The ME Global Chronicle

www.let-me.be

 # 10 – April 2015

1. Contributions - Personalia

Scientific reviews: ***Richard Podell***
Advisory board: ***Leonard A. Jason***
Cartoons: ***Djanko***

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

Contributions to this issue from:
Erica Verrillo, Dr. Richard Podell, Dr. Byron Hyde, Utting Wolff, Greg Crowhurst, Linda Crowhurst, Dr. Neil Abbot, Tjeerd de Lange, Prof. Leonard Jason, Dr. Lucinda Bateman, Dr. Derek Enlander, Dr. Nigel Speight, Emerge Australia, Teresa Grøtan, Joan McParland, Sally K. Burch, Hayley Williams, Nina & PaD from the Czech Club of ME/CFS Patients, Tom Kindlon, Rich Carson, Cort Johnson, Charmian Proskaur, Deleder2k (Phoenix Rising), Crazy Purple Mama, Herman Jan Couwenberg, Groep ME Den Haag, Michael Shepherd, Edward Drake & Jeannette Burmeister, Marloes Peters, Gunther Crick, Lisa Forstenius, Jo Best, Regina Clos, David Egan, Eddy Keuninckx, Rob Wijbenga

Distribution: ***Rob Wijbenga***
Layout: ***Eddy Keuninckx***
Translational services: *http://www.krijnetekstenvertaling.nl*
Archive: *http://let-me.be* *(here you can download all magazines for free)*

The editorial team doesn't accept any responsibility for any possible incorrect information that it has been supplied with and which has been published in this monthly issue. Anyone can subscribe to this free magazine by sending their email address to: subscribe@let-me.be
You can un-subscribe by sending a mail to: unsubscribe@let-me.be

Textual contributions for the June issue need to be supplied in Word by 10th June and sent to: contribute@let-me.be
The next issue will come out on June 22nd,2015.

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

Picture front page: ***Greg & Linda Crowhurst, Eddy Keuninckx***
Cartoon Djanko: ***page 100***

2. Table Of Contents

We as editors tried to make the magazine much more accessible by adding a link to each article as included in the Table of Contents, which gives you direct access to the article itself. Any suggestion is most welcome.

3. Editorial

Dear readers,

We are pleased to present you the tenth issue of the ME Global Chronicle. Again we did the utmost to gather the broadest possible variety of news and things worth knowing in the field of ME from all over the world, and have been lucky enough that several of you sent us written contributions.

Actually, that's the direction in which we should develop: thus we'll continue to approach our goal, which is to create a means of communication in which we can focus our strengths worldwide by letting disappear all frontiers and borders. To hopefully come to one force standing , demanding the rights a huge group of severely ill human beings have from the human and social points of view.

Instead of being covered and served off, as is the case with the German girl **Joanna** and with the Danish **Karina Hansen**, of whom no sign of life is being perceived anymore.

So send us material of which you think that ME-patients from all over should be informed. That is of vital importance. We from The editorial staff have no expediency in this. It will only cost us more work. But out us to work and if you feel like joining the editorial staff of course it would even be a still much happier event.

We pay a lot of attention to the IOM-report and the name S.E.I.D.. Because the impact may be great and because reactions have been sent to us of three persons well-known within the community: **Dr. Derek Enlander**, **Prof. Leonard Jason** and **Greg Crowhurst**. **Dr. Bateman** has been so good as to react upon their opinions.

Be it as it be and it may also be coincidental, but since the publication of the report there's been a remarkable silence re. publications from the biopsychological corner. Maybe it is dawning all over that ME is a physical disease which has the capacity to end in death by ignoring it or even treating it with reverse strategies.

Or maybe there are cracks in this field who have got to do personally with the disease. Who can tell? We can only hope for a continuation of this healing silence.

Last thing we should mention is **ProHealth** for a gift, donated to this magazine as an appreciation of the indeed most intensive work we have done and will continue to do. Part of it has been used to purchase the software to produce it, part of it has been donated to the **Dutch ME/cvs Vereniging** for an ME-congress it is organizing on September 26, 2015 to celebrate its 10th anniversary, and part of it has been donated to the **Save4Children** fund.

Let's all hope together for a beautiful second half of the spring on the Northern Hemisphere and a gorgeous autumn on the Southern part of our one world.

But most of all our deepest thoughts and feelings are lingering on the many companions we will never reach, a number of whom may leave this life and world without our ever knowing it.

Because of the 'psychosomatic' plague called ME. At least still.

Take care and be respectful and loving to all people and especially to yourselves.

The editors

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

4. Preface

Dear reader,

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

The warm, balmy and often breezy month of April provides a welcome relief from the colder months of January and February. April is a time of change, as new growth appears, and the ancient cycles of sowing, growing and reaping begin anew. April leads us gently into Summer and the 'merry month of May' providing longer days and longer evenings giving us hope of better things to come.

The controversy over SEID continues on the Internet and off the Internet. Though there is general agreement worldwide that the Canadian criteria (2003) and International Consensus criteria (2011) are far superior for diagnosing ME/CFS and ME respectively.

These two criteria have more biological tests than SEID, and they provide doctors with deeper insights into the biological abnormalities and dysfunctions present in each patient and this in turn enables the doctor(s) to apply appropriate and effective treatments and dietary recommendations. Ultimately, we cannot rely on the NIH and CDC which have consistently failed patients for over 25 years.

We are forced by circumstances to continue relying on the Canadian criteria (2003) and International Consensus criteria (2011) and the few doctors and medical clinics who are genuine and honest about the illness; some of their medical clinics are listed on http://www.me-ireland.com/diag-treat.htm

As regards research, the NIH and CDC continue to view CFS and now SEID as a non illness, a minor psychosomatic non entity, an imagined disorder, not worthy of funding, and this has been proven by their words and behavour for the last 18 years.

The British MRC had a similar view for this time period, and did not adequately fund biological research. In Ireland there was zero research and complete ignorance, despite the so called "work" of some Irish ME and CFS organisations. These government bodies have starved ME and CFS of research for nearly two decades and this neglect has led to poor diagnostics and poor prognosis for many, many patients, and to premature deaths in some cases ; read http://www.me-ireland.com/research2.htm.

And to worsen this, these government bodies refused to recognise the findings of privately funded research and integrate these findings into diagnostics (eg. SEID). Official government arrogance combined with stupidity and thousands of patents dying prematurely every year.

We patients and carers will need to use new tactics, legal means – lawyers, barristers, private investigators, investigative journalists and police – to vindicate out human rights and Constitutional rights. It's time to get tough, very tough and start serving legal papers and court orders on those who are responsible for neglecting patients and causing deaths. It's a well known fact that governments and civil servants and doctors take threats of legal action and court action very seriously.

The great work of **Jeanette Burmeister** has achieved more for ME and CFS patients than most of the ME/CFS organisations have achieved over the last decade. Her courageous and principled stand is an example to us all. We have enough biological evidence, medical evidence, and doctor's testimonies to prove ME is a serious biological illness and win court cases against certain charlatan psychiatrists and their politician and civil servant puppets.

Mady Hornig's new study has found significant cytokine differences between patients who have the illness for 3 years or less and those who have it for 3 years or more. This is one of the most important findings in recent years. The p values in this research are less than 0.05 in many cases, with several less than 0.01, proving that several cytokines are playing an important role in the illness.
Hornig et al. Distinct plasma immune signatures in ME/CFS are present early in the course of illness. 27 February 2015, Sci. Adv. 1, e1400121 (2015) DOI: 10.1126/sciadv.1400121
http://www.me-ireland.com/diag/hornig.pdf

Click here to view scientific research papers and findings:
http://www.me-ireland.com/scientific/1.immune.htm#phase

This confirms previous abnormal cytokine profiles in the past. We look forward to one or two more replicated studies to verify this. And hope that the medical authorities and government authorities will have the good sense to integrate them into diagnostics, though the high levels of prejudice and superstition of certain psychiatrists may act to block or impede this.

Its time to rise up and break the chains. Let us all in all countries use new more legalistic tactics to challenge and take down the corrupt psychiatrists, doctors and civil servants who have destroyed the lives of many patients for over 25 years.

> Patients of the world unite, you have nothing to lose but the misery, insults and neglect forced on you by some corrupt and negligent authorities.

David Egan

5. Column - Shortsightedness

If you meet me in the streets, carrying a garbage bag towards the container at the end of the street, it doesn't mean I'm not ill. And if you meet me at the supermarket, with groceries in my shopping basket, that too doesn't mean I'm not ill.

The garbage bag doesn't carry itself away and the groceries don't come to me from themselves.

If you see me walking in the streets, hand in hand with my friend, a laugh on my face, that doesn't mean I'm not ill. I'm so glad that finally I managed to get out and have a reason to laugh. His hand isn't there solely because of affection: without his hand I would fall down.

Don't think I'm not ill because I don't look ill. If you really want to know what's going on, ask me with sincerity. Don't accuse me of a 'sickness notice at my job and meanwhile enjoying going outside'.

Allow me that short moment outside, don't talk me into a sense of guilt. You have no idea how I feel, and I don't expect you to have it . But a little more comprehension and a little less shortsightedness would be fine. Be glad when you see me in the streets, because that implies I'm having a reasonably good day and am feeling well enough to catch some fresh air.

And if at times you might not see me for several weeks on end, most probably I'm going through a bad period. Consider I'm fighting right then. Fighting for a better period in which I can walk outside again, hand in hand with my friend, or do some shopping and maybe talk a few moments with someone.

If you happen to see me next time, greet me. If you want to know how I'm doing, ask sincerely and listen to what I have to say. If you don't feel like, just say nothing and walk on, that's okay as well.

But please, don't be that shortsighted.

Marloes

A Dutch ME-patient and marvelous writer. When this blog was posted on the wall of the Dutch ME/cvs Vereniging (https://www.facebook.com/ME.cvs.Vereniging) is was liked over 400 times and shared almost 200 times within a couple of days.

6. Grassroot

CDC archives the CFS toolkit

"The HHS agencies are committed to working with partners, stakeholders, experts in the field, and CFSAC to review the IOM-report's recommendations and appropriate next steps." (from the HHS website)

On February 10, 2015, the **Institute of Medicine** (**IOM**) Committee on Diagnostic Criteria for Myalgic Encephalomyelitis / Chronic Fatigue Syndrome released a report titled "Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness. The IOM Committee's work was supported by the Department of Health and Human Services (HHS) Office on Women's Health and other HHS agencies.

The website of the HHS Chronic Fatigue Syndrome Advisory Committee includes the following comment about the IOM committee report: "With their recommendation of a streamlined, yet evidence-based set of diagnostic criteria, the IOM committee has taken a critical step toward assisting medical providers in making a diagnosis for those with this serious and debilitating illness."

The website also states that the HHS agencies are committed to working with partners, stakeholders, experts in the field, and CFSAC to review the report's recommendations and appropriate next steps.

In 2011, CDC posted the CFS Toolkit on its website to provide an easy-to-use resource for clinical care. During recent months CDC scientists had been working with CFSAC and others to revise the CFS Toolkit. After publication of the IOM committee report, CDC decided to archive the CFS Toolkit and the brochure "Recognition and Management of CFS: A Resource Guide for Health Care Professionals".

Those interested in reviewing the CFS Toolkit kit in its entirety can view the document here http://www.cdc.gov/cfs/pdf/cfs-toolkit.pdf [PDF - 17 pages].

The archived brochure is available here
http://www.cdc.gov/cfs/pdf/cfs-resource-guide.pdf [PDF - 3 pages].

Forgotten Plague

What an honor to receive ProHealth's 2014 "Advocate of the Year" Award!

The last 20 months have been the voyage of a lifetime, but most interestingly, I've always felt that I was never the one truly captaining the ship.

I would have never tried to make this film if it weren't for the encouragement of the community after I first began writing. The film's Kickstarter would never have taken off had it not been for the patient community taking ownership of the project, carrying us to 150% of our goal.

Nicole and I expanded the scope of our original vision after we saw even more how much people felt a film was needed.

And most importantly, we would have never finished the film without the constant urging of people from Sweden to New Zealand, many of whom have all been commenting and corresponding with us on a daily basis.

That daily affirmation carried us through many dark days, through multiple visits to the emergency room, through the constant ache of seeing a bank account always inching towards zero, through the seemingly never-ending grind of 14-hour days.

I always knew, our team always knew, that we had the backing and the love of a much larger community behind us. I often felt I wasn't really the one making the decisions, that ultimately I was just an instrument of that larger spirit at work. I had always dreamed of doing some type of work like this, but never quite knew how to start.

Thankfully, all of you did. Thank you for helping to inject a greater purpose into my life.

Thank you for inviting me to try to be a mouthpiece for the voices of many.

Thank you ProHealth, and thank you to all of you coming along on this journey!

Ryan

http://mecfsdocumentary.com/fundraising/
http://www.prohealth.com/me-cfs/library/showarticle.cfm

The I.O.M. report and the name of the disease - Reactions

At the invitation of **Dr. Lucinda Bateman** as included in the last issue of the ME Global Chronicle, you all were invited to react upon the contents of the IOM/report and the new name. The editors received three reactions of notorious persons in the field.

Dr. Enlander wrote:

"I have read the IOM report and the defence by **Lucinda Bateman**.

I applaud the notion of reviewing the disease that we have in the past called Myalgic Encephalomelitis (ME), Post Viral Fatigue, Chronic Fatigue Syndrome (CFS) , Chronic Fatigue Immune Deficiency Syndrome (CFIDS) and a panoply of other terms.

The report may induce the medical community, and the public at large, to consider this diagnosis as a physical condition rather than a trivial manifestation of the patient's imagination.

The criteria for a diagnosis has been reviewed for at least two decades including Holmes, Fukuda and the Canadian Consensus and now the IOM criteria.

The naivete of the IOM criteria are the lack of exclusions which are contained in previous criteria. It is peculiar that **Lucinda Bateman** did not see this problem in her specialist opinion.

The IOM criteria as they now stand can include psychiatric induced fatigue or simple fatigue conditions, there are virtually no exclusions."

Derek Enlander M.D., M.R.C.S., L.R.C.P.

ME CFS CENTER
Mount Sinai School Of Medecine
NEW YORK

Dr. Bateman's answer to **Dr. Enlander**:
"There appears be some basic misunderstanding here. The SEID diagnostic criteria assume that the clinician performs a investigation of the presenting symptoms or complaints as the illness unfolds. For example, if a patient complains of fatigue, there would be an effort to check lab tests and consider common causes of fatigue.

If a patient has pain, sore throat, fevers or abdominal pain, a workup of the symptoms will be done. If a patient complains of exercise intolerance, a certain workup is indicated. Same for headaches, joint pain, gastrointestinal symptoms, chest pain, etc.

This should lead to "exclusion" of common causes of the presenting symptoms, such as hypothyroidism, anemia, Vitamin B12 deficiency, depression, sleep apnea, cardiopulmonary disease. Clinicians are trained to do such a workup. The list of other possible causes of the symptoms is rather arge, and includes the examination of medications, mental health conditions, deconditioning, etc.

This workup occurs naturally by attentive physicians in the weeks after symptoms present. Once that has been done, and symptoms persist, there are really very few illnesses that present with a combination of functional decline, PEM, sleep disturbances, cognitive impairment and/or orthostatic intolerance. The IOM felt it was unnecessary to attempt a list of all the possible causes of symptoms that a physician can, by training, evaluate and treat."

L. Bateman MD

Prof. Leonard Jason requested us to submit his article "How disease names can stigmatize' to **Dr. Bateman**, to react upon:

"On 10 February 2015, the long awaited report from the **Institute of Medicine** (**IOM**) was released regarding a new name — Systemic Exertion Intolerance Disease — and case definition for chronic fatigue syndrome (CFS). Because I was quoted regarding this report in a New York Times article, in part due to having worked on these issues for many years, hundreds of patients contacted me over the next few days.

The reaction from patients was mixed at best, and some of the critical comments include:

- "This new name is an abomination!"
- "Absolutely outrageous and intolerable!"
- "I find it highly offensive and misleading."
- "It is pathetic, degrading and demeaning."
- "It is the equivalent of calling Parkinson's Disease: Systemic Shaking Intolerance Disease."
- "(It) is a clear invitation to the prejudiced and ignorant to assume 'wimps' and 'lazy bums.'"
- "The word 'exertion,' to most people, means something substantial, like lifting something very heavy or running a marathon – not something trivial, like lifting a fork to your mouth or making your way across the hall to the bathroom.

Since avoiding substantial exertion is not very difficult, the likelihood that people who are not already knowledgeable will underestimate the challenges of having this disease based on this name seems to me extremely high."

Several individuals were even more critical in their reactions — suggesting that the Institute of Medicine-initiated name change effort represented another imperialistic US adventure, which began in 1988 when the Centers for Disease Control changed the illness name from Myalgic Encephalomyelitis (ME) to chronic fatigue syndrome.

