



ME



GLOBAL

Colofon / Personalia



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The editorial team doesn't accept any responsibility for any possible incorrect information that it has been supplied with and which has been published in this monthly issue.

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Textual contributions for the February issue need to be supplied in Word by 12 February and sent to: contribute@let-me.be

The next issue will come out on 27 February 2014.

Presently we are:

Eddy Keuninckx, Belgium, an ICT projectleader that became disabled since December 2011 at the age of 52. He's been diagnosed with CFS and Fibromyalgia and some other diseases. At first they thought he had a burn-out and his impression is that most of the doctors still have that idea. To be diagnosed would have brought any kind of treatment or cure, he thought. But when he asks his doctors about ME, most of them are unaware of this disease. So as a problem manager he always says: there are no problems, only solutions, we just have to find them. Participating in the creation of "The ME Global Chronicle" is one way to help to find a solution.

Richard Podell, M.D., U.S.A., a graduate of Harvard Medical School serves as clinical professor in the Department of Family Practice at New Jersey's Robert Wood Johnson Medical School. He has had a special interest in CFS-ME and in Fibromyalgia for more than 20 years. He will be a permanent contributor of the new international newsletter, the Global ME Chronicle by submitting reviews of scientific researches and as a corrector.

David Egan, Ireland, chair to the Irish Campaign for an Irish ME clinic-association, , has been diagnosed with ME in 2002 following a severe viral illness, chronic mononucleosis and was also diagnosed with severe allergy to mold. A graduate of Oxford University in England and National University of Ireland, Galway, he had a good career in Information Technology and computers until 2003, when he became unable to work anymore. He has put a lot of effort into researching the illness and working with other ME patients to get an ME clinic in Ireland. And to get ME accepted as a physical, neurological and immune system illness.

Djanko, Holland, is a professional Dutch cartoonist for more than 25 years. His work has been published in many media and books. Characteristic for his work is a simple drawing style and his sense of humor. He tries to relief the pain of mankind by looking for a smile behind the pain. Since many years he has been drawing cartoons about ME in magazines for ME-patients.

Rob Wijbenga, Holland, chair to the Dutch ME/cvs Vereniging, coordinator project Science to Patients, became involved in ME when he met his second wife Karen, who was bedridden at the time, but turned out to have the most severe form of ME. For more information: http://www.youtube.com/watch?v=-pDw-ClcNGE&feature=share&list=UUxrPmgVwJ7-gLqZJK_qLeFg&index=10

About Sharing And Combining Forces

Dear reader,

This is the first issue of a broadly supported international newsletter, which we have named ME Global Chronicle.



Firstly, we would like to urge you to please share this newsletter as much as possible.

If you represent a group of patients, please share this newsletter with them and ask them for feedback. If you are a doctor, researcher and/or scientist, please do share the newsletter with as much colleagues as possible and via all your channels of communication.

This is the only way the twofold theory behind this chronicle can take shape:

* Information about recent or upcoming events can be found everywhere on the internet, but is scattered about. We think it's a good idea to combine this info and centralise it, thus preserving people's searching-energy.

* ME has struck millions all over the world and an unknown number of our friends are slowly dying of it. Seeing that national governments usually have their own, isolated policies, we believe that acknowledgement of ME as a very severe disease will only come closer if we make our voices heard from many countries.

That's why we can't emphasize enough to share everything. Let's share our knowledge and combine our efforts, abilities and talents. Only then will we reach our common goal.

So share and give us your feedback and input.

Content for the February Chronicle needs to be sent to us by February 12th. Do not be shy in giving us your well-founded criticism. Affirmation of our initiative is welcome of course too. We like to know what you think!

We hope you enjoy the read.

The editorial team

Rich' Reviews: Powerful New Evidence That Chronic Fatigue Syndrome (CFS) And Fibromyalgia (FM) Are Real And Mainly Physical



Key Article: 1 Light, A et. al. Gene expression alterations at baseline and following moderate exercise in patients with Chronic Fatigue Syndrome and Fibromyalgia Syndrome. J Intern Med. 2012 Jan;271(1):64-81* Web address for complete paper is <http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2796.2011.02405.x/full>

Alan Light, Ph.D, Lucinda Bateman, M.D. and colleagues from the University of Utah School of Medicine measured messenger RNA output from 13 selected genes both before and up to 48 hours after 25 minutes of exercise on a stationary bicycle.

The subjects included 48 patients with CFS with or without co-occurring FM. 18 Patients who had FM but not CFS and 49 healthy controls. The 13 genes monitored relate to sensory nerve signaling, cytokine and immune function and the sympathetic nervous system. Gene activity was inferred from the level of messenger RNA derived from each gene as expressed on the subjects' white blood cells.

Results: All CFS and FM patients reported increased symptoms of pain or fatigue throughout the 48 hours post exercise. In controls, there was no reported fatigue and no significant change in gene expression. In 71% of patients with CFS, whether with or without co-occurring FM, moderate exercise increased messenger RNA output from 12 of the 13 genes.

In the other 29% of CFS patients exercise caused decreased transcription of messenger RNA from an adrenalin related gene. Many of these patients had a clinical history of orthostatic intolerance. In contrast, the FM-only patients showed no post exercise changes in gene expression.

