

# The ME GI bal Chronicle

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# 4 - April 2014



# Colofon / Personalia

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Scientific reviews: **Richard Podell**

Advisory board: **Leonard A. Jason**

Cartoons: **Djanko**

Editor/Editorial team: **Eddy Keuninckx, Rob Wijbenga**

Distribution: **Rob Wijbenga**

Layout: **Eddy Keuninckx**

Translational services: <http://www.krijnetekstentvertaling.nl>

Archive: <http://let-me.be>

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Textual contributions for the June issue need to be supplied in Word by June, 15<sup>th</sup> and sent to: [contribute@let-me.be](mailto:contribute@let-me.be)

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

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

Cartoon page 23: **Djanko**



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# Preface

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Dear reader,

We are happy to submit the April issue of the ME Global Chronicle to you.

Once more, many of you have expressed their appreciation and even gratitude for this initiative; your enthusiasm is the fuel that keeps our engine going.

Again, we would like to stress the fact that we need your help for this project. It is beyond the capacity of only two or three persons to deliver a monthly magazine.

Therefore, unfortunately we had to decide that for the time being we will publish on a bimonthly base, until the editorial staff will be enhanced. Kindly let us know if it will be with you or with someone you deem fit.

We would also be very obliged to you, if you could help us by:

1. Submitting material for the next issue. Please, do not doubt the worth of an article or poem or blog or report that is appealing to you, all input is of value to us. And please, do not be disappointed if we decide not to incorporate it. Just submit anything you deem worthwhile. We prefer articles of 600 to 900 words in length.
2. Presenting yourself as a co-worker or editor, and helping us to gather information for upcoming issues.

Please, email to [info@let-me.be](mailto:info@let-me.be) and help us to make this project into a lasting success, this will eventually incite others to cooperate as well.

Kindly note that the data for the funding for Save4Children have been changed. You will find more information on page 29.

We do hope that the articles we chose for this issue will be to your liking, and we are open to any suggestions.

Next issue will be published around June 27<sup>th</sup>, 2014. Please submit your copy before June 15<sup>th</sup>. If you communicate any ideas about what you would like to see added, you will be rendering a great service to all of us.

Best wishes,

## The editors

**Errata** ME Global Chronicle 3, p.41: The link to the petition was totally wrong. Instead of clicking the link Help Me/CFS Circle ask for information at [newrymournemefms@live.co.uk](mailto:newrymournemefms@live.co.uk). Our apologies to both Jan van Roijen as well as the Newry and Mourne ME and Fibromyalgia Support Group

# Rich' Reviews: LDN

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## LDN

**Low Dose Naltrexone (LDN):** Possibly a major conceptual breakthrough; probably a useful treatment for Fibromyalgia pain.



My opinion: clinicians who treat **FM** and/or **CFS/ME** should consider themselves obligated to learn more about **LDN** and, with informed consent, consider offering it to selected patients.

**Naltrexone** is an opiate antagonist, FDA approved for a dose of 50 mg. At "normal" doses **naltrexone** tends to increase pain. But at low doses, in the 3-4 mg range, **LDN** has long been used by alternative medicine-minded clinicians as a treatment for pain, fatigue and other symptoms.

This month's essay focuses on one of the very few credible double blind studies of **LDN**. In brief, **LDN** seems to help a meaningful proportion of FM patients.

And, so far, its side effect profile has been relatively benign—almost certainly more favorable than our standard FM drugs.

As importantly, **LDN's** proposed mechanism—suppression of **inflammatory cytokines** within the central nervous system might lead toward a new approach for a broad range of diseases.

This month's key article is from Stanford Medical School's Division of Pain Management. **Jarred Younger PhD**, and **Sean Mackey, M.D., PhD** are the lead authors.

Using a double blind design, each of 31 women with fibromyalgia were treated with either 4.5 mg of **naltrexone** in the evening for 12 weeks and a placebo for 4 weeks. (**Low dose naltrexone** was prepared by a local compounding pharmacy.)

Reduction in pain scores compared to baseline were significantly greater during the **LDN** period compared to placebo. (28.8% reduction versus 18% reduction;  $P=0.016$ ). **LDN** was also associated with improved general satisfaction ( $P=.045$ ) and better mood ( $P=0.039$ ).

Thirty two percent of participants had an improvement in both pain and either fatigue or sleep while on **naltrexone** in contrast to an 11% response rate during placebo ( $P=0.05$ ).

The #1 "side effect" was increased dreaming, which some subjects felt were disturbing.

Other than a small pilot trial I believe this is the only academically sound study testing **LDN** for fibromyalgia.

However, I and at least one other CFS-ME/Fibromyalgia specialist have found LDN useful. (**Nancy Klimas, M.D, PhD** personal communication).



Dramatically exciting is **LDN's** proposed mechanism—suppression of pro-inflammatory activity triggered by microglial cells within the CNS. **Inflammatory cytokines** appear to be increased within the CNS of patients with Fibromaygla, CFS-ME and a broad range of health problems.

Preclinical research indicates that **Low Dose Naltrexone** can suppress the activity of **microglial cells** and reduce the production of **pro-inflammatory cytokines**.

Might **LDN** or other **cytokine** reducing intervention help patients with **Multiple Sclerosis, Parkinson's** or **Alzheimer's**?

Hopefully, more research will follow—despite the disincentive that **naltrexone** has long been “off patent”.

Our newsletter would appreciate hearing from readers about their clinical experience with **LDN**.

**For clinicians and scientists only**, you can email me at [podell2@gmail.com](mailto:podell2@gmail.com).

The Key Article:

**Younger, J, Noor, N, McCue, R, Mackey, S**, Low-Dose Naltrexone for the Treatment of Fibromyalgia, Arthritis & Rheumatism, 2013; 65:519-538.

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

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

# Front cover

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## **Greg & Linda Crowhurst, Eddy Keuninckx**

As many of you know, **Linda Crowhurst** has been severely stricken with ME for many years. She lives in the UK with her husband **Greg** who takes care of her. Linda and Greg feature in the prize-winning documentary Voices from the Shadows (<http://voicesfromtheshadowsfilm.co.uk/>)

She is lying in the dark 24/7, in agonizing pain. The couple responded immediately to our appeal in the March 2014 issue to design a front cover for the ME Global Chronicle.

**Linda** drew the body, using only one finger, on an iPad. Her hands were numb when she did so, and she defied her poor coordination, her spasms and her severe pain.

**Eddy** improved the image to its final shape. The body was made transparent, which denounces its fragility. It is in orbit around the world. The shadow on the world signifies that one small person can make a big difference.

The world itself is on fire as living with ME is a torture, but the brilliancy of the globe also denotes the brilliancy of life. The star represents the hope for a cure.

# CFS-Research Tries Crowdfunding

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***With Significant Advances But Little Money, Chronic Fatigue Syndrome Research Tries Crowdfunding*** - An abstract of an article by **David Tuller**, *NY Times* journalist

At the IACFS/ME- conference in San Francisco (20-23 March 2014), devoted to myalgic encephalomyelitis — the devastating illness more commonly and misleadingly called chronic fatigue syndrome — it was immediately clear that researchers from leading medical centers in the U.S. and abroad have been making tremendous strides in documenting immunological, neurological, cardiovascular, and other types of dysfunctions among patients.

It was also clear that little of this compelling research is being funded by the U.S. government — so much so that one researcher recently launched a video crowdfunding campaign.



“I was thrilled to see so much good science,” said **Leonard Jason**, a psychologist from DePaul University in Chicago and a longtime researcher into ME/CFS, as the disease is usually called these days.

“That’s such a sea change. There was such a wealth of research that every session you went to you saw abnormalities being pointed out in different domains. It was breathtaking.”

**Dr. Jose Montoya**, an infectious disease expert and the leader of the Stanford research effort, said the increased understanding of ME/CFS as an inflammatory illness would generate new approaches for treatment, even in the absence of a precise understanding of the triggering events.

“Why couldn’t we treat these patients with the same approach for other inflammatory diseases, for which we don’t know the trigger?” said **Dr. Montoya**, who hopes to organize a clinical trial with anti-inflammatory drugs to test the hypothesis.

“For lupus, for rheumatoid arthritis, we don’t know the trigger — just that symptoms get significantly better when the inflammation is treated.”



**Dr. Montoya** became interested in the field a decade or so ago, when a few patients with the illness were referred to him. Colleagues warned him at the time that focusing on the issue would be harmful to his career, but he persisted in order to find ways to help his patients, he said.

Since the last IACFS/ME gathering in September 2011 top researchers have been testing samples from a cohort of 200 well-defined ME/CFS patients, culled from the clinical practices of some of the leading clinicians treating the illness, along with well-matched controls.



The repository of samples provides an excellent resource for further investigation into the promising leads uncovered by the ongoing research, the scientists have said. But last week's conference, which was attended by many people with the illness, highlighted what advocates and researchers perceive to be the government's long-standing neglect of the illness.

Much of the research presented was not funded by the National Institutes of Health or other government agencies but relied instead upon the largesse of private donors with sick family members or other reasons to support research into ME/CFS.

Even **Dr. Ian Lipkin**, a renowned Columbia infectious disease expert, has had trouble getting NIH funding for ME/CFS research. In 2010, **Dr. Lipkin** was recruited by the NIH to lead an investigation into the suspected mouse retroviruses.

His study found that no link existed and theorized that the earlier findings, which suggested an ME/CFS connection, were the result of laboratory contamination.



Following that study, he continued seeking possible infectious triggers for the illness with funds from the Hutchins Family Foundation and has recently launched a video crowdfunding campaign to raise an additional \$1 million or more.

In the unusual public appeal, which he posted on the site of his Center for Infection and Immunity at Columbia, he noted that "we are off to an excellent start but the resources are insufficient to do what needs to be done, to do what the community deserves."

The NIH spends about \$5 million a year on the illness, far less than on some diseases that afflict fewer people but have greater visibility and respectability, and perhaps a famous spokes-patient.

Nonetheless, many of those present at the IACFS/ME-meetings were buoyed by the sense that research progress was finally being made, if not into the definitive causes of the illness then at least into some of its physiological parameters.

But that silver lining comes with a giant dark cloud, said **Michael Allen**, 65, a retired psychologist in San Francisco who has been sick with ME/CFS since the early 1990s.

The researchers are generating strong leads for further research, **Allen** said, but the government is failing to pursue them aggressively.

"It's clear there's nowhere near enough money yet to follow all the leads," he said. "And the problem in the field is that people have been generating leads for years, but the money isn't there for the follow-up research. So I'm not assured that there will be any real treatment for the disease while I'm still alive."

*Source & complete text:* <http://www.buzzfeed.com/davidtuller/chronic-fatigue-syndrome-research>



# No, Thank You

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**Eileen Holderman**, spokeswoman of the CFSAC (CFS Advisory Committee) declined in a long letter an invitation of the IOM (Institutes Of Medicine) panel to come and speak from the perspective of patients experience. This was her complete response to the IOM, very noteworthy because of the summary of events and actions against the HHS/IOM contract since the fall of 2013:

"Thank you for your invitation to speak to the IOM Committee on the topic of patient experience and diagnosis. And thank you for your patience in my reply - I recently returned from the IACFS/ME Conference.

For numerous reasons stated below, I must decline your speaking invitation. I am part of a vast patient advocacy movement that opposes the HHS/IOM Contract to redefine Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS).

There are many reasons for my (and other advocates') opposition, many of which are as follows:

- ✚ The Chronic Fatigue Syndrome Advisory Committee (CFSAC), for which I serve as a member, made a recommendation to the Secretary of the Department of Health and Human Services (HHS) in October, 2012 to convene a workshop with **only** ME/CFS experts (researchers, clinicians, advocates and patients) to reach a consensus on a research **and** clinical case definition for ME/CFS starting with The Canadian Consensus Criteria (CCC).
- ✚ Unfortunately, HHS did not implement our recommendation to the **Secretary**. Instead, HHS contracted with IOM and is utilizing a majority of non-ME/CFS experts, spending 1 million dollars of taxpayers' money for a study that will take 18 months to complete, and which has the potential to devise a worse definition than CDC's Fukuda and a worse name than CDC's chronic fatigue syndrome.
- ✚ 50 ME/CFS experts have reached a consensus on a research and clinical case definition for ME/CFS called the Canadian Consensus Criteria (CCC) which they have been using for over 10 years and for which they have committed to refine. The 50 experts sent a letter to **Secretary Sebelius** and Government Health Agency Officials expressing their opposition to the HHS/IOM Contract to redefine the disease and urged HHS to adopt the CCC as they have; their letter was also sent to the Institute of Medicine (IOM).
- ✚ Over 170 advocates have sent a similar letter to Government Officials and IOM expressing the same opposition to the HHS/IOM Contract and have also urged the Government Health Agencies to adopt the CCC, as the experts have recommended.