These individuals mentioned to me that patients and advocacy groups from around the world would perceive this latest effort to rename their illness as alienating, expansionistic, and exploitive. The IOM alleged that the term ME is not medically accurate, but the names of many other diseases have not required scientific accuracy (e.g., malaria means bad air).

Regardless of how one feels about the term ME, many patients firmly support it. Our research group has found that a more medically-sounding term like ME is more likely to influence medical interns to attribute a physiological cause to the illness. In response to a past blog post that I wrote on the name change topic, **Justin Reilly** provided an insightful historical comment: for 25 years patients have experienced "malfeasance and nonfeasance" (also well described in **Hillary Johnson**'s Osler's Web). This is key to understanding the patients' outrage and anger to the IOM.

So how could this have happened? The Institute of Medicine is one of our nation's most prestigious organizations, and the IOM panel members included some of the premier researchers and clinicians in the ME and CFS arenas, many of whom are my friends and colleagues.

Their review of the literature was overall comprehensive; their conclusions were well justified regarding the seriousness of the illness, identification of fundamental symptoms, and recommendations for the need for more funding. But these important contributions might be tarnished by patient reactions to the name change.

The IOM solicited opinions from many patients as well as scientists, and I was invited to address the IOM in the spring regarding case definition issues. However, their process in making critical decisions was secretive, and whereas for most IOM initiatives this is understandable in order to be fair and unbiased in deliberations, in this area — due to patients being historically excluded and disempowered — there was a need for a more transparent, interactive, and open process.

So what might be done at this time? Needed and transformative change could be accomplished by creatively supporting structural capacities that involve patients. This could feature ongoing data collection and interactive feedback, ones that are vetted by broad based gatekeepers representing scientists, patients and government groups.

This could be achieved by either the Chronic Fatigue Syndrome Advisory Committee (that makes recommendations to the Secretary of US Department of Health and Human Services) or the International Association of ME/CFS (the scientific organization) may appoint a name change working group with international membership to engage in a process of polling patients and scientists, sharing the names and results with large constituencies, and getting buy in — with a process that is collaborative, open, interactive, and inclusive.

Different names might very well apply to different groups of patients, and there is empirical evidence for this type of differentiation. Key gatekeepers including the patients, scientists, clinicians, and government officials could work collaboratively and in a transparent way to build a consensus for change, and most critically, so that all parties are involved in the decision-making process."
Source:
http://blog.oup.com/2015/02/disease-name-chronic-fatigue-syndrome-me/

To which **Dr. Bateman** replied:
"The IOM accepted the controversial contract issued by DHHS funded by NIH, CDC, FDA, and AHRQ) and worked on the project for one year. One "Charge to the Committee," now printed in the IOM report introduction, was to "develop evidence-based diagnostic criteria for use by clinicians" which involved reviewing the higher quality, peer reviewed, published scientific papers in order to determine which of the illness criteria are best supported by the evidence.

An additional charge was to "recommend whether new terminology for ME/CFS should be adopted." The committee focused intensely on the complex project, and avoided the temptation to go beyond or outside the statement of task. The contract is now complete and the report has been delivered to the sponsor.

Now that I am intimately familiar with the IOM process, I respect the process, and do not expect the IOM to change what they do just because the scientific, clinical and political conundrums around ME/CFS are particularly challenging. The IOM almost always tackles challenging tasks.

The IOM is respected in part because of its adherence to a process with high standards. The IOM process is not a transparent, publically interactive or open process. It is a confidential, internally interactive, collaborative and "consensus building methodology" that was an intellectual and interpersonal challenge for those entrusted with the task.

It was not within the statement of task, or "Committee Charge," of this particular project to establish illness etiology/cause, assess risks of blood donation, determine best treatments, design or implement studies to validate or compare case definitions, or alter the content of the report based on how it might be received.

The clinical diagnostic criteria in the report are core symptoms drawn directly from the published ME/CFS literature---much of which came from **Dr. L. Jason**'s works and the CDC multi-site study -- informed by self-reported symptoms from patients of ME/CFS specialists (**Klimas**, **Peterson**, **Natelson**, **Levine**, **Lapp**, **Podell**, **Kogelnik**, **Komaroff**, and **Bateman**) and the **SolveCFS Biobank**.

These symptoms are important ongoing aspects of ME/CFS illness [substantially reduced functional capacity and fatigue, PEM, non-restorative sleep, neurocognitive impairment and/or orthostatic intolerance/autonomic dysfunction] that physicians have previously often missed, but that they should immediately identify and assess in order to make a diagnosis and provide care.

The symptoms must be of moderate to severe intensity and consistently present over time, an important parameter supported by **Dr. Jason'**s research. The report also lists other common symptoms and manifestations of this illness that are not considered "core" or specific to the illness, not as universally present in all cases of ME/CFS, are common in other chronic conditions, or are not supported strongly by the evidence.

Nevertheless these "other symptoms" are commonly present---pain, infection onset, immune impairment and neuroendocrine manifestations – and when present in patients who meet the major criteria support the diagnosis. The report also says clearly that the evidence isn't strong enough yet to delineate clear subgroups, at least in a report of this type and scope.

Regarding adopting new terminology, the committee decided the answer was yes. Then while still immersed in the science, the rich input from patients, and the combined experience of the group, the committee devised a name intended to send a clear message to clinicians about the profound impact of the illness.

Multisystem. Activity limiting. Punishing.

Then an aggressive plan of dissemination was recommended to DHHS, to jumpstart the process of bringing sick ME/CFS/SEID patients back into the medical and scientific mainstream.

The DHHS and the other co-sponsors have received the report and recommendations of the IOM. In distinct contrast to the IOM process, it is the responsibility of government to engage in a transparent, publically interactive and open process.

The Chronic Fatigue Syndrome Advisory Committee (that makes recommendations to the Secretary of US Department of Health and Human Services), the International Associaion of ME/CFS (the scientific organization), and interested advocates may certainly give DHHS input about what name should be endorsed, hopefully taking the IOM recommendations into consideration.

As for myself….I hope that US doctors start using the criteria right away and begin to identify this illness in their patients so they can provide compassionate and

informed care. I hope that scientific progress (large, controlled, well designed and funded studies) and breakthrough treatment ideas immediately follow at a breathtaking pace.

I hope we leave name change deliberations in the dust and focus on the people who are ill. I hope we identify subgroups, create more diagnostic tests, unravel elusive disease processes, and revise the criteria based on great scientific advances within the next 3-5 years. I hope this conversation will soon seem old and outdated."

See also http://www.offerutah.org/batemanleonard.html

Last but not least **Greg Crowhurst** from the UK submitted the following:
"I read with great interest **Dr Lucinda Bateman**'s and **Prof Jason**'s comments on SEID . Unfortunately ME and CFS are not the same, so the IOM's starting premise is wrong.

In M.E. you can never go along with a compromise or a wide fatigue definition.

The IOM tries to create a disease definition, SEID, out of an impossibly disparate group of poorly defined fatigue conditions, unfortunately including ME within them.

To its credit the Report acknowledges the ME-International Consensus Criteria , inexplicably, however, it ignores the volumes of research outlining the Neurological, Autonomic, Neuroendocrine and Immune system malfunctions that constitute M.E., a disease at least as disabling or more disabling than other chronic diseases such as lupus, multiple sclerosis or rheumatoid arthritis, more extreme than end-stage renal disease and heart disease with a sickness impact equivalent to that of terminally ill cancer and stroke patients.

CFS is a umbrella term, which can never be made into a single disease - and should never be equated with ME as defined by the WHO. ME is a disease , but the symptoms, especially the most severe are missing from this Report. It is the most severely affected, we suggest, who will appreciate most how flawed and misrepresentative this document is. All the time the most ill are neglected, ME is far too easily interpreted as a fatigue condition, with the focus on treating fatigue, rather than upon the extraordinarily serious symptoms people experience.

At once frustratingly progressive, radical yet unfortunately unaware, the IOM Report does not appear to have comprehended the neurological nature of ME and the separate nature of CFS, neither has it recognised the difference and fullness of symptom in mild, moderate and severe ME.

There is a vast difference between the mild and the most severely affected; Severe ME, is so extreme, so outside normal experience, it is virtually incomprehensible. The most hidden, most neglected have not been represented adequately enough, if at all, in our opinion, in the IOM Report to ensure that this is a document about ME, as opposed to a generalised document on fatigue conditions, which may or may not be a disease.
For too long ME has been misrepresented as CFS. The IOM has to acknowledge that SEID does not include Myalgic Encephalomyelitis; if it's intention was to be genuinely about ME, then it needs to think again."

Dr. Bateman's reaction:

"The IOM began with an extensive literature review of published research related to ME, CFS, ME/CFS and any related terms, by major symptoms listed in and common to the existing criteria, not necessarily based on a premise that ME and CFS are the same. This includes literature searches targeting PEM, sleep, neurocognitive, autonomic, neuroendocrine, immune, infection, pain and fatigue, as possible given the limitations of the literature, dating from 1950 to the present. (*See The Committee's Approach in the Summary of the IOM report*).

While it is problematic to study this illness complex as one large group, it may be the only way, since all studies historically have included patients of some mix based on each's interpretation of inclusion criteria and the case definitions. Often it wasn't completely clear how this was done, study by study. The IOM committee is well aware of the limitations of the literature and the existing case definitions. (*Some of the limitations are discussed in chapter 4 under Limitations of the Research Base*")

The new diagnostic criteria for SEID are derived from the higher quality literature, not a wide fatigue definition, except to the degree that our own literature spans these parameters.

Without a single, clear, specific definition that delineates a homogeneous population, it's probably the best that can be done currently, until we have objective markers that do better.

The diagnostic criteria in the report are an attempt to create basic criteria, derived from the literature, which can be used by clinicians to identify patients and provide better care to them. The hope is that many more of the undiagnosed patients (estimated to be >80%) will get a diagnosis and better care. Undoubtedly there will be some imperfections, which is why the committee emphasizes that the criteria should be reviewed and revised in NO MORE THAN 5 years.

The IOM report acknowledges, in chapter 4, under the section "External Validity" that the research base likely excludes the bedridden or homebound, creating a selection bias in the literature. The exclusion of the more severely affected is not a fault of the IOM but the fault of our research community to date.

The IOM's contracted task was to review the literature and recommend clinical diagnostic criteria based on the literature, not to solve all problems associated with this illness complex around the world. That is a task that remains for all of us.

In my opinion, future success rests on engaging more of the medical and scientific community in this effort. Our hope of progress rests on more eyes and ears, more research dollars, and better biomarkers."

Greg Crowhurst reiterated:

"I am deeply grateful for **Dr Bateman**'s response, which seems to affirm many of the points I raised. Her statement that the IOM's contracted task was to review the literature and recommend clinical diagnostic criteria based on the literature, highlights the Report's fundamental flaw:

The contracted task was wrongly worded; it was almost guaranteed not to bring new insight, clearly identify ME or protect it from psychiatric intervention and dominance.

The group could only review the current ME/ CFS/CF literature, which is deeply flawed, as **Dr Bateman** confirms: "The IOM report acknowledges, in chapter 4, under the section "External Validity" that the research base likely excludes the bedridden or homebound, creating a selection bias in the literature."

This means that the Group did not look at the full symptom experience in ME. In no other disease definition are the most severely affected excluded.

The illness experience of people with Severe/Very Severe ME bears little relationship to that of the mild or moderately affected, or people with fatigue. Severe ME is so extreme as to be outside most people's comprehension. The physical pain of a body that does not have enough energy even to support its own organs functioning properly, the cognitive deficits, the torment and nightmare of the profound hypersensitivities to light, touch, noise, chemicals, movement the damaged communication pathways are almost incomprehensible to the normal person.

Great harm can be done by those who do not understand how the simplest wrong action, noise, question, perfume, contact etc can cause severe harm and deterioration. The need for acute awareness, flexibility, patience and comprehension are of the utmost importance in Severe ME.

ME/CFS", which the IOM, has not attempted to separate out into ME, CFS and Chronic Fatigue, encompasses a vast range of patient. All the time that ME, as defined by Ramsay and the WHO, is confused with Chronic Fatigue, or is ignored or wrongly misrepresented as Chronic Fatigue Syndrome, there will continue to be little hope of proper medical investigation or representation.

The IOM report was an opportunity to make things right, at last, to separate ME from CFS once and for all, to validate the neurological disease Myalgic Encephalomyelitis and protect its integrity.

Instead, ignoring the recommendations of experts worldwide urging them to retain the name Myalgic Encephalomyelitis , the I.O.M. Committee has decided instead to continue to confuse ME with CFS under the highly unsatisfactory term SEID which neither describes M.E. nor excludes unrelated Fatigue conditions – and encompasses no definition of severity.

Early indications, that clinicians will take SEID seriously are profoundly discouraging (Rehmeyer 2015). The fact that SEID, so quickly has been claimed by psychiatry as its own (Lancet 2015), is a sure acknowledgment that it is not right – and should be ringing loud alarm bells at the IOM.

Simply put, if you look in a box where CFS, ME and CF are all muddled together, with no clear distinctions made in the research, you will only find more of the same: lack of clarity, ambiguity, uncertainty and confusion alongside a gross misunderstanding of Myalgic Encephalomyelitis.

If the IOM had wanted to identify ME as a distinct and clear disease, it should have looked outside the box.

It should have considered what is missing, what could be new and true, what patient experience and evidence is available to illuminate the lives , symptoms and illness experience, especially of the most severely affected, in whom the illness is most fully manifest.

My own peer reviewed nursing article, for example referenced by NICE, (Crowhurst 2005) does not seem to have been referenced. The 25% Group and Hummingbird are a huge repository of information on Severe ME, including surveys, articles, personal experience, as is my own website Stonebird.

Sophia Mirza's experience, truly highlights what happens when medicine gets it wrong. (http://www.sophiaandme.org.uk)

The book "Lost Voices from a hidden illness" (http://bit.ly/1DcL2XD) and the internationally acclaimed film "Voices from the Shadows", by **Natalie Boulton** and her son **Josh Briggs** provides important insight into the most neglected. (http://voicesfromtheshadowsfilm.co.uk/)

A new medical path needs developing for Myalgic Encephalomyelitis, alongside proper investigations, tests and treatments. That, though, will not happen without better understanding of the disease or an acknowledgment that those with a current CFS diagnosis may have a whole range of other possibly treatable conditions already.

Without acknowledging, for example, that many people with Lyme Disease are wrongly diagnosed as having ME, the necessary clarity is already lost.

The IOM should have started from the fullness of the illness and come up with something new fresh and hopeful, not more of the same tired old rehashed information, with limited symptom recognition, purporting to represent people with ME yet spectacularly failing to do so, especially the most ill whose circumstances are so dire.

If you do not have the right task, you will not come up with the right answers. Surely this is self evident? To have to wait another five years before SEID can be acknowledged as wrong might be considered abominable, especially by those suffering unimaginably already, in many cases for decades already.

It is hard to see how any one is safe with a SEID definition.

The best thing for people with ME, is for SEID to leave them well alone.

Stop using the name ME - without defining ME; that has been the issue all along."

At which **Dr. Bateman**'s last reaction was:
"The problem is that there are unrealistic expectations of the IOM report.

I understand that the severely ill are not on the radar of anyone or any definition. But the IOM report was simply a starting point -a commissioned review of the literature, with a "statement of task" to recommend diagnostic criteria based on the existing literature. IOM committees are not allowed to go beyond the "statement of task."

I can't answer for all of the unmet needs in the field. I can't answer for the deficits of the evidence base.It wasn't the IOM's "statement of task" to meet all unmet needs in the field. It also wasn't the IOM's task to consider much beyond the statement of task.

People asked to serve on the IOM committee spent hundreds of hours reviewing the existing literature and trying to make some realistic and helpful recommendations for clinic based diagnosis based on the existing literature.

In my opinion, the severely ill fall within the SEID diagnostic criteria and within ME criteria. It will be the job of everyone to call attention to the severely ill, along with all other subsets of illness.

We have a lot of work to do. I do not think we should get distracted by over analysis.

If you are interested, take a look at my most recent lecture on the diagnostic criteria at http://bit.ly/1BhcAOR"

Hip Surgery And ME: Society Has It Wrong

Last Wednesday (8th April), I had a complete hip replacement. It was a short procedure (1-1 ½ hours). No general anesthesia required. I was out of bed the day of surgery and home after two days. On Monday, I started driving again and really could have done so on Saturday already. Yesterday, I returned to work. I was comfortably working away, largely free of pain. I walk without a limp and with no assistance and am pretty much unrestricted in my activities. I never needed narcotic painkillers after the surgery. Ibuprofen does the trick.

Well-wishing family, friends and colleagues sent cards, flowers and gift baskets. These were all nice to receive and I appreciated them. There have also been numerous and repeated inquiries about my progress. Just a lot of thoughtfulness all week.