Significance: This is one of a very few studies that identified an objective laboratory marker which closely correlates with the patients' complaints of a prolonged increase symptoms after modest exertion. This is very important both politically and as a guide toward future research. Two different subgroups of CFS patients were identified. FM co-occurring with CFS may be mechanistically different from FM that occurs without major fatigue.

**The web version of the article was published in late 2011. The print version is from early 2012.*

Richard Podell

Bristol, UK



Bristol Watershed Event

When: February 4, 6:30 – 9.15 pm

Where: Watershed, Harbourside, Bristol

For whom: anyone who wants to attend.

Enquiries: (p.m. only) North Bristol FME/CFS Support Group call 0844 887 2475
Bristolnorthfm.e@gmail.com

Places are going fast for the Bristol Watershed Event, 'Exercise and ME/CFS – the evidence' on February 4th 6.30–9.15 pm. The main speaker is Prof Mark VanNess of the Pacific Fatigue Lab in California who will discuss the consequences of different kinds of exercise programmes for people with ME or CFS. He will be joined by Dr Nigel Speight, and by Dr Erinna Bowman of the CURE-ME research team. There will also be a showing of a 30-minute version the film 'Voices from the Shadows', and the Question and Answer session at the end will be chaired by Sue Waddle, Vice-chair of ME Research UK.

For further information:

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

Tickets (£ 10,=) available from www.voicesfromtheshadowsfilm.co.uk

Stanford, Ca., USA



2014 Stanford Myalgic Encephalomyelitis/chronic fatigue symposium

When: March 19, 8:30 am – 6.00 pm

Where: Li Ka Shing Center for Learning and Knowledge, Stanford, Ca.

For whom: primary care physicians, family physicians, internists, cardiologists, neurologists, psychiatrists, specialists on infectious diseases, physician assistants, nurses, researchers etc.

Enquiries: Yolanda Cervantes (650)724-9549, ycervantes@stanfordmed.org

Speakers a.o.: Jose Montoya, Elizabeth Unger, Amit Kaushal, Anthony Komaroff, Ian Lipkin.

Panel during lunch Natalie Boulton, David Tuller & Erin Allday on “Media Portrayal of ME/CFS”

For further information:

<http://chronicfatigue.stanford.edu/documents/ChronicFatigueSyndromeCME2014-FORMS-r3a.pdf>

liME – Invest in ME

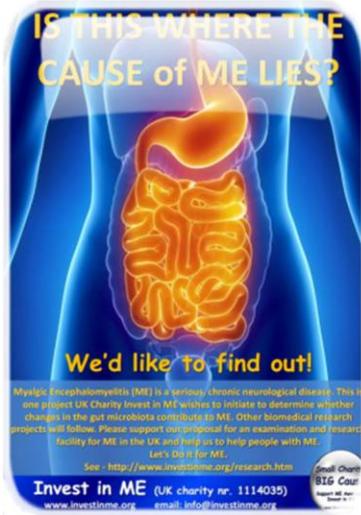


9th International ME-conference

When: May 30, 9:00 am- 5:30 pm

Where: 1 Birdcage Walk, London, England

For whom: researchers & specialist in ME, GP's, neurologists, immunologists, virologists, palliative care/community nurses, occupational therapists, specialists in pain management & in care of the chronically ill, ME Support Groups and charities



Speakers: Jonathan Edwards, Julia Newton, Mady Hornig, Sonya Marshall-Gradisnik, James Baraniuk.
Additional speakers will be announced.

For further information:

<http://www.investinme.eu/Documents/Leaflet%202014.pdf>

Invest in ME (liME) was set up with the objectives of making a change in how ME is perceived and treated in the media, by health departments and by healthcare professionals. We aim to do this by identifying the three key areas to concentrate our efforts on - funding for biomedical research, education and lobbying. Invest in ME aims to collaborate and coordinate events and activities in these areas in order to provide the focus and funding to allow biomedical research to be carried out

Our efforts are focused on setting up a UK Centre of Excellence which will provide proper examinations and diagnosis for ME patients and a coordinated strategy of biomedical research into ME in order to find treatment(s) and cure(s).

Invest in ME have no paid staff - all work is performed for free by volunteers.

Blue Ribbon



In the spirit of a true grassroots organization, The Blue Ribbon Foundation started as an idea, which manifested into a documentary (The Blue Ribbon: ME/CFS and the Future of Medicine), and eventually shaped a movement.

The Blue Ribbon Foundation's mission is to foster a national public dialogue that can lead to finding the cause, cure, and prevention of neuro-immune diseases.

The Foundation's current programs consist of:

-Producing the documentary feature film The Blue Ribbon: ME/CFS and the Future of Medicine.

-Administering the Blue Ribbon Fellowship for medical students to study ME/CFS at premier neuro-immune institutes

-Grassroots fundraising and community-building activities via the Step Up for ME program.



On Friday January 24, 2014, the initiator of the Blue Ribbon Foundation, Ryan Prior, accompanied by infectious disease researcher Dr. Andreas Kogelnik, discussed his plan to tackle the lack of understanding about Chronic Fatigue Syndrome among doctors by embedding medical school students for 10 weeks with specialists. They have also discussed the pioneering work being done on Chronic Fatigue Syndrome at Kogelnik's Open Medicine Institute in Mountain View, CA.

