The ME Global Chronicle

www.let-me.be

7 – October 2014

1. Colofon / Personalia

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Textual contributions for the December issue need to be supplied in Word by 10h December and sent to: contribute@let-me.be
The next issue will come out on December 22nd,2014.

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We are no association or society, just a bunch of idealists who want to give our best efforts towards recognition of this terrible disease. By trying to help connecting to each other all patients all over the world. Anyone who expresses the wish to receive the Newsletter will be added to the list: that's the only formality and thing to be done. subscribe@let-me.be –
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Picture front page: ***Greg & Linda Crowhurst, Eddy Keuninckx***
Cartoon page 14: ***Djanko***

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3. Introduction

Dear readers,

A bit earlier than usual, we are introducing the seventh edition of the ME Global Chronicle, containing news from all over the world. This news is not always good.

What is being done to the German **Joanne** and the Danish **Karina** and to who knows how many other children with severe ME, against their wills and the wills of their parents, is beyond all imagination. It seems that psychiatry's grip on ME and similar conditions with diagnoses that have not been recognized by governments, is continually being strengthened. How large should a practitioner's blind spot be, for them to allow a child to suffer in agony, only because they want to be proved right.

Fortunately, the following scientific news is better. Thanks to new quick technologies, the picture of the causing factors of ME is becoming clearer and clearer. Researchers are cooperating more and more and they complement each other. Read about the tremendous news of the Open Institute of Medicine in Mountain View, California. Utterly hopeful and encouraging.

The biggest problem remains the financing of repeated and follow-up researches. Governments are still unwilling to take their responsibility in this area, and keep avoiding the issue.

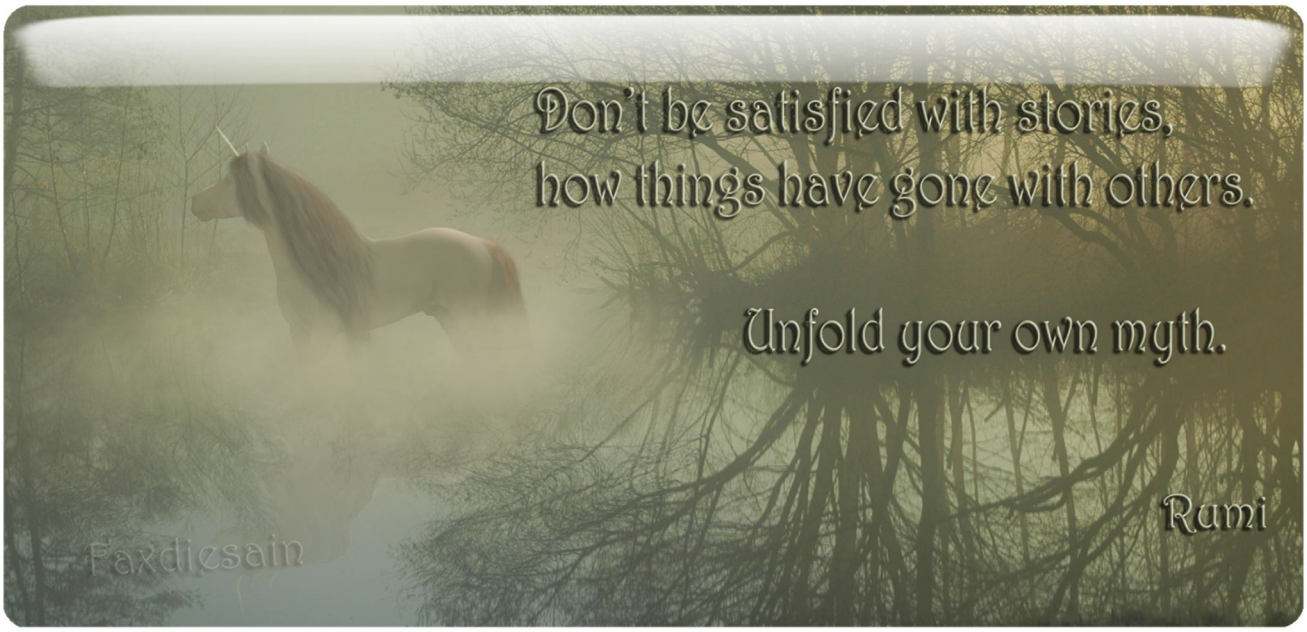
Internationally, patients from all over the world are now meeting one another; they respond to happy and horrible news collectively. This is the internet's blessing, to which unfortunately only the severest ME sufferers do not have access, for the simple reason that they are too sensitive to computers to bear them in their vicinity. This is why the ME Global Chronicle always pays special attention to this group of voices from the shadows.

However, the most important goal of this magazine is to collect as much new information from all over the world as possible. In this manner, we wish to contribute to making a well-informed, driven society possible, that can, after all these decades of denial and despise, rightly say: enough is enough. We will not take this any longer. Give us what we rightfully deserve.

You can greatly contribute to this, by bringing news and information under our attention. Please, email your news to contribute@let-me.be before 10 December, so that we can publish it in our December issue, that will be spread around 22 December.

We wish you a bearable autumn or spring with beautiful and meaningful moments.

The editors



Next issue will be published towards **22nd December**.
Written contributions in Word before **10th December** to contribute@let-me.be

4. Preface

Dear reader,

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

The Autumn Equinox has passed on the Northern hemisphere and we are now into another season. The falling leaves and golden splendour of our forests, and the cool refreshing air, provide us with some light relief, joy, appreciation of nature in an ever more frantic and fast changing world.

We are pleased to provide our readers with news about recent scientific research results, the continuing IOM debacle in the USA, the work and progress of ME and CFS advocates, analysis of some biomarkers, discussion of some treatments, the heated correspondence between ME advocates and government bodies and big researchers, and the ongoing fight to have ME recognized as a physical biological illness in all countries of the world.

And of course the lives of ordinary people trying to cope with everyday life in addition to the stigma of an illness and the discrimination and misunderstandings surrounding it. Every ME patient and advocate deserves great praise for struggling to maintain their lives and their dignity against great odds. So we need to respect each other and praise each other, and show love and appreciation for each other, and look at how far we have all come.

If we stick to the medical and scientific facts in our discussions with each other and in our dealings with doctors, medical organizations, researchers, politicians, civil servants and the press and media, we can help turn the tide in our favour. ME Global Chronicle aims to help and arm all of you with these facts and truths in the fight for justice in all countries.

David Egan

5. Grassroot

The Crisis in Medical Research Portends a Tsunami of Disease

By Llewellyn King

The Bermuda Triangle is where aircraft, ships and people disappear. That is as may be.

Another less-mysterious triangle swallows good ideas and great science, and leaves people vulnerable. It is the triangle that is formed by the way we conduct medical research in the United States, the role of the pharmaceutical industry in that research and the public's perception, driven by political ideology, of how it works.

The theory is that the private sector does research, and everything else, better than the government. But the truth is the basic research that has put the United States ahead of the rest of the world -- as a laboratory for world-changing science and medicine -- has been funded by the government.

It is the government that puts social need ahead of anticipated profit. It is the government that puts money into obscure but important research. And it is the government which will keep the United States in the forefront of discovery in science and medicine.

It is no good for politicians to rant about the importance of children taking more and harder math and science courses. Before they open their mouths, they should look at the indifferent way in which we treat mathematicians and scientists. We treat them as little better than day laborers, called on to do work ordered by government, then laid off as political chiefs change their minds.

A career in research, whether in physical sciences (such as astrophysics) or medical sciences (such as cell biology) is a life of insecurity. Had we put the dollars behind Ebola research years ago (the disease was first identified in 1976), we would not now be watching what may become a tsunami of death raging across Africa, and possibly the world. Shame.

Any gifted young person going into research nowadays needs career counseling. They will be expected to give their all, with poor pay and long hours, to serve mankind. Then the funding will be cut or the research grant will not be renewed, and they will be on the fast track from idealism to joblessness.

You may have heard of the celebrated virus hunter, **Dr. W. Ian Lipkin**, director of the Center for Infection and Immunity at Columbia University's Mailman School of Public Health, because he has been called on for expertise in Ebola. What you might not know is that **Lipkin** is so starved of funding that he has had to use crowd-funding to support his research on Myalgic Encephalomyelitis, the ghastly disease commonly known as Chronic Fatigue Syndrome (CFS).

Nothing is more damaging to research than funding instability. The universities and many research laboratories -- including those run by the government -- operate like concertinas. They expand and contract according the whim of Congress, not the needs of science, public health or American leadership.

Industry is not the answer to absent government. Pharmaceutical companies spend an astonishing amount -- up to $3 billion -- to bring a new drug to market. But traditionally agencies of government, particularly the National Institutes of Health, seed research where the social need is apparent or where the discoveries, like an Ebola treatment, are defensive. Big Pharma often comes in later, as the developer of a drug, not the discoverer. Discovery starts with lowly dedication.

Sometimes the cost and risk initially is just too high for private institutions to take a therapy from the laboratory to the doctor's office. Most drugs, contrary to legend, begin in the research hospitals, the universities and in government laboratories long before drug companies develop manufacturing techniques and shoulder the giant cost of clinical trials.

Developing new drugs has become too expensive for the private sector, according to a recent article in *Nature*. The magazine says the drug pipeline for new antibiotics, so vital in fighting infectious disease, has collapsed as Big Pharma has withdrawn. The latest to leave is Novartis, which has ceased work on its tuberculosis drug and handed it over to a charity coalition.

Government funding for medical research is now at a critical stage. It has flat-lined since 2000, as medical costs have ballooned. Also, congressional sequestration has hit hard.

Stop-and-start funding breaks careers, destroys institutional knowledge and sets the world back on its scientific heels. That is to say nothing of the sick, like those with Ebola or CFS, who lie in their beds waiting for someone to do something.

Llewellyn King *is executive producer and host of "White House Chronicle" on PBS. His e-mail is lking@kingpublishing.com.*

Forgotten Plague

We are rapidly approaching the end of post-production for our film, Forgotten Plague. The team has expanded to about 20 people working in four different U.S. states and one Canadian province. It's exhilarating to watch the pieces coming together and to see the collaborative spirit among our co-directors, editor, sound designer, colorists, animators, business advisor, producers, composer, and musicians. We have been able to attract talent from hit films and television shows who have brought great artistic skill. We're so proud of the excellent work our team is producing.

> We've seen a clear set of trends among our focus groups and will be using that feedback to make our next major wave of edits to out 80-minute rough cut.

We have been focus grouping the rough cut of the film over the month of September. We've received extensive feedback from nearly two dozen people representing key perspectives from the science, medical, patient, advocate, and outsiders points of view. Forgotten Plague will have an initial showing at the historic Chinese Theater in Hollywood, CA on October 26th as part of a private fundraiser with the Neuro-Immune Disease Alliance (NIDA) and Open Medicine Foundation (OMF).

Forgotten Plague will show in an unfinished form (without its final soundtrack), so it's important to note the true "premiere" of the film will be several months from now during a film festival. There are certain regulations in the film industry about how to do premieres, so we have to make sure we follow protocol. However we'll be delighted to show the film privately to a group of donors and movie executives to begin building the case for ME/CFS in the storytelling capital of the world.

Blue Ribbon Foundation

We are set to begin receiving applications for our Blue Ribbon Fellowship program in October 2014. U.S. students in their first year of medical school will be eligible to apply. Currently, we'll be able to accommodate 2 students for 10 weeks or research in summer 2015 for a research stipend of $4,000 apiece. Our primary host site will be the Institute for Neuro-Immune Medicine at Nova Southeastern University in Fort Lauderdale, FL. Students with interests in fields as diverse as neurology, immunology, endocrinology, computer science, genomics, exercise physiology, and gastroenterology are strongly encouraged to apply. Because ME/CFS and Gulf War Syndrome are multi-system diseases, students from wildly varying backgrounds can benefit from studying it and bring their own diverse perspectives to the growing research field in order to inject new ideas and intellectual vigor.

HHS/NIH Violated Federal Law

US District Court: HHS/NIH Violated Federal Law in Response to FOIA Request for IOM Documents.

I am pleased to give an update on my FOIA lawsuit:

Yesterday, the United States District Court for the Northern District of California ruled that **HHS and NIH (government) violated the Freedom of Information Act (FOIA)** when they **improperly withheld documents** from me in response to my FOIA request regarding HHS's contract with the Institute of Medicine (IOM) for the study of diagnostic criteria for ME/CFS.

Accordingly, **the Court granted my motion for summary judgment and ordered the government "to produce, within 60 days, all documents responsive to [my] request that are not covered by any exemption to FOIA's disclosure requirements."** [emphasis added]

The Court also **denied the government's motion for summary judgment** asking for a dismissal of my lawsuit.

I believe that holding HHS and NIH legally responsible for their violation of federal law is a tremendous victory for our patient population. However, since this litigation is ongoing, I will not, at this time, be able to comment further or answer any questions beyond the following details and quotes from the Court's ruling. Although there will hopefully be more good news before the case is over.

In January of this year, I sued the government under FOIA for failure to respond to my FOIA request for documents regarding the HHS-IOM contract. I have been represented in this legal action by the global law firm of **Baker & McKenzie LLP**.

Only after my filing of the lawsuit (and after the statutory time period for their response had lapsed) did the government produce a meager amount of documents despite the fact that my FOIA request was very broad.

It was apparent that the government's search for responsive documents was woefully inadequate, as obviously existing documents covered by my request that would have been easily available to the government and that a reasonable document search would have uncovered were not provided.

The Court agreed and held that the search was the result of "**obviously an unreasonably narrow interpretation of Burmeister's request**." [emphasis added] The Court further states, "Indeed, [the HHS FOIA specialist] explains in her supplemental declaration that **a broader search (the one the government should have conducted given the actual language of Burmeister's request) 'is a completely different type of search and**

presumably would have resulted in a much larger production.'" [emphasis added]

The Court goes on to address the unreasonably narrow interpretation of my FOIA request by the government in more detail:

"And [the HHS FOIA specialist] is correct about that. For example, without listing every document that could be responsive to Burmeister's actual request, it is obvious that all records relating to the original effort by HHS to enter into a sole-source contract with the Institute of Medicine, and documents relating to the subsequent decision to change course and proceed with a task order in response to expressions of concern by members of the public about the manner in which HHS was proceeding, would be responsive. Such records exist, but the government did not provide them to **Burmeister**.