- ✚ Nearly 10,000 patients, caregivers, advocates, and medical professionals have signed 2 petitions stating objections to the HHS/IOM Contract to redefine ME/CFS and urging The Department of Health and Human Services to adopt the CCC for ME/CFS.
- ✚ Advocates have launched letter, email, call, Facebook, and Twitter campaigns to oppose the HHS/IOM Contract to redefine ME/CFS.
- ✚ Advocates have appealed to Congress with letters, emails, calls, and meetings on Capitol Hill to cancel the HHS/IOM Contract and have called on Congress to look into the issue to stop the waste of taxpayers' money for something we already have - a clinical and research case definition for ME/CFS called the CCC.
- ✚ An advocate attorney has filed a law suit in US District Court against HHS and NIH for non-compliance with a FOIA request pertaining to the IOM Contract. The same advocate filed complaints with (a) the Office of the Inspector General regarding the IOM's organizational conflict of interest and related legal issues and (b) the HHS Competition Advocate.
- ✚ Numerous advocates/attorneys have filed Freedom of Information Act (FOIA) requests concerning the HHS/IOM Contract.
- ✚ Advocates contacted the media and press and participated in numerous radio, TV, and online interviews and articles about the HHS/IOM redefinition issue. One article about the IOM redefinition issue, by a free lance journalist who writes for the NY Times and other outlets, received over 90,000 hits on an Internet news site and over 8000 Facebook shares.
- ✚ Advocates demonstrated in San Francisco and in Washington, DC to protest the HHS contract with IOM and attracted press coverage of the demonstrations.
- ✚ Advocates for ME/CFS collaborated with advocates for Gulf War Illness (GWI) to support both communities' opposition to the VA/IOM Contract for GWI and the HHS/IOM Contract for ME/CFS. Both communities voiced concerns about the VA/IOM reports which recommended clinical "treatment" of CBT, GET, and anti-depressants for patients with GWI and ME/CFS - "treatments" known to be ineffective and in most cases harmful to patients.
- ✚ Advocates wrote and submitted a position paper on case definition to HHS, and wrote articles, blogs, and opinion posts opposing the HHS/IOM Contract to redefine the disease.
- ✚ Advocates and patients traveled at great detriment to their health and finances to voice their opposition to the HHS/IOM Contract at the January 27, 2014 IOM meeting in Washington, DC.

The above mentioned initiatives by advocates, patients, and ME/CFS experts have been and continue to be important to protect the best interests of a million Americans, and 17 million worldwide, who suffer from ME/CFS and to move research and treatment forward.

The majority in the ME/CFS community have spoken in a unified voice that ME/CFS experts already agreed on a criteria - the CCC, so it is time to use the limited funds the Government allocates to this disease for research and treatment to improve the lives of those disabled by this serious neuroimmune disease.

The advocacy initiatives will continue undeterred and will continue to call for the cancellation of the HHS/IOM Contract.

Again, I thank you for the invitation to speak to the IOM committee about patient experience and diagnosis, but must decline for the reasons stated above.

However, if you will permit me to make a dissenting, but respectful public comment in Washington or via webcast, I would accept that opportunity, particularly because I would have new information to address regarding the latest VA/IOM report for GWI, which has relevance to the HHS/IOM redefinition issue.



While I did give opposing public comment at the podium during the January 27, 2014 IOM meeting, I did not submit formal written comments, so please accept this email, which summarizes what I said at the meeting, as part of the IOM public record, and I will share my email with the ME community, as well.

Thank you for your consideration.

Best regards,

**Eileen Holderman**  
ME Advocate

<http://www.mecfsforums.com/index.php?action=printpage;topic=19833.0>

Thanks to **Wildaisy**

# 9th international ME conference, 30th May 2014 Westminster, London

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The fully CPD-accredited IiME conferences update delegates with the recent advances in ME research and bring together leading clinicians and researchers in the fields of general medicine, infection and immunity and clinical trials to discuss the central issues and current challenges involved in the diagnosis, treatment and management of patients with ME. It provides a rare opportunity in the UK to meet with world experts on ME.

Confirmed speakers are:

**Dr Ian Gibson** (Chair), Former Dean of Biological Sciences, UEA  
**Professor Jonathan Edwards**, Emeritus Professor UCL, UK  
**Professor Angela**, Vincent University of Oxford, UK  
**Dr Mady Hornig**, Columbia University, New York, USA  
**Professor Sonya Marshall-Gradisnik**, Griffith University, QLD, Australia  
**Professor Carmen Scheibenbogen**, Charite Berlin, Germany  
**Professor Simon Carding**, University of East Anglia, UK  
**Professor Julia Newton**, Newcastle University, UK  
**Dr James Baraniuk**, Georgetown University Medical Centre, USA  
**Professor Jonas Blomberg**, Uppsala University, Sweden  
**Dr Amolak Bansal**, Epsom & St. Helier NHS Trust, UK

Invest in ME initiated/ funded research at UEA (gut microbiome) and UCL (rituximab clinical trial).

The conference synergizes these and other research elements from around the world to search for cause and provide treatments and follows on from the Invest in ME CPD-accredited Biomedical Research into ME Collaborative Meeting 4 – a full day meeting of international scientists & clinicians.

Info: phone 02380 251719 or 07759 349743 [meconference@investinme.org](mailto:meconference@investinme.org)

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



# ME/CFS Manifesto

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By **Llewellyn King**

I consider this a manifesto for the ME/CFS community. These are my thoughts, after nearly five years of watching the anguish and the neglect that surrounds this disease. The manifesto states what I think should be done now.

And “now” is an important word.

There is a story that **Winston Churchill**, when he was very old and sick, summoned the gardener at his beloved country home in Kent, Chartwell, and asked him to plant an oak tree in an open space.

The gardener, looking at his enfeebled employer, swallowed and said, “But, sir, an oak tree takes a hundred years to grow.”

“Then you'd better plant it now, hadn't you?” said **Churchill**.

During World War II, **Churchill** used this same execution imperative approach to work. **Churchill** used to stick little, pre-printed notes — long before the days of Post-it notes -- on his paperwork for staff that read, “Action This Day.”

One of the first things that struck me about ME/CFS, when I started writing and broadcasting on the subject, was how slow the pace of progress was, even as the suffering suggested the need for immediate action. The second was how stingy public and private funding for research was then and is now.

I want my friends and loves, who are in the grip of a relentless affliction, whose days are torn from the calendar of hell, to be cured in my lifetime -- and I am 74.

I want to be able to hold them as whole happy people; the people they were before they were struck down by an enemy they did not provoke, a monster they do not deserve, an unseen captor, a malicious jailer that takes daily life and makes it into a tool of torture and punishment.

One year, the CFIDS Association of America was able to declare proudly that it had raised \$2 million. The National Institutes of Health, a federal agency that should be pushing research, granted a paltry \$5 million for ME/CFS in 2013. By comparison, in that same year, I learned that a consortium of foundations was sponsoring a green power marketing initiative at \$6 million a year.

I have spent nearly 50 years writing about federal funding for energy, science and technology, and the sums of money spent has been in the tens of billions of dollars. One company gets more than \$60 million year-in and year-out for nuclear fusion research -- and I see nothing wrong with that.

But when I look at the federal funding for ME/CFS research, I am aghast: It is not funded at a level that can be expected to produce results. It is, to my mind, a crime against the sick; morally, if not criminally, indictable. To allow the scale of suffering that attends ME/CFS, without making research on the disease a national priority, is close to willful neglect; an abrogation of the high purposes of **Hippocrates'** calling.

Other governments are not free of guilt for the suffering – and the United Kingdom stands out among the many offenders. These governments have been seduced by the fraudulent blandishments of the psychiatric lobby. If a ME/CFS patient refuses to accept a psychiatric diagnosis, he or she can either be imprisoned or forced to suffer the insinuation that they are not physically sick, even if they cannot get out of bed.

There are cases in Europe where patients refusing the prescribed psychiatric treatment have been imprisoned, as happened most recently to **Karina Hansen** in Denmark.

The United States is experiencing a boom in natural gas production and the deployment of solar panels on rooftops. These successes are the manifestation of substantial research money committed in the 1970s, and sustained since then.

Science needs certainty of support, both political and financial, to triumph.

The key is sustained funding; a splash here and a dash there just won't do -- it won't do anything. ME/CFS researchers need to concentrate on their work, wherever that work takes them, free from the stress of insecure funding.

ME/CFS deserves the level of effort that might lead to success. It is not getting it now, and it never has had it.



It is appalling that **Dr. Ian Lipkin**, the highly respected virus hunter, is trying to raise \$1.27 million through crowdfunding to investigate the role of microbiome in ME/CFS. What we are seeing is a scientist forced to beg. Yet this fundamental research, with application for diseases beyond ME/CFS, is at the frontier of biomedical science.

If we, as a nation, are to believe that we are in the forefront of science, we must be in the forefront of biomedical research as well as the forefront of computers, telecommunications, materials and physics. We almost humbled polio, and developed powerful drug therapies for AIDS. We can transplant vital organs and gave hope to the leper. The advances came neither cheaply nor easily, but they have saved lives beyond counting and eased suffering beyond enumeration. Why not for ME/CFS? **Why not?**

↔ There is eloquence in the voices of the community. But they are widely distributed and, sadly, they fall mostly on ears of those who already know them – the sick, their families and their advocates.

The voices need to be heard widely, need to be channeled and need to be focused. A million points of light won't do it. A laser, a great beam, will do it.

There are three principal reasons why these voices are not heard by those who need to hear them:

- ✚ ME/CFS is a hard story for the media to grasp.
- ✚ ME/CFS has no celebrity doing what **Elizabeth Taylor** did for AIDS, what **Jerry Lewis** did for Multiple Sclerosis, or what **Michael J. Fox** is doing for Parkinson's Disease.
- ✚ ME/CFS has no presence in Washington.

Of the three, the last is the most critical to act on, and it is the one that would produce the most measurable result.

Simply stated: Being on the ground in Washington every day is the essential step the community has to take.

To get results in Washington, you need to-see-and-be-seen in the daily life there. Letters and petitions do not have nearly the impact as a Washington denizen talking to a decision-maker in person.



Happily this would amount to one very visible person, who strolls the halls of Congress, lunches at the clubs and restaurants, like the Cosmos or Metropolitan clubs, or the Monocle Restaurant on Capitol Hill. Once, I was mentioned in the Wonkette blog because I was spotted entering Bistro B, a favorite restaurant of the powerful, and those who think they are powerful.

If your children attend one of the power schools, like St. Alban's or Sidwell Friends, contacts can be made and deals can be done at the events. A friend of mine enlisted **President Bill Clinton's** help for a cause because their children went to the same school.

It may strike you as banal, but it is the Washington political game. Learn to play it.

Washington is a society of people who are impressed with each other. It is important to be known. If you are invited to the annual White House Correspondents' Association or Alfalfa Club dinners, you are known. The next step is to be known for ME/CFS advocacy.

Once known, the perfect advocate/lobbyist will morph into a resource, a voice for others in Washington: a source of information for congressional aides trying to understand the budget requests of agencies, and a source of information for reporters writing about diseases of the immune system.

A voice in Washington puts pressure on government agencies to do the right thing, and on members of Congress to authorize and appropriate money. The advocate/lobbyist can learn, through the hearing process, about the diligence and transparency of the agencies and the quality of their operations; to see if they are doing the job or trading water, to see how transparent their operations are and the quality of professionals operating programs.





Another salutary source of pressure in Washington is the press corps. It covers not just politics but also the functioning of government. The pinnacle of power in the corps are still The Washington Post, The New York Times and The Wall Street Journal.