Contrast this with the way **Jeannette** and her fellow ME patients are viewed and treated by the same cohorts. Their disease, myalgic encephalomyelitis, is many multiple times worse than what I went through and it is ongoing, in **Jeannette**'s case for over nine years now. Many others have been sick much longer, some for decades. ME patients will most likely be sick for life and they are typically getting worse, as ME is often progressive.

Most activities that others don't think twice about are impossible for **Jeannette**. She cannot stand for more than just a few minutes. She cannot walk more than just a few blocks. Sometimes, she cannot walk one block. Her debilitation goes far beyond the effects on her mobility and reaches into every corner of our lives. She is never comfortable, not even for a few minutes. It is always just a matter of degree of the relentless misery.

Jeannette's only contact to the outside world, besides the infusion room, is Facebook. But her presence on social media is frequently judged by some (what her friend **Dave**, also an ME patient, calls) normal-health people. It is estimated that about 25% of ME patients are sicker than **Jeannette**, some to a point that is unimaginable to everybody who has not been around those who are near death.

Jeannette is unable to leave the house on most days, and then generally only to receive thrice-weekly infusions, and spends most of her time lying down. Even sitting is impossible for extended periods. If she ignores her limits, it comes at a big price in the form of feeling considerably worse. Last Wednesday, the day of my surgery, **Jeannette** had no choice but to sit in the hospital waiting room for hours. There was no way to elevate her legs, which would have helped somewhat. Her only alternative was to lie on the floor, which she has done at the airport and other places in the past, but couldn't risk in a hospital due to her being immunocompromised.

At the end of the day, she was at least as impaired as I was having just come out of major surgery. The next day, she was too sick to visit me in the hospital, for which she beat herself up. She wanted nothing more than to be there next to me in the recliner the hospital staff had kindly moved into my room to accommodate her disability. But she couldn't. That day, she didn't eat, she could hardly move or talk. It was her payback for the sin of being there for me on my day of surgery.

It breaks my heart to see what **Jeannette** and other ME patients go through every day of their lives due to being this sick. But something else is almost more unbearable and that is how society treats them.

The thing is, when she is able to go out to the doctor or for an occasional meal with me, Jeannette often looks normal, often fantastic actually, despite being quite sick because she rests up for her outings in order to be able to make them and she probably also operates on a fair amount of adrenaline when she does leave the house for which she pays dearly. There are times when her appearance matches her debilitation and she looks like death warmed over, but at those times, she is usually too sick to leave the house. Nobody sees it.

When others see her on those better days, they simply cannot seem to take in the degree of suffering she endures on an ongoing basis. It is as if, despite her achievements, she has no credibility with society, which makes split-second assumptions about her health merely due to her particular diagnosis and what people think they know about it, which typically has very little to do with reality. At best, her disability is ignored. At worst, she isn't believed. Hence, she does not receive flowers or gift baskets or cards wishing her well. Much worse, she does not receive the consideration and understanding that even a modest comprehension of her disease should provide.

I think it is as hard on her as the suffering from the disease to have to endure this constant indifference and complete lack of understanding by those around her. The absence of any validation of the degree of her disability and of any consideration for her special needs is, in and of itself, debilitating and robs **Jeannette**'s soul of the nourishment and support she so desperately needs.

The determination with which society refuses to acknowledge the severity of ME would be hard for me to believe if I didn't witness it almost daily. A week after major surgery, I am multiple degrees less sick than Jeannette is almost every day, but—except for her fellow patients from whom she fortunately draws a lot of strength— nobody around her knows it. Worse, it seems that people don't want to know it.

Edward Drake Burmeister

*Editor's note: **Ed Burmeister** is the husband of patient advocate **Jeannette Burmeister**. He is an attorney practicing law at **Baker & McKenzie LLP**.*

Michael Shepherd's North Pole Marathon

A major international awareness and fundraising event took place in April. **Michael Shepherd** ran a full marathon at the North Pole.

He had a pacemaker fitted for a heart condition in 2012. Whilerecovering from the operation he saw a TV documentary about the UVU North Pole Marathon and decided he wanted to take part to prove that "there is life after a pacemaker".

His teenage daughter, an ME sufferer since 2008, walked into the room seconds later and he decided at that moment that he would do this incredible challenge to raise awareness and funds for Invest in ME Research.

Mike's wife then fell ill and was diagnosed with fibromyalgia, so he became carer to them both, while also working full-time and continuing his grueling training schedule to prepare for one of the toughest marathons on earth.

The race finally took place on 10th April in the worst weather the event had ever had, and after a nightmare start for Mike as he had missed his flight and did not get his luggage until the night before the race.

It's a truly incredible story and we'll hear more about it in the future. **Mike** will give the pre-dinner speech at the 10th Invest in ME International Conference in London in May.

Meanwhile, you can see updates on Mike's North Pole Challenge on Facebook : https://www.facebook.com/Northpolechallenge or visit his website http://www.shepherdfitness.co.uk/ or donate to his fundraising page https://www.justgiving.com/Mike-Shepherd/

Submitted by **Jo Best**

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**

We're in a moment of highest attention and media coverage of ME/CFS since XMRV and despite the content of the IOM report, old, destructive and wholly inaccurate media images of our disease continue to circulate widely.

Let's make it easy for journalists to find more accurate images. Let's have a central place to point editors and producers to when they make a mistake either selecting subjects for a news segment or use an unfortunate stock photo in a written piece, so they can do better next time.

Submit to your photos and video to this new photo pool:
https://www.flickr.com/groups/meaction/pool/

#MEAction

We are going to be launching **#MEAction** this month (likely in the next two weeks) and we need your help! We are looking for actions to host in advance of our launch to the public.

Our core features right now are:

- petitions and petitions campaigns (larger overarching endeavors comprising many sub-petitions that can be, say, organized by congressional district)
- event campaigns (tools for organizing a day of protests, a month of film screenings)
- a membership directory to allow activists to connect and find others with skills or resources
- a stack exchange-style tool for proposing new actions
- user-submitted news and opinion pieces (both original pieces and links to content hosted elsewhere)

In time we hope to add:

- Training modules and articles on best practices.
- Google Hangouts with activists from other communities
- One Click Politics (for contacting members of congress – US, ––Canada and Australia with UK + New Zealand coming soon) – this is something that is pricey but we can add it immediately if there is an emerging action that could use this tool.
- Fundraising tools

If you are planning an action, we'd love to promote it. And if you are planning a petition, event, or have a plan to lobby Congress, please do be in touch. (We are also looking for actions hosted elsewhere that we can help promote/spread the word!)

Jen Brea

info@meaction.net

Canary in a Coalmine

Dear Canary Community,

I just want to say that I love y'all. I get so much healing from you: everything I post, everything you share. I heal through the anger, the sadness, the catharsis, the support, and the fact that in spite of it all, there is still so much humor. Thank you so much.

I have many versions of what I call "the origin story" – what I tell people when they ask me why I decided to make a film. All versions are more or less equally true.

The version that feels most true today is that when I decided to make this film, I had never met another patient and had barely interacted with anyone online. I was living with what felt like a rare disease. I started making the film because I did not want to be alone.

When you follow your own calling (which often starts with a deep, emotional need), you can't always imagine where that journey will take you. I never imagined I'd find the community I've found here (and in many other watering holes around the internet). But I am so grateful I (we) have!

Thank God for the Worldwide Web

Jen

What's in a name?

Quite a lot.

Erica Verrillo compared four polls on the name of the disease. Outcome on SEID without any shadow of doubt.

Polls were held by the
- ME Association(724 p.) ,
- Health Rising (550 p.),
- ProHealth (3059 p.) and
- Paradigma Change & ME Advocacy (1147 p.).

Although the questions were different in each poll (different options), some conclusions could be drawn.

As **Erica Verrillo** writes: "*In sum, it is clear from these surveys that the people whom the new name will most affect - patients, as well as researchers and ME/CFS specialists - have been entirely left out of the process of devising a name for this illness.*

It is also clear that the preferred name - on both sides of the Atlantic - is Myalgic Encephalomyelitis. Regardless of the IOM's opinion that brain inflammation is not yet proven be part of the illness, or their belief that pain is "nonspecific," there are historical reasons for choosing ***ME****.*

It is more than likely that the decision to abandon ME was not primarily based on medical reasons - as there are numerous illnesses whose names have been assigned by history - but on politics.

ME is associated with outbreaks. One of the forces that drives decisions made by HHS, as well as most state health agencies, is downplaying epidemics. AIDS and Lyme are cases in point. Both of these epidemics - one with a human vector, and one transmitted by ticks - were ignored until they became too big to sweep under the rug. Sadly, the agencies that are supposed to be responsible for protecting public health have consistently used the same tactic with ME.

Ultimately, SEID needs to be rejected not only because it is an inadequate name that does a disservice to people who must bear it, but because through inventing yet another name it denies one of the fundamental aspects of the disease, which is its history of outbreaks."

See more at: http://bit.ly/1HqxiOV

12 May – ME Awareness Day

Also see http://bit.ly/1OBssyw
This document will be used to record events planned for 2015. If you have an event to add, please either email info@may12th.org or post the details of your event on https://www.facebook.com/events/1687966454755997/.

For more information about May 12th International Awareness Day please see http://www.may12th.org or www.facebook.com/may12th.awareness. There is also a list being maintained here: https://www.facebook.com/groups/The.M.E.Chat.Room/permalink/848189741885450/?hc_location=ufi.

All over
3 Thunderclaps are set up to go off on May 12th:

- https://www.thunderclap.it/my/edit/23688-may-12th-int-l-awareness-day
- https://www.thunderclap.it/projects/24471-12-mai-internat-me-cfs-tag
- https://www.thunderclap.it/projects/24360-

---

https://youtu.be/O4Bzevj6WGA
International May 12th Light Up the Night Challenge on May 12th International Awareness Day for Myalgic Encephalomyelitis (ME), Chronic Fatigue Syndrome (CFS),
Fibromyalgia (FM) and Multiple Chemical Sensitivity (MCS)

Australia

Do Something for ME

ME/CFS International Awareness Day is on 12th May every year. It's a day to focus on getting the message out there loud and clear and in a coordinated way. But as far as we're concerned every day is Awareness Day.

The Do Something for ME project is designed to raise awareness in the general community about ME/CFS and to raise funds to support Emerge Australia to continue its work advocating for, educating about and providing information on the condition. http://bit.ly/1G2Q8HG
The project has lots of ideas about how you can raise awareness - whether you're out in the community or in your room, awareness raising is for everyone.

Canada
Langevan Bridge in Calgary, Alberta will light up on May 12th.

along with many other places, buildings and spots like the Niagara Falls (will light up blue on May 12th at 10pm It can be watched on either of these 2 webcams http://www.earthcam.com/canada/niagarafalls/ or http://www.niagarafallslive.com/niagara_falls_webcam_info.htm)

and the city halls of Mississauga, Ontario; Brampton, Ontario; Ottawa, Ontario; Halifax, Nova Scotia and Toronto, Ontario.

The Montreal Olympic Stadium in Quebec will be lit with all colours and the Ontario's CN Tower in Toronto will be lit with all 3 colours
(blue for ME, green for Lyme and purple for fibromyalgia)

Northern Ireland

#May12BlogBomb is back!!

May 12th is Awareness Day for ME, Fibromyalgia, Lyme Disease, Chronic Fatigue Syndrome and Multiple Chemical Sensitivity.

Every year bloggers use this opportunity to express their views and to raise the profile of these much misunderstood and often maligned conditions.

Last year I called for bloggers to promote their blogs using the hashtag #May12BlogBomb.

I'm not sure we managed to get the #May12BlogBomb tag trending for the day (wouldn't THAT be an achievement) but it was certainly popular.

Hashtags are useful because they become hyperlinks, and clicking on one in a tweet or Facebook post, lets you see who else has posted something using the same hashtag. This works both on Twitter and Facebook.

Following the #May12BlogBomb tag allows social media peeps to discover new blogs, read new points of view, connect with other bloggers, and generally to explore the subject further.

This year, like last year, I hope to collate a page of links to the blog posts written for the 2015 #May12BlogBomb.

It will become live on the morning of 12th May, get updated throughout the day, and if it takes off the way it did last year, it might take a week to gather all the links together.

Last year's list of links can be found here: May 12 Blog Bomb Link List I have to admit, the response was phenomenal last year. I had set out thinking I might collate a dozen or so links and was totally blown away by the number of blog posts I received!

So let's get this year's Blog Bomb EXPLODING for 2015!

P.S. I've just been asked if there is to be a theme this year. Last year I suggested one and whilst there were many posts on that theme there were also many other topics explored.

I think were I to suggest a theme this year it would be on looking towards the future . So maybe "A Vision for the Future!" might be a suggestion. In my view the aim of these posts is to reach out to the wider community and help them understand our lives, hopes and dreams...

Perhaps the angle of how your future would look if you were free of illness from tomorrow, would be good?

It's up to you! I look forward to reading everyone's thoughts...

List of links from 2014 can be found here:
http://sallyjustme.blogspot.co.uk/2014/05/May12BlogBombLinks.html

---

The Netherlands

May 12th is again World-ME day, a day the twitterteam of the ME/cvs Vereniging doesn't want to let go by unnoticed.

That's why they are making an appeal to all readers of facebook http://www.facebook.com/ME.cvs.Vereniging and site http://www.me-cvsvereniging.nl/ to join their action.
Which song or poem or book or film helps you somewhat in hard times? You may explain in a few words why, but it's not obligated. Sending the link to it suffices.

If you are on twitter, please send them a DM, but you can also respond by email: contact@me-cvsvereniging.nl

On May 12 they will publish all tweets using #12MEi http://on.fb.me/1GdXVVF and your first name. They do hope a lot of people will join them again so that they will create a lot of attention for ME!

Dear all,

RMEs different Facebook pages and groups will be observing 12th May by using the attached header from the 10th May to 13th May.

Those of our members who wish to will also be using the attached "Profile Picture" as a temporary profile picture. The original was made by one of our members, with graphic help from an other of our members.

I am sending you the pictures in case you would like to do the same in your countries and we in that case make it not just a Swedish but a European manifestation. We would very much like to know if you do use it in your countries, as this would mean, as I said, that it will be a European manifestation, so please send me an email in that case

All the best to you all,
Lisa

RME RIKSFÖRENINGEN FÖR ME-PATIENTER Sverige

Box 11037
404 21 GÖTEBORG
Sweden

Epost: lisa.forstenius@rme.nu
Tel: 0733-10 04 24
Webb: http://www.rme.nu

7. Science

Rich' Reviews: The MTHFR Mutation

The MTHFR Mutation: Is It Important? Probably Yes; But We Can't Yet Be Sure.

Folic Acid along with vitamin B12 plays critical roles in human biochemistry. We need both nutrients to transform the amino acid Homocysteine into Methionine and then to S-Adenosyl Methionine (SAMe). SAMe is one of the body's main methyl group donors (A methyl group is a single carbon atom plus 3 hydrogen atoms=CH3). ***You have to add methyl groups (methylation) to create most long chain organic molecules. For example: serotonin, norepinephrine, dopamine, creatine, carnitine and more.*** Active folate is also required in order to repair damaged DNA.

A study of 1000+ newborn babies in Wisconsin showed that 8% were homozygous for a mutation in folic acid metabolism—called the MTHFR mutation. (1) With two abnormal genes, the ability to turn synthetic folic acid into the active vitamin—L methylfolate) is reduced by roughly 60%. About 30% of infants were heterozygous for the MTHFR mutation (one normal and one abnormal gene). This reduces the ability to produce active methyl folate by about 30%.

A Gigantic Problem? Possibly, maybe probably. But we can't be sure because there have been almost no first rate studies on the clinical effects of treating with methylfolate. Here's my take on where things stand now.

For many Americans much or most of our folic acid intake is in the form of synthetic folic acid—added to our grains to help prevent spina bifida. Multivitamin pills and B complex capsules typically provide synthetic folic acid.

Therefore, in theory, people with MTHFR mutations whose folate intake is mainly synthetic—these people should have major difficulty also depend on synthetic folic acid should have major difficulty creating SAMe along with a broad range of key molecules. *(Please note: This need not be a problem since raw green leafy vegetables already contain large amounts of active methyl folate. But, for those who don't regularly eat raw green leafies, biochemical theory predicts that the MTHFR mutation should increase vulnerability to a broad range of health problems.)*

A number of rough-cut epidemiological studies tentatively suggest that MTHFR mutation is more common among persons with major depression, chronic fatigue syndrome, Alzheimer's, autism and Parkinson's. disease. In my practice, so far, the large majority of ME-CFS and fibromyalgia patients have at least one mutation. Also, from the "Web" we have anecdotal testimony of individual's having been helped by methylfolate/Vitamin B12 treatment.

Very sadly, what we lack are first rate controlled studies of the clinical results of treating sick people with methylfolate/vitamin B12 supplements(which are now available by prescription and which can be purchased over the counter e.g. at Amazon).