The event took place at The National Press Club, Washington, DC and has been facilitated by Llewellyn King, executive producer and host, "White House Chronicle" on PBS and columnist, Hearst-New York Times Syndicate (see hereafter).

Washington Press Event Breaks Ground



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 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.

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.

Prior, who must swallow a cocktail of 20 pills a day, get an injection one a week and an infusion once a month, says he is one of the lucky ones who can function most of the time. To promote his medical student-embed program, he founded the not-for-profit Blue Ribbon Foundation. He is producing a documentary on ME.

Kogelnik said that the disease is sometimes referred to in medical schools, but only in passing. He said it was important for the students to intern early because their third year of medical school, they already begin to specialize and it might be too late.

There are some states where there are no specialists at all, and it is very hard to get a diagnosis of any sort. Prior said he went from doctor to doctor before he got help. “I am one of the lucky ones who found the right doctor, who was able to help me. My heart goes out to the many who are never correctly diagnosed,” he said.

Kogelnik said this was particularly terrible in the case of very young children who while incapacitated by ME could be thought to be slow-learners. In some cases, this led to them be diagnosed as being autistic, although he did not absolutely rule out a relationship between ME and autism.

The night before the press briefing Kogelnik, Prior and King appeared on “The Jim Bohannon Show,” which is carried on 500 radio stations. Following the press briefing, Kogelnik and King were interviewed on Sirius XM Satellite Radio, which is available throughout the United States and most of Canada.

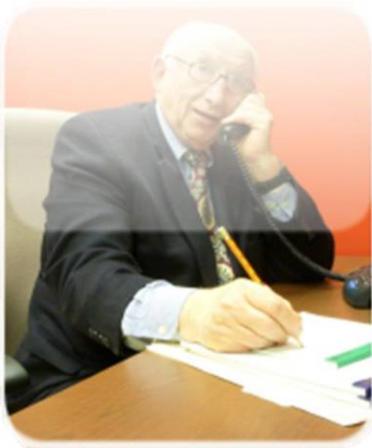
King said he had talked to important media outlets that expressed interest but were unable to attend. These included C-SPAN, The New York Times and Reuters.

King pointed out that a week earlier, “White House Chronicle,” the weekly news and public affairs program on PBS which he hosts, had been completely devoted to a discussion of ME with activist Mary Dimmock. That program aired on 200 television stations in the United States and worldwide on Voice of America Television. An audio version of the show aired three times on Sirius XM Radio's popular POTUS (Politics of the United States) Channel 124.

During the press briefing, Kogelnik said there were no magic bullets in fighting a disease like ME and he emphasized the need for research at the molecular level.

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.”

He added that “just because this disease is hidden-in-plain-sight, it does not mean that there is not terrible suffering and a moral and human imperative for action.”

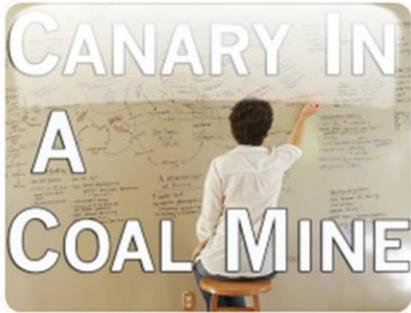


In June 2011 King and a friend, Deborah Waroff, created a YouTube Channel, ME/CFS Alert, to “comfort the sick, educate the doctors and shame the government.”

There are now more than 50 videos on the channel.
<http://www.youtube.com/user/MECFSAAlert/featured>

Earlier this month, he began raising money to continue making these informative videos -- filmed by award-winning videographer Barry Worthington, featuring interviews with specialists and patients -- on
<http://www.gofundme.com/5yhjdo>.

Canary in a Coalmine



A film about life with M.E., the most prevalent and devastating disease your doctor has never heard of. On Indiewire, this project won a creative consultation with the kind folks at the famous Tribeca Film Institute.

Jennifer Brea (Director/Producer), Kiran Chitanvis (Producer/DP), Blake Ashman-Kipervaser (who produced THE LOTTERY), Deborah Hoffmann (Complaints of a Dutiful Daughter).

"I was a PhD student at Harvard when I came down with the worst flu of my life. A year later, I was signing a check at a restaurant and found I could not write my own name.

Months before my wedding, I became progressively more ill, losing the ability even to sit in a wheelchair. Some doctors insisted my condition was psychosomatic rather than real. This film is my answer to them and my love letter to anyone who has ever suffered from a chronic illness no one could see."

Canary in a Coal Mine is a documentary film about Myalgic Encephalomyelitis ("Chronic Fatigue Syndrome"), one of the world's most misunderstood diseases.

It is a story about a medical system that is ill-equipped to treat an illness that challenges its every assumption, the danger of ignorance, and the power of a name.

It's the history of a community of millions that to most of the world is invisible.

This project was funded on November 23, 2013 by 2.593 backers that pledged \$212.962, which is 425% of the initially needed budget to produce the documentary.

For Jennifer Brea, basic tasks like brushing her teeth and taking her medication are debilitating.

"I would describe it like being a broken battery, where every time you try to charge me, you know, I maybe fill to 5 percent," she said. "I think the thing that is really hard to understand about this illness is just how much it takes away from you and how so many of the basic things that make one feel like a human being just become impossible."