But the news agencies, The Associated Press, Bloomberg and Reuters, followed by a veritable media army that cover politics and programs, including Politico, The Hill, Roll Call, National Journal, and the specialized medical publications also play important roles.

Fifty years ago, the center of media activity was New York. Now it is Washington. A professional advocate for ME/CFS needs to cultivate the media and to be comfortable with the currency of Washington and to trade in it. That currency is information.

Washington is a great information market. The successful lobbyist/advocate is, by the nature of the city and its functioning, an information broker. The sums of money that will be needed to accelerate research cannot be calculated and could be very substantial. Research funding, above all, needs to be sustained at predictable levels.

The pharmaceutical industry figures that a new drug can cost upwards of \$1.2 billion. I mention it only to hint at the vast amount of money needed for drug research and development.

How much ME/CFS will need and for how long is an existential question. Money stimulates research, attracts new young minds to the field and leads to success. Right now, there is so little money funding so few researchers in ME/CFS.

In the United States, that success may be a long time in coming – too long for those for whom today will be a living hell, as yesterday was and tomorrow will be.

I figure that for as little as \$1 million, a start toward a Washington presence can be made. That would cover one advocate/lobbyist, one office and one assistant for one year; not a smidgeon of attention from a giant lobbying firm, but a dedicated ME/CFS standard-bearer. Funding should grow within a year, as the ME/CFS cause comes out of the shadows.

I operated a small business in Washington for 33 years, and I am confident that a new ME/CFS presence there will reverse the disease's funding fortunes at NIH, increase media awareness, and cause the big foundations to sit up and take notice. It would give ME/CFS the kind of presence that other diseases with active advocates – COPD, ALS, MS and others -- have in Washington and the nation.

If this is not done the government will continue to ignore the case for ME/CFS. Worse, the new billionaires who are beginning to throw real money into biomedical research will not know about ME/CFS. It will be hidden in plain sight much as it has been from the wider public.



ME/CFS needs a place on the national agenda if it is to be understood and cured in reasonable time, and if the very best minds are to be attracted to the task and to stay with it. That **Churchill** oak needs to be planted now, and in sight of the U.S. Capitol.

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

### **Llewellyn King**

Executive Producer and Host,  
"White House Chronicle" on PBS;  
Columnist, Hearst-New York Times Syndicate;  
Commentator, SiriusXM Satellite Radio

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

# Dutch International Project - Science to Patients



**Newest broadcast: dr. Charles Shepherd on Promising discoveries & researches: due for May 5th, 2014. <http://www.me-cvsvereniging.nl/>**

*Followed by a chatwing – session on **Thursday 15 May**, from **5:00-5:45 pm CET***

<http://chatwing.com/mecvsvereniging.wvp>

Since January 2013 the Dutch ME/cvs Vereniging is running a government subsidized project, called Science to Patients.

English subtitled broadcasts of the Belgian clinical scientist **Kenny De Meirleir** have been broadcast <http://bit.ly/1q1yZGE>, as well of the Dutch cardiologist **Frans Visser** <http://bit.ly/1fSY8OQ>.

Starting this year, YouTube-films of short talks of English speaking clinicians and scientists are being broadcast.



A beautiful interview with **Nigel Speight**, British pediatrician plus six short talks on children & ME (<http://bit.ly/1efQEVO>) could be viewed in January and February, after which **dr. Charles Shepherd** took over.

## **Who is he?**

**Dr Charles Shepherd MB BS**, is honorary medical adviser of the ME Association.

He is a private physician with a longstanding personal interest in ME/CFS - having developed the condition following an episode of chickenpox encephalitis that he caught from one of his hospital patients.

He has been involved with all aspects of the illness - benefits, education, management, media, politics, research, services - for over 30 years. He was a member of the Chief Medical Officer's Working Group on ME/CFS and the Medical Research Council's Expert Group on ME/CFS research.

He is currently a member of the Department of Work and Pensions Fluctuating Conditions Group, whose recommendations regarding changes to the way

eligibility for work-related sickness benefits (ie ESA) are assessed has recently been tested in an evidence based review.



He is also involved with parliamentary work - including forming part of Secretariat for the All Party Parliamentary Group on ME at Westminster.

His research involvement includes supervising all the research that is currently being funded by the ME Association - in particular the setting up of an ME Biobank for blood samples at the Royal Free Hospital in London - and he is an executive board member of the UK ME/CFS Research Collaborative.

Research interests include the role of vaccines as trigger factors for ME/CFS, post-mortem tissue collection and analysis, and muscle/mitochondrial abnormalities in ME/CFS

He has written a self-help guide for people with ME/CFS ('Living with ME' - Vermilion) and guidelines for health professionals ('ME/CFS/PVFS: An Exploration of the Key Clinical Issues' - MEA) along with numerous contributions to the medical literature.

He is married with three children and lives in Gloucestershire.

Until so far, each speaker did also enable Q&A-sessions, in which Dutch speaking patients could ask them questions on both theoretic and practical aspects of ME/CFS.

The sessions were not meant to be a consultation, but have proven to be a mine of knowledge to many a patient about his/her own condition.

On **May 15th, from 5:00 p.m.CET, dr. Charles Shepherd** is holding a Q&A-session of  $\frac{3}{4}$  of an hour for patients all over the world, in which questions can be put to him in English.

Log in with <http://bit.ly/1hdys55>

# A Speight of Little Victories

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A few impressions of a talk given by **dr. Nigel Speight** during the edmesh (Edinburgh ME Selfhelp Group) Open Meeting – 19th October 2013



Early in his career **Dr Speight** saw his first ME patient, a teenage girl, and became convinced of the reality of ME as an organic illness.

Gradually he became known as a doctor knowledgeable about, and sympathetic towards, the condition and its sufferers; to date he has seen 200 cases in Durham, and over 600 cases altogether from England, Scotland and Northern Ireland.

His main aim has been to provide an official diagnosis of ME for the children he examined who met the international ME criteria, and to offer understanding and sympathy to them, suggestions for treatment to their parents and GPs and referrals to other hospitals.

He would often work with families to prevent the imposition of fines for non-attendance at school, or the refusal or withdrawal of state benefits, and to combat threats of Care Proceedings, leading to inappropriate or harmful treatments.

## **The role of viruses, and the mitochondria**

**Dr Speight** referred to **dr. Betty Dowsett** who, along with **Jane Colby**, former Head Teacher and ME sufferer, published a study of ME in schools in 1995 in which they noted that ME/CFS case clusters were associated with virus infection, female predominance, and peak incidence in the early teens.

## **Persistent microbes**

**Dr Speight** explained that in some countries there are “clever tests for unusual germs”. In the USA, for example, **Professor Garth Nicolson** of the Institute for Molecular Medicine, California, specializes in diagnosing persistent chronic infections relating to a large number of autoimmune diseases.

**Dr Nicolson** has examples of detailed practical treatments that are multi-anti-antibiotic, multi-factored and multi-staged, with nutritional supplements, antimicrobial foods, and mitochondria-energy-enhancing supplements, though he warns that patients should consult their own personal physicians for advice on exact dosing and schedules, which can vary among individuals.

### **Immunoglobulin and vitamin B12**

**Dr Speight spoke** favourably of immunoglobulin as a treatment for ME. It is used as a modulating agent. In a study of 49 cases in North Durham by **dr. Speight** between 1988 and 1996, three of the six most severely affected patients who received immunoglobulin treatment made virtually complete recoveries during the follow-up period.

Another treatment found helpful by **dr. Speight** is Vitamin B12 therapy. Vitamin B12 deficiency is a syndrome in itself – not the cause of ME, but it can be a factor, affecting the working of the brain.

### **Merits**

**Dr. Speight** has been consistent and courageous in pursuing his course of action and is continuing to do so, telling us that he has had recent and ongoing involvement as a paediatric adviser to family members of severely ill children.

His informed reports, quoting, for example, the 2006 NICE Guidelines on no exercise benefiting severe cases, and the need for “informed consent” by the patients and their parents or guardians, have reversed Child Protection proceedings more than 20 times.

These are **dr. Speight’s** “little victories”, but they total up as a large contribution to the health and happiness of some very vulnerable youngsters

### **Valerie Brotherton**

Full text:

<http://www.edmesh.org.uk/2014/03/speight-little-victories/>

# The Half Remarkable Question? ME or CFS

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Myalgic Encephalomyelitis (ME) and Chronic Fatigue Syndrome (CFS): The need of objective assessment, accurate diagnosis, and acknowledging biological and clinical subgroups. An Extract

Although Myalgic Encephalomyelitis (ME) and Chronic Fatigue Syndrome (CFS) are often considered to be synonyms, the diagnostic criteria for ME and CFS define distinct clinical entities.

Cognitive impairment, (muscle) weakness, circulatory disturbances, marked variability of symptoms, and, above all, post-exertional "malaise": a long-lasting increase of symptoms after minor exertion, are distinctive symptoms of ME.

This latter phenomenon separates ME, a neuro-immune illness, from chronic fatigue (syndrome), other disorders and deconditioning. The introduction of the label "CFS", but more importantly the diagnostic criteria for CFS have generated much confusion, mostly because chronic fatigue is a subjective and ambiguous notion.

12 MAY: 'WORLD M.E.-DAY...'



CFS was redefined in 1994 into unexplained (persistent or relapsing) chronic fatigue, accompanied by at least four out of eight symptoms, e.g. headaches and unrefreshing sleep.

Since the diagnosis ME doesn't require "fatigue" and post-exertional malaise and cognitive impairment are not obligatory for the diagnosis CFS, the criteria for ME and CFS define two different patient populations.

However, most of the research into ME and CFS in the last decades was based upon the multivalent CFS criteria, which define a heterogeneous patient group.

Due to the fact that fatigue and other symptoms are non-discriminative, subjective experiences, research has been hampered. Despite the use of subjective and ambiguous criteria and measures, research has established typical abnormalities in ME/CFS repetitively, e.g. immunological aberrations, oxidative and nitrosative stress, neurological anomalies, circulatory deficits and mitochondrial dysfunction.

After describing the context, including the controversy about the nature of ME and CFS, the diagnostic criteria, the etiology, the pathophysiology and presumed effective therapies (Cognitive Behavioral Therapy: CBT and Graded Exercise Therapy: GET), this article reviews the historical context of ME and CFS and the

diagnostic criteria (Ramsay, Holmes, Fukuda and International Consensus Criteria) and substantiates why ME and CFS are two partially overlapping, partially disjoint clinical entities.

After stressing the importance of an accurate diagnosis, the article proposes various methods to assess characteristic symptoms objectively. Various authors have questioned the physiological nature of the symptoms and qualified ME/CFS as somatisation.

By using objective measures endless discussions due to using questionnaires and subjective measures can be avoided, e.g. with regard to the physiological origin of symptoms, the level of disability, and the proposed positive and/or negative effects of CBT and CGT in specific patient well-defined groups.

The article then summarizes various characteristic abnormalities which have been repeatedly observed in ME/CFS patients or substantial subgroups repeatedly and the potentially relevant clinical and biological subgroups.

The remainder of the article focuses on recommendations for improvements of patient care (assessment and diagnosis) and more effective research in the future.

To improve future research standards and patient care, it is crucial

- ✚ that patients with post-exertional "malaise" (ME) and "CFS" patients without post-exertional phenomena are acknowledged as two separate clinical and research entities;
- ✚ that typical symptoms of ME and CFS are assessed objectively as much as possible; by using repeated exercise tests (CPETs) and cognitive tests;
- ✚ that the diagnosis of ME and CFS in research and clinical practice is based upon accurate criteria;
- ✚ that well-defined clinical subgroups of ME and CFS, e.g., patients with orthostatic intolerance or patients with sudden-onset, are investigated in more detail;
- ✚ that biomarkers, e.g. immunological status in rest and after exertion, are used to distinguish and investigate biological subtypes in research;
- ✚ and that trials into the efficacy of therapies use objective measures of the clinical status and biomarkers to establish the effects of these therapies in ME or CFS patients or subgroups thereof impartially, e.g. by a (positive) change in the oxygen uptake at the anaerobic threshold and cognitive tests scores.