"Because [the HHS FOIA specialist's] supplemental declaration demonstrates that the government adopted an **unreasonably narrow interpretation of Burmeister's request**, because [the HHS FOIA specialist] concedes she would have performed a much broader search had she interpreted the request correctly, and because that search would have uncovered additional records responsive to the request, **the government has 'improperly withheld agency records' in violation of FOIA."** [emphasis added]

The Court then addresses the government's meritless claim that my lawsuit is moot due to the government's production of some documents after the complaint was filed despite the fact that the document search was inadequate:

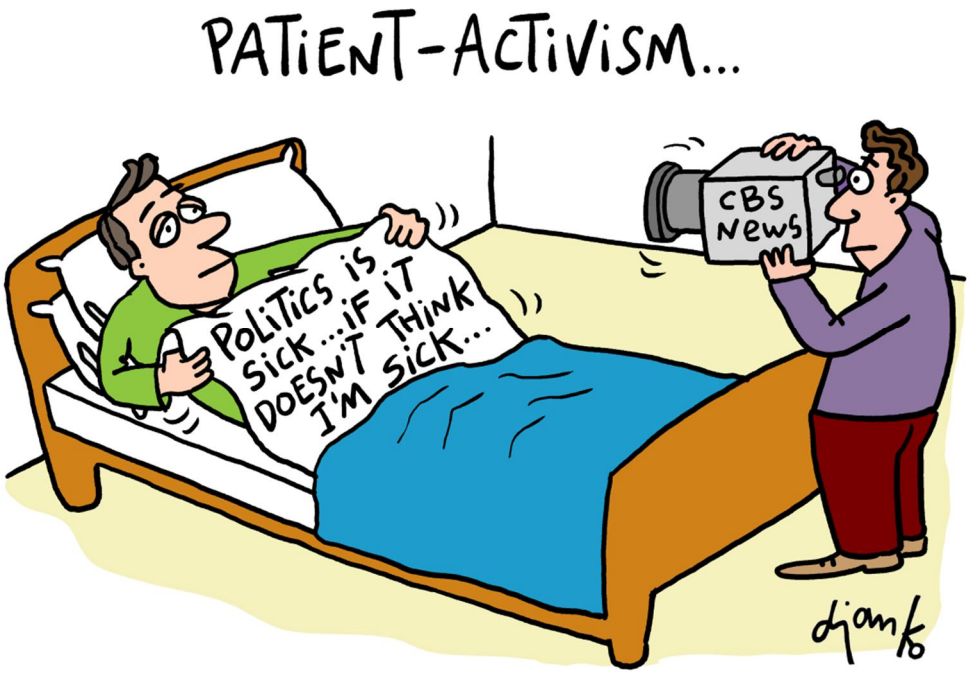
"To avoid this conclusion, the government argues that **Burmeister**'s lawsuit should be dismissed as moot. Specifically, the government contends that even if **Burmeister** had the right to file her lawsuit because HHS failed to respond to her request within the time period required by FOIA, its subsequent production to **Burmeister** moots the lawsuit, even if the production was deficient.

At the hearing on this motion, counsel for the government insisted that the case law compels this result – he argued that even if the production was deficient, the case law required that the lawsuit be dismissed as moot and that **Burmeister** be left to submit a response to the government's production explaining how she believed it was deficient, so that the government would have a chance to remedy the deficiencies. However, **the case law says exactly the opposite of what counsel for the government represented at the hearing,** " namely, " To moot a FOIA claim, however, the agency's production must give the plaintiff everything to which he is entitled. [emphasis added] Otherwise, there remains some 'effective relief' that can be provided the plaintiff, and the case is not moot."

According to the Court, the government's argument that I did not exhaust my administrative remedies and, thus, my lawsuit should be dismissed also fails:

"The government also contends **Burmeister**'s lawsuit should be dismissed for failure to exhaust her administrative remedies with respect to her claim that the agency's search was inadequate.

Specifically, the government argues that it responded to **Burmeister**'s request on January 7, two days before **Burmeister** sued, and that **Burmeister** should have objected to HHS about the adequacy of the response before filing the lawsuit. But the government's response was not postmarked until January 8, and **Burmeister** credibly asserts she did not receive it until several days after she filed her complaint. Nor, in any event, was the government's response a final or complete one – in other words, it was not a real response.



The real response (which was, as discussed above, inadequate) came on February 3. **Because the government failed to timely respond to Burmeister's records request, and because Burmeister did not receive a final decision from the government until after she filed this lawsuit, her case is properly before the Court.**" [emphasis added]

The 60-day period the Court allowed for the government to produce all documents responsive to my request (and not exempt under FOIA from production) runs on November 3. Let's hope that the Court's ruling will be a wake-up call for the government and a reminder that it is not above the law.

Jeannette Burmeister
September 3, 2014
Source: Thoughts about ME

http://thoughtsaboutme.com/2014/09/03/us-district-court-hhsnih-violated-federal-law-in-response-to-foia-request-for-iom-documents/

P2P: Don't Buy the Hype! Protest!

Introduction: what exactly is the P2P?

The NIH P2P workshop was set up by NIH to summarize the current research and needs for future research; however, **Nancy Lee** said at CFSAC that it would also be used as a reference for a definition of ME/CFS.

With great sececy, the NIH planned a closed Workshop where the panel of non-experts will evaluate the state of current research and future needs. Now this P2P Workshop has received full approval and is scheduled for Dec. 9-10, 2014.

The NIH/P2P has paid no attention at all to patient comments and requests, and it is clear that the end result is likely to be a psychological definition for ME/CFS, possibly as "Chronic Multisymptom Illness" (CMI) with recommendations to our doctors to prescribe us antidepressants, CBT and GET.

Patricia Carter

P2P: Don't Buy the Hype! Protest!

The reason why I will not cooperate with, or participate or engage in, the P2P process is very simple. HHS and NIH have shown time and time again that they do not have ME patients' interest at heart.

This disturbing and indisputable fact has been confirmed again very recently in my FOIA lawsuit regarding documents relating to the IOM contract (the diagnostic equivalent of P2P), in which I won my motion for summary judgment against HHS and NIH in early September with a ruling by the court that the government violated federal law. The government, in turn, lost their motion for a summary judgment against me. HHS's and NIH's conduct in this matter has been dilatory, obstructionist and unlawful.

I initially filed my lawsuit pro se (meaning without engaging lawyers) because I was hoping that, when faced with a lawsuit, the government would finally comply with the law. I wanted to give them a chance to resolve the matter swiftly and without incurring any legal fees.

Before filing my complaint, but sadly to no avail, I even gave them a warning that legal action was imminent, unless they complied. Even after filing my complaint, the government did not avail itself of the opportunity to moot the lawsuit (i.e., end it with a relatively small legal bill) by conducting a reasonable document search. Instead, the government filed a frivolous summary-judgment motion five months after I initiated litigation when they could have used all that time to remedy their prior FOIA violations.

When faced with my opposition motion that clearly demonstrated that the government was in violation of federal law, they doubled down by filing another motion making frivolous and meritless legal arguments and misstating the law and the facts—the latter, under penalty of perjury. Even as late as in the oral-argument phase did they incorrectly cite the law, as noted by the court.

HHS and NIH have wasted the court's time and energy and worse, they have directly caused my health to dramatically deteriorate as a result of their unreasonable conduct and stonewalling, as the case was factually extremely complex and required my close involvement in discussing strategy with my attorneys, reviewing documents, drafting and revising the motions, etc.

This has predictably triggered an intense post-exertional crash, the hallmark symptom of ME. Ironically, HHS and NIH continue to boast of their commitment to our disease. It would follow that they knew about the post-exertional fall-out that their indefensible approach would have on my physical health and yet they passed on every opportunity to right their wrong.

Instead, they have done everything to prolong this litigation and drive up my attorneys' fees. Counsel for the government stated during oral arguments that he didn't even understand the case until July of this year, six months into the litigation! Half a year! That is how seriously they take this patient population.

In short, HHS and NIH have acted like bullies vis-à-vis a disabled ME patient whose only "infraction" was to avail herself of her statutory rights.

After all that litigating, the court ordered HHS and NIH to do what they should have done more than eight months ago, without a dime spent and without any additional damage to my health: to produce the requested documents.

Does anybody honestly believe that the government is somehow, miraculously, going to conduct itself differently in this ludicrous and high, stakes jury, model P2P project when they don't even take a very simple and straightforward FOIA request seriously and instead fight it tooth and nail contrary to explicit instructions by the US Attorney General for clear-cut cases like mine?

Please see "P2P: 'Patients to Purgatory' or the Jury Model Stood on its Head" for an explanation of why the jury-model analogy of NIH is preposterous.

http://bit.ly/1eD2eNJ

I urge patients and other stakeholders to voice their unambiguous opposition to the P2P in strong, but professional, terms.

Opposing this effort means making our voices heard; quite obviously, it is the opposite of silence. Getting our opposition on the record is crucial because the government will try to claim that they had the support of the patient community for P2P when that is clearly not the case, as even most of those who suggest that patients should cooperate with the process are against the P2P in principle.

Engaging the government allows them to claim that they took the community's concerns into account when they have no intention of doing so. Their outreach to the patient community, the comment period, is a mirage. The distinction between opposing/protesting and participating / cooperating / engaging is subtle, but very important. To clarify:

Do not participate or cooperate by making suggestions on how the P2P should be conducted or which areas it should focus on or by engaging regarding the seriousness of the disease, etc. Basically, do not make any substantive comments, in writing or in person at the workshop, because that will, without a doubt, be entirely ignored, as has been the case with the IOM and will allow the government to pretend that our concerns have been heard and will be reflected in the P2P outcome.

Remember the changes that were made to the IOM panel in response to patients' concerns about various suggested panel members' conflict of interests? No? I don't either. The make-up of the committee was not changed at all despite a few advocates researching the background of the proposed panel members and finding some troubling facts. The feedback of those advocates was entirely ignored. If the government wanted our input, they would have designed the whole process completely differently instead of merely having one token, hand-picked patient advocate at the P2P workshop purporting to speak for the entire community. Giving our input means legitimizing the farce. Don't fall for it.

Opposing/protesting, on the other hand, is stating one's unequivocal disapproval of this redundant, unscientific and ludicrous effort without making any substantive suggestions whatsoever. This effort is redundant because we already have a research definition that has been adopted by our experts, the Canadian Consensus Criteria. P2P is unscientific because it precludes anybody with ME/CFS expertise from being a member of the P2P panel. And it is ludicrous because the utilization of the jury-model approach in this context is, frankly, beyond comprehension. Therefore, I will send a letter protesting the entire effort in no uncertain terms, but without engaging substantively.

There is no doubt in my mind that P2P will harm patients greatly and I will have no part in that by being seduced into thinking that my engaging will result in any meaningful effect on the process.

Jeannette Burmeister - http://wp.me/p1vio1-yX

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

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

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

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

Sign up here**:** **http://meactionnetwork.org/**

Follow us on Twitter: **https://twitter.com/MEActNet**

Like us on Facebook: **http://facebook.com/MEActNet**

Jennifer Brea

Letter From An Irish ME-Patients Activist

Letter from an Irish ME-patients activist to the Agency for Healthcare Research and Quality Office of Communications and Knowledge Transfer 540 Gaither Road, Suite 2000 Rockville, MD 20850.
NB This letter is a good summary of the state of the art re. ME, and is written by ***David Egan*** *on personal title, not as an editor of the ME Global Magazine.*

Dear Sir / Madam,
I am an American citizen temporarily living in Ireland. I am contacting you in relation to your web page http://1.usa.gov/ZjqUXn which contains several serious errors and omissions. I have detailed them below

- ME/CFS is not a "constellation of symptoms, with post-exertional malaise and/or chronic and disabling fatigue being the hallmark."

- It is a physical biological illness, classified by the WHO as neurological, originating from a viral or other pathogen infection(s) and accompanying immune dysfunctions and subsequent neurological, endocrine, mitochondria and cardiac abnormalities, or in some cases or organophosphate or toxin poisoning which causes some of the aforementioned abnormalities. The post exertional malaise and disabling fatigue is a consequence of this, in a similar way to that encountered in Cancer, cardiac illnesses, diabetes, MS and other neurological illnesses.

- The "term ME was first used in the 1930s after an outbreak of neuromyesthenia" is a lie and factually wrong. ME was first used to define the illness by **Dr. Donald Acheson** in the Lancet medical journal in 1955 and has been used ever since - Outbreak at the Royal Free. E.D Acheson. The Lancet, Volume 266, Issue 6886, Pages 394 - 395, 20 August 1955.

- "CFS was first coined in the 1980s".

- The term 'CFS' was used to describe an ME outbreak in **Lake Tahoe** in the mid 1980's. The very term 'CFS' is misleading and unscientific, and this was deliberately done by a **Dr. Straus** who wished to make ME disappear by using a new invented term 'CFS'. This term was then perverted into an unspecific psychological illness by certain individuals in the **CDC** and **NIH**. **Dr. Straus**' letter to **Dr. Fukuda** shows an attempt to do this, and leave many patients with no proper diagnostics and no proper treatments for a serious biological illness http://bit.ly/1xdXW6X. This has had serious consequences, including premature death for many patients http://bit.ly/1xdWn8Y

- ME is ME, it should not have been called 'CFS' or any other name. So let us call ME what it really is 'ME' and diagnose and treat it as a biological illness.

- "Over the years, there has been disagreement on the underlying etiology and whether the conditions represented by these terms reflect a single pathologically discrete syndrome, subsets of the same illness, or a nonspecific condition shared by other disease entities"

- This is factually wrong. ME has been well documented since 1955, the WHO classified it in 1969. Please read http://www.me-ireland.com and learn the facts about ME and outbreaks and epidemics prior to and after 1955.