Brea is one of at least 1 million Americans with ME, the vast majority of whom are women. It's a devastating disease that still puzzles doctors, and only a fraction of sufferers are properly diagnosed. Once derided as "yuppie flu," ME (CFS) actually cuts across all races and economic groups. But it still battles a heavy stigma, and research funding is scarce. Thirty years after its first discovery, there is no single diagnostic test and no treatment.

More at this link:

<http://america.aljazeera.com/watch/shows/america-tonight/america-tonight-blog/2014/1/3/1-million-americanshavethisdebilitatingdiseasewithalousynome.html>

OMI, Mountain View CA



We hope to make a lot of announcements regarding research starting this year. We have a lot on the table but the funded ones that are in progress and beginning are as follows:

- 1. Multi-Site Clinical Assessment of ME/CFS – Year 3.** Open Medicine Institute is the coordinator for 5 of the sites of the CDC's 7-site clinical assessment project of ME/CFS to better define the illness. Year 3 just began for this study funded by the CDC.
- 2. OpenMedNet, OMI's Enhanced Data Platform** is on track for release in early 2014. This will help gather medical data regarding treatment successes and failures as well as open the door for answers as commonalities between illnesses are studied.
- 3. DNA Genetics study –** This study, establishing or refuting a role for genetics and potential heritable risk in ME/CFS is to be completed first quarter 2014.
- 4. Just beginning: In-depth study of 20 ME/CFS patients:**
 - Whole genome sequencing
 - A virome survey of oral viral flora
 - A gene expression study
 - Two proteomic/metabolomic pilot studies
 - Study of Natural killer cells, B-cells, and T-cells
 - Single cell measurements, acetylation and other cellular parameters
 - Breath testing for GI flora
 - Mitochondrial and related pathways that play a role in oxidative stress and energy production
 - Brain/Cognitive Data - unique on-line measurement program
 - Quantified-Self (self measurement) projects using wearable devices
- 5. Crowdfunding efforts are underway for a full-placebo-controlled clinical trial to study B12 and Folate supplementation in patients with and without a MTHFR gene mutation and has already raised over \$81,000 for this project!** B12 and Folate have been shown to reduce fatigue and cognitive symptoms in 20-50% of neuro-immune disease patients.

To join in the Crowdfund, please visit our website at

<http://www.openmedicinefoundation.org/ways-of-giving/current-funding-campaigns/>

More to come for the next newsletter!! It will be a year of discovery ahead!

NSU, Fort Lauderdale, FL

Great news from Florida!



Prof. Gordon Broderick and his group in Clinical Systems Biology recently published a paper on the role of homeostatic drive in men and women and the possibility that this may be contributing to illness persistence in ME/CFS and Gulf War Illness.

Here is the link:

<http://www.ncbi.nlm.nih.gov/pubmed/24416298>

Prof. Gordon Broderick's group is affiliated with the Institute for Neuro-immune Medicine at Nova Southeastern University (NSU) at Fort Lauderdale, FL, with dr. Nancy Klimas as its director.

They just received news that they have been awarded funding by the US Veterans Affairs to study sex-related differences in Gulf War Illness as part of a team grant under the leadership of Dr. Nancy Klimas.



It is their belief that because of the differences in endocrine system separating men and women that these illnesses may require different approaches in each sex. The grant is a two million dollar 4-year project entitled:

“Women vs. Men with GWI: Differences in Computational Models and Therapeutic Target”.

As a senior VA investigator Dr. Klimas is also the principal investigator (PI) on this grant.

Prof. Broderick is co-investigator along with Dr. Mary Ann Fletcher, Cell and Molecular Medicine also with the Institute at NSU.

News from...Holland



Civilian initiative

As mentioned in the predecessor of the Chronicle, the Worldwide Newsletter #3 (<http://www.me-cvsvereniging.nl/sites/default/files/wwn%203-%20nov.%202013.pdf>), on 29 October 2013 a petition of nearly 54.000 signatures was presented to a specially appointed committee of the Dutch parliament.

During the event around the presentation of this civilian initiative to the committee, they shot a tv item interviewing two ME patients.

The ME/cfs Association has provided this item with subtitles:

<http://youtu.be/hAYQwC7Yi70>

Science to Patients

The short webinars that have been broadcasted on our YouTube channel as part of the project Science to Patients, <http://www.youtube.com/user/WetenschapvMEcvsVer>, have received 100.000 views during the fourteen months since the start.

Here are the links to webinars:

#31. ME/cfs and the course of the disease

<http://youtu.be/XgBSZtc-NpU>

#32. ME & Children, part 1

<http://youtu.be/pmBnlZh9GI0>

both by British paediatrician dr. Nigel Speight.

Important! On Friday February 14th dr.

Speight will try to answer your questions on ME and children in an international chat session. No matter what part of the world you are from, you are welcome to attend this chat session.

The chat session will take place between 17.00-17.30 CET. You can participate by using this link: <http://www.me-cvsvereniging.nl/chatvenster>

If it turns out to be possible for our moderators and if the lecturers comply, later on this year several international chat sessions will take place. You will be informed of this through this magazine, among other things.



News From...Belgium



CVS-Contactgroep

During the autumn of last year, this association organized a round of questions among their members to learn more about the problems of ME / CFS and fibromyalgia. When the surveys are processed, the results will be communicated so we get a view of the problems the patients are facing now. They'll also decide then on what steps needs to be taking next.

facebook group "ICARUS-project" Belgium



This facebook group is sending letters to politicians to ask them for their engagement to change the situation in Belgium for ME/CFS sufferers.