## **Frank N.M. Twisk**

Full-text available through:

<http://journal.frontiersin.org/Journal/10.3389/fphys.2014.00109/abstract>



# The Memory Game

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Poor short term memory is one of many symptoms my friend, myalgic encephalomyelitis, has inflicted upon me. Remembering an oven is on and remembering a bill needs to be paid are challenges.

Thanks to modern technology, my beeping phone is my note reminder. To such an extent, my husband often asks if I have it set to prompt me to breathe.



Last January, one of those beep-eddy-beeps went off and I found myself in a very short queue at our local driving license center. My license was about to expire and while I rarely drive, having a valid license is a necessity.

Not least because letting it expire would force me to take over my original driving test and we all know what that outcome would be.

The appointment was seamless. My application processed immediately and a smiling lady told me my new license would arrive in the post within three weeks. Back in the car where my husband waited, I deleted the reminder.

Fast forward to March, when I suddenly realized my handbag was naked, there was no horrible picture in my wallet telling me I could drive. Contacting the center, I was told there was a problem with my application.

I'd signed my marriage surname and not my maiden name and was asked to return to the office to remedy it, in the meantime, my application was put on hold.

Yesterday was a good body day and decided to sort out this hiccup. Only this time there was a queue. An Irish queue. One in which there were no tickets issued. There was no line. It was simply a room with scattered chairs and I was expected to remember who was in the room ahead of me.

Memorizing the lady in the blue jacket, the girl with the long black hair, the guy with the moustache and another two or three I've long since forgotten, I settled into my chair, waiting for each to step up to the counter.

Then, an older gentleman joined us and asked as to the order of the queue. Remarkably, everyone knew the exact order and the man was told to join the game. Happy, he sat down.

Another few moments passed and more people joined our haphazard queuing system. Only this time, a lady stood in the center of the room puzzled.



Realizing her predicament, the gentleman spoke up telling her "it's a memory test". To which she replied "O sorry, I'm in the wrong room, I'm here to have my license renewed."

There were shaking shoulders and stifled giggles as the man apologized for his sarcasm and pointed out the person she was to watch.

Luckily, I stood up at the right moment, no one accused me of skipping ahead and my license application was moved along for processing. Fingers crossed I will receive it in the next few weeks, or there'll be another beep-eddy-beep.

<http://currankentucky.wordpress.com/>

**Marie Curran**

# Joanne still in hospital –waiting for court decision on appeal

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**Joanne's** story is further going down Wessely's road to disaster. You will be familiar with her story from the second and third issue of this Chronicle – she has severe ME, is tube fed, can't stand or walk due to paralysis of her legs, has severe neurological symptoms and pain, and she is forced to be "treated" in hospital for more than five months now, with all kinds of "activation therapies" that make her worse.

There is only bad news. Lately, **Joanne** was threatened to be entirely separated from her mother when she would not do what they want her to do. (Remember: at present her mother is allowed to see her daughter for 30 minutes a day – giving all the "therapists" a free hand). The mother reports that the girl is completely demoralized meanwhile and that she is crying all the time about the detrimental effects of all the stress and "therapies" imposed on her and the utter disbelief and hostility she has to endure every day.

With the threat to separate mother and daughter completely they blackmail both into anything they want and they try to force the girl to "cooperate". In view of being yelled at and not believed she has stopped to complain about her symptoms and of the terrible effect the ever increased "activation" measures have on her neurological symptoms.

Of course she cannot come up to their demands for physical activity, and then she is blamed of "subconsciously" blocking herself, of having the famous false illness beliefs and consequently a dysfunctional illness behavior. According to the view of her doctors, the nurses and psychologists/psychiatrists she simply doesn't "dare" to do something. So in their perverted view it is now also the girl's fault that she doesn't become better, not only the mother's fault.

And even the "unconscious mind" of the girl is now blamed for their lack of success. There is a massive pressure on the girl to make her unconscious mind finally behave properly. Even if it were true that the lack of success would be a function of her misbehaving unconscious mind - since when can anyone influence his unconscious mind with his conscious mind?

This must be an entirely new definition of the unconscious. Would it be unconscious if it were to be influenced by the conscious? Any sound psychologist would immediately describe such an idea as proof of absolute ignorance and incompetence.

Whenever **Joanne** has survived some of their "activation" measures they declare it as success, no matter how bad the girl feels afterwards. They seem to run mad in view of the fact that without a considerable weight gain (due to massive tube feeding which they do literally day and night) there is no progress at all in five months of "treatment". So they impose more stressful "therapies" on the poor girl by the day.

There are plans and preparations to admit her into a psychiatric ward. Their argument for this is (apart from financial pressure of the health insurance company that doesn't want to continue their payments for the hospital stay) that their lack of success is due to some kind of undefined "psychological overlay" of the ME/CFS.

Moreover, they want to force the mother into a psychiatric treatment of her own in order "to get her into the boat", that means, to make her agree into the "treatment" and to stop "boycotting" their "treatment" of the daughter. Any resistance of the mother against the cruel and damaging "activation" measures is regarded by the doctors and psychologist/psychiatrists as a symptom of her alleged mental disorder. They neither take her nor Joanne seriously. We wonder how long both will survive this "treatment".

Her mother is waiting for the next court hearing in which her appeal (and the girl's own appeal) to reverse the withdrawal of mother's parental rights will be decided. The judge has not yet decided on the request to allow **Nigel Speight** to testify in court, but he will come anyway, hoping that mother's lawyer will manage to call him to the witness stand or that the judge will do so on the very day of the court hearing.

So far all the advice given by **Nigel Speight** is dismissed and decried as "warfare", and courteous questions of a highly competent psychotherapist for children who is well familiar with ME/CFS have been decried as "interrogation".

But even if the mother gets back her parental rights there is still the father who closely cooperates with the doctors and psychiatrists/psychologists as well as the social workers from the child protection agency.

**Joanne's** prospects are bleak unless a medical lawyer will sue them for medical malpractice. This will certainly not bring them to their senses but it might help to release **Joanne** from the claws of a "treatment" that comes up to outright torture.

A heartfelt **THANK YOU** to everyone who donated so far for **Nigel Speight's** visits and the costs of the lawyer(s).

Already one third of **Nigel Speight's** two trips to Germany are covered by your donations! Please spread the message and ask friends and relatives to support the new fund **Save4Children!**

# Save for Children

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In the March issue of the ME Global Chronicle we announced that a fund has been started called **Save4Children**. We would very much appreciate your continued help with this project.

To explain: in Germany 14 year old **Joanne** has, against both her wishes and her mother's wishes, been removed from her home and taken 'into care' in a hospital where very limited access is allowed to her mother. She is being forced to undergo **GET** and is exposed to light and noise the whole day long despite being oversensitive to both, resulting in a deterioration in her serious condition.

The British paediatrician **Dr. Nigel Speight** was asked to visit **Joanne** and the relevant authorities, arranged through the mediation of a few German patient-advocates. He has written a report on **Joanne's** condition, which has been submitted to the judge involved in her case and to the lawyer for **Joanne** and her mother. It remains to be seen what the outcome of this humane invention by **Dr. Speight** will be, but doing nothing was not an option.

At first the Dutch ME/cvs Vereniging were asked to help with raising the money to enable **Dr. Speight** to help **Joanne**: for travelling expenses and accommodation. Now, at our suggestion, this original objective has been broadened since we expect **Dr Speight's** involvement will be needed in other cases anywhere. **Dr. Speight** has already played a very important role in around 30 more or less similar cases in Great Britain and has managed to help 28 young patients to remain with or return to parental care. He talks about some of these cases in an interview which has been broadcast on YouTube on January 7th, 2014 (<http://youtu.be/XcRZo1vO53c>).

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

If the scope of this project expands, you, our readers, will all be asked about your ideas and opinions as to how we should develop it further. Currently the donations do not exceed **Dr. Speight's** expenses so far for this first EU visit, but further travel will be needed for this and other cases.

So please continue to donate.

You can transfer your donation to:



IBAN: NL85 INGB 0004 286957 - BIC-code (SWIFT): INGBNL2A  
ME/cvs Vereniging  
Den Bosch - The Netherlands  
Please mention: **Save4Children**

On April 24th a sum total of **€604,60** had been donated.

# Spanish Research & Funding For Follow Up Study

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Immunological abnormalities and two biomarkers of chronic fatigue found

Sufferers of Myalgic Encephalomyelitis, also known as Chronic Fatigue Syndrome (ME/CFS) have immunologic abnormalities, which allowed us to identify two potential biomarkers of the disease.

This discovery was made thanks to a study released today by the Spanish association of health workers supporting Myalgic Encephalomyelitis (Asociación de Sanitarios al Servicio de la Encefalomiéltis Miálgica - ASSSEM).

About 200 patients who are suffering from ME/CFS and have assumed the cost of their analyzes, participated in the study, which was based on a comparison of biomarkers of the disease.

This made it possible to confirm the existence of immunological abnormalities and two potential biomarkers in a high percentage of people affected by ME/CFS.

The comparison of biomarkers was based in part on the results of an initial study led last year by the Spanish institute for AIDS research (Instituto de Investigación del Sida - IrsiCaixa).

This study, coordinated by the researcher of the research institute Germans Trias i Pujol in IrsiCaixa, **Julià Blanco**, identified alterations in 8 molecules in the immune system of 12 CFS patients, associated with a poorer immune system functioning, which could serve to improve the diagnosis of this disease.

Following this work, ASSSEM IrsiCaixa proposed to include more patients in the study, but because of the lack of public funding to cover the cost of the project and the lack of patients that are diagnosed in specialized units, this extension of the research couldn't take place.

Fearing that this development did not have clinical impact, ASSSEM decided to bear the costs, with the collaboration of those affected, to make a comparison of biomarkers.

As explained ASSSEM president, **José Luis Rivas**, preliminary results "reaffirm that the investigation of the immune system is the way to know this disease, diagnose and develop a treatment."

"We need allies in basic research, as IrsiCaixa, to further investigate our disease and its relation to the immune system," said **Rivas**.

Therefore, ASSSEM today launched a campaign based on micro-donations on the social networks to fund the research project "Characterization of regulatory T cells in patients with Myalgic Encefalomyelitis/Chronic Fatigue Syndrome".

The association needs to raise 29,000 euros and they hope to do this with the microfinance campaign that has started today and will last 40 days, with the title "Research of new tools for diagnosis of ME/CFS."

The researcher **Julià Blanco** explained that the research project that will be carried out if the money is collected, will be a continuation of the project done last year with the same researchers.



Regulatory T cells are a key element in the immune system, controlling both the response to pathogens and autoimmune responses.

"Because the control of pathogens and autoimmune disorders are altered in patients with ME/CFS, we believe that the study of these cells may provide relevant data to understand the involvement of the immune system in this disease", that affects 2% of the population", said **Blanco**.

The researchers' goal is also to define new diagnostic tools, better understand the causes of Chronic Fatigue Syndrome and identify therapeutic targets.

The study will last for one year and will be done with samples already stored in the laboratory IrsiCaixa, so it will not mean any discomfort to those affected.

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Link to the original text: <http://bit.ly/1dbIGmI>



# IOM Meeting: Open? Participate At Your Own Risk

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"As I have said before, this is a very personal decision and, at the end of the day, we all have to live with our choices. Having said that, it is my strong conviction that cooperating with the IOM by providing substantive comments will do nothing but lend legitimacy to a flawed process that has the very real risk and is, in fact, designed by HHS, to harm this patient population greatly."

"There is a snowball's chance in hell that patients' comments will have the slightest impact. First of all, how did that work out for us when some members of our community provided input on the provisional panel members and their potential conflicts of interest? In short, it didn't."

"You still don't believe me? Ok, let me try to convince you some more. It is true that the Statement of Work provides for patient input. However, the clear task spelled out in the Statement of Work is an evidence-based review of the literature. By definition, that rules out taking into account anecdotal patient stories or comments. The Statement of Work, in effect, prohibits giving weight to patient input because that would be outside the scope of the evidence-based review. Clever, isn't it?"

Also, are patient comments reflected in the Gulf War Illness IOM reports? Remember, the best predictor for future behavior is past behavior.

Providing written comments or, if invited, giving comments at the meeting will not make a single difference in the outcome of the "study." All it will accomplish is for HHS to be able to claim that patients were given a voice and were on board with this farce when most patients familiar with the issue are not.