Please correct me if I'm wrong, but so far as I've seen, the only first rate clinical study in the entire literature focuses on unipolar depression. This is from the psychiatry department of **Harvard Medical School**'s Massachusetts General Hospital.(**2**)

The study subjects included 75 people who had remained depressed despite being treated with fluoxetine or one of the other SSRI anti-depression medicines. Researchers kept up the SSRI and added either 15 mgs (15,000 ugms) daily of methylfolate or a placebo and compared outcomes after just 30 days of this combined treatment. The result: 15mgs daily of methylfolate was more effective than placebo for improving depression.

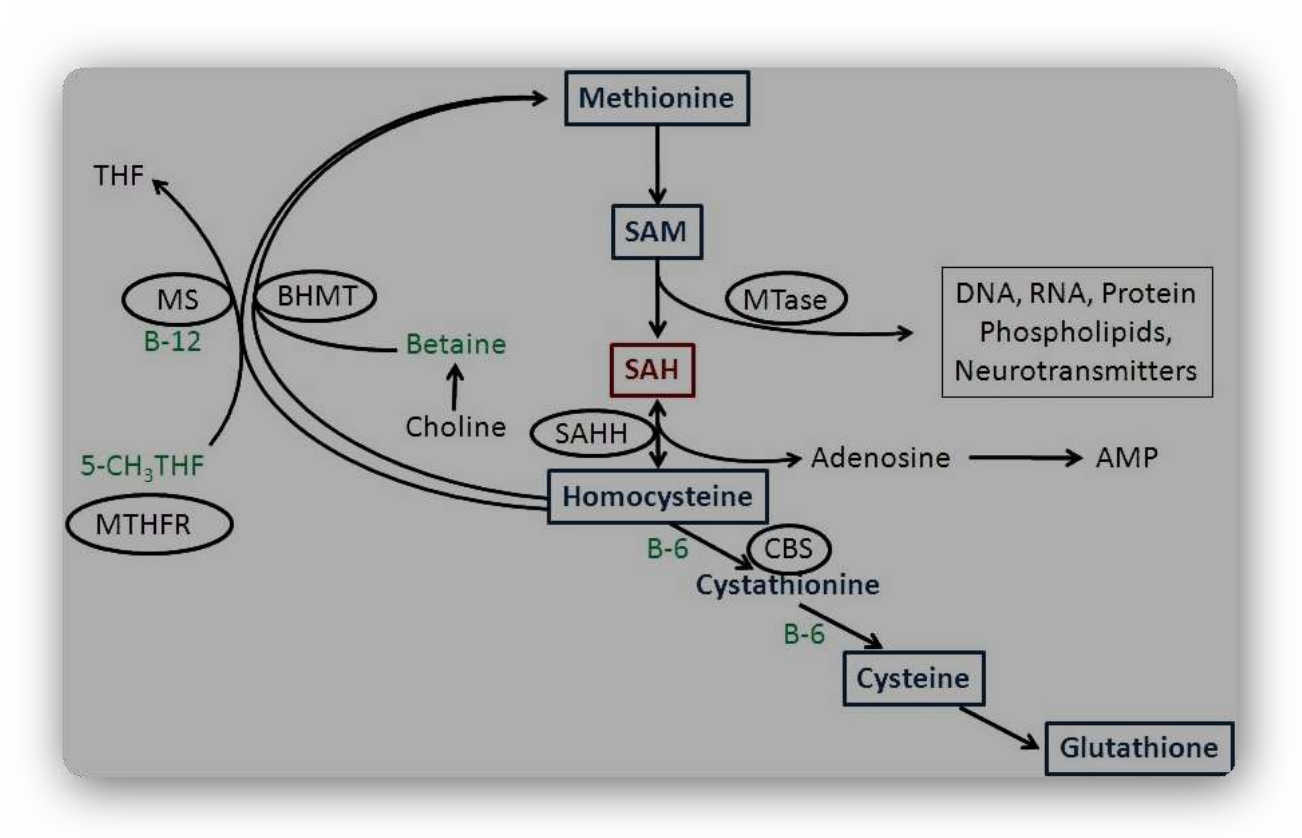
Thirty two percent of those treated with 15 mg L-methylfolate improved within 30 days in contrast to only 14.6% who improved with placebo. This difference was statistically significant, P-0.04. Secondary measures of outcome also favored methylfolate over placebo. Side effect rates did not differ significantly between the two treatments. However, one patient taking methylfolate had to drop out because of manic symptoms. (Patients with known bipolar disorder were excluded from the study).

(In an earlier study 7.5 mgs of methylfolate was not better than placebo after 30 days. When the dose was increased to 15 mgs for a second 30 day period, results for methylfolate subjects improved, but did not quite meet statistical significance. Please note that the "official" Recommended Dietary Allowance/RDA for folic acid is only 400 ugms (micrograms) daily, which is 0.4 mgs. So, both the ineffective 7.5 mg dose and the effective 15 mg doses should be considered to be "megadose" quantities.).

My Comment: Although the N for the Mass General study was not large, the study design was reasonably good, and the positive results are encouraging. The proportion of patients improving within this relatively drug resistant population was roughly comparable to that found for other accepted augmentation treatments including lithium and atypical antipsychotic medicines.

My guess is that the 15 mg dose is probably effective, and that lower doses might work for less resistant populations. Of course, it would have been nice to know whether the responders tended to be those with or without an MTHFR mutation. But, maybe next time.

I believe we should be cautious but not deterred by the fact that one patient developed new symptoms of mania while taking methylfolate. All standard anti-depressants also carry some risk of inducing mania. (Mania has also been reported in association with S-Adenosyl Methionine (SAMe) treatment. (**3**) As illustrated in the chart below increasing methylfolate would be expected to increase SAMe.



Real World Implications: For some patients with MTHFR it should be fairly simple to titrate with methylfolate in steps up toward the 15 mg range, provided that care is taken to also provide vitamins B 12 and B6. But, for many others, additional genetic and/or epigenetic problems will co-exist. These can make treatment considerably more complex.

Ben Lynch, ND, perhaps the leading "guru" on MTHFR and related issues emphasizes the complexity and unpredictability he has encountered while treating MTHFR mutation patients. Unfortunately, the number of clinicians who have studied these issues in detail are relatively few. I have just started to climb this fairly steep and rocky learning curve.

Congratulations to **Dr. Papakostas** and the **Psychiatry Team** at **Massachusetts General** for having the gumption, dedication (and financial resources) to organize their clinical trial. This builds on their earlier pioneering work, which confirmed the anti-depressant benefit from S-Adenosyl Methionine. (**4**)

As controlled studies for treating MTHFR among patients with ME-CFS are not likely to be reported soon, what should clinicians and patients do next? I am offering MTHFR testing for all my patients whose insurance offers coverage. In the Northeast USA region Medicare covers this test (CPT 9 code 270.4) as does New Jersey Blue Cross. Out of pocket charges at major labs are in the $300 range.

Interpretation of test results and treatment should be done in consultation with a qualified clinician. The following webpages discuss MTHFR and related issues.
http://SeekingHealth.com
http://SeekingHealth.org
http://MTHFR.net
http://Dramyyasko.com
http://Heartfixer.com

ADDED COMMENT: **Papakostas** and the **Massachusetts General** group recently published more detailed information from their 2012 study. This contains information about the gene mutations present in their patients as well as a few metabolic parameters. Not surprisingly, depressed subjects whosebaseline blood concentrations of S-Adenosyl Methionine (SAMe) were relatively low, were more likely to improve than were those whose initial SAMe levels were relatively high. Please recall: you need methylfolate to turn homocysteine into Methionine, which in turn can transform into SAMe.

But, the presence of an MTHFR mutation by itself was not highly predictive of response to Methylfolate over placebo. In contrast, MTHFR mutation combined with certain other genetic abnormalities did predict improvement with methylfolate. Most intriguingly, variations of several other genes involved in the methylation pathways also highly predicted a better response to methylfolate.

Richard Podell, **M.D.**, practices in **Summit and Somerset New Jersey**. He is a **clinical professor in the Department of Family Medicine**, **Rutgers-Robert Wood Johnson Medical School**. **Dr. Podell** has no financial interest in any of the products mentioned in this article.

Mailing Address is Richard Podell, M.D.,
suite 140,
11 Overlook Rd, Summit,
NJ 07901

Richard Podell, **M.D., MPH**, Summit, NJ
http://www.DrPodell.org
podell2@gmail.com

1. Qi Z, Hoffman G, Kurtycz D, Yu J. Prevalence of the C677T substitution of the methylenetetrahydrofolate reductase (MTHFR) gene in Wisconsin, Genet Med. 2003 Nov-Dec;5(6):458-9.

2. Papakostas, G et al, L-Methylfolate as Adjunctive Therapy for SSRI-Resistant Major Depression: Results of Two Randomized Double-Blind, Parallel-Sequential Trials Am J Psychiatry 169;12, December 2012

3. Papakostas, G, Cassiello, B, Iovieno, N, Folates and S-Adenosylmethionine, Folates and S-Adenosylmethionine for Major Depressive Disorders, CanJ Psychiatry 2012:57(7):406-413

4. Papakostas GI1(http://1.usa.gov/1HxC916), Mischoulon D (http://1.usa.gov/1OjfO7b), Shyu I (http://1.usa.gov/1DnXSpf), Alpert JE (http://1.usa.gov/1JN2Bmx), Fava M. S-Adenosyl Methionine (SAMe) augmentation of serotonin reuptake inhibitors for antidepressant non-responders with major depressive disorder: a double-blind, randomized clinical trial. Am J Psychiatry (http://1.usa.gov/1zl2qsz). 2010 Aug;167(8):942-8. doi: 10.1176/appi.ajp.2009.09081198.

5. Papakostas, G, Shelton R…Fava, M, Effects of Adjunctive L-Methylfolate 15 mg Among Inadequate Responders to SSRIs in Depressed Patients Who Were Stratified by Biomarker levels and Genotypes: Results from a Randomized Trial. J Clin Psychiatry 75: 855-863, August 2014..
To see abstract from Pubmed.gov:
http://www.ncbi.nlm.nih.gov/pubmed/24813065

Science to Patients

Interview with **Prof. Alan Light**, **University of Utah**, **Dec. 3, 2014**

Part 2

In part 1 (published in the ME Global Chronicle 9 http://let-me.be/request.php?16 p. 30-31) **Prof. Alan Light** told us about himself and how he and his wife **Kathleen** got involved in research of ME and fibromyalgia.

In this second part he talks about his discoveries with ME and about his hopes for the future.

Q: You also saw patients. How many up till now?
A: There were a hundred patients in that particular study and since that we've done another fifty I think and we did a hundred in another study too.

Q: Now my question about what shocked you most was more in the emotional field. What did you find most shocking in seeing those patients?
A: In the patients? Again, these patients are totally debilitated. Often we had to wheelchair them up here. If we put them on the bicycle we'd see dramatic things happening to their muscles as they were trying to exercise on the machine. That was another big shock to me. The other thing was simply the lack of expression in these patients. They seemed so beaten down that they didn't respond too much to anything anymore. That was the other thing that became really obvious. I had no idea about that at all, how bad off a lot of these patients were.

Q: Is that one of your motivating factors?
A; These days it is. Originally, and still it's the case that I love finding out new things. Things that people never knew before. That led me to the fatigue problem. What is fatigue at all, period? So I would be doing that, no matter what. But now that I've actually dealt with these chronic fatigue patients it makes me even more strongly want to work in this area.

Q: Is a solution near? From which direction do you think it will come?
A: It's a very complex disease. And we know there are multiple different varieties of it now. We believe that even at this point we actually do have some ideas about these diseases that do work at least to a certain extent. And that's one of the things we will try to show people in the near future. We think that actually the genomic and genetic side of this which has been worked on by a number of us now will be giving us a number of answers for first of all how many different forms of this disease there are, and secondly some very strong potential treatments to at least control the symptoms. For an actual cure of this it could actually take a good deal of time longer but I think there's also a number of just incredible

powerful new techniques that can actually solve that problem as well over the next ten to twenty years.

Q: Now you're not a clinician but I'll ask you anyway. You can just say you don't know. What practical advice or treatments can you offer to patients whom you are seeing?

A: We continue to use the gene-expression data that we get. We actually show that to **Dr. Bateman** and we use that to help find some form of treatment for them. Some of the treatments that do work particularly for the patients who do have the orthostatic intolerance are treatments with midodrine, a drug that controls your blood pressure, as well as the beta2 adrenergic blocker which also, paradoxically controls blood pressure in the opposite way. So those things are actually working in at least some of the patient population quite well. The other patients we also have seen that there very often will be things dysregulated in the people including the amount of hydration that the patients aren't aware of. And that helps in terms of treating them. We also see differences in the receptors that control the temperature of the people, and we find that treatment warm baths helps in those particular people and not in the others that don't have them.

Q: Could you give them any word of encouragement and hope?

A: One of the really important things that has happened in the last two years is that the NIH and the Health and Human Services are finally awakening to the fact that this is a problem that can be solved if we put enough money into it. We can actually determine what exactly is causing some of the kinds of chronic fatigue and at least come up with some hypotheses for those we don't understand yet. The fact that there's so many good groups now starting to work on this should give all patients a lot of hope that there can be at least some good treatments coming up soon. And we hope cures will be coming up for at least some patients within a very few years.

Q: But that's a new development then?

A: Very new. In the past there were so many grants being funded in many areas and chronic fatigue syndrome was receiving no funding at all. This past year there were at least three major groups that got a substantial amount of money which is something that just hadn't happened. And I tell you right now that the top scientist who ran the genomics institute at Stanford is really starting to work on the Chronic Fatigue project There's a group of scientists that start working on this project big time and bringing lots of money into this and there's at least two independently funded studies from major donors. They are spending now hundreds of millions of dollars. Which has just not been done in the past.

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

Webinars produced by the Dutch ME/cvs Vereniging and filmed in Salt Lake City on December 4, 2014 of **Prof. Alan Light** are being broadcast since March 24, 2015.

On that day a webinar has been broadcast about fatigue, with the following subtopics:

- What is fatigue and how can it be measured?
- How does fatigue in ME/cfs differ from fatigue in other diseases?
- What is the best way to cope with fatigue in ME/cfs?
- Exercising too much and too long

Link: https://youtu.be/OAv3vhCL2pU

On April 7, 2015 webinar 59 has been broadcast about genes and gene-expression with the following subtopics:

- What exactly is meant by gene-expression?
- What is a gene?
- Which genes play a role in ME/cfs and how?
- Is ME/cfs a hereditary condition?
- Are new important genes being discovered still?

Link: https://youtu.be/ghUtM44yfm0

and on April 21, 2015 webinar 60 has been broadcast about gene expression markers of ME/cfs:

- Discoveries in gene-expression markers of ME/cfs
- Relation gene-expression with symptoms of ME/cfs
- What is the genome?
- What is transcription?

Link: https://youtu.be/6G4hJDlk-mk

Webinars of **Prof. Light** on ME/cfs & exclusive conditions, Fatigue & pain, Effects of ME/cfs on the brain, and ME/cfs, the immune system and cell functioning are to follow. After the summer seven webinars of **Dr. Lucinda Bateman** will be broadcast.
You will all be informed on time, via next issue of this magazine and via http://www.facebook.com/ME.cvs.Vereniging

In a Q & A session with **Prof. Light** on 27th March via chatwing he answered a lot of interesting questions. An extract of the most remarkable ones we hope to publish in the next (June) issue of the ME Global Chronicle.

On Sunday April 19, 2015 the counter of the webinar-views reached the magic number of 199.999...

This is due to an unimaginable amount of effort and labour of a small group of Dutch patients, some of whom are severely ill , who at the cost of their own energies continuously are busy translating, correcting, subtitling, broadcasting and disseminating the webinars.

The editorial staff of the ME Global Chronicle wishes to express its gratitude and compliments to the team Science to Patients with this huge achievement.

Dr. Byron Hyde Answers

October 27, 2012 Part 2

"*Why Doctors Can't Diagnose and What Tests Should be Considered*" was the title of the lecture by **Dr. Byron Hyde**, Founder and Director of the **Nightingale Research Foundation**, Ottawa, Canada, co-sponsored by the **Massachusetts CFIDS/ME & FM Association** and the **Massachusetts Department of Public Health** on Saturday, **October 27, 2012**.

After the talk there was an opportunity to ask him questions of all sorts. As many answers are quite practical, they're not outdated.

Q: What is POTS?

A: Postural Orthostatic Tachycardia Syndrome is one of the classic dysautonomias. We see it most commonly after the recombinant hepatitis B immunization. We have 200 patients I mentioned earlier with POTS. What is POTS—your heart rate, which should be running around 60-80 beats per minute, should drop to 45 beats per minute when sleeping. What happens with POTS people when they're sleeping, is that their heart rate may drop down to 55-60 beats per minute and then when they awake, and try to move or do anything, their heart rate rises to over 100 beats per minute, which is tachycardia, or close to it in the 90's. If they get excited or if they try to do anything their heart rate may instantly go up to 150 to 200 beats per minute. If you put them on a treadmill, their heart rate can go up to 300 and you have to stop them. POTS is a major consequence to several other conditions. One is a brain injury, and injury to the system regulating the pressure in the blood vessel. I spoke about it earlier, I just didn't use the word POTS.