Letter can be downloaded from their page (in dutch):

<https://www.facebook.com/groups/202265279960998/215794898608036/>

Tom Mees



In a one-man-action, Tom requested a clarification on why ME/CFS - fibromyalgia -patients can't donate blood to the Red Cross. In a response, the minister replied that ME/CFS is recognized as a disease since April 1st, , 2012. The minister didn't answer on why these patients are excluded as a blood donor.

Wake Up Call Beweging



This movement is supporting several international initiatives. They also go in discussion with the government. On March 14th, 2013 they've sent a petition with **18.369** signatures to the Belgian House of Representatives to request recognition and better medicine through research for ME/CFS.

The WUCB hopes that the ME, CFS and fibromyalgia issues being addressed by the politicians. (This year there are elections for the different governments). They keep pressure high to get hearings into the House or the Senate.

They will organise public meetings to create awareness on May 10th ,2014 in several Belgian cities.

<http://www.wakeupcallbeweging.be/#>

A new impending case of Sophia Mirza?



The Germans' reputation of being thorough in everything they do again seems to turn out to be true – this time at the possible cost of a girl's life. Joanne (which is not her real name) got acute Mononucleosis at the age of ten which was the beginning of a downward spiral into severe ME. Now she is 14 years old and at the brink of dying, after having been “treated” for 8 weeks in a hospital. She was forcibly admitted to a neuropsychiatric ward after massive pressure of the child protection authorities who for a long time already blame the mother for the child's disease.

In the beginning they intervened because Joanne could no longer attend school. At that time mother and child freely admitted themselves to a hospital after their former doctor had urgently recommended this. Their hope to find some help was soon frustrated because the doctors and the nurses were heavily influenced by the Wessely school's ideology. As a consequence of the mistreatment by nurses and doctors Joanne had to be tube fed, became doubly incontinent and was much worse when released home.

Joanne has a definite diagnosis of ME, and in Germany that means that you are forced to physical activity, that you brainwashed you'd just have a psychological disease, that it would be a behavioral disorder and that it would be up to you to become better. When forced into hospitals you are (of course) not provided a light and sound protected room, and the stressful hospital environment alone will make you worse. The Wessely school's ideology permeates each and every textbook and guideline so that almost all doctors and all social workers and judges follow the “treatment” recommendations of the Wessely-Fink-White-Henningsen-Rief-Crawley-Wearden-Bleijenberg-Knoop etc. school. And when they inevitably fail with their “treatment” approaches they deny to see the reality and blame the patient or, in case of children, the mother. It would be her who by means of “psychodynamics” (in the dark ages they would have called it witchcraft) would make her child ill. They call it Münchhausen by proxy syndrome or pervasive refusal syndrome or whatever.

Joanne's mother always cared for her only child with utmost dedication and love, literally day and night, 24/7, and when she had Joanne at home again she tried to undo the damage that was done by that hospital “treatment”. Because she was always under the surveillance of the child protection authorities they started accusing her of “overprotecting” her child, of “loving her to death” and of “tenderly abusing” her when Joanne deteriorated. Finally she had to be tube fed again. They persecuted her and harassed her with imposts and orders, and after a court decision she practically had lost custody and was submitted to the orders of the child protection authorities who supervised the girl's health care.

It is a perverted world in which (not only) this mother and child have to live: while the mother mounted everything to help her child they were completely left alone by the medical and social system – in the end they had no doctor willing to care for the child

at home, no mobile nursing service would come to help with tube feeding or drawing blood for lab tests, let alone helping with any kind of treatment like IV infusions. Yet it is the mother who is now accused by the hospital doctors of almost having killed her child by not giving her food and fluids. They would not listen to the mother that she had desperately searched for help and had found none. They prefer to twist things around: it is not the medical system that failed this terribly ill child and her mother – in their perverted view it is the mother who is guilty and failed her child's essential needs.

Last summer, Joanne had a reactivated EBV infection and became again very ill. Finally, she was in such a bad condition, that she couldn't even be nourished by tube feeding. She vomited all the time and had lost so much weight that she was in a life-threatening condition. In her despair the mother had called a doctor whom the child's grandfather knew from the church choir but who had never seen the child before. He seemed to be kind and understanding at first but said he'd need to discuss this with his colleague. In the afternoon of the very day a child protection officer came to the child's house and said that someone had notified the child protection authorities of possible child abuse. And in the evening the doctor's colleague appeared at Joanne's and her mother's door. He NEVER examined Joanne but instead talked for two hours to the mother, declaring that it couldn't be that EBV would be the reason for Joanne's bad condition.

Even though this doctor knew nothing about the child's medical history he immediately accused the mother of neglecting and abusing her child, and instead of helping he set in motion the child protection proceedings. As a consequence the child was forcibly removed into hospital by court order where she got worse by the day through a much too aggressive tube feeding, intravenous feeding, "activation" (GET), immunoglobulins and just the noisy and stressful environment. And now the mother lost custody and the right to stay at her daughter's bedside. They may both be doomed by that decision of the authorities.