I know it's unsettling to feel helpless and to have no control. But submitting comments is not the way to gain any control. The only thing we can control is not to legitimize this "study" by refusing to participate and to continue our protest."

**Jeannette Burmeister**

For the full article: <http://bit.ly/1hMKOj7>



# Thunderclap to STOP the IOM/HHS- contract

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## Let our voices be heard!

Defining a disease as complex as ME/CFS is not purely an intellectual exercise. It requires the expertise of ME/CFS specialists who have substantial experience in treating and researching this disease.

The IOM, hired by HHS to define ME/CFS, does not have that necessary expertise, just as it didn't for Gulf War Illness, a disease as complex as ME/CFS and the first disease the IOM has tried to define.

Shamefully, the IOM had to admit that it was unable to do so despite having been paid \$850,000 of taxpayer money for it.

<http://www8.nationalacademies.org/onpinews/newsitem.aspx?RecordID=18623>

If the ME/CFS IOM study proceeds, the continued abuse of ME/CFS patients based on an unscientific and flawed IOM definition is all but guaranteed for decades to come.

The IOM study is a train headed for a cliff that needs to be stopped now before any more of \$1 million in taxpayer money is wasted and before patients are further harmed.

Please join this advocacy movement to stop the IOM from redefining a disease that our experts have already defined and participate in this Thunderclap campaign here before the day of the next IOM meeting on May 5, 2014:

<https://www.thunderclap.it/projects/10666-stop-the-iom-adopt-the-ccc>

You can participate using:

Facebook **AND** 

Twitter **AND** 

Tumblr. 

If you have trouble with the Thunderclap steps, here are detailed instructions:

<http://thoughtsaboutme.com/2014/04/16/thunderclap-to-oppose-the-iom-support-the-ccc-let-our-voices-be-heard-loud-and-clear/>

Thank you!

# IACFS/ME-conference

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## Key points

At the very end of the three days long IACFS/ME-conference in San Francisco, **prof. Anthony Komaroff** presented a summary of the entire conference. Following are some impressions, extracted from an excellent report of **Margaret Williams**.

**Anthony Komaroff** is a distinguished Professor of Medicine at Harvard Medical School; his summary at the end of the 51 minute video should not be ignored:

“Case-control studies comparing patients with CFS to both disease comparison groups and healthy controls subjects find robust evidence of an underlying biological process involving:

- + the brain and autonomic nervous system
- + immune system
- + energy metabolism
- + oxidative and nitrosative stress

**“In summary, the illness is not simply the expression of somatic symptoms by people with a primary psychological disorder”.**



**Komaroff** divided his highlights of the proceedings into various sections including immunology: basic biology, virology and infectious agents, public health/epidemiology, case definition, exercise provocation studies, paediatrics, brain research and neuro-inflammation.

In the Immunology section, **Komaroff** said that a highlight for him was the CFI (multi-centre Chronic Fatigue Initiative) study that found elevated levels of allergy-associated cytokines and chemokines and other pro-inflammatory cytokines and chemokines in patients who had been ill for less than 3 years when compared with those who had been ill for longer than 3 years.

He said that this validated the concept that most of the biological action that people were going to be able to detect is more likely to be in the earlier stages of the illness than in the later stages.

In the basic biology section, **Komaroff** noted that telomeres (the ends of chromosomes) are shorter in CFS patients compared with matched healthy controls and that telomere length is a marker for cellular ageing in that their length reflects the viability of the cell.

So a shorter telomere predicts an increased vulnerability to diseases of ageing such as atherosclerosis, neuro-degenerative diseases and several malignancies CFS” age more quickly.

**Komaroff** spoke about the Stanford Inflammation Studies which looked at 51 inflammation-related molecules (cytokines, chemokines and hormones) and which found that 15 such molecules distinguished cases from controls, or correlated with symptoms severity, or both.

**Komaroff** then considered the importance of the Hornig/Lipkin study on IF-gamma. "IF-gamma is thought to be commonly released by viral infection or infection of intra-cellular bacteria, so it suggest but by no means proves that in CFS there may be an underlying infectious agent".

**Komaroff** noted the role of infectious agents and the fact that essentially no infectious microorganism had been found in serum but he questioned whether this was the case in circulating white blood cells, brain or other tissue. He noted particularly the impressive work of **Dr John Chia** on enteroviruses in CFS.



In the brain research section of his highlights, **Komaroff** discussed the work of **Marcie** and **Mark Zinn** from Stanford.

On the issue of neuro-inflammation, **Komaroff** said: "There is, and you've heard it repeatedly in the last three days, a theory that CFS might reflect an ongoing activation of immune cells in the brain, not in the periphery, but in the brain" and he went on to discuss the Japanese study that clearly showed an increased signal, giving evidence of immune activation in multiple areas of the brain, the intensity of the signal correlating with cognitive impairment.

In his presentation, **Komaroff** said: "It was a fair question 30 years ago to ask whether people with these symptoms might not just be expressing psychiatric distress, amplifying normal body sensations or even fabricating for secondary gain...but today it is no longer a fair question".

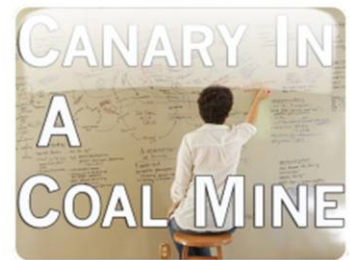
Full speech: <http://youtu.be/nyyjRdbvPj0>

Fullarticle:

<http://www.meactionuk.org.uk/Komaroff-Summary-San-Francisco-March-2014.htm>

# Canary in a Coalmine

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Canary in a Coal Mine and Thrive Show are different (and should remain) separate properties.

The two projects have distinct but I hope sometimes synergistic missions. The goal of Canary in a Coal Mine is to change public perception of ME.

The goal of Thrive Show is be a platform to discuss a wide range of issues related to people living with chronic health conditions.

Some kinds of cancer, Grave's Disease, MS, Guillain-Barre, HIV/AIDS, Chron's, Colitis, IBD, IBS, Fibro, bipolar disorder, Lyme, RA, CRPS...the list goes on.

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

I thought the latter would be of interest to people supporting the former, but that is clearly not the case, and so I will no longer be cross-promoting content. It's clearly muddying the waters.

A small but substantial number of people with those conditions, by the way, supported the film because they saw pieces of their story in our story, which was a large part of the inspiration behind the show. I want to expand that circle of allies!

**There has been absolutely no shift away from the film in terms of what's actually happening behind the scenes.**

My life has been 90% CIACM, 10% Thrive Show, 100% stuck in bed. You have not heard much about it because I have been tirelessly working on producing and directing some amazing shoots.

It's going to take a lot of time before all that work is ready for the world, but I'm working with some amazing DPs, and some amazing patients, and when it's done, it will be gorgeous, and moving, and hopefully do a tremendous amount of good in the world.

Unfortunately, there are challenges inherent in trying to build a cosmopolitan space. People with one disease may inadvertently touch hot spots for people with other diseases without meaning to b/c the disease experience, the nature of the disability, the politics and medical treatment, social context etc. are all going to be a different. And that's a challenge.

It's like when people with cancer think my life is a cakewalk. Or when people with ME tell cancer patients they'd rather have cancer (don't do that!).

But my intuition is that it will be worth it in the long run because the best, most exciting, world-changing stuff grows out of diverse groups and cosmopolitan spaces.

I received a lot of emails from patients during the campaign who believed their own disease onset had something to do with major stress, childhood events, or physical trauma. Yes, I am ashamed to admit I rolled my eyes a bit when I received these emails.

What I realize now is that I was doing to those patients exactly what had been done to me in the past in so many doctor's offices. I had incredibly strong priors and so I imposed my beliefs on another person and completely failed to appreciate, listen to, or engage with their subjective experience. I was also uncurious.

There are severely ill patients for whom mind-body techniques are an incredibly important tool (one among many) for coping with their illness and yes, even healing.

It's not going to get someone out of a wheelchair, but it might be one important piece among many. And if it is for them, and it is for **Donna Nakazawa**, who am I to begrudge them that additional level of peace and healing?

(<http://www.thriveshow.org/donna-jackson-nakazawa/>)

I know this may all sound incredibly naive, but if I wasn't an idealist, I would not be making this film. Moreover, I can't kill that former self who was a university professor in training.

I believe people with important things to say should have platforms, even if we disagree with them, and that we should never be afraid of good science.

But the politics is tough.

Most of the doctors/psychologists/psychiatrists don't understand the science, we are where we are, and I have no intention to cover Adverse Childhood Events in the film.

If anything, a major focus of the film will be the harm caused by psychological explanations.

**Jen**



# I Cannot Be Silent!

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I cannot be silent! I have to speak up and let the Institute of Medicine ME/CFS panel know how ME affects me and others. They want to know what doctors need to know to diagnose ME.

I am compelled to tell them my professional perspective from a bedside nurse's view, and what I experienced as a patient and patient advocate. To be silent when someone is willing to listen can be deadly.

Especially, if someone else is whispering harmful ideas in their ears. I respect others decision to boycott. I will not.

And, everyone is entitled to their opinion without criticism or bullying. That will not be allowed on my page.

There is one week left to send in comment to the IOM for their May 5 open meeting. The deadline is April 23. They want two questions answered and sent to [mecfsopensession@nas.edu](mailto:mecfsopensession@nas.edu)

After April 23 send comments to [mecfs@nas.edu](mailto:mecfs@nas.edu) but they will not be distributed to panel members until alter the meeting.

1. "What are the most important issues that the healthcare providers should be educated about when it comes to diagnosis of ME/CFS?"
2. "What are your thoughts on the current terminology used to describe this disease Myalgic Encephalomyelitis / Chronic fatigue Syndrome? If you could suggest a new terminology, what would you suggest and why?"

Here is my comment to the IOM. You can use it as a template or use any part of the letter to create your own.

**Lori Chapo Kroger**

<http://bit.ly/1i9VM3f>

# Diseases can stigmatize

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Names of diseases have never required scientific accuracy (e.g. malaria means bad air, lyme is a town, and ebola is a river). But some disease names are offensive, victim-blaming, and stigmatizing.

Multiple sclerosis was once called hysterical paralysis when people believed that this disease was caused by stress linked with oedipal fixations.

AIDS was initially called "Gay Men's disease" when it was considered a disease only affecting white gay men.

Fortunately, when these disease names were changed, those afflicted with Multiple Sclerosis and AIDS experienced less stigma. Inspired patient activists from around the world are currently engaged in another major effort to rename chronic fatigue syndrome (CFS). It is a political struggle to alleviate some of the stigma caused by the language of scientists at the CDC 25 years ago.

Chronic fatigue syndrome is an illness as debilitating as Type II diabetes mellitus, congestive heart failure, multiple sclerosis, and end-stage renal disease.

Yet 95% of individuals seeking medical treatment for CFS reported feelings of estrangement; 85% of clinicians view CFS as a wholly or partially psychiatric disorder; and hundreds of thousands of patients cannot find a single knowledgeable and sympathetic physician to take care of them.

Patients believe that the name CFS has contributed to health care providers as well as the general public having negative attitudes towards them. They feel that the word "fatigue" trivializes their illness, as fatigue is generally regarded as a common symptom experienced by many otherwise healthy individuals. Activists add, that if bronchitis or emphysema were called chronic cough syndrome, the results would be a trivialization of those illnesses.

Powerful vested forces have opposed changes. In the late 1990s and early 2000s, when I mentioned over the years that patients were stigmatized by the term chronic fatigue syndrome, I was explicitly told it was reckless and irresponsible to change the name.

This was despite the fact that patients wanted more medical-sounding name, and our research group had found that a more medical-sounding term like myalgic encephalopathy (ME) was more likely to influence participants to attribute a physiological cause to the illness.

Over the last decade, patient demands for change have grown louder. New names have occurred for several patient organizations (e.g. the Patient Alliance for Neuroendocrine-immune Disorders Organization for Research and Advocacy and the Myalgic Encephalomyelitis Society of America) and research/clinical settings (Whittemore/Peterson Institute for Neuro-Immune Disease).