Q: How does POTS contribute to CFS?

A: It doesn't contribute. POTS patients have it the worst. The POTS and autonomic nervous dysfunction people are so terribly ill—those are the ones that are not usually here. The better POTS patients might be here, but the serious ones are home in bed right now. They don't even know there is a Massachusetts organization to help them.

Q: I had acute onset of ME 1990 after a bout of pneumonia – had years of recurring infections. Now, in 2012, diagnosed with Sjőgren's (via positive salivary gland biopsy), joint enlargement deformity/pain – worsening of dental issues with tooth loss. Do I have autoimmune disease replacing ME? Both?

A: Of course you do. Forget about the names ME, CFIDS & FM. Ask what is causing this real symptom. You can't run off and have a test. You have to have a total body examination.

Q: What can you tell us about the relationship to gender and CFS/ME?
A: I mentioned earlier about the difference between RA and girls and boys. Boys don't get it and the girls do. What you are looking at with women is that they have a very different immune system. 80% of the all of the ME/CFS type patients are women. 80% of all of the MS patients are women. 80% of the RA patients are women. They have an immune system that is organized so that when they get pregnant they don't reject the baby as an autoimmune reaction. Their immune system shuts off as part of their natural reproductive ability to develop and build a healthy child. They already have an immune system which shuts off and starts on its own, so they are more vulnerable to any autoimmune disease and most of the CFS diseases that we have talked about are highly related to the autoimmune system.

Q: Are women who had children more likely to get ill?
A: I don't know. I've never done the statistics on that. The last time we did statistics was around 15 years ago when we were looking at patients after the epidemic period of 1984 and that is one question we didn't ask, and that would have been a really useful question.

Q: What's the difference between acute ME & CFS and gradual onset?
A: ME is a diffuse brain injury that is measurable. If you can't measure it you don't have ME. CFS depends on whether the onset is acute or gradual—if acute, it can be a combination of genetics, immunizations, medication, viral infections, things you can't always prove, trauma, brain injury. It can be a combination of things.

Q: Can you explain more about gradual onset?
A: Gradual onset patients are one of the most interesting sub-types of CFS because it almost always is something which is building in the patient. Those patients are the ones we find cancers in, those are the ones we find organ injury in, but those are the ones that are often best treatable. But you have to find out why.

Q: What's the difference between acute and chronic?
A: Most people who have acute onset ME get better. If they are not better within a year, they lapse into what we would call chronic. And very few of those people get better. On their own, probably 25 % of that group does get better. But that still leaves a large percentage of patients that don't get better. You have to stop thinking in terms of ME, CFS and FM. You have to ask what is causing my Chronic Fatigue Syndrome. That is absolutely essential. If you can answer that question you have a chance of curing the patient.

Q: Did you have the polio vaccine before getting polio?
A: I fell ill in grade 8 so I must have been around 11-12 years old and that was 1948. The vaccine came out in 1954-55. But even before the vaccine was introduced in 1954, it had been tested on people in the island of Newfoundland and in the island of Granada, and it killed pretty well everyone they gave the immunization to. So the vaccine was withdrawn and retooled. It was reintroduced somewhere else and it didn't kill the people and ever since it has been the safest immunization known to God and man. It was a wonderful invention.

There had been a high risk of having your child die from polio. You hear about all the paralysis, but not about the deaths. Most of these kids died. It was also mainly women who died, not kids, but you didn't hear about those statistics because there was no research money for women in those days. Money was easier to get if children were being studied. I don't know if any of you remember Little Jimmie, the March of Dimes advertisement. Even then, women would give money for the study of children. Only later did the advertisers bring in a girl.

Q: Is medical cannabis an option for replacing other meds?
A: I was on the medical committee in Canada, the LeDain commission, which looked at the safety of drugs. The LeDain commission came out showing that marijuana was not dangerous at all. Medical cannabis depends if you are taking it by a pill form, inhaling it from a cigarette or taking it internally as in the wild stuff. All my friends who grow cannabis are as ill as can be physically. And they smoke it all the time. Does it help you sleep, yes, it does, so does cocaine, so does morphine. Do you get good sleep? Anything you inhale into your lungs is causing you major, major damage. I'm not one for cannabis.

Q: Do you win when you go up against American insurance companies?
A: We almost always win. It is not because we're good; it is because of what we do.

Q: How do you win against insurance companies?
A: Insurance companies are really easy to beat if you know what is wrong with the patient, and these patients are seriously ill. We have done about 2000 patients since 1984 and most of them were in the early years. Now we take much longer per patient and only take about 20 new patients a year. They are easy to win because the patients are so ill. The cases never go to court because the insurance companies settle.

Source: http://bit.ly/1b0xgkg

.

The Power of Macrophages

The immune response, the process by which the adaptive immune system reacts to, and eliminates foreign substances and cells, depends on a complex interplay between several different cell types.

So-called dendritic cells, which recognize and internalize invasive pathogens, play a crucial role in this process. Inside the dendritic cells, the invader's proteins, including those "antigens" that distinguish it from host cells, are degraded into short fragments, and displayed on the cell surface in association with a specific binding protein. The foreign antigens exposed on dendritic cells in turn alerts another class of immune cells called T-cells to actively attack the invader, effectively inducing an immune response to that specific pathogen.

A team led by **Professor Thomas Brocker**, Director of the **Institute of Immunology** at LMU, has now shown that macrophages that function as a first line of defense in the innate immune system can also present antigens to T-cells, thus revealing a previously unknown role for macrophages in the induction of adaptive immune responses. The results of the study are reported in the Proceedings of the National Academy of Sciences (PNAS).

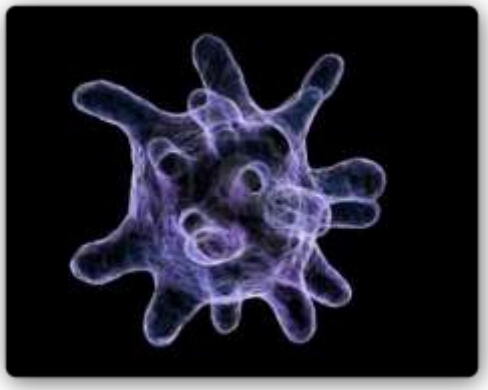
"It has been assumed until now that the dendritic cells are considered to be essentially the only cell type responsible for antigen presentation in the immune system. We have now discovered that macrophages can also do this job. Not only that, in certain situations, they can be more effective than dendritic cells," says **Thomas Brocker**.

Exploiting the filtering role of macrophages

Dendritic cells present antigens to so-called cytotoxic T-lymphocytes (CTLs) if they have been directly infected, but they can also capture and display antigens from other cells. This type of indirect antigen presentation is referred to as cross-presentation. "So, theoretically, dendritic cells could be responsible for the induction of all CTL-based responses, regardless of whether they are themselves infected or not. But the significance of cross-presentation is hotly debated in the literature," says **Brocker**.

In the study, **Brocker** and his team used several antigens that were specifically targeted to and processed by macrophages, but could not be taken up directly by dendritic cells. They were able to demonstrate that each antigen nevertheless induces a normal immune response in a mouse model system, and even in a mouse strain that lacked dendritic cells altogether. Further experiments showed that the targeted macrophages were actually able to prime a more comprehensive immune reaction than cross-presenting dendritic cells. They activated T-cells specific for all antigen-binding sites (so-called epitopes) presented, whereas cross-presentation by dendritic cells stimulates only those T-cells that recognize immunodominant, i.e., the most effective, epitopes.

Macrophages are normally the first immune cells in the body that come into contact with invading pathogens. "Macrophages naturally function as filters; they gobble everything up that might be harmful to the organism. And our study shows that, in contrast to cross-priming dendritic cells, they are capable of producing and presenting all T-cell-priming epitopes we tested. Macrophages therefore induce a complete immune response. These observations indicate that the significance of cross-presentation by dendritic cells has been overrated," says **Brocker**.



The new findings are relevant for the development of immunization strategies. "Preclinical trials are already underway with vaccines that are designed to activate specific sets of dendritic cells. But the weak epitopes are important for a broadly directed immune response, because they can potentially recognize mutant variants of viruses, for instance. Cross-priming dendritic cells fail to induce weakly antigenic epitopes, as our study shows. Our results indicate that it may make more sense to manipulate macrophages directly, because they stimulate a wider-ranging immune response," says **Brocker**.

Source:
Science Daily,
http://www.sciencedaily.com/releases/2015/04/150415125852.htm

Story Source:
The above story is based on materials provided by **Ludwig-Maximilians-Universität München**. Note: Materials may be edited for content and length.

Journal Reference:
1. **Caroline A. Bernhard**, **Christine Ried**, **Stefan Kochanek**, **Thomas Brocker**. CD169 macrophages are sufficient for priming of CTLs with specificities left out by cross-priming dendritic cells. Proceedings of the National Academy of Sciences, 2015; 201423356 DOI: 10.1073/pnas.1423356112

Dr. Martin Lerner's Treatment Protocol for ME/CFS

Dr. Martin Lerner has been a long-time proponent of antiviral therapies for treating ME/CFS. His background as an infectious disease specialist naturally led him to explore antimicrobials because he believes that microbial infections lie at the heart of ME/CFS symptomatology. He has authored numerous papers on antiviral treatments for ME/CFS, and has treated patients for decades.

Below is his guide to treating patients with ME/CFS using antimicrobial agents. He also includes the roster of tests he uses for diagnosis, and a section on patient care.

Dr. Lerner makes the disclaimer that his guide has not been peer-reviewed, but that does not make it any less valid. The guide is a summary of decades of clinical experience and, as such, stands on its own.

Source: http://www.cfstreatmentguide.com/blog

Subjects **Dr. Lerner** treats in this guide are:

Diagnostic Methodology
- Initial patient visit
- ME/CFS analysis
- Cardiac testing
- Viral testing for EBV, HCMV, HHV6
- Co-infection testing

Physicians Caring for Patients with CFS

Antiviral Treatment of EBV

Antiviral Treatment of HCMV & HHV6

Antibiotic Treatment of Co-infections
- Treatment of Lyme Disease
- Treatment of Mycoplasma Pneumonia
- Treatment of Adult Rheumatic Fever

Patient Management
- Diet and Exercise
- Lifestyle

8. Research

Cerebrospinal Fluid, Autoimmunity, and Cognitive Dysfunction in ME/CFS

Columbia University has published the second of two significant studies examining immune system markers in ME/CFS. The study, "Cytokine network analysis of cerebrospinal fluid in myalgic encephalomyelitis/chronic fatigue syndrome," was published in **Molecular Psychiatry**, a top-ranked journal in the field of neuroscience.

The first study, "Distinct plasma immune signatures in ME/CFS are present early in the course of illness" (February 27, 2015), showed that pro-inflammatory cytokines were elevated in the early phase of the disease, but depressed in later stages. After examining cerebrospinal fluid in long-term patients, the **Columbia research team** found a similar decrease in pro-inflammatory cytokine IL-1 signaling.

What is interesting about the cerebrospinal fluid study is that patients showed an increase in a chemokine called CCL11 (eotaxin).

Eotaxin is a chemical involved in stimulating eosinophils, immune molecules that are implicated in allergic responses. Studies have shown that increased eotaxin reduces cognitive performance. Particularly affected are spatial navigation and the processing of short into long-term memory (learning). These are both functions of the hippocampus, a small organ in the limbic system.

In his book, The Limbic Hypothesis (1993), **Dr. Jay Goldstein** proposed the damage to the limbic system was the driving force behind ME/CFS. Research conducted since then has repeatedly confirmed **Dr. Goldstein**'s theory. Now, evidence is mounting that the damage is caused by an autoimmune response.

The Columbia researchers concluded that their results:

"...indicate a markedly disturbed immune signature in the cerebrospinal fluid of cases that is consistent with immune activation in the central nervous system, and a shift toward an allergic or T helper type-2 pattern associated with autoimmunity."

Scientists find clues into cognitive dysfunction in chronic fatigue syndrome

Press Release: **Columbia University's Mailman School of Public Health**, March 31, 2015. Scientists at **Columbia University's Mailman School of Public Health** have identified a unique pattern of immune molecules in the cerebrospinal fluid of people with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) that provides insights into the basis for cognitive dysfunction - frequently described by patients as "brain fog" - as well as new hope for improvements in diagnosis and treatment.

In the study published in Molecular Psychiatry, **Mady Hornig**, MD, and colleagues used immunoassay testing methods to measure the levels of 51 immune biomarkers called cytokines in the cerebrospinal fluid of 32 people with ME/CFS for an average of seven years, 40 with multiple sclerosis, and 19 non-diseased controls. The researchers found that levels of most cytokines, including the inflammatory immune molecule, interleukin 1, were depressed in individuals with ME/CFS compared with the other two groups, matching what was seen in the blood study in patients who had the disease for more than three years. One cytokine - eotaxin - was elevated in the ME/CFS and MS groups, but not in the control group.

"We now know that the same changes to the immune system that we recently reported in the blood of people with ME/CFS with long-standing disease are also present in the central nervous system," says **Dr. Hornig**, professor of Epidemiology and director of translational research at the Center for Infection and Immunity at the **Mailman School**. "These immune findings may contribute to symptoms in both the peripheral parts of the body and the brain, from muscle weakness to brain fog."

Implications for Diagnosis and Treatment

"Diagnosis of ME/CFS is now based on clinical criteria. Our findings offer the hope of objective diagnostic tests for disease as well as the potential for therapies that correct the imbalance in cytokine levels seen in people with ME/CFS at different stages of their disease," adds **W. Ian Lipkin**, MD, **John Snow** Professor of Epidemiology and director of the Center for Infection and Immunity. There is precedent for use of human monoclonal antibodies that regulate the immune response in a wide range of disorders from rheumatoid arthritis to multiple sclerosis. However, the researchers note, additional work will be needed to assess the safety and efficacy of this approach.

Journal Reference: **M Hornig**, **G Gottschalk**, **D L Peterson**, **K K Knox**, **A F Schultz**, **M L Eddy**, **X Che**, **W I Lipkin**. Cytokine network analysis of cerebrospinal fluid in myalgic encephalomyelitis/chronic fatigue syndrome. Molecular Psychiatry, 2015; DOI:10.1038/mp.2015.29
Source: http://www.cfstreatmentguide.com/blog

Robust Evidence

Drs Lipkin, **Hornig** and colleagues discover robust evidence that chronic fatigue syndrome is a biological illness

February 27, 2015

The researchers and team at CII would like to dedicate this paper as a tribute to the life of **Vanessa Li**.

Breaking news from Columbia scientists, press release 2pm EST today:

Immune Signatures in Blood Point to Distinct Disease Stages, Open Door to Better Diagnosis and Treatment

NEW YORK (Feb. 27, 2015)—Researchers at the Center for Infection and Immunity at **Columbia University's Mailman School of Public Health** identified distinct immune changes in patients diagnosed with chronic fatigue syndrome, known medically as myalgic encephalomyelitis (ME/CFS) or systemic exertion intolerance disease. The findings could help improve diagnosis and identify treatment options for the disabling disorder, in which symptoms range from extreme fatigue and difficulty concentrating to headaches and muscle pain.

These immune signatures represent the first robust physical evidence that ME/CFS is a biological illness as opposed to a psychological disorder, and the first evidence that the disease has distinct stages. Results appear online in the new American Association for the Advancement of Science journal, *Science Advances*.

With funding to support studies of immune and infectious mechanisms of disease from the Chronic Fatigue Initiative of the **Hutchins Family Foundation**, the researchers used immunoassay testing methods to determine the levels of 51 immune biomarkers in blood plasma samples collected through two multicenter studies that represented a total of 298 ME/CFS patients and 348 healthy controls.

They found specific patterns in patients who had the disease three years or less that were not present in controls or in patients who had the disease for more than three years. Short duration patients had increased amounts of many different types of immune molecules called cytokines. The association was unusually strong with a cytokine called interferon gamma that has been linked to the fatigue that follows many viral infections, including Epstein-Barr virus (the cause of infectious mononucleosis). Cytokine levels were not explained by symptom severity.

"**We now have evidence confirming what millions of people with this disease already know, that ME/CFS isn't psychological,**" states lead author **Mady Hornig, MD**, director of translational research at the Center for Infection and Immunity and associate professor of Epidemiology at **Columbia's Mailman School**. "Our results should accelerate the process of establishing the diagnosis after individuals first fall ill as well as discovery of new treatment strategies focusing on these early blood markers." http://bit.ly/1Dw8pQE

There are already human monoclonal antibodies on the market that can dampen levels of a cytokine called interleukin-17A that is among those the study shows were elevated in early-stage patients. Before any drugs can be tested in a clinical trial, **Dr. Hornig** and colleagues hope to replicate the current, cross-sectional results in a longitudinal study that follows patients for a year to see how cytokine levels, including interleukin-17A, differ within individual patients over time, depending on how long they have had the disease.