- "The first set of clinical criteria defining the condition were published in 1988" This is factually wrong. The first clinical criteria were described and used
    - by **Dr. Acheson** in 1959, updated by **Dr. Richardson** in the early 1960's and
    - by **Dr. Ramsey** in 1986
    - **Dr. Acheson** http://www.me-ireland.com/Acheson1959.pdf
    - **Dr. Richardson** http://bit.ly/Zjs2do
    - **Dr. Ramsey** http://www.cfids-me.org/ramsay86.html

- "The variable symptomatology and lack of an identifiable disease process with gold standard of measurement have challenged researchers and clinicians in their attempts to better understand the disease process and its effects on patients." This is the direct result of calling ME and CFS psychological illnesses. Most doctors and researchers have been told these lies for over 25 years, and this belitting and mocking of the illness as psychological and "all in the mind" has resulted in very little or no government, academic and private funding for research into ME. The illness ME has been starved of research for 25 years. The NICE clinics in Britain forbid many biological tests to identify subgroup biomarkers for the illness. Patients and patient-groups with their own personal funds have funded some biological research into ME, and a few governments have put a small amount of funding into biological research over the years. From this have emerged some biological biomarkers for subgroups.

- A few biological biomarkers have been found for the illness, please view http://www.me-ireland.com/scientific.htm

- "Thus finding ways to accurately diagnose patients to optimize management has significant public health importance and consequences."

- Start doing biological tests and stop using the subjective and useless psychological tests. Then you will make some progress in the area of diagnostics and treatments. You could start here at http://bit.ly/1xdWn8Y

- "Currently there are no U.S. Food and Drug Administration (FDA) approved medications for the treatment of ME/CFS"
- The FDA can fast track psychological and psychiatric treatments, and regularly ignores dangerous side effects when approving these new drugs and treatments. It breaks it's own rules. Using this logic, it should be able to fast track **Ampligen** and other biological treatments for the ME subgroups.

- The Fukuda criteria 1994 do not describe ME or CFS. The criteria is vague and ambiguous, it is unscientific, un-medical, and could be describing any number of illnesses, biological or psychological. It lacks specificity and sensitivity. It deliberately omits important medical and scientific findings in 1994 and prior to 1994. The critera actually describes nothing and was open to abuse and was abused. The letter by **Dr. Straus** to **Dr. Fukuda** clarifies these points http://www.me-ireland.com/straus/straus.htm

- The criteria led to premature patient deaths, see http://bit.ly/1pXMDK8

- The Fukuda criteria needs to be declared null and void by the US Government and it's constituent agencies such as the DHHS, NIH, CDC and IOM.

The Key Questions

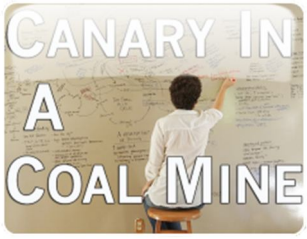
- What methods are available to clinicians to diagnose ME/CFS and how do the use of these methods vary by patient subgroups?
- What are widely accepted diagnostic methods and what conditions are required to be ruled out or excluded before assigning a diagnosis of ME/CFS?
- What is the accuracy and concordance of diagnostic methods?
- What harms are associated with diagnosing ME/CFS?
- What are the (a) benefits and (b) harms of therapeutic interventions for patients with ME/CFS and how do they vary by patient subgroups?
- What are the characteristics of responders and non-responders to interventions?

The answer to the above is detailed on http://bit.ly/1xdWn8Y. These are based on medical and scientific facts dating back to 1955.
I hope this fully informs you about ME. I would refer you to the web site http://www.me-ireland.com/scientific.htm for a more comprehensive analysis of this illness, it's dynamics, its diagnostic and it's treatments and the areas for research most likely to produce the best and most useful results.

I would be happy to discuss this with you further, and help and assist you in any way I can to bring about effective biological based diagnostics and treatments for all ME patients.

Best Regards
David Egan.

Canary in a Coalmine



Dear Canary Community,

I am deeply grateful for your support of this film and the trust you have placed in me. In everything I do, I am mindful of the investments of money, time, energy and love that have made this film possible.

In recent weeks, I have received several messages written in anger about either not responding to a message, failing to follow up a lead, or failing to cast a specific patient in this film. I understand that it comes from a place of enthusiasm for the project, or a wish that the story I tell will reflect the story you hold to be true, or the fear that I'm going to get it all horribly wrong. Or maybe it's just the fact that we have, collectively, been in excruciating pain for millions of years.

As with many of you, since developing ME I have a very low tolerance for stress, and as much as I endeavor to take it all in stride, messages like these are quite frankly, stressful. I just wanted to emphasize a few things:

1. **I am a person**
2. **I am one person**. 2,500+ people supported the Kickstarter campaign. 4,686 people like the Facebook page. Tens of thousands have watched our videos. I have received hundreds upon hundreds of emails and handwritten letters since the campaign last year and am contacted by new patients every single day. (Thank you, thank you.)
   I love getting mail! I have had many, many people send me their life stories, their music, poems, art, and their ideas. I have responded to almost none of these messages. If I don't write back, there is a very simple explanation: I am either attending to my own, very fragile health or working hard to make the best film possible. Even if I don't respond, I read everything I can and try to channel that energy and knowledge back into the film.
   I have learned so much from all of you. It is my dream, when this whole process is finished, to open some of those emails and letters and begin to express my gratitude for the beautiful words and stories you have all shared.
   But for right now, my primary focus has to be on actually doing the work. The finished film will be my ultimate answer and my thank you letter for making all this possible.
3. **I miss things – a lot.** I do not read all of the comments on this Facebook page and sometimes go months without checking Canary's Facebook inbox. My email inbox is so flooded that I often miss emails, especially if I have been sick or off email for several days.
   If you have a truly urgent need to reach me, you can do so through my website: http://canaryinacoalminefilm.com. However, I cannot promise that I can respond to every message. I simply do not have the physical or energetic capacity.
   And if you sent something that requires a reply, and I have not replied, there's a good chance I just haven't even seen it.

4. **I have ME**

I know this might come as a shock, but I have ME.

I sometimes wonder, when I receive these messages, whether people know that I am profoundly ill with a devastating and incapacitating disease. It takes me days, weeks and sometimes months to recover from a shoot. After the Kickstarter campaign, I was 99% bedridden for six months retaining only enough capacity to walk to the bathroom, and just barely.

Often times, these messages have an almost comic timing. I may literally be crawling on the floor, in bed unable to roll over, or on the grass in the dark, waiting for someone to find me because I have collapsed and don't have the strength to call out. Most of the time, I imagine that if the person writing that message could see my life and conceive of me as a human in as much pain and desperation as they are, they would never have written it at all.

I am risking my health and my one life to try to do something incredible for all of us. I may or may not succeed in that ambition, but I am already giving everything that I have to give. It is hard to be asked for more.

If you do write to me, even if it's to say that I am "harming ME patients everywhere" or that the film will "suck" or that I must be "incredibly stupid" or to tell me how much I have hurt you, pretend you are sitting at my bedside on my worst day, holding my hand and I am sobbing quietly. Use that voice, and I will try to do the same.

5. **I am homeless**

I have not stepped foot in my house since May and am living in a tent in my backyard in an attempt to improve (if not eradicate) my symptoms. It's (mostly) working, which is great, but it also means that in addition to the above I am coping with the cold, the heat, the wet, the dark. Nothing is simple. I often feel like I just barely holding my life together. I know eventually my husband and I will get through this, but it's an inordinate amount of stress to have to manage on a day to day basis, independent of being severely ill and independent of the film.

I am so grateful for everyone's support and I just want to emphasize that this constitutes about 1-2% of the messages I get. Or less. I just had to say something because I've been internalizing this for 12 months and came to the realization that it was harming my health and my ability to make this film. I don't want to lose my temper or take it out on any one individual and I want to stay healthy and well.

OK, back to work!

(Our footage is thrilling and wonderful and gorgeous and I can't wait until the edit!!)

Jen

6. Science

Rich' Reviews: Natural Immune System Boosters - Can They Help Our ME-CFS Patients?

What causes chronic fatigue syndrome? A leading hypothesis is that suppression of the immune system, cause yet unknown, allows reactivation of Herpes Class Viruses such as **Epstein-Barr** or other infectious organisms. Recent interest in treating with anti-viral drugs reflects these hypotheses.

Logically, anti-viral drugs should be more effective if the immune system is more competent. And if the immune system were strong, perhaps it could control these infections on its own, without adding anti-viral drugs.

This month's key article introduces a natural product called **AHCC** (active hexose correlated compound). **AHCC** derives from Shitake mushroom. Like Reishi mushroom and the pharmaceutical, Imunovir, AHCC has -proved immune activating effects in animal and in vitro systems. Human studies are limited.

Today I will raise this question: Should we offer AHCC or similar immune boosters to our patients? Should we study these as a primary treatment and/or as adjuncts to antiviral drugs such as Valcyte, Valtrex or Famvir?

Our Key Research Article: Japanese researchers tested whether adding **AHCC** to a cancer chemotherapy regimen decreased adverse effects due to cancer chemotherapy.

Twenty four patients with various cancers received their first weekly dose of standard chemotherapy without adding **AHCC**. One week later they received their second dose along with oral AHCC. End points included standard blood tests, a quality of life questionnaire and a post-chemo therapy quantitative measure of HHV-6 viral DNA in the patients' saliva.

Comparing results after the second chemotherapy dose done with **AHCC** with the first dose lacking **AHCC** gives the following results.

With AHCC:

Quality of Life Scores were significantly higher.
Blood toxicity and Liver toxicity rates were significantly lower
DNA levels of HHV-6 in the saliva were significantly lower.

The authors concluded: 1) AHCC may have a beneficial effect on chemotherapy-associated adverse effect and 2) HHV-6 DNA levels in saliva may be a good biomarker.

Adapting these results to ME-CFS, it is tempting to speculate that AHCC improved the immune system's ability to control infections and that this partially countered the immune-suppressing effects that occur due to chemotherapy.

We can't take this single study too far. But, it should focus attention on potential clinical trials and/or empirical treatment for ME-CFS using immune-strengthening agents such as **AHCC**, Reishi or Imunovir.

AHCC has a considerable in vitro and animal literature supporting its immune boosting and anti-viral effects. AHCC's toxicity profile seems favorable, but with this theoretical caution. AHCC activates several cytokines. This might do harm if autoimmune issues are a problem.

The Key Article:
http://www.ncbi.nlm.nih.gov/pubmed/?term=ahcc+chemotherapy+dna

Ito, **T**…..**Kondo**, **K**, Reduction of Adverse Effects by a Mushroom Product, active hexose correlated compound (AHCC) in patients with advanced cancer during chemotherapy--the significance of the levels of HHV-6 DNA in saliva as a surrogate biomarker during chemotherapy, Nutr Cancer, 2014; 66(3):377-82

Other references for potential "immune boosting" options. Please refer to abstracts on PubMed.gov.

Imunovir: **Petrova**, **M** et al, Isoprinosine affects the serum cytokine levels in healthy adults, J Interferon Cytokine Res, 2010; 30: 223-8

Inosine: **Tay**, **S**, Efficacy of Inosine pranobex oral therapy in subclinical human papillomavirus infections of the vulva: a randomized double-blinded placebo controlled study, Int J STD AIDS, 1996; 7:276-80

Reishi Mushroom: **Gao Y** et al, Effects of Ganop (A Ganoderma lucidum Polysaccharide Extract) on the Immune Functions in Advanced-Stage Cancer Patients, Immunological Investigations, 32; 201-215, 2003

Repair Nutritional Deficiencies e.g. Zinc: ***Meksawan, K*** *et al,* Zinc supplementation improves anticancer activity of monocytes in type-2 diabetic patients with metabolic syndrome. . Anticancer Res. 2014 Jan;34(1):295-9.

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

Science to Patients

As a reader of this magazine (and a viewer of the webinars of Science to Patients, which many of you are) you can very well contribute to the success of this project:

1. In Salt Lake City new webinars will be filmed from **Alan Light** and **Lucinda Bateman** on 4 or 5 December. We need questions to both researchers to use as a framework for them to discuss topics you want them to.

Mail your wishes to wvp@me-cvsvereniging.nl

2. Share the webinars with as many people as possible, and try to find out how they can reach clinicians and medical researchers. This is of utmost importance, as in such cases the information contained in them will reach beyond the ME community. That's our constant struggle.

If you know of ways and means to share them with doctors and specialists, please let us know. We may learn a lot from each other.

3. Watch the webinars carefully and take part of the Q&A-sessions. It is a unique opportunity to discuss actual and practical topics with the researchers giving the talks.

Next Q&A-sessions are both with Lenny Jason:
on October 24, 2014 and
on November 21, 2014.

Both from 5:00-5:45 pm CET (Amsterdam).

For local timings, see http://www.timeanddate.com/worldclock/

You can participate by using this link:
http://chatwing.com/mecvsvereniging.wvp

As for the 1st of October 2014, all webinars together had been watched almost 163.000 times. Almost 700 persons subscribed to receive them shortly after publication.

All webinars and transcripts can be seen and read here:
http://www.me-cvsvereniging.nl/english-page

Lenny Jason Answers Questions

On several occasions after the publication of a webinar of prof. Leonard Jason within the Dutch project Science to Patients:

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

he answered questions from patients in chatsessions.

Next Q & A session with him will be on
October 24, 2014, from 5:00-5:45 pm CET.

You can participate via http://chatwing.com/mecvsvereniging.wvp

Here are a couple of questions and answers from the 9/26 session:

Q: In webinar 53 (http://youtu.be/RKSaYlR7ZHU) you say that it has been proven that patients with ME have lower levels of cortisol and patients with a depression have higher levels of cortisol. Can you explain this difference?

A: Low levels of cortisol result in an overactive immune response, so this is very compatible with what we see in patient data. To be more specific, it is really a reduction increase of cortisol when one is waking up to about half an hour later that the results seem to apply to.

