justice for Karina Hansen) – **Greg Crowhurst**

More info & way to purchase: <http://www.stonebird.co.uk/severemebook/severeme.html>

## **ME/CFS - Nationally Syndicated "Jim Bohannon Show"**



On Friday, January 23, 2014, **Dr. Andy Kogelnik**, **Ryan Prior** and PBS's **Llewellyn King** appeared on "The Jim Bohannon Show," which is carried on 500 radio stations in the United States.

The following is a 15-minute discussion on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, a severe neuro-immune disease affecting a million Americans and 20 million people worldwide.

Play Radio Broadcast:

<https://soundcloud.com/ryan-prior-1/jimbo>

# Value

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Now I value my life  
Though nothing is the same  
So much has been stolen  
Yet here I still remain

How I value myself  
This person deep inside  
Although my life has changed  
The real me is alive

Did I value my life  
Before illness arrived?  
I thought I was dying  
But somehow I survived

Now I value my life  
It's so precious to me  
And I go on living  
Despite having ME

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( My A-Z of M.E.-ebook, [www.amazon.co.uk](http://www.amazon.co.uk))

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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](mailto:subscribe@let-me.be) - Visit our website to subscribe to this newsletter or to download previous <http://let-me.be> -

Contact us at [info@let-me.be](mailto:info@let-me.be)

Picture front page: The international ME community logo, a global outlook (by Eddy Keuninckx – idea David Egan)  
Cartoon page 31: Djanko