Stuck in High Gear

The study supports the idea that ME/CFS may reflect an infectious "hit-and-run" event. Patients often report getting sick, sometimes from something as common as infectious mononucleosis (**Epstein-Barr virus**), and never fully recover. The new research suggests that these infections throw a wrench in the immune system's ability to quiet itself after the acute infection, to return to a homeostatic balance; the immune response becomes like a car stuck in high gear. "It appears that ME/CFS patients are flush with cytokines until around the three-year mark, at which point the immune system shows evidence of exhaustion and cytokine levels drop," says **Dr. Hornig**. "Early diagnosis may provide unique opportunities for treatment that likely differ from those that would be appropriate in later phases of the illness."

The investigators went to great lengths to carefully screen participants to make sure they had the disease. The researchers also recruited greater numbers of patients whose diagnosis was of relatively recent onset. Patients' stress levels were standardized; before each blood draw, patients were asked to complete standardized paperwork, in part to engender fatigue. The scientists also controlled for factors known to affect the immune system, including the time of day, season and geographic location where the samples were taken, as well as age, sex and ethnicity/race.

In 2012, **W. Ian Lipkin, MD**, director of the Center for Infection and Immunity, and colleagues reported the results of a multicenter study that definitively ruled out two viruses thought to be implicated in ME/CFS: XMRV (xenotropic murine leukemia virus [MLV]-related virus) and murine retrovirus-like sequences (designated pMLV: polytropic MLV). In the coming weeks, **Drs. Hornig** and **Lipkin** expect to report the results of a second study of cerebrospinal fluid from ME/CFS patients. In separate ongoing studies, they are looking for "molecular footprints" of the specific agents behind the disease—be they viral, bacterial, or fungal—as well as the longitudinal look at how plasma cytokine patterns change within ME/CFS patients and controls across a one-year period, as noted above.

"This study delivers what has eluded us for so long: unequivocal evidence of immunological dysfunction in ME/CFS and diagnostic biomarkers for disease," says senior author **W. Ian Lipkin, MD**, also the **John Snow** Professor of Epidemiology at **Columbia's Mailman School**. "The question we are trying to address in a parallel microbiome project is what triggers this dysfunction."

Co-authors include **Andrew F. Schultz**, **Xiaoyu Che**, and **Meredith L. Eddy** at the **Center for Infection and Immunity**; **Jose G. Montoya** at **Stanford University**; **Anthony L. Komaroff** at **Harvard Medical School**; **Nancy G. Klimas** at **Nova Southeastern University**; **Susan Levine** at **Levine Clinic**; **Donna Felsenstein** at **Massachusetts General Hospital**; **Lucinda Bateman** at **Fatigue Consultation Clinic**; and **Daniel L. Peterson** and **Gunnar Gottschalk** at **Sierra Internal Medicine**. The authors report no competing interests.

Support for the study was provided by the **Chronic Fatigue Initiative** of the **Hutchins Family Foundation** and the **National Institutes of Health** (AI057158; Northeast Biodefense Center-Lipkin).

http://bit.ly/1LSyqMf

A Research Study That Should Be Done - But Who Will Care Enough To Fund It?

My focus today is on a commercially available species of probiotic called *Bifidobacterium infantis 35624.* Proctor and Gamble sells this product under the brand name Align. Natren sells a different but closely related B infantis species.

Substantial animal and test tube research suggests that certain Bifidobacterium species can suppress and/or increase inflammatory markers (1-4). Recently, an Irish research group from University College in Cork fed high doses of the B infantis 35624 strain versus placebo to 48 subjects who had Chronic Fatigue Syndrome. After 8 weeks persons taking the probiotic had significantly reduced levels of 3 inflammatory markers compared to levels observed with placebo. These markers were CRP, Interleukin 6 and Tumor Necrosis Factor Alpha.

Researchers did not evaluate the course of clinical symptoms for these patients. So, we don't know whether or not clinical symptoms also improved. (Anecdotally, in a similar study of patients with psoriasis, one of the investigator's "impression" was that clinical improvement also occurred.)

This raises several Can the improvement in the 3 inflammatory markers be confirmed? What happens to other inflammatory markers such as IL17? Do clinical symptoms improve? Would other species of Bifidobacteria be as effective? Who might fund further clinical studies? Can we at ME Global Chronicle help persuade potential funding sources that further research is worth supporting?

The subjects of this double blind trial included 48 patients with CFS. Diagnosis was based on the Center for Disease Control Criteria. There were also 22 patients who had ulcerative colitis and 26 with psoriasis. Researchers measured the blood levels for three inflammatory mediators: C-reactive protein (CRP), Tumor Necrosis Factor alpha (TNF-alpha) and Interleukin 6 (IL-6).

At baseline all three inflammatory markers tended to be higher among patients compared to healthy controls.

Subjects took one packet daily containing either ten billion colony forming units (cfu) of B infantis 35264 or a placebo. For CFS and psoriasis patients the study lasted 8 weeks. For Ulcerative Colitis patients, the duration was 6 weeks.

(Please note that B infantis 35264 is available under the brand name Align. The dose used in the Irish study was 10 billion colony forming units daily. Align comes in capsules of one billion cfu.)

The Results:
CRP: For all three diseases CRP levels declined significantly among subjects taking the probiotic compared to those taking placebo. For chronic fatigue syndrome the P value was 0.0285. The majority of CFS patients showed a decrease in their CRP.

Tumor Necrosis Factor Alpha: TNF alpha levels declined with probiotic compared to placebo for subjects with CFS and for Psoriasis. TNF alpha did not decline for patients with ulcerative colitis. For CFS P=0.0214.

Interleukin 6: IL-6 levels were significantly lower among CFS patients fed probiotic compared to placebo (P=0.054). IL-6 declined significantly with B. infantis compared to placebo for ulcerative colitis. IL-6 did not decline significantly among patients with psoriasis.

The Key Article: Greoger, D…..Quigley, M., Bifidobacterium infantis 35624 modulates host inflammatory processes beyond the gut, Gut Microbes, 2013, 4(4):325-339.

You can download the full article on line for free from this URL:
http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3744517/

Here's my tentative take on what I think we have learned:
Bifidobacteria infantis 35624 at 10 billion cfu per day taken for 8 weeks tends to reduces three markers of systemic inflammation, CRP, TNF alpha, and IL-6. Please note: this conclusion has two parts. One: B. infantis 35624 has anti-inflammatory actions. *Two: these anti-inflammatory effects are not limited to the gut—where probiotics live. Rather they affect the body systemically.*

Did the patients who were took B infantis 35624 tend to feel better than those on placebo? *I emailed the lead author, Dr. Quigley. (Dr.Quigley's email address is listed in the Key Article.) He confirmed that his group did not collect data on clinical outcomes.* ***To do so would have required a considerably more expensive study.***

Critical Question Addressed to All Readers: Does anyone know a high executive at Proctor and Gamble—the producer of the Align brand of B infantis 35624? *Align has supported several clinical studies. If their product truly helps CFS, psoriasis and or ulcerative colitis that could certainly expand their product. Or might another strain of B infantis also be effective, e.g. B infantis sold by Natren?*

Open Question: Should clinicians who treat ME/CFS offer patients the option of take a B infantis product based despite limitations of current evidence?

Pro: As interventions go, adding a probiotic is relatively safe. Taking B. infantis is not likely to cause any major harm. If a significant number of patients with ME/CFS report improvement to their doctors, that information might create support for a double blind study. (Or should we ask for postings to a prominent

ME/CFS website such as http://ProHealth.com, Phoenix Rising (http://phoenixrising) or to ME-Global Chronicle?

Cons: **One small double blind study without clinical end points isn't much to go on. Also, please note that the dose used in this study (10 billion cfu) is ten times higher than the dose in one capsule of Align (one billion CFU).** Currently Target sells forty two capsules of Align each with one billion cfu for about $37. So a 68week trial of 10 billion cfu would cost about $300,

Another concern: My understanding is that **Dr. Quigley**'s group developed the B infantis 35624 strain, and then licensed it to Proctor and Gamble, who now sells it as Align. I'll guess that the Irish group treated their subjects with freshly made probiotic. This would have maintained its initial potency. Commercially available Align, in contrast, might have sat on shelves for many months. Its potency when taken is likely to be much less than one billion cfu per capsule.

For example, one point that has always been prominent in Natren's marketing is that they ship fresh product and keep it on ice.They guarantee it's potency.

Your thoughts will be appreciated.

Further References:

1. Underwood, M.Dvorak, B, Bifidobacterium longum subsp. Infantis in experimental necrotizing enterocolitis: alterations in inflammation, innate immune response and the microbiota, Pediatr Res, 2014;76:326-33
2. Rodes L, Saha, S, Tomaro-Duchensneau C, Prakash S, Microencapsulated Bifidobacterium longum subsp. Infantis ATCC 15697 favorably modulates gut microbiota and reduces circulating endotoxins in F 344 rats, Biomed Res Int 2014:602832. Doi: 10.1155/606832 E pub 2014
3. Whorwell P, Do probiotics improve symptoms in patients with irritable bowel syndrome? Therap Adv Gastroenterol 12009; 2:37044
4. Tanabe S, Kinuta Y, Saito Y, Biforbacterium infantis suppresses proinflammatory interleukin-17 production in murine splenocytes and dextran sodium sulfate-induced intestinal inflammation, Int J Mol Med 2008;22:181-5

Ewaschuk, J….Madsen K, Secreted bioactive factors from Bifidobacterium infantis enhance epithelial cell barrier function, Am J Physiol Gastrointest Liver Physiol 2008; 295:G1025-34

Richard Podell, **M.D.**, practices in **Summit and Somerset New Jersey**. He is a **clinical professor in the Department of Family Medicine**, **Rutgers-Robert Wood Johnson Medical School**. **Dr. Podell** has no financial interest in any of the products mentioned in this article.

Mailing Address is Richard Podell, M.D.,
suite 140, 11 Overlook Rd, Summit, NJ 07901

Richard Podell, **M.D., MPH**,
http://www.DrPodell.org - podell2@gmail.com

Enteroviruses

Enteroviruses have been associated with ME since the 1930's. Names such as 'Epidemic Neuromyasthenia', 'Encephalitis', 'Akureyri Disease', 'atypical poliomyelitis', 'Iceland disease', 'poliomyelitis-like epidemic neuromyasthenia' 'Abortive Poliomyelitis' were used to describe the illness prior to the term 'Myalgic Encephalomyelitis' being created by **Dr. Acheson** in 1955. Coxsackie viruses, other Enteroviruses and ECHO 7 virus appear to be infecting significant numbers of ill people, as evidenced from prior ME (CFS) epidemics dating back to the 1930's.

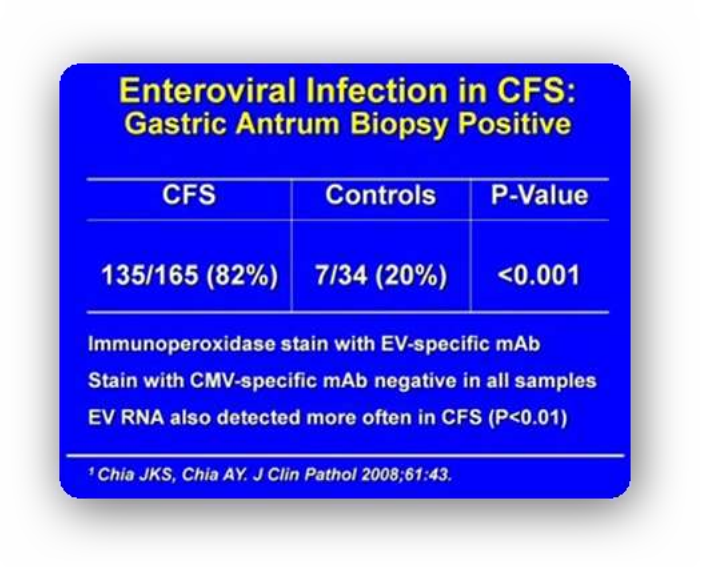
" Primary M.E. is always an acute onset illness. Doctors A. Gilliam, A. Melvin Ramsay and **Elizabeth Dowsett** (who assisted in much of his later work,) **John Richardson** of Newcastle-upon-Tyne, **W.H. Lyle**, **Elizabeth Bell** of **Ruckhill Hospital**, **James Mowbray** of **St Mary's**, and **Peter Behan** all believed that the majority of primary M.E. patients fell ill following exposure to an Enterovirus. (Poliovirus, ECHO, Coxsackie and the numbered viruses are the significant viruses in this group, but there are other enteroviruses that exist that have been discovered in the past few decades that do not appear in any textbook that I have perused.) I share this belief that enteroviruses are a major cause. "

Source: http://www.nightingale.ca/documents/Nightingale_ME_Definition_en.pdf
"Virological studies revealed that 76% of the patients with suspected myalgic encephalomyelitis had elevated Coxsackie B neutralising titres (and symptoms included) malaise, exhaustion on physical or mental effort, chest pain, palpitations, tachycardia, polyarthralgia, muscle pains, back pain, true vertigo, dizziness, tinnitus, nausea, diarrhoea, abdominal cramps, epigastric pain, headaches, paraesthesiae, dysuria)…. The group described here are patients who have had this miserable illness. Most have lost many weeks of employment or the enjoyment of their family (and) marriages have been threatened…"
(**BD Keighley**, **EJ Bell.** JRCP 1983:33:339-341).

Dr. John Chia, is a world renowned doctor who has successfully treated ME patients. He has found that Enteroviruses are present in some subgroups of ME patients and that treating these Enterovirus infections can lead to significant improvement and recovery.

His research paper provides some important insights - Chronic fatigue syndrome is associated with chronic enterovirus infection of the stomach. **Chia JK**, **Chia AY.** **J** Clin Pathol. 2008 Jan;61(1):43-8. Epub 2007 Sep 1.

See diagram below:



Dr. John Chia presents his research findings up to the year 2011 to the National Institutes of Health (NIH) in the USA below:

- http://www.youtube.com/watch?v=obHtCwhg3-0 Part 1
- http://www.youtube.com/watch?v=BO-yxqZuXTY Part 2

Dr. Chia's work and findings are similar to those of John Richardson, a medical doctor who was based in Newcastle in England who treated ME patients from many parts of Britain for over 40 years. He developed an expertise in diagnosing the illness, and became one of the world's foremost experts in ME. He even used autopsy results from dead patients to investigate the illness. He found that Enteroviruses and toxins played a major role in ME, and that this led to immune dysfunction, neurological abnormalities, endocrine dysfunction, and over time to increased risk of cardiac failure, cancers, carcinomas, and other organ failure. He wrote a book about his medical experiences called Enteroviral and Toxin Mediated Myalgic Encephalomyelitis/Chronic Fatigue Syndrome.
http://amzn.to/1DHAymu

The outbreak in Iceland was important, and provided some vital clues about the illness and the role of Enteroviruses.

"However, children in epidemic Neuromyasthenia areas responded to poliomyelitis vaccination with higher antibody titres than in other areas not affected by the poliomyelitis epidemic, as if these children had already been exposed to an agent immunologically similar to poliomyelitis virus (**Sigurdsson**, **Gudnad6ttir Petursson**, 1958). Thus, the agent responsible for epidemic Neuromyasthenia would appear to be able to inhibit the pathological effects of poliomyelitis infection. When an American airman was affected in the 1955 epidemic and returned home, a similar secondary epidemic occurred in Pittsfield, Massachusetts, U.S.A. (**Hart**, 1969: **Henderson** and **Shelokov**, 1959)."

Many outbreaks of ME or epidemic Neuromyasthenia worldwide followed an outbreak of polio virus.

Parish JG (1978), Early outbreaks of 'epidemic neuromyasthenia', Postgraduate Medical Journal, Nov;54(637):711-7, PMID: 370810.
http://1.usa.gov/1K1m6YC

He also presents his medical experiences in the videos and chart below:
https://youtu.be/NhU-G0loqtY
https://youtu.be/I44G-tGgLNE
https://youtu.be/A1h0elEhSO0

Table 1. Probable causes of chronic fatigue syndrome in 200 patients.