Q: Why do people with a depression have high levels of cortisol?

A: There are a number of theories about low cortisol in patients with ME, and it probably has something to do with the HPA axis which is probably dysregulated. My guess is that this is centrally mediated and we are most interested in better understanding why this might occur.

Q: Are you any further into discovering any medication apart from painkillers or antidepressants that will work for ME?

A: Lily Chu published some results of the influence of different medications last year as part of the FDA and you might want to check out her findings. You can find them here: http://bit.ly/1yJbZ8V

Q: You say that if one asks the right questions, it is possible to distinguish ME from depression. What questions have to be asked? By whom? And does your group develop such a questionnaire? To me it seems a very important attribution for examination.

A: Yes, it is important to develop reliable and valid questionnaires that allow us to ask questions that can discriminate between those with ME and other illnesses. Our group has developed an instrument that is called the DePaul Symptom Questionnaire and we have made it available to investigators around the world.

It has good psychometric properties and we now have a dataset of about 1,000 people who have filled it out, and this is the type of sample that is needed to do the types of statistical analyses that are needed. As for questions, we now have a detailed questionnaire that assesses 54 symptoms. For each one, we try to assess the frequency and severity, as we feel both are important to assess.

Q: Has your group discovered more biological differences between ME and depression?

A: Our group has found self-report differences between patients with major depressive disorder and ME. For example, patients with ME have PEM that is severe as well as other core symptoms. Patients with major depressive disorder have self-reproach, and this is generally not found in ME. What is found in ME is sometimes demoralization that can occur when so many doubt the legitimacy of their illness.

Q: I read that patients with ME often do not respond well to medication against depression. Is this correct? And if this is the case, why is this? What alternative medication/treatment they can use?

A: As a psychologist I do not prescribe medications, but from the research I have looked at it seems that the evidence is unclear for antidepressants. Some people say it helps, and others that it does not.

Q: How can differences between ME and somatization disorder become clear? Same for anxiety disorders?

A: There are many psychiatric disorders that can cause fatigue. The most prevalent is substance use disorders, but other important ones are depression and anxiety. Just as we expect to have a good medical examination to determine whether a person has ME, we need to also expect that a good psychiatric screen occurs for patients so that we can be sure that they have ME and not some psychiatric disorder.

Q: You are calling PEM one of the three main symptoms of ME. What do you exactly mean with Malaise, the M of PEM?

A: Malaise is not a great word, because it can be misinterpreted. What occurs after exercise is that a person experiences severe symptoms in multiple domains that include physical, cognitive, and other symptoms, but PEM has been used for so long that it is now very prevalent in the literature. The ME-ICC uses PENE instead (post exertional neuroimmune exhaustion).

Q: I suffer from neuro cognitive damage because of ME/cfs. I notice that it is becoming more and more difficult to keep a conversation going. I cannot think of what groceries are needed, etc. What should I do to keep this from becoming worse? What can I do to improve?

A: Sorry to hear about the intensification of symptoms. One long-term follow-up study suggested that cognitive symptoms can become worse over time. The IACFS/ME primer has some useful material that you might want to take a look at. You can find it here:
http://www.iacfsme.org/LinkClick.aspx?fileticket=Pil0KeDIc2M%3d&tabid=509

Q: My condition is continually getting worse. How can I improve this, while staying within my limits?

A: Our group has worked with the energy envelope, which is a concept that was developed by a patient many years ago. We believe that this is similar to pacing with some differences. Clearly, our approach involves helping people monitor and stay within their available energy resources.

Often, in my experience, patients are engaging in more activities than they have available energy for. This is understandable because they have so much less available energy with the onset of ME. Learning to stay within the energy envelope has been shown to have positive results in a number of our studies.
Here is a link to a study on the energy envelope:
http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3596172/

Q: Does arthritis worsen due to ME/cfs?

A: ME certainly can result in multiple dysfunctions in the body. It would make sense that this could lead to other illnesses.
One of my graduate students is now doing her dissertation to try to find out what happens when people die after having ME. Clearly, many people have a number of illnesses that occur after having ME, including cancer and heart disease.

Q: Is that the main reason why ME patients have a lower life expectancy?

A: In one study we published, we found that about one third of people who had died after having ME died of heart disease, and another third died of cancer. Their deaths were much younger than would have been expected from national death rates with these illnesses. We now want to look more closely at this.

Q: Your current research is on risk factors. What risk factors do you expect to play a part in getting ME?

A: One risk factor might be exposure to molds. Another risk factor might be getting mono. These are just a few of the important risk factors that we need more research on.

Pain Receptor On T-Cells Discovered

Date: October 5, 2014
Source: University of California, San Diego Health Sciences
Summary:
T-cells -- a type of white blood cell that learns to recognize and attack microbial pathogens -- are activated by a pain receptor, scientists have discovered. The study shows that the receptor helps regulate intestinal inflammation in mice and that its activity can be manipulated, offering a potential new target for treating certain autoimmune disorders, such as **Crohn's disease** and possibly **multiple sclerosis**.

Researchers at **University of California**, **San Diego School of Medicine** have discovered that T-cells -- a type of white blood cell that learns to recognize and attack microbial pathogens -- are activated by a pain receptor.

The study, reported online Oct. 5 in *Nature Immunology*, shows that the receptor helps regulate intestinal inflammation in mice and that its activity can be manipulated, offering a potential new target for treating certain autoimmune disorders, such as Crohn's disease and possibly multiple sclerosis.

"We have a new way to regulate T-cell activation and potentially better control immune-mediated diseases," said senior author **Eyal Raz**, **MD**, **professor of medicine**.

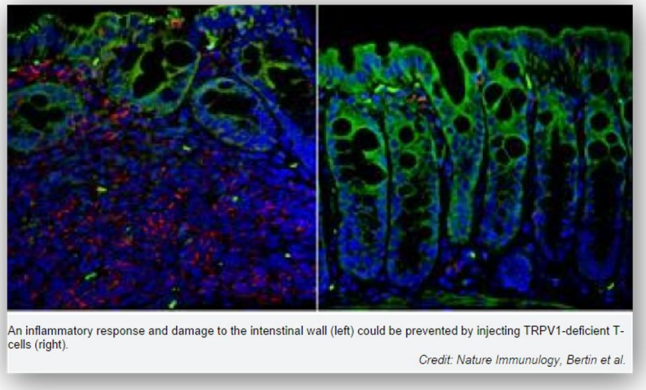
The receptor, called a TRPV1 channel, has a well-recognized role on nerve cells that help regulate body temperature and alert the brain to heat and pain. It is also sometimes called the capsaicin receptor because of its role in producing the sensation of heat from chili peppers.

The study is the first to show that these channels are also present on T-cells, where they are involved in gating the influx of calcium ions into cells -- a process that is required for T-cell activation.

"Our study breaks current dogma in which certain ion channels called CRAC are the only players involved in calcium entry required for T-cell function," said lead author **Samuel Bertin**, a postdoctoral researcher in the **Raz laboratory**. "Understanding the physical structures that enable calcium influx is critical to understanding the body's immune response."

T-cells are targeted by the HIV virus and their destruction is why people with AIDS have compromised immune function. Certain vaccines also exploit T-cells by harnessing their ability to recognize antigens and trigger the production of antibodies, conferring disease resistance. Allergies, in contrast, may occur when T-cells recognize harmless substances as pathogenic.

TRPV1 channels appear to offer a way to manipulate T-cell response as needed for health. Specifically, in in vitro experiments researchers showed that T-cell inflammatory response could be reduced by knocking down the gene that encodes for the protein that comprises the TRPV1 channel.



An inflammatory response and damage to the intenstinal wall (left) could be prevented by injecting TRPV1-deficient T-cells (right).

Credit: Nature Immunology, Bertin et al.

Overexpression of this gene was shown to lead to a surge in T-cell activation, which in human health may contribute to autoimmune diseases. T-cells also responded to pharmaceutical agents that block or activate the TRPV1 channel.

In experiments with mice models, researchers were able to reduce colitis with a TRPV1-blocker, initially developed as a new painkiller. One of the promising discoveries is that colitis in mice could be treated with much lower doses than what is needed to dull pain. "This suggests we could potentially treat some autoimmune diseases with doses that would not affect people's protective pain response," **Raz** said.

Story Source:

The above story is based on materials (http://bit.ly/1vKq3dD) provided by **University of California, San Diego Health Sciences**. (http://bit.ly/1uVxMb7)

Note: Materials may be edited for content and length.

Journal Reference:

Samuel Bertin, **Yukari Aoki-Nonaka**, **Petrus Rudolf de Jong**, **Lilian L Nohara**, **Hongjian Xu**, **Shawna R Stanwood**, **Sonal Srikanth, Jihyung Lee**, **Keith To**, **Lior Abramson, Timothy Yu**, **Tiffany Han**, **Ranim Touma**, **Xiangli Li**, **José M González-Navajas**, **Scott Herdman**, **Maripat Corr**, **Guo Fu**, **Hui Dong**, **Yousang Gwack**, **Alessandra Franco**, **Wilfred A Jefferies**, **Eyal Raz**.

The ion channel TRPV1 regulates the activation and proinflammatory properties of CD4 T cells.

Nature Immunology, 2014; DOI: http://dx.doi.org/10.1038/ni.3009

Link to the article above: http://bit.ly/1q9ERx4

7. Research

NCNED/Griffith

NCNED/Griffith

Being asked, **prof. Sonya Marshall-Gradisnik** told the editors she and her team were too busy to provide us with news about their work, but she promised to do so for the next issue of the Me Global Chronicle.

That they *are* very busy, is proven by a significant research paper on cytokines and their similarities in ME and Multiple Sclerosis:
http://www.sciencedirect.com/science/article/pii/S1043466614004165

They researched the Th1, Th2 and Th17 helper cells.

Be it noted that **prof. Kenny DeMeirleir** told about those in webinar 18 of the Science to Patients-project:
http://youtu.be/vQNOzCqHq6c?list=UUPZtpMdUGvQblEJ3IfgYQ8Q

Multi-disciplinary Collaboration to END ME/CFS

THE OMF **END ME/CFS** PROJECT
http://www.openmedicinefoundation.org

Open Medicine Foundation (OMF) and top experts under the guidance of world-renowned geneticist **Ronald W. Davis**, **PhD** are launching a bold new project of collaborative research. The ultimate goal is to unlock the mystery of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS).

"I really enjoy working on problems that others think are unsolvable, and I've been finding, to my surprise, that the older I get, the easier it is to take on those problems", says **Ronald W. Davis**, **PhD**, **OMF Scientific Advisory Board Director**.

OMF's new END ME/CFS Project will create a large consortium of scientists and clinicians with expertise in ME/CFS and top-notch experts in relevant scientific fields and will also include world-class scientists not currently working on this disease.
It will be modeled after two former success stories:

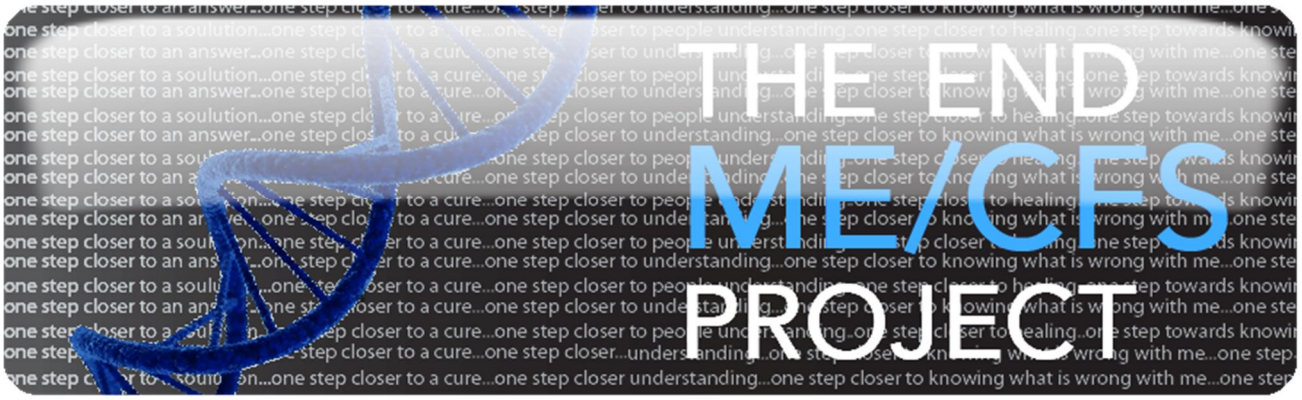
- The Human Genome Project, launched by **James D. Watson**, **PhD** (who has joined our Scientific Advisory Board).
- The Consortium on Inflammation and Host Response to Injury in Humans (http://gluegrant.org), led by **Ronald G. Tompkins**, **MD**, **ScD** (who has also joined).

The project will find grants and funding, and determine the most effective course of research. The goal is to understand the disease at a molecular level, finding diagnostic markers, effective treatments, cure and prevention. Basic research will be conducted in the best scientific laboratories. ME/CFS clinicians will provide their intimate knowledge of the disease and conduct any clinical trials. We will work until answers are found.

World-renowned scientists

The Open Medicine Foundation is honored to announce that **Dr. Ronald W. Davis** will join the OMF as its new ME/CFS Scientific Advisory Board Director. **Dr. Davis** is **Professor of Biochemistry and Genetics** at Stanford University and **Director of the Stanford Genome Technology Center**. The originator of numerous innovations in genetics technology, molecular instrumentation, **Dr. Davis** is known as one of the "fathers of the modern era of human genetics".

He was a key scientist in the Human Genome Project, perhaps the most groundbreaking project in medicine in the last 15 years. His pioneering and collaborative work has gained **Dr. Davis** the respect of scientists and clinicians worldwide.