You may ask why there was no way to avert these cruelties? It is just as Nigel Speight said: the mother was so downtrodden and scared stiff that she always tried to talk to the doctors and the social workers on amicable terms. She did not employ a lawyer and she refused to go public. She was afraid to lodge objections against the decisions of the family court and the child protection authorities. She was afraid to spur even more adversity and hostility. All the information we gave her for the doctors – Voices from the Shadows, medical literature en masse, Nigel Speight's most recent interview etc. – was brushed away by them and only considered as proof of the mother's mental disease which, in their view, was responsible for the child's ME.

Now that the mother is no longer allowed to stay at her daughter's bedside to protect her from the worst mistreatment we expect the worst to happen. The hospital doctors wanted to have her out of the way to implement "phase IV treatment" – that's their euphemistic description of enforced and incremental GET. They do not want to see that the child gets worse by the day. They say, oh, she's so much better now! When she has cramps they say, oh look, she can move her legs again! When the child says she never felt as bad as she does now they simply ignore it and accuse the mother of having prompted the child to say so.

And when the child will die from their “treatment” – now or later, because Joanne might never recover from the damage that has been done – they will claim that everything was the mother’s fault. She might even face to be sued for manslaughter. It is not only outrageous what is done to Joanne and her mother – it completely lacks any logic or medical ethics or responsibility. Any psychologist or psychiatrist who is in his right mind would say that it is simply impossible to make a child that ill by psychological influence whatsoever.

It is the psychodynamics on the doctors’ side that causes such an idea. And it is not the psychodynamics between mother and child that causes such a severe case of ME. The doctors can’t stand reality, even less so when they would have to realize that it is their own “treatment” that had caused a severe deterioration or even the death of the child, that they were seriously mistaken and that they might reasonably be sued for mistreatment.

Then their only way out is to look for a scapegoat to cover up their own malpractices– and the easiest and most vulnerable target for such an escape strategy is the downtrodden mother. And we know that this case is just the tip of the iceberg.

And that it is not a regrettable individual case or an “accident” – it is a sign of the systematic denial of ME by our healthcare system, backed up by the inhumane ideology of a certain school of psychiatrists.



WHEN WILL SUCH A REVIVAL OF THE DARK AGES FINALLY COME TO AN END?

Regina Clos, Germany

News From...Denmark



Justice for Karina Hansen
We know the latest news about Karina is very upsetting for everyone.

https://www.facebook.com/JusticeForKarinaHansen?hc_location=timeline

We are aware that this is distressing information that has come to light but please note that YOU can help.

Please use the template or write one yourself if you prefer, to call upon Amnesty International to help by intervening. We have tried this once with no response, there are over 2,800 people on this campaign. Time to get our voices heard by writing to them again.

Please let us know if you have any response and we will do the same! Let's not give up but be ME warriors for the sake of Karina.

Template for writing Amnesty International

You can use this link to send your letter to Amnesty International.
<http://www.amnesty.org/en/contact>

News From...Norway



In Norway right now we have one of the most severe cases this country has seen when it comes to ME. A 14-year old girl is forced to receive treatment of sensory stimulation. This blog post is just meant to inform about the situation, not to start fundraising abroad.

The girl was admitted to hospital of her own free will to start tube feeding. She was not able to eat enough to sustain her weight. Once admitted, the hospital decided that she needed to stay, if she left the hospital she was not allowed to keep the feeding tube.

If her family took her home and refused to follow the hospital's management plan with directions of Graded Exercise Therapy GET and Cognitive Behavioral Therapy (CBT) they would take her feeding tube away.

The girl's condition continued to deteriorate during her 3.5 month hospital stay. Finally, the family reluctantly agreed to the management plan the hospital made for the girl, with activities and stimulation.

The family does not have enough money to pay for legal help from a lawyer, and ask for help. However, this translation is mainly to inform our English speaking contacts about the situation.

The group that initiated the fundraising wrote a letter (in Norwegian, use Google translate) describing the situation. This is a private fundraising to pay for legal help, a lawyer, for the girl. We ask that those who know the case – or think they know it – do not share who this girl is.

The family needs to be protected.

Everybody who has seen or been in close contact to a severely ill ME-patient know how important it is to shield the patient for him or her to heal.

Unfortunately the health services has not understood this point.

News From...England



MEA UK ME/CFS Biobank – mini-charm offensive continues

The UK ME/CFS Biobank – which won a \$1.5m American grant to boost its work last summer – continued with its mini-charm offensive to keep its British stakeholders in touch with progress in Surrey on Monday, January 27.

One of its three key researchers, Dr Eliana Lacerda, has been giving a talk about its work at a meeting being organised by the Richmond and Kingston ME Group in south London. This took place at The Albert pub, 57 Kingston Hill, Norbiton, Surrey KT2 7PX, for a 3pm start.

Dr Lacerda (pictured right) is the ME/CFS research project lead at the London School for Hygiene and Tropical Medicine (LSHTM) where the three team members also run the ME/CFS Biobank. This is a vital infrastructure project which is actually housed at the Royal Free Hospital where there are major, pan-disease biobank facilities.

Dr Lacerda works with LSHTM public health consultant Dr Luis Nacul and Dr Erinna Bowman in the ME/CFS research project. Dr Bowman will also talk about their work at an open meeting on the subject of Exercise and ME/CFS in The Watershed, Bristol, on February 5.