Even the federal government has begun to use the term ME/CFS, and the organization of researchers changed their name to the International Association of CFS/ME. Ultimately, many activist groups want the term myalgic encephalomyelitis to replace CFS. Bringing about a name change is a complicated endeavor, and small variations of language can have significant consequences among the stakeholders.

In addition to this effort to rename chronic fatigue syndrome, there is considerable patient activism to change the case definition, which was arrived at by consensus at the CDC rather than through empirical methods. Patients report and surveys confirm that core symptoms of the illness include post-exertional malaise, memory/concentration problems, or unrefreshing sleep.

Yet these fundamental symptoms are not required within the current case definition. Patients want the current case definition to be replaced with one that requires these types of fundamental symptoms.

If laboratories in different settings identify samples that are not homogenous, then consistent biological markers will not be found, and then many will continue to believe the illness is one of a psychogenic nature, just as once occurred for multiple sclerosis. Clearly, issues concerning reliability of clinical diagnosis are complex and have important research and practical implications.

In order to progress the search for biological markers and effective treatments, essential features of this illness need to be empirically identified to increase the probability that individuals included in samples have the same underlying illness.

If progress is to be made on both the name change and an empirical case definition, key gatekeepers including the patients, scientists, clinicians, and government officials will need to work collaboratively and in a transparent way to build a consensus for change.

Considerable activity is currently ongoing at the federal level on these critical issues, but only through open communications and the building of trust will there be the possibility of overcoming the past 25 years, which have been marked by feelings of anger and hostility due to being excluded from the decision-making process.

## **Leonard A. Jason**

**Leonard A. Jason** is a professor of clinical and community psychology at DePaul University, director of the Center for Community Research, and the author of *Principles of Social Change*.

See more at: <http://bit.ly/1ikACQW>



# The ME and CFS Documentary Project



Project Update:

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

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



Production is 99% Complete.  
9 Trips, 9 States, 9 Months.

3 Terabytes. 70-80 hours of footage. More than 20 of the top neuro-immune scientists in the world. Nearly 40 patients featured. Nearly 20 caregivers, family members, journalists, and activists on film.

A projected 47 scenes. A projected running time of 96 minutes. 54 screenings in 6 nations already penciled in.

### **Are you ready to rock the world?**

Take a look at some of our newest and most exciting interview scenes yet. (From the Stanford ME/CFS Symposium and the International Association of CFS/ME conference in San Francisco)

[https://www.facebook.com/CFSDocumentary/photos\\_stream](https://www.facebook.com/CFSDocumentary/photos_stream)

## **Blue Ribbon transformed into Forgotten Plague.**

Forgotten Plague is a title designed to capture a much wider audience than we have so far; it's also meant to encapsulate the breadth of the story we seek to tell. The name echoes through history back to the earliest days in the Book of Exodus.

It penetrates deep into the hearts of patients that their suffering is validated as comparable to the greatest of all human suffering. It brings a poetic and philosophic sensibility that our narrative strives to channel. On the most practical level, it can grab a viewer's attention simply searching through a Netflix queue.

We want a title that seizes the viewer's attention, and from the very beginning, cries out to them that they are indeed witnessing the great under-reported medical story of our time.

To be clear, we had always intended "The Blue Ribbon" as a working title, as something that would capture the attention of the patient community from day one and signal our allegiances. But we've been discussing for months how to grab the attention of the wider public.

The Blue Ribbon has a specific set of meanings to a specific set of ME/CFS patients. We feel that Forgotten Plague has a universal set of meanings for a much broader swath of humanity, past, present, and future.

**Ryan Prior & Nicole Castillo**

# Protein M

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The Ultimate Decoy: Scientist Find Unique Protein that Misdirects Immune System

A team led by scientists at The Scripps Research Institute (TSRI) has discovered an unusual bacterial protein that attaches to virtually any antibody and prevents it from binding to its target. Protein M, as it is called, probably helps some bacteria evade the immune response and establish long-term infections.

If follow-up studies confirm Protein M's ability to defeat the antibody response, it is likely to become a target of new antibacterial therapies. The protein's unique ability to bind generally to antibodies also should make it a valuable tool for research and drug development.

"What Protein M does to antibodies represents a very clever trick of evolution," said **Richard A. Lerner, Lita Annenberg Hazen Professor** of Immunochemistry and Institute Professor at TSRI who led the research.

The new findings, which were achieved through collaboration among several laboratories at TSRI and elsewhere, are described in the February 7, 2014 issue of the journal *Science*.

## **Unexpected Discovery**

The unexpected discovery originated from an effort to understand the origin of multiple myeloma, a B-cell carcinoma. Clonal B-cell proliferation, as well as lymphomas and myelomas, can result from chronic infections by organisms such as *Escherichia coli* (*E. coli*), *Helicobacter pylori* (*H. pylori*) and hepatitis C virus.

To better understand this process, the team investigated mycoplasma, a parasite that infects people chronically and is largely confined to the surface of cells.

In a search for factors associated with long-term mycoplasma infection, **Rajesh Grover, PhD**, a senior staff scientist in the Lerner laboratory, tested samples of antibodies from multiple myeloma patients' blood against a variety of mycoplasma species.

One of the proteins recognized by the antibodies was from *Mycoplasma genitalium*, which causes sexually transmitted infections in humans.

To the scientists' surprise, every antibody sample tested showed reactivity to this protein. But further tests made clear that these antibody reactions were not in response to mass infection with *M. genitalium*.

Instead, the scientists found, the mysterious *M. genitalium* protein appeared to have evolved simply to bind to any antibody it encounters.

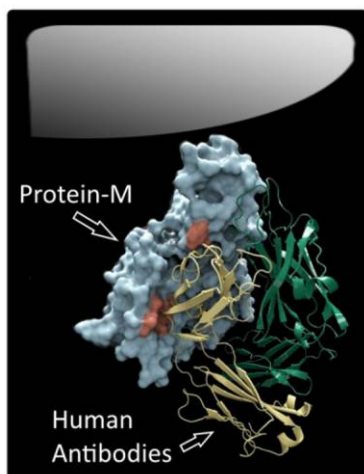
That presents a potentially major problem for the immune system. The antibody response is meant to combat invading pathogens with precisely targeted attacks, each selected from an enormous repertoire of hundreds of millions of distinct antibodies.

In effect, the system is designed not to bind universally to any one target. If it did, then such a target could act as a universal decoy, potentially nullifying the entire antibody response.

The current research suggested that *M. genitalium* has evolved such a decoy. “It binds to every antibody generically—capable of hijacking the entire diversity of antibody repertoire—but at the same time it blocks the specific interaction between that antibody and its intended biomolecular target,” said **Grover**.

### 'Protein M'

The team decided to call it “Protein M.”



To better understand how Protein M works, **Xueyong Zhu, PhD**, a staff scientist in the laboratory of **Ian Wilson, DPhil, Hansen Professor** of Structural Biology and chair of the Department of Integrative Structural and Computational Biology at TSRI, and colleagues took a structural biology approach.

Using X-ray crystallography and other techniques, including electron microscopy in the TSRI lab of **Assistant Professor Andrew Ward, PhD**, the team determined the protein’s 3D atomic structure while the protein was bound to various human antibodies.

Compared to thousands of known structures in the Protein Data Bank, the worldwide structure database, Protein M appeared to be unique.

The data also revealed that Protein M binds to a small, unchanging—“conserved”—region at the outer tip of every antibody’s antigen-binding arm. “It likely extends the other end of itself, like a tail, over the antibody’s main antigen-binding region,” **Zhu** said.

The team is now studying Protein M’s function during *M. genitalium* infections. It seems likely that the oddball protein evolved to help *M. genitalium* cope with the immune response despite having one of the smallest bacterial genomes in nature.

“It appears to represent an elegant evolutionary solution to the special problem that mycoplasma have in evading the adaptive immune system,” said **Grover**. “The smallest parasitic bacteria on planet earth seems to have evolved the most sophisticated invading molecular machine.”

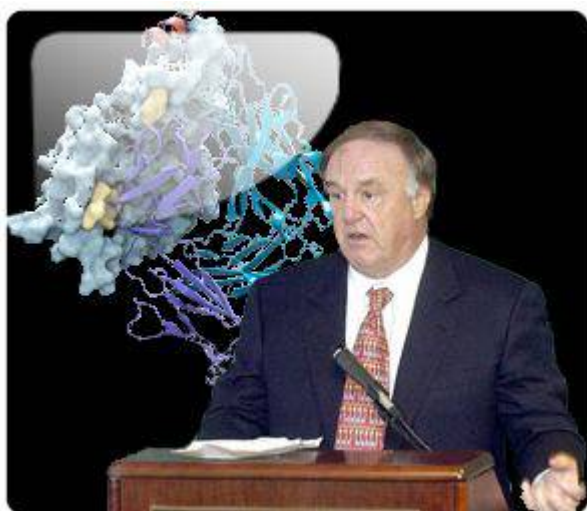
### *Unusual—and Unusually Useful*

If Protein M is confirmed as a universal decoy for antibodies, it will become a target for new drugs, which could make it easier to treat chronic, sometimes silent infections by *M. genitalium* and by any other microbes that have evolved a similar antibody-thwarting defense. Chronic infections can lead to a host of other problems, including inflammatory diseases and cancers.

In principle, Protein M also could be engineered to target specific groups of B cells—immune cells that produce antibodies and express them on their surfaces. Thus, Protein M could deliver cell-killing toxins to cancerous B cells but not healthy ones, for example to treat certain lymphomas.

In the era of antibody-based drugs, the most immediate use of Protein M is likely to be as a tool for grabbing antibodies in test tubes and cell cultures, useful for the preparation of highly pure antibody for research and drug manufacturing.

Other generic antibody-binding proteins have been put to use in this way, but so far it appears that none does the job quite as well as Protein M.



“It may be the most useful antibody purification device ever found,” said **Lerner**, who is already in talks with industry to commercialize the protein.

Source:

[http://www.scripps.edu/newsandviews/e\\_20140303/lerner.html](http://www.scripps.edu/newsandviews/e_20140303/lerner.html)



# May 12th: International Awareness Day

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It is the dream of our patient community to erase the stigma and finally be taken seriously by friends, family, researchers, government and people in our local communities.

May 12th Awareness Day is a chance for the millions of patients worldwide suffering from Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and Fibromyalgia (FM) to be seen and heard!

These illnesses are real; the people are real; and they need help NOW! These are chronic and severely disabling illnesses. They are as disabling as MS.

People are frequently bedridden and become isolated from friends and family – invisible in their own communities. **Dr Nancy Klimas**, an expert in both ME/CFS and AIDS, was quoted as saying:

*"A CFS patient feels the same or worse than congestive heart failure. The same or worse than late stage AIDS. If I had to choose between the two illnesses I would rather have H.I.V. "*

These illnesses do not discriminate. All races, men and women, adults and children can be afflicted. It is particularly devastating when a child is forced to cope with such a disabling illness.

We are on a mission to bring awareness around the world for this patient community and to set the stage for fundraising for research and more physician education and ultimately a cure.

## **With awareness, will come action!**

Our community is desperately in need of treatment facilities and funding is required to support research and our scientists. A successful May 12th will bring many rewards for years to come.

These activities will not only benefit us today, but they will be an investment in our future. To quote **Helen Keller**:

"Alone we can do so little; together we can do so much."

Source:

<https://www.thunderclap.it/projects/10106-may12th-int-l-awareness-day?locale>

## **International Awareness Day**

An event has been set up you can join <http://on.fb.me/1htmrYk>

What started as a friendly challenge between Canada and Northern Ireland is now growing to be international. The challenge is to get as many buildings as possible in your country to light up with one of the 3 colours used on May 12th - **blue, purple** or **green**.

We want public buildings/places like City Halls, Niagara Falls and we want individual homes lit up too!

We'll all be winners but there will be bragging rights awarded to the country with the most photos in each of these categories:

1. # of Public Buildings/Places
2. # of Private Residences

The contest will be coordinated by May Twelfth and photos and final results posted on the May 12th International Awareness Day page:  
<http://www.facebook.com/may12th.awareness>.

To enter, photos should be taken and sent to May Twelfth at [info@may12th.org](mailto:info@may12th.org). All pictures must be emailed by May 19th to be included.