Other renowned scientists will join **Dr. Davis** on the Scientific Advisory Board. These include: **Mark M. Davis**, **PhD** - renowned immunologist; **H. Craig Heller**, **PhD** - sports fatigue expert with broad knowledge of physiology; **Andreas M. Kogelnik**, **MD**, **PhD** prominent ME/CFS clinician-scientist; **Baldomero M. Olivera**, **PhD** - innovative neurobiologist; **Ronald G. Tompkins**, **MD**, **ScD** - prestigious trauma physician; **James D. Watson**, **PhD** - **Nobel Prize Laureate** for his determination of the structure of DNA (see bios below).

A few additional top scientists are yet to be recruited. Together, they will recruit a large consortium of leading researchers and clinicians including many already involved in ME/CFS.

This collaboration will bring in expertise in a wide range of body systems and a diversity of disciplines including medicine, genetics, biochemistry, immunology, infectious disease, neurophysiology, bioinformatics, and statistics.

Producing a breakthrough

The **END ME/CFS** Project was founded on the idea that a comprehensive, interdisciplinary effort is needed to produce breakthroughs in our understanding of ME/CFS and neuro-immune diseases. The OMF's goal is to connect the best experts, from inside and outside the field, through openness and information sharing.

Linda Tannenbaum, **Executive Director** of the OMF, and **Ronald W. Davis**, **PhD** also have a personal goal to find answers as quickly as possible as they have a daughter and a son, respectively, suffering from ME/CFS. Personal dedication can be a powerful force for making breakthroughs in difficult to understand diseases.

The Scientific Advisory Board under the guidance of **Dr. Davis** will lead the consortium in a collaborative manner to move research as fast as possible in the least expensive and most systematic manner. At their first meeting they will draw up a comprehensive list of doctors and scientists to join the consortium.

Five million dollars

OMF is setting an initial minimum goal of **$5 million per year** for the "**End ME/CFS"** project.

To join in this campaign to End ME/CFS and Donate to the Open Medicine Foundation, please go today to http://bit.ly/1q3gRvt or contact us at donate@openmedicinefoundation.org. Ask your friends, your family and your peers to donate to this ground-breaking project that will be a catalyst to the understanding of all Neuro-Immune Diseases.

Be part of this historic effort to unlock the mystery to find a cure & share the hope of millions of patients worldwide!
CDC states up to 4 million affected by ME/CFS in the US alone
Over 8 million affected by ME/CFS world-wide
An estimated 1 in 500 school-aged children are at home due to ME/CFS
Estimated 1 in 300 people are affected
There is no lab test or biomarker for ME/CFS
Many patients are bed-ridden or home-bound
Many patients cannot work or live normal lives
No clear diagnosis.
No effective treatments or cure.

[more]
http://let-me.be/page.php?6

Nova Southeastern, Miami

Nova Southeastern, Miami

Extracts of an article by **Cort Johnson**
Source: Health Rising
http://www.cortjohnson.org/blog/2014/09/13/big-chronic-fatigue-syndrome-grant-men/

Dr. Mary Fletcher and the ME/CFS research team at the Institute for Neuroimmune Medicine at Nova Southeastern University have received a very large grant ($1.9 million) from the National Institute of Neurological Disorders and Stroke at the NIH. This grant will look for biomarkers in men with Chronic Fatigue Syndrome. The grant builds on the work provided by $10 million worth of work on Gulf War Syndrome – a syndrome populated mostly by men. It may be first study devoted to specifically understanding this disease in men.

The NSU research group has been focused mainly on women, and this big grant will balance that out. ME/CFS is often spoken of as a "woman's disorder", but men make up twenty to forty percent of the million people in the U.S. believed to have Chronic Fatigue Syndrome. (The press release, interestingly, suggests that this figure is too low. One wonders who they feel the epidemiological studies missed.)

Study to illuminate new treatment possibilities

The goal is to use those biomarkers to select existing drugs to be repurposed to treat people with ME/CFS. A similar effort in GWI in men has produced a treatment that's now in phase 1 clinical trials. **Dr. Klimas** reported they'll be performing a series of GWI clinical trials over the coming 2 years. The best way to keep abreast is to watch NSU's web site .

They clearly have specific drugs in mind. The **Klimas**-**Fletcher**-**Broderick** team has been circling around the subject of repurposing drugs for some time. Their focus on neuro-inflammatory and neuro-degenerative disorders such as ME/CFS, GWI, Parkinson's disease, and Multiple Sclerosis suggests they may be considering a wide variety of drugs. The focus on repurposing in this grant suggests they're getting closer to clinical trials.

Dr. Fletcher's goal to precisely pin down the differences between men and women with ME/CFS suggests they already have a good idea what they are, and now it's just a matter of zeroing in on them. They will also use the grant to identify gender differences as they relate to their ability to keep the lid on latent viruses in the body.

Pathways to neuroimmune disease being mapped out

Analyses suggests different pathways to disease exist in ME/CFS Analyses suggests different pathways to disease exist in ME/CFS. ME/CFS and GWS look very similar; not only are their symptoms — highlighted by post-exertional

relapse — similar, but they also share common autonomic, inflammatory, and cellular immune dysfunctions. Digging deeper into the molecular basis of these disorders has revealed fundamental differences, however.

Differing gene expression and cytokine responses to exercise indicate that strikingly different pathways at the molecular level are producing similar-appearing diseases on the surface. Will the same pattern extend to gender differences in ME/CFS? Are very different pathways of disease creating similar disorders on the surface? Could men and women with ME/CFS – at the molecular level have different diseases?

Good Day/Bad Day Study Extension

In this extension of the Good Day/Bad Day (GD/BD) study examining ME/CFS patients on their good days and their bad days, biomarkers are the key again. This study will attempt to identify the mechanisms behind the altered immune functioning highlighted in the first GD/BD study. IL-15 may be a key target for treatment in ME/CFS

Their goal is to build a gene expression assay that identifies the key markers driving the neuro-immune-endocrine mess that is ME/CFS. They'll also assess the effectiveness – in the lab – of targeting immunotherapies at the IL-15 cytokine to increase natural killer cell functioning. They believe it will qualify for clinical trials in ME/CFS. This study, then, could produce a diagnostic test for ME/CFS and identify an immunotherapy that increases NK cell functioning. This study is two-thirds done and ends in 2015.

The molecular basis of the exercise problems in ME/CFS

This study focuses on the 'regulatory' failure they believe occurs during exercise in ME/CFS. They believe ME/CFS, at least in part, derives from a failure to properly regulate the immune, endocrine, and neurological systems during exercise. Their past studies, for instance, reveal that convoluted immune networks in people with ME/CFS have replaced smaller and more effective immune networks in healthy people.

In this study they examine the molecular ramifications of hitting the immune, endocrine, and neurological systems in ME/CFS patients hard with an exercise stressor. Then they'll integrate those molecular findings into an interpretable map showing how the different systems link together in ME/CFS and in healthy controls.

Then they'll identify weak links in the "wiring". Using computer simulations they'll assess the effectiveness of different treatments in repairing these weak links and resetting homeostasis; i.e., returning the system to its normal resting state (health) in which the normal response to exercise found in the healthy controls occurs.

This study ends in 2015.

8. ME And Children

Joanne – Now Almost A Year In Hospital Against Her Will

In November it will be a year that **Joanne**, the 14 year old girl with severe ME, is incarcerated in a German hospital against her own and her mother's will. (Read about her fate in the former issues of The Global Chronicle.)

The Child Protection officers together with her father obtained a respective court decision to forcibly admit her in a neuropaediatric ward in November 2013, and so far none of our combined attempts to get her free or to at least stop the detrimental "treatment" approaches of the hospital doctors and therapists have born any fruit.

Mother has lost custody in February this year because she tried to protect her daughter from the "activation programme" and the resulting deterioration, andshe will most probably never get back her parental rights. **Nigel Speight** unremittingly supports **Joanne**'s mother and tries to give advice and influence the doctors and other institutions involved, among them the ethics committee of the hospital whose job would have been to assess the constant violation of Joanne's human rights and her explicit refusal of all the "activation therapies" they enforce on her.

Instead of doing their job and address these issues they fell victim to the tales of the doctors that Joanne would have improved under their "treatment" and that this was the only appropriate way to make her healthy in the end. So the ethics committee eventually strengthened the doctors' approach and determination to keep her in hospital for years, if need be.

Since **Joanne**'s manifold and severe neurological, cardiologic, gastric and immunological symptoms worsen constantly this means in fact: they will keep her in hospital until she is dead. And her end might be quite near because they now plan to place her in a room with another girl on the ward. According to the doctors they want to "bring her back to a normal life".

She couldn't even bear the stress and noise of the hospital environment in a single room without deterioration, so the noise and stress of another girl in the room who is cared for, who has visitors and causes other noise like talking, watching TV etc.will definitely render her in a constant almost unconscious state and a further worsening of all her horrible symptoms like overwhelming exhaustion, constant vomiting and sickness, fever and sweating, headache, severe dizziness, tachycardia, sleeplessness and sensitivity to touch, sound and light.

Already now there are days when she is hardly able to speak a few sentences when her mother visits her in the afternoon – to tell her all the things that are done to her like being permanently observed and tapped by the staff through a one-way mirror in the wall to an adjacent room, like being humiliated by doctors, nurses and therapists, like being accused of just not wanting to talk and cooperate and become healthy, like being denied her ear plugs (they would allegedly cause the headache and dizziness), like having to wait endlessly when calling for a nurse to change her nappies, like having the curtains and windows wide open so that the noise of the near building site and the traffic of the outward road torture her etc. The way they "treat" her is, according to everything she tells her mother, simply an ordeal, physically as well as psychologically.

There is no way that she will ever get better under their "treatment" and come up with their demands they consider as precondition to send her home. So this is a catch-22 situation for everyone involved, but the only persons who realize this are Joanne and her mother. The health care professionals still seem to believe that they may reach their unrealistic goal by the use of force and coercion.

The prospects of **Joanne** being allowed to go home to her mother are more than bleak. Even though **Joanne**'s mother involved another legal expert all their combined efforts had been in vain. Mother still faces a hostile alliance of **Joanne**'s father (who rarely cares about his daughter and leaves everything to the doctors), the Child Protection officers and the doctors.

They all depict **Joanne**'s mother as some kind of sorcerer who made her daughter ill by witchcraft (the modern lingo for that is "psychological") and almost let her die and who now prevents any healing by badly influencing her daughter.

Most probably, the impending court decision on mother's appeal against the withdrawal of her parental rights will only confirm this withdrawal. She is the scape goat for everyone involved, and ratio, compassion, humane behaviour, well, even simply being able to see the reality and the incredible suffering of **Joanne** (and her mother) seem to havevanished into thin air, if ever existent before.

The behaviour of all professionals involved in this case resembles a collective psychosis. And **Joanne**'s ominous "psyche" is the second scape goat, she would in their perverted view just not want to become healthy. They assume some kind of weird "psychic blockage" to be the reason for her lying in bed, being paralysed, not able to sit or walk or eat by herself and endure all the hostile treatment she has to endure.

And now they seem to run wild and seem to push their wrong "treatment" approach through with a vengeance: The "activation program" is even increased and **Joanne** will be placed in a double room in order to provide her some "entertainment".

The fact that they never seem to realize how close to death **Joanne** is (they switch off the machines that give alarm when her pulse rate is over 185 or the oxygen saturation of her blood is below 85% - arguing that the stress of the alarm beeping would *cause* her symptoms) and that they never seem to be afraid of killing her with this "treatment" approach is indicative of their complete lack of knowledge about the disease.

We wonder whether they might finally have second thoughts about their "treatment" when **Joanne** will die? Or will they still blame the mother or **Joanne**'s mysterious "psyche"?

If you want to help **Joanne**'s mother (whose income is very low) with her legal fees you may donate for the **Save4Children** Fund.

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

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

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

A large gift has been received from an anonymous giver to cover the expenses of Joannes's mother for lawyers etc.

Families Investigated By Social Services In UK

40 UK families with ME investigated by social services

Explosive claims, that up to 40 families in the UK have been investigated by child protection officers because they disagreed with doctors about the diagnosis and treatment of children with myalgic encephalopathy (ME), are part of a larger, escalating problem.

Dr Nigel Speight, a paediatrician and adviser to the Tymes Trust (The Young ME Sufferers Trust), told The Sunday Times last week: "I know of 35 to 40 families abused in this way. I am getting more cases all around the country.

"It is easy to blame the social workers but I blame the doctors. If the doctors got it right, the social workers wouldn't be involved.

…once the whole process gets going, there is a kind of almost sadistic element to some of the worst cases. They must be able to see the suffering they are causing.

In one case, a mother, **Sophie Sleep**, of Lipson, Plymouth, had her two sons referred to social services "behind her back" in March 2011. Doctors then demanded that one of her children, whose condition had worsened despite being put on an exercise regime, be admitted to hospital for physiotherapy and sleep monitoring, against her wishes.

The numbers may be much higher

In the wake of the **Speight** revelations, **Jane Colby**, Director of the Tymes Trust, issued a statement which extended the number of families Tymes Trust has assisted to 125.

"Commonly, such cases are sparked by paediatricians wanting to impose graded exercise or physiotherapy and school attendance. They often seem convinced that such methods will work, and will effect an improvement," **Ms Colby** said.

"They do not accept it at face value when parents say that these management regimes make their children worse and withdraw them from the regime, requesting home or virtual tuition, as is their educational right. Suspicions then arise, social services are informed and have to investigate."

NHS turns a blind eye

The poor treatment of ME children is not a recent development. In 2001, the Countess of Mar, **Margaret Mar**, then Deputy Speaker of the House of Lords, pointed a finger at the UK Department of Health when she wrote in The Telegraph that the Children Act 1989 was being misused to accuse innocent parents of seriously harming their sick children and to enforce potentially harmful treatment on their children without parental consent.

"When it comes to these children being taken into council care, the parents' fundamental liberty to bring them up is being denied," the **Countess Mar** said.

"When questioned, the Department of Health acknowledges both the seriousness of the illness and the lack of effective treatment for it."

"In practice, the department ambivalently turns a blind eye to its own officers who, without hard evidence, blame parents for their child's illness and invoke child protection law.