And Dr Nacul briefed ME Association trustees on the work of the Biobank at one of their meetings last summer. The MEA is one of three UK charities who have funded the work of the biobank since its inception, together with a private donor.

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

[Sign the petition](#)



Millions of people worldwide suffer from Myalgic Encephalomyelitis (M.E.). For decades, sufferers have been left with no real biomedical research and no effective treatments.

Now the HHS is attempting to prolong this time by contracting with the Institute of Medicine (IOM) to redefine the illness. This is unnecessary

because experts in the illness, researchers and clinicians alike, have reached a consensus that the Canadian Consensus Criteria (CCC) should be used for both research and clinical purposes. They have sent an Open Letter to Secretary Sebelius expressing their support for the CCC.

This HHS contract with IOM would simply be a waste of precious resources.

Edward Burmeister is an attorney with the world's largest law firm. His wife, Jeannette Burmeister, is also an attorney who worked at the same firm until she became disabled with ME eight years ago:

“The IOM Contract cannot be “saved” by tinkering around the edges. In light of the essential facts:

- (1) NIH control,
- (2) organizational conflict of interest,
- (3) majority of non-experts and several IOM “regulars” as committee members and
- (4) very little by way of public meetings or review, particularly of the ultimate recommendation”

“The only appropriate course of action is to terminate this contract or task order now before the inevitable damage to the ME/CFS patient community becomes permanent.”



See:

<http://thoughtsaboutme.com/2014/01/23/want-to-help-in-the-iom-fight-sign-this-petition/>

[Sign Here:](#)

https://secure.avaaz.org/en/petition/Stop_the_HHSIOM_contract_and_accept_the_CCC_definition_of_ME/

IOM-hearing, Washington DC, 27 January 2014

A handful of short first impressions



In the afternoon of Monday 27 January the panel of the Institute of Medicine, which is to define new clinic criteria for ME/CFS, held an open hearing in which it received instructions from the HHS by mouth of Mrs. Nancy Lee, and heard patients and patients' advocates.

The event could be followed by live stream.

First of all Mrs. Lee summarized the tasks of the panel which can be broadly divided into five aspects:

1. A thorough study of the existing criteria such as the Fukuda of 1994, the CCC of 2003, the CDC of 2004, the NICE of 2010 and the ICC of 2011.
2. To map the delicacies and controversies of ME and CFS.
3. To find out if a new terminology for ME/CFS has to be defined, Mrs. Lee admitting and agreeing with the ME-scientists that the name CFS indeed has done damage to the patients and is harmful.
4. A broad dissemination of the possible new name and diagnostic criteria. E.g. the CCC are well known by all researchers and scientists, but not with practitioners and the public in general. This should change drastically.
5. This should be an ongoing effort to do right to the suffering of the many patients. On a question from member of the panel Dr. Nancy Klimas, Mrs. Lee informed her that the main task of the IOM-panel is to define clinic criteria, and not research criteria.

Subsequently several speakers, amongst which Mrs. Elisabeth Unger from the CDC, elaborated on the processes and the time schedules the panel is required to follow.

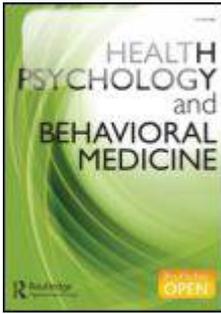
Patients advocates were heard online, many of them illustrating their talk with slides and powerpoints: Phoenix Rising, Pandora, the CFIDS, the NJCFS Association, the Massachusetts CFIDS Association and the Wisconsin ME/CFS Association by mouth of Mary Schweitzer being among them.

The last hour of the event patients had the occasion to personally speak for some 3-5 minutes each. Mindy Keitel impressed everybody in the audience and around the world by her sensitive appeal in which she highlighted how much harm has already been done to the ME-community by the authorities who refuse to accept the CCC as diagnostic criteria up till now. Many patients have died a possibly unnecessary death as a consequence.

Most impressive were the words of Jeannette Burmeister, ME-patient and lawyer, who didn't mince matters and guaranteed the panel she and her husband, a well known and highly esteemed lawyer as well, are going to fight the heinous decision of the HHS to contract the IOM to redefine ME/CFS until the bitter end. She completely silenced all and sundry.

Suzan Kreutzer who recently demonstrated and handed over petitions at Capitol Hill, unfolded a large sheet with some 3700+ signatures of those who at the start of her action had voted against this HHS-decision. She told the panel that just before this hearing the sum total had reached 5002. The effort will go on and the panel will be informed continuously about the amount of persons speaking out against this HHS-IOM project.

Worth Reading & Watching



Predictors of post-infectious chronic fatigue syndrome in adolescents-
Leonard Jason et al.

Jason LA, Katz BZ, Shiraishi Y, Mears CJ, Im Y, Taylor RA.

Health Psychology and Behavioral Medicine. 2014 Jan 2. (2)1: 41-51.

doi: 10.1080/21642850.2013.869176

Abstract

This study focused on identifying risk factors for adolescent post-infectious chronic fatigue syndrome (CFS), utilizing a prospective, nested case-control longitudinal design in which over 300 teenagers with infectious mononucleosis (IM) were identified through primary care sites and followed.

Baseline variables that were gathered several months following IM, included autonomic symptoms, days in bed since IM, perceived stress, stressful life events, family stress, difficulty functioning and attending school, family stress, and psychiatric disorders.