Probable cause	Criteria for inclusion	No. of patients (n = 200)
Chlamydia pneumoniae infection	High antibody titer compared with control subjects from the community; response to macrolide therapy [5]	18
Epstein-Barr virus infection	Whole blood (at 1:1000 dilution) or urine sample positive for EBV DNA; response to Val or iv Cid therapy[a]	6
Cytomegalovirus infection	Surveillance of acute infection for a period >6 months; positive culture results; response to iv Cid or IVIG therapy	3
Recurrent VZV infection	Recurrent lesions; response to antiviral drugs	6
Recurrent HHV6-like disease	Recurrent roseola-like illness for a period of 3 years; response to iv Cid therapy	1
Parvovirus B19 infection	Test results positive for IgM or viral DNA	3
Hepatitis C	Resolution of symptoms after interferon/ribavirin therapy	3
Neurocardiogenic hypotension	Initial flulike illness; tilt test positive for NMS; response to midodrine therapy	2
Toxic mold exposure	Documented cultures of environmental samples positive for toxic mold; >1 household member was affected; symptoms improved after leaving the house	2
Postvaccination	Received pneumovax, MMR, or influenza vaccine	3
Enterovirus infection	Persistent, significantly elevated levels of neutralizing antibody for coxsackievirus B or high echovirus titer compared with controls from the community; PBMC sample positive for enteroviral RNA[b]	109
Unknown	—	44

NOTE. Cid, cidofovir; EBV, Epstein-Barr virus; HHV6, human herpesvirus 6; IVIG, intravenous immunoglobin; MMR, measles, mumps, and rubella; NMS, neurally mediated syncope; Val, valacyclovir; VZV, varicella-zoster virus.

[a] The EBV DNA assay of whole blood was performed by the University of Southern California (USC) reference laboratory. One urine sample positive for EBV DNA was confirmed by the USC reference laboratory, the Associate Regional University Pathologist's laboratory, and the Microbiology Reference Laboratory.

[b] There were 150 control subjects who visited the medical clinic for whom determination of neutralizing antibody for coxsackievirus B1-6 and echovirus 6, 7, 9, 11, and 30 was done. A significant elevation of antibody level was defined as a titer greater than 2× (mean level + 2 SDs) for control subjects.

Invest In ME conference 2015

IIMEC10, the tenth such annual biomedical research conference to be organized by the charity Invest in ME (IiME), is a big ticket event attracting researchers, physicians, patient groups and journalists from around the world.

The conference showcases the current and future directions of diagnosis, treatment and biomedical research into myalgic encephalomyelitis (ME), sometimes called chronic fatigue syndrome (CFS).
Other sponsors of IIMEC10 include the Irish ME Trust (IMET) and Riksföreningen för ME-patienter (RME).

In an area that is woefully underfunded and under-researched, the conference fulfills a vital role in increasing international collaboration between researchers looking into ME.

Biomedical research is high on the agenda
Underlining IiME's strong focus on biomedical research, an international lineup of ME researchers will present their latest findings at the conference. Professor Ian Charles, the conference keynote speaker, will present Solving ME: What a Research Park Has to Offer in Resolving a Chronic Disease.

Other prominent speakers already committed include:

Dr. John Chia (USA),
Professor Olav Mella and **Dr. Oystein Fluge** (Norway),
Professor Sonya Marshall-Gradisnik and **Dr. Don Staines** (Australia),
Professor Mady Hornig (USA),
Dr. Amolak Bansal (UK),
Professor Betsy Keller (USA),
Dr. Luis Nacul (UK),
Professor Jonas Bergquist (Sweden),
Dr. Jo Cambridge (UK),
Dr. Neil Harrison (UK).
Dr. Ian Gibson is the conference Chair.

All information & registration: http://www.investinme.eu

BRMEC 5

The 5th Invest in ME Biomedical Research into ME Colloquium 5 (BRMEC5) will take place in London over two days from 27th-28th May 2015. This involves researchers from around the world convening in London to discuss research, strategies and future planning.

It builds on past years and has evolved into a major international event, with CPD accreditation. It involves the most experienced researchers in areas such as immunology, virology, neurology and bioinformatics.

Full details of the colloquium, the conference, IIMEC10 speakers, sponsors and welcome message from Invest in ME Research Chairman **Kathleen McCall** are at http://www.investinme.eu

9. ME And Children

What It Is Like As A Teen To Suffer From A Chronic Illness - I

British **Tanya Mawer** is a mother to a.o. two girls with ME. In her blog of Saturday, 21 February 2015 under her penname **Crazy Purple Mama** she writes about the kind of life they are forced to live and what they do encounter. We split it up into three parts.

As an introduction she writes:

"Due to our intimate dealings with the dastardly ME, my 2 youngest daughters suffer from this chronic incurable illness, I have become a huge supporter of a fundraising group called Let's Do It for M.E. and like to raise funds for Invest in ME Research with the hope they can find a treatment or even a cure one day (soon I hope)."

Tanya introduces her family and herself in this blog:
http://crazypurplemama.blogspot.co.uk/2014/01/introduction.html

What it is like as a teen to suffer from a chronic illness?

Part 1 – The First Week

This is a different blog from my usual format. I think it is important to share with you how my daughters lives have been altered by the debilitating disease they both suffer from which is the chronic "invisible" illness Myalgic Encephalomyelitis (otherwise known as ME), Some doctors prefer to call it CFS and then there is now the new name that's being proposed which is the not so easy to trip off the tongue "Systemic Exertion Intolerance Disease" or SEID for short (ironically spells DIES backwards!).

To be fair, it makes no difference what you call it, the fact remains that they are sick, their lives are restricted and they are not able to live their life the way they would like to. Instead they have to choose each day how to spend their limited energy resources and work within those confines. Also, as with most sufferers, they have other health issues to contend with too.

So, in a bid to try and help raise awareness about chronic illnesses both girls have completed this "Chronic Illness Challenge". Originally it was designed as a instagram or facebook challenge and the idea was to answer a question a day for a month. However, for someone who suffers from cognitive issues this isn't always possible and there may be days go by when typing or texting isn't possible. Which is why the girls decided to take their time and compose a blog post to have it posted altogether as a comprehensive post about their specific journey with this illness.

They have both provided their answers beneath each question to explain how it affects them...

Day 1. Introduce yourself. What illnesses do you have? How long have you had them?
I have been diagnosed with M.E. (Myalgic Encephalomyelitis), Hypermobility, Orthastatic Intolerance, Arthralgia, Lacto-Intolerance, Asthma, Depression, Anxiety, Dissociative Disorder, Trichotillomania and Dermatillomania, Skin sensitivity and allergies along with Intermittent paralysis of my legs and pretty bad cognitive issues (have days when can't read or write, find it hard to remember words or say the wrong words when I don't mean to).

I have had these illnesses ranging from childhood to the most recent diagnosis which was 5 years ago.

I have ME/CFS, along with a number of things, such as; Hypermobility, Irritable Bowel Syndrome, Orthostatic Intolerance, Chronic Back Pain, Restless Leg Syndrome and Social Anxiety/Avoidance Issues.
I've had ME for about 5 years.

Day 2. How have these illnesses affected your life?
I can't even begin to describe how they have changed my life. I have missed out on the most important teenage years and my education, lost so many friends and become unable to cope in social situations as well as being in pain 24/7.

They've affected my life in a number of ways, I used to enjoy dance a lot and I had to stop altogether, I've fully missed my opportunity to experience secondary school and I've missed out on major topics via virtual school because we don't have the money to fund my education in more than two subjects (Maths and English) privately ourselves and we haven't been given any funding from anywhere else.

Day 3. How did you get a diagnosis?
After having viral meningitis I never got better and had a severe case of Scarlet Fever and any and every illness going around. I had two CT scans and after many tests they finally diagnosed me as having ME/CFS.

Originally we assumed it to be glandular fever because of my glands being so swollen and my initial symptoms were text book glandular fever, I had had 10 cases of tonsillitis already running up to it and had spent almost all of 2010 off school sick. When I didn't get better and after lots of tests coming back negative it was obviously thought to be ME by the GP. I got a proper diagnosis in January 2011 from the hospital.

Day 4. How have your friends and family reacted to it?
My family have been extremely supportive along with a handful of friends who have stood by me. I couldn't ask for better people in my life - my mum especially has been absolutely amazing, she is my rock and best friend and I love her.

Obviously it was sad to see me become so ill after being so well, I could barely see my friends for any longer than half an hour. Also, we had next to no knowledge of the illness so everyone was trying to push me and get me back to normal more than anything.

Day 5. How does being chronically ill make you feel?
Like shit haha

It's upsetting that I have this illness because people misjudge me with what I can and can't do. Recently my good and bad days are very sudden but people tend to judge me on 'what I did yesterday'. I hate that I'll never have the experience of school and that I've missed out on so many events (including Prom) and haven't had the opportunity to learn the same amount or have the life opportunities as other people.

Day 6. If you could have told yourself something when you first remember these symptoms arising what would you have said?
Be kind to yourself.

If I could, I would've told myself to not push myself into doing things too soon. Trying to go into school and doing exercise just prolonged recovery and messed up my back.

Day 7. What was the biggest realisation you have had?
There is a difference between living and being alive.

The biggest realisation isn't for myself, but so many people take things for granted. They complain about school, dance, and a simple headache when they could have things so much worse, if people come to me saying they have a sore throat, I really won't have any sympathy, they should try living with ME.

Joanne

Progress report on "**Joanne**" by **Dr Nigel Speight**

This is the 15 yr old girl in Germany with very severe ME/CFS who is being subjected to an "activation regime" in hospital, which has now been for 16 months. This is against her strongly expressed will and that of her mother.

Mother has already had her parental rights removed by the court for opposing the treatment regime. Social services are now asking the court to terminate contact between Joanne and her mother, completely. In my opinion this is not only just plain cruel to the point of sadism, it is also a gross violation of **Joanne**'s human rights, and a very clear case of Emotional Abuse of a young person by professionals and the courts.

In view of the severity of **Joanne**'s condition, it may even be that this act of emotional abuse will put her very life at risk. Mother is still desperately in need of funds to help oppose all this in court, so please consider donating again to her cause

Plea from **Joanne**'s mother, shared with her permission
The situation is even more desperate than before, a real nightmare:
The doctors at the clinic with the help of the child protection agencies want a complete contact ban (!) between **Joanne** and her **Mum**. This would be urgently necessary for **Joanne** to get healthy again!

In case of acting against this **Joanne**'s mother would have to pay up to € 25.000,= or go into jail for up to 6 months! They want to have her out of the way to force even more vigorous GET on this completely helpless girl.

During 17 months of their treatment **Joanne** has not improved, in fact she is much worse. **Joanne** is forced to ride a bed bicycle every day longer and faster and she is chained on a tilt table every day, wearing a corset and heavy orthesis, where she has to remain in an upright position 3 times for 4 minutes. She nearly faints but there are no pulse or blood pressure controls.

She has absolutely no right to say anything and they treat her as if she had a psychiatric disorder. Now they are looking for a scapegoat and came up with her mother.

Her mother has a rather big request: her latest lawyers invoice is € 4372,=, she even has no idea how to pay this one and there are court hearings pending.

Without a good lawyer she and her daughter are lost. For **Joanne** it is a matter of life or death, as she is in a very bad state and if she loses her last support her mother fears that she gives up (she said: "Mummy, not without you!"). They are torturing her to death.

Dr. Speight was willing to come to the next court hearing, but unfortunately isn't in a position to do so.

"Please help us!", **Joanne**'s mother writes: "We would be so very grateful as we don't know how to go on..."

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

As reported in the last ME Global (http://let-me.be/download.php?view.10 , p.40) we are no longer in a position to publish details about **Joanne** due to the untimely disclosure of her true identity and the restriction imposed on her mother not to have published anything about her daughter on the internet.

However the editors are in close contact with **Joannes** mother, and as soon as there will be a possibility to report on both mother and daughter, we will definitely do so.

It is hard to tell if the legal procedures and **Dr. Speights** mediation had any effect at all. Doing nothing at all was no option, that may be clear.

So please continue to donate, and if any a case like **Joanne**'s is known to you, please let us know via info@let-me.be

We thank those of you who donated from the bottom of our hearts.

The editors

A Proposal

Nb this project runs until the end of May 2015
Growing up with ME:
Surviving childhood and becoming an adult while chronically ill.

We would like to invite you to participate in an anthology on children with ME. If you are an adult who became ill as a child or teenager, we would like to hear from you (see below for further information on how to contact us).

Background: children and teenagers suffering from myalgic encephalomyelitis are especially vulnerable; having become ill as children ourselves, their welfare is of particular concern to us. The experience of becoming chronically ill when young is quite different to becoming ill as an adult. Children often endure illness unheard and ignored, with none of the life experience or authority of an adult to help them cope with their significantly altered condition. They have the added problems of dealing with incompetent medics, school psychologists, physiotherapists, uncooperative school staff and social workers, without many of the rights adults take for granted.

Purpose of this project/anthology: the aim of this project is to contribute towards a shift in attitude among the relevant professions and society. The **Tymes Trust** have been working with and for children and their families for years[1]. As a contribution towards such a shift we would like to reach children, teenagers and their parents with this anthology, in support and recognition of their situation and, ultimately, to donate money to the **Tymes Trust**. We would also like to take this opportunity to creatively collaborate with people who are in similar circumstances but have perspectives and insights to offer that may be new, creative, inspiring or in some other way helpful.

Method: the compilation of up to a dozen stories, each about ten A4 pages long, by those who were diagnosed with ME as children. We would like to encourage you to contact us regarding the possibility of your participating in this project. We realise this would be an additional strain on your health, so we would like to ensure from the outset that anyone wanting to participate would be capable of completing their work.

Timeline: we would like your story to be submitted by the end of May 2015 if possible.

Proposed content: areas we would like to cover in each narrative are,

- When and how were you diagnosed.
- How were/are you provided for?
- How did you obtain an education?
- Who cares for you in your adult years?
- Looking back, what is your experience of the welfare state's stance on children/adults in terms of benefits?
- In conclusion of your story, we would like you to reflect on the support you had and based on your experience what you would like to suggest happen in order to improve the situation for children and their families.

We believe every narrative should contain what the authors feel is most relevant and necessary to be shared with a wider audience.

A brief example: see http://uttingwolffspouts.com/2015/02/04/a-proposal/

We would like to encourage you to disseminate this blog post, especially to friends and family members who you think might have an interest in this project. Please note that this is a project which will, at best, generate some money to be donated to the Tymes Trust but that those taking part will not be financially rewarded. That said, we hope that we all derive some fun and a sense of purpose from this project.

If you are interested in participating in this book project your first step is to fill in the contact form attached to this post and drop us some lines including when you became ill as a child or teenager. We will give you more specific information about the writing process.

Please do not write your story and submit it without communicating with us first as we would like to make certain we know all our participants. International participation is welcome; this anthology is not intended to be written from purely a UK perspective. Any contributions will need to be written in English please as translation would be too much for us due to ill-health.

Thank you for reading & we hope to hear from you soon.

Claudia and **Geoff**

10. Severe ME

Blaze A Trail For Truth

That way, ultimately, we win.
This book (**Severe ME**, ed.) lays bare the medical, political and personal facts of ME.

To survive, to bring about change you need to be knowledgeable about ME; you need to find out what it is and what it is not.

You need to know if the person you are caring for even has ME or not. You cannot afford to trust others too easily, you need to develop discernment.

You need to understand what you are up against, medically, politically as well as practically; that is what this book offers: vision.

Without vision there is no direction, there is no urgency, there is no responsibility.

Martin Luther King famously declared: "I have a dream"; I still dream, even after all this time, of making my wife well.

Nelson Mandela famously said: "In my country we go to prison first and then become President".

You too will have to take a stand, if you really want to help people with Severe ME, and it is a Herculean one.

Mother Teresa, a penniless nun, built a ministry that reaches out to the poor on every continent. How? She once said: "Do not wait for leaders; do it alone, person to person".

I can think of no better summary of the message of this book.

Greg Crowhurst - Severe ME, featuring "Justice for **Karina Hansen**", p. 59

To be had from:
http://bit.ly/1wwcDlN

Poem – Brain Fog

Brain fog, not just the odd word forgotten
Or misspoken
More, like the snow has quietly fallen
Filling my mind up

With cold, icy, soft, empty nothingness
Or shattering shards of ice crystal
Painfully poking inside my head

Freezing every image
Covering over every thought
With shivering powdery emptiness
So that all is white, bland, bear
And hidden from view
Like furniture
Wrapped away in a vacant house

My mind long vacant too
With dust sheets hastily thrown over everything
So that nothing is identifiable
Nothing is recognisable
Except perhaps an odd shape here and there
That looks like it should be vaguely familiar
This is all that remains

In a brain fogged mind
Of clarity, vision, beauty,

In what was once a multi-coloured, multi-layered, deep and delving
Dynamic, active, engaging place.

Now gone to sleep in an unstoppable snow storm,
Barely waking now,

Just silently empty

And unexpectedly transformed

Into nothing.

Linda Crowhurst

Source: http://carersfight.blogspot.co.uk/2015_03_01_archive.html

11. News from

Australia

Next seminar will be held on **Saturday 13 June 2015** at the same time and location.

The **ME/CFS Australia** usually produces DVDs of their seminars (although getting them all completed, organised and indexed is another "in progress" task for their overloaded volunteers!).