When sending the photo, include information about where the photo was taken (ie town, region, country). The May 12th team will count and post the photos as they come in and post the final results as soon as possible after the 19th.

Country coordinators helping so far are:



Australia - Fibromyalgia Awareness Day 2012

<https://www.facebook.com/FMawareness>



Canada - NATIONAL ME/FM ACTION NETWORK

<https://www.facebook.com/MEFMAActionNetwork>



Northern Ireland - NEWRY & MOURNE ME/FIBROMYALGIA SUPPORT GROUP

<https://www.facebook.com/groups/newryandmourne.me.fms/>



United Kingdom / Europe - INVEST IN ME / EUROPEAN ME ALLIANCE

[https://www.facebook.com/groups/5804522506/?ref=br\\_tf](https://www.facebook.com/groups/5804522506/?ref=br_tf)

Separate from this combined event, other events will be held in:



### **Belgium**

On Wednesday, May 7, 2014, the  WUCB will be organizing a symposium on CFS in the context of the International Awareness Day for Chronic Immunological and Neurological Diseases. More information: <http://www.wakeupcallbeweging.be/>



### **Holland**

May 10 - Amsterdam

International ME-awareness day in Holland will feature for the third time an event which is being organized by **Sonja Silva**, ME-patient, singer and celebrity.

The program on Saturday 10 May will start at 1 pm and last until 5 pm local time.

**Sonja** and her friend **Pyke** will perform several songs, accompanied by their group of musicians. After that **prof.dr. K. De Meirleir** from Brussels will give a talk, and subsequently there will be ample time to ask him questions.

The afternoon will be ended again by **Sonja & Pyke**.

At the request of the Dutch community there will be a lot of time to socialize and get to know friends who were known through the social media only till so far.

Dresscode: blue

Wereld ME Dag benefiet

Saturday 10 May 2014

Boerderij Langerlust

Provincialeweg 24, 1108 AB Amsterdam Zuidoost

To participate: mail to [wereldmedagbenefiet@live.nl](mailto:wereldmedagbenefiet@live.nl)



### **Ireland**

May 11 – Dublin

Carlton Hotel Dublin Airport, Old Airport Road, Cloghran (Santry), Dublin Airport, Co. Dublin, 3pm.

Irish ME/CFS Association event to mark International ME Awareness Week. Talk by **Dr Charles Shepherd**, medical adviser to The ME Association (UK). Admission £5 per person at the door, towards the costs. The Irish ME/CFS Association's contact details are – Tel: (01) 2350965. E-mail: [info@irishmecfs.org](mailto:info@irishmecfs.org). PO Box 3075, Dublin 2.





### Japan

There is an event on May 11th in Osaka organized by CFS Patient support Group called " Kiboo no Kai"(Hope Association). There are other things planned but not confirmed. Mark House & Projects designed May 12th CFS awareness budes and sent those out to related patient groups. I will also be interviewed by several newspapers, Kobe Newspaper and Asahi newspaper to raise awareness. I listened to the Japanese parliament discussion on April 16th and they were discussing the lack of welfare support for ME/CFS patients in Japan and asking the government to not to exclude patients from welfare support from the name of illness but to really determine who really need the help. **Masako**



### Scotland

May 12 – Edinburgh

Scottish Story-Telling Centre, 43-45 High Street, Edinburgh EH1 1SR, 1.30pm

Story-Telling Workshop; Journeys with ME. Event organised by Action for ME. Tickets cost £8 (£6 concession). To book tickets for either the afternoon workshop or the evening film screening, please contact the Scottish Storytelling Centre Box office on: 0131 556 9579 (open 10am-6pm Mon-Sat), Tickets can also be booked online through the following links:

<http://tinyurl.com/q238jyy> <http://tinyurl.com/q238jyy>



### USA – San-Francisco

On Monday, May 12th from noon-1PM there will be a gathering at HHS headquarters at the Federal Building (90 7TH Street)

### **"30 Years of Neglect"**

Please join us at the Federal Building on 90 7th Street on May 12th noon – **1PM!** Afterwards, we will go to McKesson Plaza to take our message to Dianne Feinstein (5 blocks from Federal Building – there is a bus stop close by).

This will be a peaceful demonstration (we have a permit). For your convenience, there is a bathroom in the café next to the Federal Building.

For more information please contact Erica at [everrillo@yahoo.com](mailto:everrillo@yahoo.com)



### Wales

May 12 – Glamorgan

Film Voices from the Shadows being shown in Penarth Pavilion, Glamorgan, 12th May at 2pm. Tickets £4 available from Mesig 02920 762 347. Eventbrite website or Penarth box office.

We are suggesting that this film is not for those with ME but those who need to understand about ME. Ideally Assembly Members/ Members of Parliament, medical or health professionals, social services, benefit agencies staff, etc.

# News from...Australia

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## *Who will be held responsible if Karina Hansen dies?*

I have been personally involved in a case in Brisbane similar to that of **Karina Hansen**. At that time, I had no support from my local colleagues. The private hospital legally removed me from my patient's case and I have no knowledge as to whether my patient is alive or dead now.

However, I have also witnessed several other unnecessary deaths here in Brisbane due to ME/CFS under circumstances of medical negligence relating to ignorance over the proper management of these disorders. In **Karina Hansen's** case, medical expertise assistance has been offered to her current treating doctors. Unfortunately, **Karina's** doctors have refused such assistance. I suggest that they fear criticism and accusations of negligence. **Karina** is literally becoming the sacrificial lamb in the name of psychosomatic illness.

However, **Karina** should not become a martyr to our efforts, that is to ensure that ME/CFS becomes recognised as a legitimate medical illness with real organic underpinnings. **Karina's** life should be respected, regardless of other agendas. By now, **Karina** may well have developed secondary psychiatric phenomena whilst in hospital brought about by inappropriate care due to the ill informed efforts of those trying to help her.

The fact that she is still in hospital and is no better and by the sound of things, is much worse than when she was admitted to hospital, in itself, is evidence that her care givers have no idea about the illness that they are trying to treat. How many illnesses do we know of, that require such lengthy in hospital care?

I will assure you that the medical records of her hospitalisation will not reflect the true history of **Karina's** inpatient experiences. I kept my own personal medical records of the patient I looked after 15 or so years ago, as I could see how my observations differed so greatly from those of other staff (such as nurses) and that what was documented in the hospital records did not reflect the reality of the situation.

Her records were clearly doctored in favour of the hospital's image and reputation. For an individual such as **Karina** to be denied the right to live or die because of political and so called 'medical controversy' is beyond the bounds of what modern medicine is intended to achieve.

I personally accuse the doctors looking after **Karina** of medical negligence, on the ground of the information I have cited above. My goal is accountability now, as my prediction is that **Karina** is no better than she was before and is likely to be much worse and not better since she was admitted to hospital.

**Dr John L Whiting** - one of Australia's most pre-eminent ME specialists and passionate advocates - Brisbane, Australia

# News from...Belgium

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The public hearing on CFS, held on March 19th, evoked emotional responses. Even though these reactions are very understandable, they do not help the CFS / ME / Fibromyalgia community.

In Belgium we have always been able to find a solution by talking to each other. We should uphold this behaviour instead of provoking or showing disrespect to other people.

Moreover, we should join forces. I have the impression that some CFS / ME associations no longer follow their initial goals. Their primary goal should be to find a cure for these illnesses rather than maintain their association as it is.

The focus should lie on the results and effectiveness rather than the number of members. This is not a competition.

Talk to each other, act together.

**Eddy H. Keuninckx**

# News from...Finland

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We are a new association from Finland and we are established at Tampere. We registered in March, 2014.

The idea for this kind of action started from a few people on Facebook. Me and my friend have a support group there, CFS/Suomi which is not related with our action.

In Finland we battle with all healthcare, it is so hard to get treatment here, especially this illness, which is hard to believe in and to diagnose.

Here we have only one doctor who believes in us, researches ME and takes care of us. His name is **doctor Olli Polo**. He has approximately 500-800 patients around this country. He is also about to find more ways to help us.

There are few doctors more who do not turn us down but they are rare. Unfortunately.



At this point, our associations mission is to get this illness well-known, increase ways to teach diagnostics to other doctors, support our members in dealing with many agencies. And so much more. We have a long way ahead. But we are willing to do it!

I have also the diagnose myself and so many more in our group. So there will be relapses and lots of rest. But the measure of the consignment among these people is outstanding! We only have each other and **dr. Polo** now, but soon, who knows, we have more and more doctors who are willing to take action for our health and recover.

Now my eyes are getting opened that this is a worldwide problem and so many are fighting for their health and getting none of treatment. That is the problem we need support globally.

This is not the end. This is a new beginning.

All of our group are out of order presently, but we are gathering our troops now, maybe for a little demonstration at government buildings stairs, in 12th of May.

Sincerely,

**Sanna Pohjaniemi**

Chairwoman from Finnish association of CFS

<http://cfs.suntuubi.com/>

<https://www.facebook.com/SuomenCFSyhdistysry/info>

# News from...Germany

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Meet **Katharina Voss**, ME/cfs advocate in Germany and abroad.

In the frequently watched German television-program Menschen... das Magazin (People... the Magazine) **Katharina Voss**, a German sufferer from ME with two daughters with severe ME were filmed and interviewed on 15 September 2012.

**Katharina** and both her daughters **Pauline** and **Adele** talked about their situation and their hopes and expectations. The broadcast was in German, but has now been translated and subtitled in English by two German patients: <http://youtu.be/XgZ1ayI7J6w>

Recently, on 29 March in continuation of that broadcast a new episode, depicting the present situation **Katharina** and her daughters, has been shown in the same program: <http://youtu.be/fws-oAExvAs>.

It is harrowing to witness the deterioration in health of the two girls, and most confronting to note the differences between those two episodes.



Again, this broadcast has been watched by some **1,5 to 2 million people** and has been translated and subtitled in English by the same patients.

**Katharina** for one had to cope with threats of being deprived of her parental rights re her younger daughter, being accused of Münchhausen by proxy and over-protectiveness.

The real impact of ME... deepest respect for **Katharina** and her daughters...

# News from...Malta

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In an article in The Times of Malta from Sunday, March 23, 2014 with the title TheNeeds of people living with ME, **Etienne St John**, Communications Coordinator, Ministry of Health, Valletta referred to the Health Minister who had commissioned a working party a few months earlier to address a number of issues on ME/CFS.

His finishing line was "Additionally, although to date there are no recognized treatments for ME, on March 7, a Legal Notice was published in the Government Gazette for fibromyalgia and ME to be included as Schedule V illnesses under the Social Security Act.

This will allow sufferers to be prescribed adjunctive medicines commonly used in both conditions".

Reacting on this article Maltese patient advocate and ME-sufferer **Bibo Gatt** commented in the same newspaper: "While it is commendable that steps are being taken in the right direction, this letter is misleading on several counts. It omits to mention a compromised immune system as being one of the hallmarks of ME".

The composition of the Working Party is definitely not "comprehensive". ME Sufferers Malta is the oldest patient support group for this condition in Malta. Its members are long-term patients who have had to perforce inform themselves over several decades.

Some of the members are also very familiar with international standards of care for this condition in different countries, having at great personal sacrifice, spent a lot of money to seek treatment abroad. And yet, despite having initially been invited to form part of this committee, were ultimately excluded. One asks whether those convening the group were afraid of having patient groups that were well informed present.

Finally, it is a gross error to state that "there are no recognized treatments for ME". Recognized by whom? The medical establishment? There is an International Consensus Criteria Document on ME for diagnostic purposes and also a Primer Document for Medical Practitioners.

Collectively, the authors have diagnosed and/or treated more than 50,000 patients who have ME; more than 500 years of clinical experience; more than 500 years of teaching experience; authored hundreds of peer-reviewed publications, as well as written chapters and medical books.

These documents are highly referenced with the latest research, for those who care to inform themselves.

Source: <http://bit.ly/1guuxis>

# News from...Spain

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Crowdfunding for ME research in Spain until the end of April 2014, please share!

## **Who are we?**

ASSEM (Spanish Association of Health Professionals and Patients in Support of Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome) is a non-profit organization established by people living with ME/CFS and professionals.

We are now joining forces with the Insituto de Investigación del Sida IrsiCaixa (IrsiCaixa AIDS Research Institute) to help the research the relationship between the immune system and this illness.