A number of variables were predictors of post-infectious CFS at six months; however, when autonomic symptoms were used as a control variable, only days spent in bed since mono was a significant predictor.

Full article:

<http://www.tandfonline.com/doi/pdf/10.1080/21642850.2013.869176>

Could the Vagus Nerve Infection Hypothesis Explain Chronic Fatigue Syndrome?



If it's correct VanElzakker's hypothesis could explain a lot about chronic fatigue syndrome

It could explain the disappointing Lipkin Chronic Fatigue Initiative pathogen study results. It shows how an infection could trigger ME/CFS and then – poof – seemingly disappear. It includes two hot research topics in ME/CFS; the autonomic nervous and immune systems.

It explains how sickness behavior could occur in ME/CFS without high cytokine results. It even includes the sensory nerves – another not research topic in fibromyalgia.

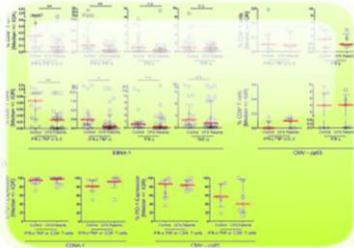
It may incorporate more aspects about ME/CFS into it than any other hypothesis. Plus it suggests some new treatment possibilities. It's called the Vagus Nerve Infection Hypothesis for ME/CFS and it's got a lot of people excited.

Cort Johnson - Simmaron Foundation website

Read more:

<http://www.cortjohnson.org/blog/2013/12/28/vagus-nerve-infection-hypothesis-explain-chronic-fatigue-syndrome/>

Deficient EBV-Specific B- and T-Cell Response in Patients with Chronic Fatigue Syndrome



Carolin Giannini, Uwe Koelsch, Sandra Bauer, Cornelia Doebis, Sybill Thomas, Nadine Unterwalder, Volker von Baehr, Petra Reinke, Michael Knops, Leif G. Hanitsch, Christian Meisel, Hans-Dieter Volk, Carmen Scheibenbogen

Epstein-Barr virus (EBV) has long been discussed as a possible cause or trigger of Chronic Fatigue Syndrome (CFS). In a subset of patients the disease starts with infectious mononucleosis and both enhanced and diminished EBV-specific antibody titers have been reported. In this study, we comprehensively analyzed the EBV-specific memory B- and T-cell response in patients with CFS.

While we observed no difference in viral capsid antigen (VCA)-IgG antibodies, EBV nuclear antigen (EBNA)-IgG titers were low or absent in 10% of CFS patients. Remarkably, when analyzing the EBV-specific memory B-cell reservoir *in vitro* a diminished or absent number of EBNA-1- and VCA-antibody secreting cells was found in up to 76% of patients.

Moreover, the *ex vivo* EBV-induced secretion of TNF- α and IFN- γ was significantly lower in patients. Multicolor flow cytometry revealed that the frequencies of EBNA-1-specific triple TNF- α /IFN- γ /IL-2 producing CD4⁺ and CD8⁺ T-cell subsets were significantly diminished whereas no difference could be detected for HCMV-specific T-cell responses.

When comparing EBV load in blood immune cells, we found more frequently EBER-DNA but not BZLF-1 RNA in CFS patients compared to healthy controls suggesting more frequent latent replication.

Taken together, our findings give evidence for a deficient EBV-specific B- and T-cell memory response in CFS patients and suggest an impaired ability to control early steps of EBV reactivation. In addition the diminished EBV response might be suitable to develop diagnostic marker in CFS.

Full article:

<http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0085387#s4>

Greg Crowhurst – Severe ME (second edition)



This book Greg has written is unique in its kind. He describes what many others are knowing and are going through, living in the dark with and caring in the dark for the ones they love most. With no voices from the shadows. Or, to use his own words:

“The situation you find yourself in as a carer is a sort of solitary confinement, year after year without change. Make no mistake, it is likely to stretch your sanity and your strength to the limit.”

With unparalleled imagery and quotations the book describes like a surgeon what it is like to live a life as and with someone who is severely stricken with the devastating disease Myalgic Encephalomyelitis. If there isn't any hope and no source of information, it may become a one way ticket to hell, utter darkness and death.

“Imagine living in a world where things coming in and things going out do not happen”. This is exactly what severe ME is like. And : “You are just left with a space. You are confined in a space with nothing and no one in it” .

It is hard to believe that this disease is still being ignored as a real, tangible, physical illness by authorities and policymakers all over the world. In spite of the immense amount of researches proving that what we see in ME may even be just the tip of an iceberg. How long is it possible to ‘protect’ oneself from a disaster by denying it....

This book is a gem amongst the many books published on ME, and a gem amongst the not so many books published from the point of view of a caregiver who is partner and partner in distress as well.

It is breathtaking, impressive, touching and practical. For it offers tools to enter into a relation with those who are so intensely hit by a severe disease, that they themselves can't stretch out their hands to you anymore. Try to stretch out yours with full awareness of their fragility, vulnerability and extreme solitude. It will prove to be the most rewarding experience you may have in your life.

For more information and ordering this most precious book:

<http://www.stonebird.co.uk/severemebook/severeme.html>

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Subscribe to this newsletter

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

Picture front page: The international ME community logo, a global outlook (by Eddy Keuninckx – idea David Egan)
Cartoon page 13: Djanko