"Apart from anything else, this is a breach of a family's right to a private life under the Human Rights Act 1998.

Countess Mar noted that children were being taken away from parents and subjected to often futile cognitive-behavioral therapy and physical exercises.

Source: Shout out about ME

http://bit.ly/1BDzTyS

Karina

It is **Karina Hansen**'s birthday on November 7th. She has been moved from the hospital in Hammel and is now being held here: Tagdækkervej 10, 8450 Hammel, in a home for people with braindamage! No one knows why… **Karina**'s parents are still not allowed to visit her and are kept out of her 'case'… and **Karina** herself still has a guard, who is not very talkative or helpful. We all dearly hope that she has not been injured by the treatment she has had in the Hammel Neurocenter.

I hope you will all send **Karina** a card for her birthday. A lot of cards will show that she is NOT forgotten, and that she will never be forgotten.
You can either send your card to:

Karina Hansen
Tagdækkervej 10
8450 Hammel, Denmark

or to her parents
Per og Ketty Hansen
Kløvermarken 8
7500 Holstebro, Denmark

Karina's parents will try to give all the cards they get from you to **Karina** on the day of her birthday. So please show **Karina Hansen** and her parents that they are not forgotten, by sending cards for **Karina** on her birthday on the 7th November.

Also equally important is to show the psychiatrists and the politicians that we still remember what they did to a severely ill young ME woman, and that we are a LOT of people, who do hope something like this will never ever happen again. It was illegal and wrong, and the psychiatrists hurt a young woman and her parents unforgivably.

Bente Stenfalk

My own opinion is that anyone opting to send their cards to the new hospital unit will be wasting their money and energy, as VERY FEW informed people believe that they will give the cards to **Karina**.

My view is that you are better sending your cards to the address of **Karina**'s parents in good time for her birthday. That way, **Karina**'s parents will see the outpouring of worldwide support for **Karina** from PWME on her birthday and every day that **Fink** is holding **Karina** against hers and her parents will.

Karina's mother is very touched by your generosity towards **Karina** and looks forward to seeing the many cards from around the ME world.

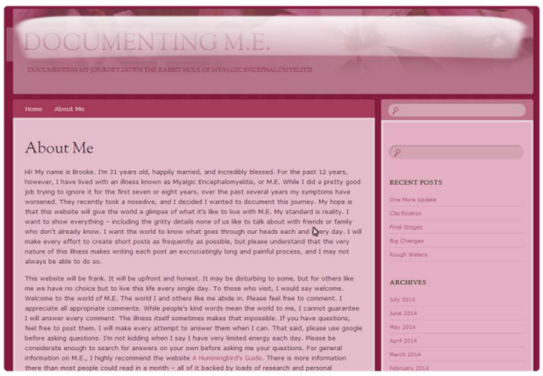
Thank you all

Michael Evison

9. Severe ME

Final Stages - One More Update

Dear Friends,



Recently there have been a lot of questions in the community about what has happened to me and where I am with things.

I am now very near the end of life, and writing posts has become next to impossible, but I wanted to try to get one more out.

This post will be written in many parts, and may seem rough around the edges, but it is the best that I can do at this point. I know you will understand.

First, regarding care. My initial reevaluation for hospice care was denied – in part due to misinformation coming from the whole CFS mixup. After this, my doctor agreed to treat me himself, without the aid of nurses since he couldn't find a way to get any into the home.

Things began going downhill so fast, however, that he recently talked the hospice team into readmitting me for 60 days, which should be plenty of time for things to finish playing out. So I do have care once again, and words can't express how much I owe my doctor.

No matter how many doors were slammed in his face while trying to get me appropriate care at home, he never gave up, never walked away like so many doctors do. He is an incredibly rare find, and I am blessed to have him overseeing my care.

Second, regarding the medical side of things. My doctor has me on subcutaneous Dilaudid, which is working pretty well for my pain, and finally stopping those horrendous 10s.

My bowels have quit working on their own (the nurses can't hear any bowel sounds whatsoever), so every third day we force them using a suppository or two. So far that's working out okay. For a week or two I had heavy bleeding out of my private area – the cause of which is unknown since I experienced menopause nearly two years ago, and the symptoms didn't fit menstruation anyway.

It seems to be letting up somewhat now, but the whole thing is still a mystery. I am extremely fatigued and have difficulty staying awake most of the time. I also experience mental confusion, slurring of speech, extreme muscle weakness, lack of fine motor control, and other such symptoms more severely and frequently than I did before. And of course I'm still losing weight.

Recently, my body has begun refusing all liquids. It's like the food fiasco all over again, but with liquids this time. Everything I try to drink comes back up. I am vomiting many, many times a day. I have tried many natural and prescription "cures" for nausea, without success.

The one thing I have found I can sometimes keep a tiny bit down of is Red Raspberry Leaf Tea, although I still vomit that up more often than not. I have not given up the battle for fluids yet, as I'd rather not die of dehydration if it can be helped.

There are other things happening in my body which will kill me soon enough without adding dehydration to the table. Recent blood work has shown the biggest contender at the moment to be dangerously low potassium levels. The levels I am experiencing are fatal if not treated, and I have chosen not to treat them.

The low potassium is almost certainly a result of both lack of nutrition entering the body and frequent vomiting, and thus is simply one more part of the disease process I am allowing to play out.

As time is now so limited, my husband has taken advantage of a federal law (the Family and Medical Leave Act) in order to stay home with me full time until the end. This has been not only a tremendous help, but a real necessity as things have progressed.

But enough of that. In happier news, I was recently contacted by **Jen Brea** of the "**Canary In A Coalmine**" project about possibly appearing in the film. Readers here know my stance on never combining or interchanging the terms ME and CFS (http://bit.ly/1vEC57p), so I was understandably hesitant at first since the film uses both terms.

However, after talking extensively with **Jen**, it became apparent that this film *is* going to explain clearly the problem with the term CFS and the tremendous damage done to ME patients (and others) by its creation.

> Overall, I feel that this film will accomplish great things in raising awareness for ME, and I have agreed to participate.

Jen's goal in filming my particular story is to show absolute proof that ME can and does kill by documenting the dying process on film. Viewers will hear my story, in my own voice, then, as difficult as it sounds, watch me die (http://bit.ly/Z53Tqw).

Not in a gruesome way, but in a way that makes it real. This should hopefully help refute 30 years of misinformation claiming that ME absolutely is not fatal.

The film crew has already been here once, and plans to return again this weekend. I won't go into any more detail, but I can say that **Jen** and her team of top notch filmmakers have big plans for this film, and I would encourage you to support this film and be sure to watch it when it comes out.

Jen is someone I have tremendous respect for both as a person and as an ME patient who stood up and did something huge for the community, and I can assure you she absolutely has the best interests of the ME community at heart in all that she does.

Looking forward, there are several more posts I felt strongly about writing. I do not think that they can happen at this point. This may well be my last post, although as I've said, my mother has the login details for this site and has promised to post an update once I'm gone.

She is also fully qualified to answer any questions you may have for her at that time, and has promised to do so as time and circumstances permit.

I just wanted to say how very much I appreciate all of you. The fact that you all have been so supportive, both in your comments and in sharing my posts around the web, means more to me than you will ever know.

The ME community may be very ill, but we are also very strong. Thank you for showing and sharing that strength with me. God bless.

Moore, July 31, 2014

http://documentingme.net/2014/07/31/one-more-update/

What it's like to live with severe ME – part 2

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

Within 24 hours it was liked by over 5000 persons. The article itself we published in the ME Global Chronicle of June 2014.

Here is **Naomi**'s response to the 273 comments at http://bit.ly/1EgUDk4

14 August 2014
Thank you to everyone who has contributed here. I am not well enough to engage in an ongoing discussion myself, but, as the author of this article, would like to respond to a couple of points that have been raised.

Firstly I feel it is important to acknowledge those too ill to participate in this discussion in any way. It is impossible to overemphasise the gravity of the most severe cases of ME.

As others here have described, they are totally bedridden and forced to exist in darkened, silent rooms because any sensory stimulation results in a catastrophic escalation of symptoms. Many are on morphine and tube fed.

It is a level of illness that is shocking to witness. For these very severely affected ME sufferers, every moment is a battle to survive. Some do not survive. Some never improve.

The level of suffering has been compared to the final stages of AIDS or cancer, yet little or nothing is available by way of medical support or symptomatic relief.

A recurring misconception about ME is that sufferers are prejudiced against mental illness. This is far from true. Living with a marginalised, misunderstood illness tends to give one greater understanding of all types of suffering.

When a psychological explanation for my illness was repeatedly offered, I worked hard to accept it. It is through the failure of this approach to help me, and countless others, that I now reject the notion of a psychiatric component to ME - not because I am prejudiced against mental illness.

There is inevitably a psychological aspect to having any illness, inasmuch as there is a psychological element to being human. Support aimed at addressing the significant emotional complications of severe illness - particularly in childhood and adolescence - can be of great benefit, and at times has been for me.

I do not know anyone with ME who would reject this. Problems arise when psychiatric and psychological interventions are used in an attempt to treat the underlying illness.

Far from refusing to engage with such treatment, many ME sufferers have pushed themselves way beyond their limits to follow therapies prescribed by doctors lacking a true understanding of ME. Many have been made irreparably worse as a result.

What ME patients object to is not so much the suggestion that we could have a biological mental illness - though I cannot think of any ME experts or patients who would consider this an accurate description - but claims that we do not have any ongoing disease process at all.

What is deeply offensive is the idea that ME sufferers are, intentionally or otherwise, creating a set of symptoms in order to avoid life; that the condition amounts to little more than maladaptive illness beliefs and that recovery could be achieved if enough effort were applied. Anyone with neurological ME knows from long and bitter experience that this is emphatically not the case.

For anyone wishing to learn more about the extensive biomedical evidence available, I recommend the websites of ME Research UK, IiME and Stanford University.

http://www.meresearch.org.uk
http://www.investinme.org
http://chronicfatigue.stanford.edu/

The Voices from the Shadows website is also very informative: http://voicesfromtheshadowsfilm.co.uk/

The lack of appropriate research into ME is scandalous, but even worse is the lack of compassion and respect too often shown to sufferers. If I could change one thing today, it would be that.

Thank you again for your comments.

Naomi Whittingham

Extemporaneous notes from Invest in ME IIMEC8 conference

The situation of severely ill bedbound ME patients was discussed by some of the presenters at the 2013 Invest in ME International ME conference – IIMEC8.

Dr Daniel Peterson (Director Simmaron Research, USA) said that the healthcare system is not geared for these types of patients. In the past these patients would have been cared for in hospitals with alimentary treatments but now the cost is prohibitive.

Dr Don Staines (Public Health Medical Officer, Queensland Health, Australia) said the situation is bizarre as normally the most severe patients in any illness get most attention and are hospitalized but in ME the situation seems to be reversed.

The Australian Marshall-Gradisnik research group has included severe ME patients in their studies but have not found any differences in the immune system parameters in groups rated according to severity. **Dr Staines** pointed out that ME is, however, a multisystem illness and the immune system is only one part of it.

The Griffiths University, where the Marshall-Gradisnik group is located, also has beds for patients so that they can include severely ill patients in their studies as well as monitor patients for 24 hours or more. This is something that should be possible elsewhere too.

Doctors simply do not know what to do with these patients so there is an urgent need for education.

After the conference **Dr Amolak Bansal** (Consultant Clinical Immunology and Immunopathology, Epsom and St. Helier University Hospitals NHS Trust, Surrey) added the following especially for Invest in ME, explaining severe ME in the following way -

"While it is presently very difficult for modern medicine to fully explain all severe ME symptoms, disordered neural function within the brain and spinal cord would come close.

How this occurs is unknown but there are counterparts in certain newly described autoimmune conditions and viral infections of the nervous system.

In addition to a direct stimulation of neurones in different parts of the brain and spinal cord there is also an impaired filtering function of the brain stem and a reduced threshold for neurones to fire off.

This allows external stimuli such as movement, light, sounds, touch and sometimes even worrying thoughts to produce widespread neuronal activation with ultimate excitotoxic damage to these cells.

The consequence is impaired activity of the brain generally but particularly the hypothalamus and prefrontal cortex leading to fatigue, disordered sleep, impaired memory, attention, faintness, palpitations, disordered respiration, temperature dysregulation etc.

Outwardly many patients appear well and routine blood and other investigations are normal.

Internally there are severe symptoms which, if unchecked, escalate leading ultimately to immobility and increasing pain and spasms in a proportion of patients.

Clearly a greater understanding of this highly disabling condition is required with a greater focus on disrupted immune and neural pathways and not just psychosocial factors as has previously been the case."

Original source
http://www.investinme.org/IIME-Newslet-1306-04%20Severe%20ME.htm

BRMEC4/IIMEC9 Report

http://www.investinme.org/IIME-Newslet-1407-01%20BRMEC4.htm

Fatigue : a slap in the face and an insult

The situation regarding Severe ME is so dire as to be almost incomprehensible. You have to ask : why are people not bending over backwards to help those who have been pushed, through unimaginable physical suffering to the very edge of society?

Imagine if cancer was treated mainly with psychiatric therapy while those with malignant or terminal cancer were left at home with no treatment, help or support, to die, their serious disease ignored.

There would be such an outcry! You do not get that outcry with ME.

Why ?
The seriousness of the illness is no longer understood or adequately represented. "Myalgic Encephalomyelitis", the neurological disease, has become hopelessly lost in a sea of poorly identified fatigue issues, in which Severe ME barely registers.

After three decades of psychiatric misdirection, a bewildering array of inappropriate and vague terms : "CFS/ME", "CFS", "ME/ CFS", even "Chronic Fatigue" are routinely used to mean ME.

The terminology leads researchers and clinicians to focus on fatigue, rather than ME.

It shows how little comprehension they have of the true reality of the illness.

It is unrecognizable to us, the way ME is generally described, a fanciful view that is not real or based on lived experience. How can there ever be real progress all the time ME is so poorly defined as to be unrecognizable?