“Characterization of the T regulating cells in patients with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome” is the name of the project we are seeking funds for.

The objective of the study is to establish new tools for diagnosing, as well as understanding better the causes of ME/CFS and possible therapeutic directions.

This project gives continuity to the study published last year by the same researchers which proves that there are 8 molecular alterations in people with ME/CFS which seem to be related to a faulty functioning of the immune system.

## **How much do we need?**

We need 29,000 euros to cover the whole research project. Initially we have set ourselves the objective of 5,000 euros, which is the minimum necessary to get this research going."

<http://www.verkami.com/projects/8246>

# News from San Francisco

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## **20-23 March 2014: The IACFS/ME 4 day conference – a bird’s-eye view**

It is impossible to capture in two or three pages the multifarious events that took place in California during those memorable days packed up with presentations, workshops, talks by almost all top scientist on ME from all over the world, and what not.

So let’s just take a bird’s eye-view of the first day, as seen by the eye of a bird of Phoenix Rising, **Searcher**.

The event has been highlighted by many national and international sites, fb-walls, blogs and tweets, so it is pointless and useless to repeat all that again.

It might be useful though to once more give you the link to the entire program of those four memorable days.

Personally I printed it out and it proved very useful as a handle and a framework to read those reports in their context:

<http://bit.ly/1hAd60T>

<http://www.iacfsme.org/>

## **20 March 2014, San Francisco**

Although each day was divided into a professionals session and a patients one, in this short survey we’ll focus on the professionals sessions.

20 March: **Fred Friedberg** as chair of the IACFS/ME opened the conference and gave an intro, mostly focused on logistics.

**José Montoya** gave a warm shout-out to patients who are bed-bound or house-bound so can’t attend the conference. The purpose of the Stanford ME/CFS Initiative is “to become a center of excellence that improves the health of patients with chronic diseases in which infection or its immune system plays a major etiologic role”.

**Ian Lipkin** is consistently looking for new infections outside of humans too as many originate outside. He is making use of High frequency sequencing (next generation sequencing).

“ME/CFS is very complex, can be open to a wide range of interpretations – but not psychosomatic. Caution is needed: modulation of the immune system is very dangerous. Future CFS studies: RNA Seq, CFS gastrointestinal microbiome, metabolomics, proteomics, high-throughput sequencing of PBMC, but all need funding”.



**Sonya Marshall – Gradisnik:** natural killers don't just do lysing, they also affect the adaptive immune system. They affect the T-cells and the B-cells. They have a bigger immunomodulatory effect than we knew before.

**Nancy Klimas:** more than one thing wrong is needed in the immune system to get sick. You need more than one thing broken to explain the illness known as Chronic Fatigue Syndrome. Biomarkers can be therapeutic markers.

**Paula Waziry,** Ph.D, Assistant Professor, Neuro Immune Medicine, Nova Southeastern, Miami: viral infection reactivation needs genetic predisposition, environmental components plus epigenetic effects on gene expression.

**Charles Lapp:** The sicker the patient, the more comorbidities they tend to have. 85% of his patients have IBS, up to 80% have irritable bladder or IC, 50% of his patients, and 100% of **Peter Rowe's** pediatric patients have OI.

The **NICE** guidelines on severe patients aren't helpful and are "not very nice."

**Abraham Verghese,** M.D., Professor of Medicine, Stanford University Medical School: "The average American physician interrupts their patient within 14 seconds." He has his patients tell them their story during their first appointment.

He doesn't do an exam – he wants to give them time and not rush them.

Source:

<http://phoenixrising.me/archives/24390>

as reported by **Searcher.**



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

# 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>



Northern Ireland has a chance to lead the way:

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

**Let's make change together,**  
Newry and Mourne ME and Fibromyalgia  
<http://bit.ly/1dzrbX3>



Please join this advocacy movement to stop the IOM from redefining a disease that our experts have already defined and participate in this **Thunderclap** campaign before the day of the next IOM meeting on **May 5, 2014**.

**Let our voices be heard!**

<https://www.thunderclap.it/projects/10666-stop-the-iom-adopt-the-ccc>

# Major fundraisings

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## **Llewellyn King is raising funds**

to be able to continue his 100% free and very important and useful interviews with well known scientists researching ME/cfs

Raised: \$4,500.00      Goal: \$20,000.00

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



## **Ian Lipkin study.**

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

Info: <http://phoenixrising.me/archives/21929>

<http://www.microbediscovery.org/>



## **Raising Funds for the UK Rituximab Trial**

Info: <http://bit.ly/1jVGHng>

Thanks to an amazing effort across many countries the Biomedical Research Fund for the IiME/UCL UK rituximab clinical trial has now reached £288,000.

The goal is £ 350,000.

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



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

<http://theblueribbon.storenvy.com/>



Support The Norwegian ME Association's fundraising for biomedical research into Myalgic Encephalomyelitis! We would very much appreciate your help! Donations can be made on our website:

<http://me-forskning.no/donations/>

Or you can wire transfer a donation to our bank account:

1503.32.04334 - IBAN NO67 1503 3204 334 - BIC DNBANOKKXXX



If you wish to donate to **Dr. Enlander's** ongoing and future research.

Please contact: [cfsconference@gmail.com](mailto:cfsconference@gmail.com)



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

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

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



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

You can transfer your donation to:

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

ME/cvs Vereniging

Den Bosch - The Netherlands

Please mention: Save4Children

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





"Characterization of the T regulating cells in patients with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome" is the name of the project the Spanish ASSEM (Spanish Association of Health Professionals and Patients in Support of Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome) is seeking funds for.

They need € 29.000 to cover the whole research project. Initially they have set themselves the objective of € 5000 euros, which is the minimum necessary to get this research going.

<http://www.verkami.com/projects/8246>



# Worth reading & watching



Severe ME (feat. 'Justice for **Karina Hansen**') is such an impressive piece of art, practice and thoroughly lived experience that we will continue to quote from it in issues to come.



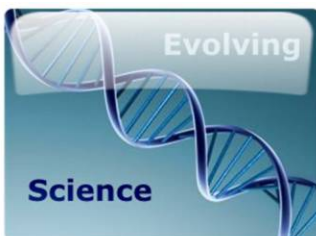
This month's quote is from an ME and Pain Web Seminar 2012 by **prof. Kenny De Meirleir** (also watch <http://bit.ly/1mLpbnl>):

*"There may be various sorts of pain and odd sensations experienced. Pain may come and go or be constant. It may vary in intensity and may migrate around the body so that different parts hurt more at different times.*

*There maybe no drugs available to alleviate the pain or the person may be too drug sensitive to tolerate any drugs. There may be drugs that partially alleviate, but still leave the person in severe pain."*

Severe ME-**Greg Crowhurst** – page 219

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



## **Evolving Science**

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

<http://on.fb.me/QEG4T0>



Might be worth to consider this in the light of symptomology with ME/CFS:

Oxygen diminishes heart's ability to regenerate, researchers discover

Scientific research previously discovered that the newborn animal heart can heal itself completely, whereas the adult heart lacks this ability. New research by the same team today has revealed why the heart loses its incredible regenerative capability in adulthood, and the answer is quite simple -- oxygen.

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





Examining case definition criteria for chronic fatigue syndrome and myalgic encephalomyelitis

**Leonard A. Jason, Madison Sunnquist, Abigail Brown, Meredyth Evans, Suzanne D. Vernon, Jacob D. Furst & Valerie Simonis**

<http://bit.ly/1I73rRM>



Poems from Conflicted Hearts:

Poems of Kentuckycurran. **Tayen Lane** Publishing / Smooth Stones Press

Published March 1st, 2014

eBook: \$4.99 (Amazon, Barnes & Noble, iTunes & Tayen Lane).

To request a review copy, schedule a contributor interview, or obtain more information regarding publishing an excerpt, please send an email to [info@tayenlane.com](mailto:info@tayenlane.com)



**Dr. Charles Shepherd** on ME, exercise and the mitochondria

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

on ME & possible treatments

<http://bit.ly/1iUWTn3>



Summarizing the IACFS/ME-conference, San Francisco, CA March 20-23, 2014:

**Dr. Anthony L. Komaroff** highlighting the biological research presentations of the 11<sup>th</sup> International IACFS/ME Conference:

"Translating Science Into Clinical Practice"

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



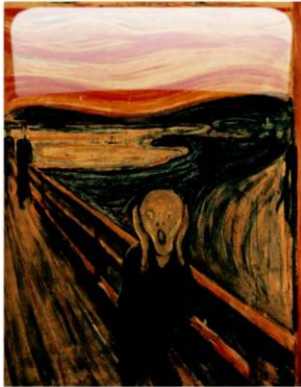




**Llewellyn King**, episode 59 of ME/CFS Alert

<http://youtu.be/R7JtNImePIY>

What the ME-community needs most in terms of recognition: one single person being constantly present in Washington DC might change the sad terrible plight millions of sufferers of ME worldwide are in.



Presentation **Mark VanNess**

The video of the Feb 2014 Bristol Watershed presentation by **Mark VanNess** has been watched by over 1,600 people already, but needs to be seen by many, many more people.

[https://www.youtube.com/watch?v=q\\_cnva7zyKM](https://www.youtube.com/watch?v=q_cnva7zyKM)

It clearly shows just how harmful the usual approach to aerobic activity can be, in causing delayed and prolonged post exertional amplification of symptoms in those with ME. Please share or repost it. Ideally it is best watched in combination

with the other presentations from the evening.  
<http://voicesfromtheshadowsfilm.co.uk/exercise-mecfs-event/>

Source: fb wall Voices from the Shadows  
(<https://www.facebook.com/VoicesfromtheShadows>)



Mom Needs To Lie Down:

The years and lives slept away by ME/CFC  
Canadian documentary explaining ME/CFS:

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



Thrive Show

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



# Theda's Poem

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When the night is black and starless and you ache,  
When you have to bear much more than you can take,  
When your soul is full of sorrow and your sleep  
Is the only bit of respite you can keep

Every breath you take is brave, each day you fight  
Is another noble step towards the light  
And the beating of your heart's the greatest sound.  
It says "I may be lost but I will be found!"

When the battle for your freedom has been won,  
you will shine with glory like the golden sun.  
And the mountains you have climbed have made you strong,  
The bird who has been caged sings the sweetest song

When the night is black and starless, don't despair,  
The dawn is close at hand and you'll make it there,  
You don't have to believe me, just don't let go.  
If you hold on long enough then you will know!

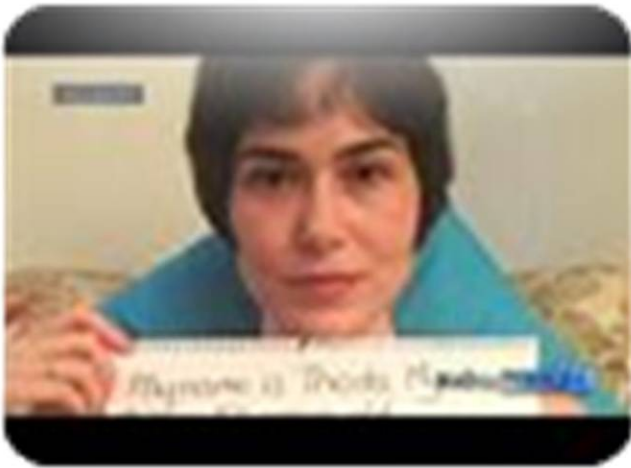
© **Sarah Louise Feather**

**Sarah** writes:

I wrote this poem for **Theda** during her lifetime.

**Theda** was a light, she was a beautiful warrior and this world is so much less without her in it! And last night I kept thinking: we have to get better, we have to live beautiful lives for our own sakes and in her honour. She was utterly unique and having been the few who met an angel, we need to get well enough to go out into the world to try and pass some of the light she gave us onto others who need it too.

This was **Theda**:



[Today Tonight Perth - \*\*Theda\*\*'s legacy for Lyme recognition in Australia](#)

<http://www.youtube.com/watch?v=U29UAqR2RfE>

***For more of this impressive poetry, go to***

**<https://www.facebook.com/TheMoonsDaughter>**

# Connecting You To M.E.

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**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."