Practitioners and services, in our experience, have no idea how to relate to people with Severe ME; they either ignore, downplay, neglect or overlook the most serious symptoms, the complex hypersensitivities, with frightening consequences. How can it be that the more severe and extreme symptoms, like paralysis and muscle spasms are constantly ignored or downplayed by medicine and research ?

To try and engage with a medical profession, that has not engaged with the medical truth of ME is terrifying the more ill you are .

The use of any term, that attaches the modifier "fatigue" to ME, is wholly inappropriate, especially in Severe ME.

Fatigue for my wife, as someone who has suffered from Very Severe ME for over two decades, is the least of her worries.

Here is what she has to say about this derisory term :
"It is not fatigue, it is Paralysis : a complete Inability to move, think or function.
It is not the tiredness that comes from doing things, it is no energy to do them in the first place.
It is not weariness, it is stultifying incapacity and profound disability, caused by multi-system dysfunction on a major scale.

It is like your body has turned to stone and cannot move by willpower, whim or wish.
It is like you are dying.
It is like someone pulled a plug and everything drained away leaving an empty nothing.

It is not even recognizable as fatigue because it is embedded in pain, overlaid with numbness and crushed by paralysis, defied by shaking and muscle spasms.

The more severely ill you are, the less you can find fatigue in the haystack of more serious, severe and ignored symptoms that define your days and your isolation. I am so very sick of being under-represented and misdescribed.

It is a slap in the face and an insult, a step too far, to be continually told your illness is primarily about fatigue when paralysis defines your days. Just to be weary and tired would be a miracle."

How can people have an honest prognosis all the time a psychosocial model of interpretation denies the true reality of this serious and life threatening disease, while "b*eing positive*" is used to deny the true seriousness of the illness and its unlikelihood of recovery without biomedical treatment?

How come the psychosocial lobby, in active collaboration with the major ME charities, has been allowed to spread its misinterpretation of ME as chronic fatigue so agressively across the UK without effective challenge by the medical profession?

How can there ever be accurate research, when the pool of research patients is drawn from those that who attend CFS fatigue clinics while the most severely ill, too ill to see consultants in hospital settings, are medically neglected and ignored?

If the most ill dare to engage with a medical establishment which does not understand the underlying mechanisms of their illness, they are at serious risk of harm, even death.

Any Severe ME sufferer will tell you that at the heart of ME there are crippling hypersensitivities which dominate and destroy lives, yet this is barely acknowledged. There is no effort, we are aware of, to create innovative aids to

deal with crushing noise sensitivity, for example, for those in too much pain to use earplugs or earphones, or light sensitivity: how to safely help someone who cannot have the light turned on.

That basic thinking is not there yet. There is no highly skilled specialist ME service, to our knowledge, dealing with the moment to moment torment people with Severe ME experience.

Until professionals and clinicians become interested enough, genuinely concerned and knowledgeable enough about the disease, especially Severe / Very Severe ME, there is no hope of an adequate and safe medical service.

The greatest danger for people with ME is its misrepresentation as fatigue. Its misinterpretation as a condition or syndrome, its mispresentation as a mental health disorder. It is caused by physical dysfunction. It is a neurological disease. There is no cure.

The greatest danger comes from complacency from not realising the name does matter. From compromising away its true nature and reality, from putting funding or power or a voice or compliance with the fatigue lobby.

Before speaking and representing the Truth of ME, the result of complacency and compliance is the current lack of appropriate biomedical services for people with ME
The abuse and wrong treatment of people with genuine ME, the denial of symptoms and the legitimisation of misinformation and medical neglect.
When will the people who have genuine ME be seen, acknowledged, heard, listened to, respected and properly provided for?

What do we have to say to be effective ? What do we have to do to get a fair response?

What do we have to experience before the world listens? What more do we have to suffer before the governments and the health services of the world act responsibly and treat us properly for the neurological severely debilitating physical Disease that we actually have?

Greg & Linda Crowhurst

10. Column – This Song…

Yesterday I had a discussion with somebody.
About posting stuff on invisible illnesses.
It wasn't even about my own posts
But all about his sister's posts.
They were clearly irritating him.
Whilst he has such a cute niece battling an invisible illness.

Since birth.
Such a beautiful, strong young girl.

Is it really so strange that her mom posts about this?
Or about any other invisible illness?

Do people really think that it's just a cry for pity?
I'm afraid some people actually think this way.

I even know for a fact.
I've had people saying this to me.

About my posts on ME.
But I've come so far that I don't care anymore.

It says more about them than about me.
My posts are never about asking for pity.

They are always about raising awareness.
Unfortunately there will always be people who don't get this.

For whatever reason.
But thank God there are so many people who do understand.

People who actually want to understand.
Or at least try.

And for all those people struggling to be heard.
Because they are too afraid to face the reactions from others.

This song is for you....
http://youtu.be/vaAVByGaON0

Muzzly

Column - To our heroes

Chronic Fatigue Syndrome: A Salute To 10 Kinds of Heroes

I don't think many people with Chronic Fatigue Syndrome see themselves as heroes. Or, maybe they do but they don't expect anyone else to see them in that light.

The limitations we face are so enormous that it can take everything we've got to accomplish very little at times. It goes against our grain, but we have to lower the bar for even small every day activities.

But the people with CFS who accomplish things, and those whose accomplishment is to just manage to keep breathing ... those who overcome their bonds, and those who must learn to rest within them are all heroes. Trying to move a rock that is too big, with energy that is too small and very often with next to no help from ... well, from anyone.

I have referred to our community in the past as a CFS Ghetto. But we are also a clan. Here's to the heroes of Clan CFS. My hat is off to every one of you.

1. To the heroes who manage to get up and go to work, then collapse when they get back home. They use up all their precious teaspoons of energy to earn a living. Because they can work, people don't see them as ill. There's nothing left of them by the time the workday is over but there's no other way to pay the bills. And these are the lucky ones, who live a half-life.

2. To the heroes who stay home and raise their kids, from their beds and couches. If they are lucky they have pensions or they have healthy spouses who shoulder the financial load. But their energy tank is always on E for empty as they give their tiny all to care for their families.

3. To the heroes who write about CFS in blogs, articles and websites. This takes a lot of energy. And it requires the mental clarity that is so precious and rare in CFS. To protect this mental clarity, the rest of their time is spent regenerating, working up just a little more of that ability to get the word out that we exist.

4. To the heroes who must live cocooned away from the world. Many people with CFS can't work, can't write, maybe can't read ... can't function as normal people think of functioning. Their accomplishments might be making breakfast and maybe getting dressed. If they're lucky they can sit or recline near a window, their only connection to the rest of the world.

5. To the heroes who petition for pensions. People who are this sick should be on a disability pension. Many of us aren't. We can't prove we're sick or we are too sick to make the petitions and appeals. That minority who can speak up and make headway in this arena are performing a service for all of us.

6. To the heroes who don't. Getting by on next to no money when you are too sick to work or are without a pension is a horrifying experience. It is however an experience that is the daily reality for far too many of us. Much harder than being able to work. Many end up homeless.

7.To the heroes who can't get out of bed. Can't hold their heads up. Can't speak. This is a special and unique kind of hell. This creates a kind of isolation that's like being the living dead.

8. To the heroes who have been sick now for decades, heading into old age. Many of us can look back on ten, twenty, thirty years of illness. The hope for a better future dies hard when you're sixty and haven't been well since early adulthood.

9. To the heroes who got sick so young they've never had a job, never had a driver's license, never fallen in love. These hurt my heart the most, I think. The old can treasure memories, as they reflect back on healthier times. The young ones haven't had the chance to form these memories. The future is uncertain at best.

10. To the doctors, scientists and researchers and journalists who are determined to help us. Chronic Fatigue Syndrome is not a popular disease. We don't have huge sums of money or support for research. We don't make the evening news, we don't have celebrity spokespersons or fund-raisers. The people who want to find answers for us are few, but they are precious to us. They are our lifeline. Many thanks.

Resources: Chronic Fatigue Syndrome Hits Teens Too
http://www.businessweek.com/lifestyle/content/healthday/652127.html

Jody Smith

http://www.empowher.com/users/jody-smith

11. News from

Australia

* RECRUITMENT OF CFS/ME AND HEALTHY PARTICIPANTS *

Dear all,

We are looking for participants for some upcoming studies.

All participants must be between the ages of 20-60 years of age. Participants may be housebound with CFS/ME, mobile with CFS/ME or healthy controls. All participants must be located between **Tweed Heads** and **Brisbane** as we are situated on the **Gold Coast**.

If you are willing to participate or would like further information, please contact us at ncned@griffith.edu.au or 56789283 if you are a healthy control participant.

If you are a CFS/ME participant please email
sharni.hardcastle@griffithuni.edu.au

Please share this with anyone who you think may be interested and thank you again for your support for our research.

Best wishes,
NCNED team

https://www.facebook.com/changeformeaustralia?fref=ts

Belgium

Not much positive news from Belgium. Some studies are going on here and there, but one can hardly speak of thorough research.

Moreover the focus is just on Lyme-disease. Which is of course easier to explain. One is being bitten by a small insect and becomes ill. I don't mean to say that Lyme doesn't exist or there should be no research into Lyme. But when we look at the community here and notice the number of people being 'converted' to Lyme, I have my questions and doubts.

My daily experience is also that people confuse being ill with having a political point of view. First of all a patient is ill: this should not be influenced by his political conviction. The same is valid for patients organizations: their foremost function is to defend the rights of the patients, not to have a political point of view.

So I make an appeal on all associations, foundations and agencies to for a while put aside politics and own gain, and join forces to look for a solution or to support current (foreign) research.

You may say I'm a dreamer, but I can't do much more than that.

Eddy H. Keuninckx

Canada

In March of this year, representatives of the Canadian Institutes for Health Research promised a research workshop for the ME/FM community to be held before the end of 2014. That workshop was held on Friday September 26.

I wish I could report that the workshop moved the ME/FM research situation forward, but I cannot.

The proposal put on the table goes as follows: CIHR would fund a research network on "chronic pain and fatigue" at a rate of $1M per year for five years starting a year or two from now. In preparation, stakeholders with an interest in chronic pain and fatigue would participate in a exercise to identify research priorities.

A similar priority setting exercise on a different health condition took a year to complete. Included in the proposal was the possibility of a research fellowship for "chronic pain" and another for "chronic fatigue".

Thus, the ME/FM community is being asked to devote considerable resources to this priority setting exercise along with research heavyweights like the arthritis community. If a ME/FM issue miraculously gets picked as one of the top priorities, then it might get a bit of the $1M a year funding. In other words, the ME/FM community is being asked to make a major time-commitment and will be rewarded with a small amount of funding in the best case scenario and no funding at all in the worst case scenario.

Further we would have to wait a year or two to find out if we get anything. We know that the terms "chronic pain" and "chronic fatigue" are far too vague. All in all, the CIHR proposal does not sound like much of an offer.

As I see it, the next step would be to hold a meeting between senior officials of CIHR and ME/FM community representatives to discuss the state of ME/FM research and to look for ways forward. Senior officials of CIHR need to attend because CIHR is divided into institutes and it not clear how ME and FM fit within the institute structure – they overlap with many of the institutes.

Margaret Parlor, president

[More…]

http://let-me.be/page.php?5

Finland

As you know, in Finland we have only one clinic which is treating CFS-patients. But from the news of today we learnt that at the end of this year we will have **NONE**!

Because Unesta, the one clinic we had, is going bankrupt. We are working now very hard to try and change something in this overwhelming situation.

Our association has been publishing a brochure, has been meeting the Finnish parliament and had interviews in many newspapers and much more.

We are getting somewhere and we have to proceed. But how does this looks like from the outside? Who knows?

Will we be able to get research funded or has the illness been dumped for good?

I don't know.

CFS-yhdistys

Greetings, **Sanna Pohjaniemi**
Chairwoman of the Finnish CFS association

Japan

The petition to the Japanese government has been accepted by the Upper House and now NPO ME Association is trying to have it accepted by the Lower House by carrying out another petition to submit by the end of April next year.

The government decided to fund a research to find out the level of disabilities for ME/CFS people in Japan. The research group will be giving out a questionnaire to more than 100 patients of all levels.

NPO ME Association is insisting to have ME/CFS included for the welfare service entitlements, and it is necessary for the government to have a clear picture of what is really happening to the lives of ME/ CFS patients. So this research will be very meaningful

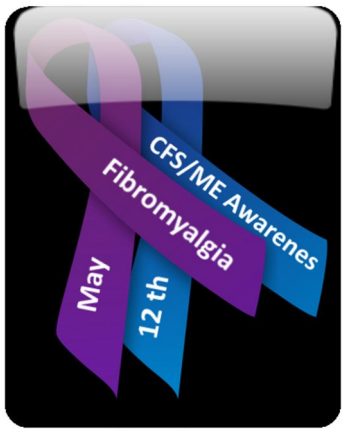
Thanks to all the patients involved in the petitions. Since a few years it became possible for the severe patients to get a disability pension from the government. I personally can get the pension for the next three years now until it will be reassessed. However, the scarcity of the doctors who can diagnose and write the application for the pension or welfare services is another issue. Still a long long way to go…

Best wishes to all of you,

Masako

Northern Ireland

Great news from Northern Ireland, from a great and superactive group of patients…



Newry & Mourne ME/Fibromyalgia Support Group (N&M ME/FM SG) are pleased to announce we have finally been successful in our efforts to inform and secure the support of the Patient & Client Council for Northern Ireland (PCC) on the dire situation and lack of specialist NHS services in N.I. for patients suffering from M.E. and Fibromyalgia.

PCC MISSION STATEMENT :
"The overarching objective of the PCC is to provide a powerful, independent voice for patients, clients, carers, and communities on health and social care issues."

THE RESULTING ACTION PLAN HAS NOW BEEN CONFIRMED :
1. The PCC are currently in the process of contacting all constituted patient support groups in N.I.

2. Each Support Group Committee will be invited to send representatives to attend a workshop to further review and establish current patient's needs and concerns. Evidence of patient need was highlighted and presented to the PCC by the recorded large numbers of people who attended the past six conferences N&M ME/FM SG have hosted in N.I. since 2011.

The ongoing requirement for a professional needs assessment is also very evident by the large volume of patients and professionals who are contacting the various NI support groups on a daily basis for information and help. In order to further educate and inform all those working in this field, we have requested the PCC open the workshop to various interested parties.

This to specifically include medical professionals, decision and policy makers.

3. We are presently advising the PCC coordinators of appropriate and specialist speakers for the workshop and also reviewing potential venues. These venues need to be central in Northern Ireland with good access & facilities to best accommodate all support group participants.

Many a step has been taken by the group to bring their situation to the attention of the PCC and to convince them to finally take this step, like in February 2014 when a representative from the PCC was invited and attended **Professor Mark VanNess**'s presentation in Stormont Buildings. And in June 2014, when **Louise Skelly**, Head of Operations, PCC, came to speak to all members at the monthly support group meeting. **Mrs.Skelly** made the commitment to support their ongoing campaign and this has now been confirmed as above.

The latest news from Northern Ireland:

A written confirmation has been received of the acceptance from Chief Medical Officer for Northern Ireland, **Dr. Michael McBride** and his office of WHO classification.....

"The World Health Organization International Classification of Diseases (ICD-10) classifies chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) under neurological disorders at Reference 93.3 and uses the terms post-viral fatigue syndrome (PVS) and benign myalgic encephalomyelitis."

Moreover the Irish ME-community managed to get a **N.I. Health Minister** to an ME and FMS conference!!

Big achievements....

Norway

Perversly Dark, the film that touched the hearts of Norway, was ready for an international audience at the start of August 2014.

In conjunction with Severe ME Awareness and Remembrance Day on 8th August, the film could be streamed for only $20 (for one week): https://vimeo.com/ondemand/18252

Perversly Dark is a documentary about two of the sickest people in Norway.

Through a periode of six years we have followed the gripping story of **Bjørnar** and **Kristine**, who live their lifes in dark bedrooms have been followed. Read more about the film here:

http://bit.ly/1y4SDWh (also in English)

The film has been shown on national tv in Norway on Monday 25th August 2014.

The documentary can be bought on dvd with English subtitles.

Facebook wall of **Sykt Mørkt**:
https://www.facebook.com/syktmorkt?fref=ts

With thanks to **Helle Rasmussen**

United Kingdom

Just request data…

An appeal to our English readers

Please share as much as possible

How hard it is to obtain relevant data and how self-protective and powerful the psychosocial network around ME is, is being proven in Great Britain by a simple request from **dr. Anna Sheridan** to the Queen Mary University of London of data on the 6 minutes walking test from those who had 'recovered' .

Kind of Neverending Story:

https://www.whatdotheyknow.com/request/raw_data_for_6mwt

This is something that is an ongoing problem in the UK. **Dr. Sheridan** is just the latest person to question the legitimacy of **dr. Peter Whites** PACE trials raw data but has sadly been refused access to them. This has been in question now for seven years and dr. Peter White had used the power of the establishment to block access to this data.

Michael Evison has launched an email campaign to UK MP's to support **Dr Sheridans** FOI request to gain access to the data. It's success or failure is totally dependent on two things

1. How many PWME actually take part

2. Whether the MP's take this matter seriously and try change the refusal decision.

[More…]

http://let-me.be/page.php?4

12. Vote For…

The National ME/FM Action Network Competing in Aviva Contest for $100,000 for Biomedical Research!

The National ME/FM Action Network in Canada is competing in the 2014 Aviva Contest to win $100,000 for biomedical research! Winning entries are determined by DAILY public voting and are also judged.

There will be three Qualifying Rounds:
Sept. 29-Oct. 13;
Oct. 20-Nov 3;
Nov. 10-Nov. 24.

The ME and FM communities will vote daily in Qualifying Rounds until the Action Network secures a spot in the Semi-Finals (Dec. 1-Dec. 10).

You can check at the Aviva Community Fund website https://www.avivacommunityfund.org to see if the Action Network qualified in the first Qualifying Round.

If so, we will not need to vote during the next two Qualifying Rounds. If not, we will be voting daily in Round 2 and, if necessary, in Round 3 until we qualify.

The Semi-Finals also require daily voting. Winners in the Semi-Finals become finalists and compete in the final Judging phase (Dec.17-Jan. 2, 2015). Judges will determine how much each finalist receives. All forty finalists will receive a minimum of $5,000.

The daily voting takes place at https://www.avivacommunityfund.org/ideas/acf19712.

When you vote, please leave a comment about the critical need for ME and FM biomedical research.

For those on Facebook, you may join the project event and get a daily reminder to vote at https://www.facebook.com/events/436713819800556/ .

From the event page, be sure to invite your friends, and share contest information widely. You may also get a daily reminder to vote by email by sending your email address to office@mefmaction.com.

With everyone's help, we can win this one! Thank you very much for your support of this research effort!

13. Major Fundraising

Llewellyn King is raising funds

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

Raised: $6,108.00 Goal: $20,000.00

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

Ian Lipkin study. Raised: **$141,214 from 739 donations!**

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

The Center for Infection and Immunity is internationally recognized as the world's largest and most advanced academic center in microbe discovery, identification and diagnosis.

The Center's laboratories, directed by **Dr. Lipkin**, have developed and validated techniques – high-throughput sequencing – for the rapid identification of disease-causing microbes and have thus discovered more than 500 viruses: more than anyone else. **Dr. Lipkin** and his team are actively engaged in state-of-the-art research to identify the factors that contribute to the onset of ME/CFS. They aim to provide insights into the disease that will allow for the development of diagnostic tests and eventual treatments.

The Center is part of the Mailman School of Public Health at Columbia University in New York.

Info:
http://phoenixrising.me/archives/21929
http://www.microbediscovery.org/

Raising Funds for the UK Rituximab Trial

Info: http://bit.ly/1jVGHng
Thanks to an amazing effort across many countries the Biomedical Research Fund for the IiME/UCL UK rituximab clinical trial is now funded for **£357,500**. The goal was **£450,000**.
To donate: http://bit.ly/1dc1wmS

The "Step Up for M.E." Store!

http://theblueribbon.storenvy.com/

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

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

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

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

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

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

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

info@let-me.be

Till so far **€ 1961,38** has been donated. **Dr. Speight** had to travel twice to Germany to see **Joanne**, her mother and authorities. His covered expenses were € 1150,06. Bank charges over this period were € 14,48. Current balance is € 796,84

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

14. Worth Reading & Watching

Observant Observances-new book from Marie H. Curran

Radio-interview with Irish ME-patient, columnist and poet **Marie H, Curran**, on the occasion of the publication of her first book of poems, Observant Observances:
http://youtu.be/SydfEeAX2MY

The softcopy (and a limited number of hardcopies) can be ordered via the publisher directly:
http://tayen-lane.squarespace.com/shop/observant-observings

And the eBook can be ordered via Amazon:
http://amzn.to/1vIDdrP

Here's the link to the beautiful ***September 2014 Newsletter of Invest in ME*** with among others a tribute to longterm patient advocate **Margaret Williams**:
http://bit.ly/1vICTJr

New webinars of the Dutch project Science to Patients:

Starting a series of short talks of **Prof. Leonard Jason**:

webinar 50: Introduction / experience with ME
http://youtu.be/01WSwZWuc0o?list=UUPZtpMdUGvQblEJ3IfgYQ8Q

webinar 51: Criteria and diagnosis, part 1
http://youtu.be/GkGX0kpp62w

webinar 52: Criteria and diagnosis, part 2
http://youtu.be/6OKQs-1GJCo

webinar 53: ME versus psychiatric disorders
http://youtu.be/RKSaYlR7ZHU

webinar 54: Treating ME / managing techniques
http://youtu.be/mu_6j_vHRpo

Great new site, created by Greg Crowhurst from Great Britain. With an introductory video from and by himself:
http://www.homeboundmusic.co.uk/

A simply incredible guy, a great example of a caregiver to his wife **Linda** who suffers for decades from the most severe ME, and yet so glad to be able to play his dulcimer and other instruments…

Llewellyn King, ME/cfs Alert, produced by **Llewellyn King** and **Deborah Waroff**:
Two new videos from ME/cfs Alert:

http://youtu.be/Kz2yhqp74eg
ME/cfs Alert, episode 66: You are not alone. Llewellyn King consoling the isolated ME-patients suffering all over, unseen, unheard

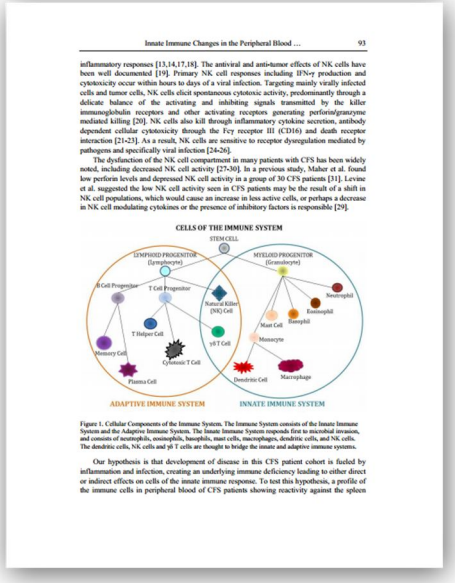
http://youtu.be/IC1_O67xgis
ME/cfs Alert, episode 67: Llewellyn King talking with Sean O'Neill on how to get our voices heard and our needs for research funded

IiME has set up an advisory board to ensure that they build a strategy of high-quality biomedical research for the future. Info:
http://www.investinme.org/IIME%20AB.htm

Moreover they have announced a two-day BRMEC5 Colloquium for 2015 - in addition to our tenth International ME Conference -
http://www.investinme.org/IIME%20IIMEC10.htm

In the research field they have expanded our B-Cell research with plans for supporting another PhD at UCL -
http://www.ukrituximabtrial.org/Rituximab%20news-Sep14%2002.htm

And here's an update on their Gut Microbiota project -
http://www.investinme.org/IIME-Newslet-1409-02.htm by **Daniel Vipond**, the charity's first funded student



Innate Immune Changes in the Peripheral Blood ... 93

inflammatory responses [13,14,17,18]. The antiviral and anti-tumor effects of NK cells have been well documented [19]. Primary NK cell responses including IFNγ production and cytotoxicity occur within hours to days of a viral infection. Targeting mainly virally infected cells and tumor cells, NK cells elicit spontaneous cytotoxic activity, predominantly through a delicate balance of the activating and inhibiting signals transmitted by the killer immunoglobulin receptors and other activating receptors generating perforin/granzyme mediated killing [20]. NK cells also kill through inflammatory cytokine secretion, antibody dependent cellular cytotoxicity through the Fcγ receptor III (CD16) and death receptor interaction [21-23]. As a result, NK cells are sensitive to receptor dysregulation mediated by pathogens and specifically viral infection [24-26].

The dysfunction of the NK cell compartment in many patients with CFS has been widely noted, including decreased NK cell activity [27-30]. In a previous study, Maher et al. found low perforin levels and depressed NK cell activity in a group of 30 CFS patients [31]. Levine et al. suggested the low NK cell activity seen in CFS patients may be the result of a shift in NK cell populations, which would cause an increase in less active cells, or perhaps a decrease in NK cell modulating cytokines or the presence of inhibitory factors is responsible [29].

CELLS OF THE IMMUNE SYSTEM

Figure 1. Cellular Components of the Immune System. The Immune System consists of the Innate Immune System and the Adaptive Immune System. The Innate Immune System responds first to microbial invasion, and consists of neutrophils, eosinophils, basophils, mast cells, macrophages, dendritic cells, and NK cells. The dendritic cells, NK cells and γδ T cells are thought to bridge the innate and adaptive immune systems.

Our hypothesis is that development of disease in this CFS patient cohort is fueled by inflammation and infection, creating an underlying immune deficiency leading to either direct or indirect effects on cells of the innate immune response. To test this hypothesis, a profile of the immune cells in peripheral blood of CFS patients showing reactivity against the spleen

A new book by prof. Nancy Klimas et al.

Nova Science Publishers last week published a book by **Deborah L.S Goetz**, **Judy A. Mikovits**, **Jamie Deckoff-Jones**, **Francis W.Ruscetti**, and others, called Chronic Fatigue Syndrome (ISBN:978-1-63321-961-8 - © 2014 Nova SciencePublishers , Inc.)

A chapter on Innate Immune Changes in the Peripheral Blood of Chronic Fatigue Syndrome Patients can be read and downloaded free of costs with http://bit.ly/1rfStqB

Thanks to **Jan van Roijen** and **Patricia Carter**

Second edition of **Erica Verrillo**'s ***versatile*** book
Chronic Fatique Syndrome: A treatment Guide
http://bit.ly/1sZrCqd

Appeal from **Rich Podell**, see article on page 8, Global 5
http://let-me.be/download.php?view.7

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

Kindly mail to: podell2@gmail.com

15. Poem – I Did Not Die

I did not die

Do not stand at my grave and weep:
I am not there.
I do not sleep.

I am the diamond glints on snow.
I am the sunlight on ripened grain.
I am the gentle autumn rain
When you awake in the morning's hush
I am the swift uplifting rush
of quiet birds in circled flight.
I am the soft stars that shine at night.

Do not stand at my grave and cry;
I am not there
I did not die

Mary Elizabeth Frye

16. Connecting You To M.E.

Leonard A. Jason, Ph.D. DePaul University - Chicago, USA

"The future of the field is in connecting the many patient and scientific groups into one larger body that is united for change. Any events that bring people together across countries and organizations should be promoted.

The message is simple, we have more impact with numbers, and when we flex our collective muscles, then we become a movement like the civil rights, women's and disability revolutions of the 60s, 70s and 80s.

The HIV/AIDS groups changed policy throughout the world, but they did it by keeping their focus on critical issues and demanding change, and although the voices in that movement were also divided, for a few things like increased funding and provision of services, they were all together."