Just in case you or anyone else in your group may be interested in obtaining any of them, if you have any funding to cover the cost (AU$5.00 each) and postage, as they operate on a shoestring budget based on members' donations.

Info: sacfs@sacfs.asn.au

Mercy of the Wind by **Naomi Flanagan**

Melbourne based singer/songwriter **Naomi Flanagan** has recently released her first solo EP 'Mercy of the Wind'. http://bit.ly/1ywv4Mc

Naomi has lived with ME/CFS for the last 20 years which leaves her mostly housebound and sometimes bedbound.

In 2013, with the help of her brother and a friend, **Naomi** wrote, recorded and produced this five-song EP from her home. The songs on the EP convey the difficulty of living with restriction and uncertainty, but at the same time speak of hope and resilience.

Health and Welfare Survey - Federation University, in collaboration with **Emerge Australia**, would like to invite you to participate in a health and welfare study of people with ME/CFS.

If you have been diagnosed with Chronic Fatigue Syndrome, you are invited to participate in a study investigating involving the completion of an anonymous questionnaire related to your experiences with diagnosis, symptoms, impacts, healthcare, and support.We would be enormously grateful if you could take the time and energy to complete this anonymous survey. We will use the results of this survey to inform our education and advocacy work.

To complete the survey, simply go to the Emerge Australia website by clicking this link

"ME/CFS Health and Welfare Survey" - http://bit.ly/1NRB4Gu

Belgium

A first sign of resistance here in Belgium.

The Wake Up Call Movement
(WUCB, http://www.wakeupcallbeweging.be/) is launching the campaign 'Stop the Diagnosis CFS'.

Aim of this campaign is to demolish the wall of disbelief and medical ignorance around the disease ME.

It is to attract attention to the harrowing situations among which the many cancelations of invalidity pensions and the resulting poverty. Furthermore it wants to draw attention to the fact that this disease is not a psychogenic one.

Recent research results show more and more evidence that indeed biomedical factors are at the base of the disease.

The campaign started on 22nd April with a press conference and will continue the whole year.
A new website has been built for the purpose: http://www.stopdediagnosecvs.be

Former radio- and tv producer (for the BRT and the VRT) Luk Saffloer will be the face of this campaign. Four campaign shows are planned with information and artists performing. Each and everyone can help to make this campaign a success by handing out flyers and posters with information.

Eddy H. Keuninckx

Czech Republic

Statement, opinions and concerns relating to the IOM report 'Beyond ME/CFS Redefining an Illness'

By **Nina** from the **Czech Club of ME/CFS Patients**
(http://www.me-cfs.cz)
Translated by PaD and others

Firstly, we would like to express our thanks to the IOM Committee for the enormous effort with which they carried out the assigned tasks, as can be seen in the resulting report.

We welcome the media attention which the report has drawn to the issue of ME/CFS. The IOM report is a high quality and complex scientific overview of ME/CFS.

It contains much information which deserves attention but in the following paragraphs, we would like to focus solely on items which give us cause for concern. We expect these items will be clarified by the leading experts in the field in the future.

We expect that more in-depth analyses conducted by experts in the field will follow. Many questions need to be answered. We hope that the IOM report will result in a rapid increase in funding of biomedical ME/CFS research which will therefore accelerate the fulfilling of clinicians´ and patients´ needs.

Statement by ME/CFS.cz on the IOM diagnostic criteria

- We welcome the effort of the Committee to accelerate and simplify the diagnostic process in clinical practice.
- Nevertheless, we would prefer the recommendation to use the Canadian Consensus Criteria (CCC, 2003), or the International Consensus Criteria (ICC, 2011), at least until such time when the accuracy of the new diagnostic criteria proposed by the IOM can be scientifically verified.
- For research we unequivocally propose to use the proven CCC.

To read the entire comment:
http://let-me.be/download.php?view.18

Ireland

The Irish ME/CFS Association is pleased to announce the following two talks as part of its ME Awareness Month activities in May by **Dr. Abhijit Chaudhuri** from the UK. The talks will include questions-and-answers sessions.

Admission is E5, on the door, to help towards the costs of organising these two meetings, and **Dr. Chaudhuri**'s trip.

- Saturday, May 30: 2:45 pm, **Connacht Hotel** (formerly Carlton Hotel), Dublin Road, Renmore, **Galway** City. Hotel tel: 091 381 200. http://theconnacht.ie/ Free parking.
- Sunday, May 31: 11 am, **Carlton Hotel** Dublin Airport, Old Airport Road, Cloghran (Santry), Dublin Airport, Co. Dublin. Hotel tel: (01) 8667500. E-mail: info.dublin@carlton.ie . Free parking.

Dr. Abhijit Chaudhuri, consultant neurologist at the **Essex Centre of Neurological Science**, is now arguably the leading practising neurologist with an interest in ME/CFS/post-viral syndromes in Great Britain and Ireland.

Research on fatigue in common neurological disorders is the main theme of **Dr. Chaudhuri**'s work. He takes special interest in myalgic encephalomyelitis (ME) and did his PhD thesis on it. His other areas of interest are multiple sclerosis, neuroimmunity, neurological infections and adult neurometabolic diseases. **Dr. Chaudhuri** was involved in research looking at the spinal tissue of a few patients with ME

For more information, contact:
Irish ME/CFS Association,
PO Box 3075,
Dublin 2.

Tel: (Dublin) 2350965
Email: info@irishmecfs.org
Website: http://www.irishmecfs.org

Do please invite others from Ireland to this event.

Northern Ireland

InvisibleME Symposium - Belfast
This meeting took place in Riddel Hall, Belfast, on Monday 23rd February at 6.30pm. Details of the background to the meeting can be found here:

http://sallyjustme.blogspot.co.uk/2015/03/invisibleme-symposium.html

"One of the speakers being Iain Deboys, Commissioning Officer for the Health and Social Care Board. It was very clear that he had been moved by the patient testimonies, and that he appeared to agree that care in N.Ireland was decidedly lacking. He also said he recognised that there was a problem getting GPs to read and implement guidelines about these conditions.

His solution was to suggest an expansion of a Condition Management Programme (CMP) that has been trialed by the Northern Trust.
http://www.northerntrust.hscni.net/about/2287.htm

Joan McParland, **Antoinette Christie** and **Jeannette Marley** followed **Mr Deboys** out the door to put their questions to him in the corridor! **Joan** had had the foresight to bring a sheet of typed out questions with her, which she handed to **Mr Deboys**, requesting that he make a written reply.

She also demanded that the **Northern Trust** claims that, "many people" have gone back to work after completing the condition management programme, be removed from online descriptions of the programme.
http://www.northerntrust.hscni.net/about/2287.htm

She told **Mr Deboys** that she had Freedom of Information replies that clearly demonstrated the fact that only ONE person had returned to full-time employment to date! He agreed that the word "many" should be deleted."

Northern Ireland Leads the Way!

Newry & Mourne Group are delighted to announce that senior officials from the Health & Social Care Board & Public Health Agency will attend the 10th Invest in M.E. Conference in London on 29th May 2015!

N&M offered sponsorship which was declined but the invitation was graciously accepted!

Our Medical Adviser, Dr. W.Weir has also been sponsored to attend for the third year.

Speakers at this prestigious event will include lead researcher Mady Hornig presenting the major breakthrough for immune signatures in the blood. This points to distinct disease stages and opens the door to better diagnosis and treatment.

STOP PRESS!

Newry & Mourne ME Fibromyalgia Support Group
is delighted to announce that we have a new

PATRON:
THE COUNTESS OF MAR

"The countess of Mar is delighted to be able to accept the invitation of the Newry and Mourne ME and Fibromyalgia Support Group to become one of their patrons.

She is aware of the enormous amount of work done by the Group, whose members, many of them ME or fibromyalgia sufferers themselves, do their utmost to help each other and to inform the public about the severity of these conditions. She applauds them for their campaign for a specialist ME and fibromyalgia clinic in Northern Ireland"

The Netherlands

The Dutch Citizens' Initiative

Step by Step

We informed you on a regular basis about the Dutch citizens' initiative Recognize ME as a biomedical disease. This is an initiative of ten independent (seriously) ill ME-patients, the Groep ME Den Haag, who have already had a far reaching influence and probably will continue to do so.

In the last issue of the ME Global Chronicle we reported: "Promises have been made to the Group ME The Hague that they will speed things up in order to enable a start in 2015 instead of 2016. Both the Health council and the Commission share this thought. In this way the Commission makes good on the promise that was made to Group ME The Hague on 28 May 2014."

On 10th March the House of Commons took the decision to ask (new) advice about ME from the Health Council. This council is an independent advisory body of parliament. This decision was instigated by the citizens' initiative, organized by the Groep ME Den Haag which had been signed by 56.000 Dutch citizens.

In accordance with the wishes of the Groep ME Den Haag, MP's asked the Health Council to especially focus on the following issues:

- Definition of ME and diagnostic criteria
- Origin, progress and prevalence of the disease
- Possibilities to prevent and treat ME
- Impact of ME on patients and people concerned and their participation in society
- Organization of treatment(s) and support of patients with ME in the Netherlands
- Current scientific developments and perspectives

Moreover the MP's indicated that they would appreciate it if the Health Council was to start formulating their advice in 2015, instead of 2016 as was initially planned, which meanwhile has been vowed by the Health Council.

In the meantime the Groep ME Den Haag also sent an extensive letter to the Health Council to bring a number of issues to their attention. The Groep makes a plea to focus on ME as a biomedical disease, the use of the right diagnostic criteria (ICC), to formulate an advice based on the three pillars of evidence based medicine: scientific outcomes, clinical proof and patients experience, and to ensure a proportional contribution from patients and their representatives.

Moreover to pay extra attention to patients with severe ME who are never heard or researched and to include the most recent research outcomes.

The current situation in which there is a lack of knowledge about ME with authorities and medical examiners has been underscored in their letter, and a list of international experts on ME has been attached.

ME-conference in September 2015

On Saturday September 26, 2015 the Dutch ME/cvs Vereniging is organizing a conference on ME to celebrate its tenth anniversary. The aim is to contract eight speakers, each giving a speech of about half an hour on different aspects of ME, after which questions will be answered.

Speakers who already confirmed their participation are **Dr. Byron Hyde**, **Dr. Nigel Speight**, **Christine Tobback** and **Prof. Frans Visser**.

The conference is not only meant as a show of gratitude to the faithful members of the association, but to inform as many healthcare professionals as possible about the complexity and severity of ME.

In the next two issues of the ME Global Chronicle they hope to inform us with more details.

Dutch celebrity and patient **Sonja Silva** is organizing an ME-day for the fourth time on May 10, 2015 from 2-5 pm at Boerderij Langerlust in Amsterdam. There will be music by her and her husband **Pyke Pos** and his band, and Dutch cardiologist and ME-expert **Prof. Visser** will give a talk and answer questions.

The access is free, as usual, and an ambulance of the Dutch organization Ambulancewens will transport two bedridden patients from door to door.

Info & sign-up: wereldmedagbenefiet@live.nl

United Kingdom

Our newly funded projects

We recently funded two new investigations – one at the **University of Dundee** looking at Nrf2 activity and its link to oxidative stress http://bit.ly/1DeLYAr, and the other at the **University of Leicester** investigating the impact of visual problems on reading http://bit.ly/1DTyisR.

Muscle cell abnormalities

An ME Research UK-funded study from the **University of Newcastle** http://bit.ly/1Gq2Nbf published by the international journal **PLoS ONE**, and it makes fascinating, if complicated, reading. The authors examined cultures of isolated skeletal muscle cells from ME/CFS patients and controls, and used electrical pulse stimulation for up to 24h to simulate an 'exercise challenge' in the laboratory. Their evidence points to an exercise-related, primary abnormality in the muscle of ME/CFS patients which, because it was observed in cultured isolated muscle cells, could well have a genetic or epigenetic basis.

Publications from funded studies

Five new research papers from studies funded by **ME Research UK** have appeared in the scientific literature in 2015. This brings the total number of **ME Research UK**-funded research papers to more than 60, and you can read their abstracts, often with extended essays from our team, at our 'completed research' pages http://bit.ly/1acrkxx.

Breakthrough" magazine

Our Spring 2015 "**Breakthrough**" magazine has gone out free in the post to friends and supporters, and the electronic edition will be available shortly, along with past issues http://bit.ly/1oHZELa. The contents of this issue include: Oxidative stress; Reading difficulties; UK ME/CFS Biobank established; Vitamin D and arterial stiffness; Gene SNP analysis at the **University of London**; Epigenetics and immune dysfunction; Brain abnormalities in ME/CFS; Research Collaborative Conference report. Plus research "bites" on faecal transplants, gynaecological problems, diagnosis in children, "Robust evidence" of biological illness, link with Alzheimer's, midbrain nerve conduction. If you would like to receive a free hard copy in the post, please email us with your address.

Call for research applications

ME Research UK actively encourages researchers to send their ideas for new studies, and in 2014 we issued a call for applications for ME/CFS research funding from active research groups across the world http://bit.ly/1ziWbdk. This was successful, and a range of outline and full applications have been undergoing our review processes. We hope to announce the new projects shortly. The call remains open, so if you know of researchers who might like to apply, please send them the link!

The Countess of Mar at the Royal Society of Medicine
A short summary of **The Countess'** talk on 'The Politics of ME' to the **Royal Society of Medicine** is now on our website http://bit.ly/1xcKSmC. She told the assembled professionals how extraordinary it is to her that men and women who are trained to 'first do no harm' and to 'listen to the patient' seem to remain aware of the enormous damage they are doing to a very large number of patients with this condition.

Walk for ME 2015
'Walk for ME' is a great initiative created to raise awareness and funds for ME charities. There is no minimum distance, no targets and, although it runs principally through ME Awareness Week (11th to 17th May 2015), no set dates. You choose when you wish to walk, the distance, the location and the charity to support. More details can be found on our website - http://bit.ly/1aiRPBP. **ME Research UK** Ambassador **Rochelle Hanslow**, husband, and **Vader** the dog have signed up for **Walk for ME 2015** and will take the stunning **Abbey Trail** around the **Wallace Monument** near **Stirling** next month. And **Emma Griffiths** will be walking a mile along **Helensburgh** riverfront for us.

Submitted by
Dr Neil C. Abbot

U.K. Nurse of the Year

On 20th March 2015, **Greg Crowhurst** was awarded third place in the prestigious **BJN Nurse of the Year Award**. This is an amazing achievement for an unwaged Carer, isolated from the world by the necessity of caring full time for me, his wife, with Very Severe ME.

We were both stunned and excited to hear that he had been short listed. For it meant not only an acknowledgement of his own compassion and commitment over two decades to Severe ME, but also it feels like an important, much needed breakthrough, in recognising the needs and neglect of the neurological disease Myalgic Encephalomyelitis and the people most severely affected in particular.

We hope it shines a light on the truth: that we are seriously physically ill and isolated from mainstream medicine, that our physical health is at risk all the time that nurses and the medical profession generally do not understand or properly recognise our illness and understand how to care for us. It acknowledges there is a need and **Greg** has been raising awareness and shining a light on that need repeatedly till it has been seen and recognised, by this main stream prominent event.

Greg has always had a passion for truth and an enthusiasm for life and learning that continually pushes himself to grow and develop new skills, new perspectives, to reach out in love and understanding, to forge genuine and caring relationships with all he meets, to develop new and better understanding and to challenge both himself and others to recognise their own skills and abilities, to be better professionals, to understand and empathise as much as possible with some of the most vulnerable people in the care and health care system.

This is demonstrated clearly in the many ways he has tried to engage with the medical world, the political world and society generally, to raise awareness of our illness and its clinical neglect, to continually counteract the misrepresentation, misinterpretation and misdirection and mistreatment that is rife.

Some of the ways **Greg** has supported us all:

- The Secretary of the 25 % group for many years, including writing many documents, papers and articles on Severe ME and Carer issues. http://www.25megroup.org/
- The Gibson Inquiry Severe ME Survey and much remembered presentation. http://www.erythos.com/gibsonenquiry/
- The EAME survey. http://www.stonebird.co.uk/eame.doc
- The Stonebird website http://www.stonebird.co.uk
- Homebound Music website http://homeboundmusic.co.uk/
- Holy Way website http://www.holyway.co.uk/
- Free Carer Documents
- Two Severe ME books with a third book specifically for carers coming soon, plus three spiritual books and many, many articles. http://www.stonebird.co.uk/severemebook/severeme.html
- The only peer reviewed article on Severe ME, recommended by NICE. http://me-foreningen.com/meforeningen/innhold/div/2012/08/Crowhurst-Severely-affected-i-Nursing-Standard.pdf
- A new, innovative free Severe ME App on the MOMENT approach. http://www.stonebird.co.uk/moment/index.html

This is what **Greg Crowhurst** has done within the field of Severe and Very Severe ME, where there are no reference books, where there is no body of medical expertise, where there is no cure, no treatment, little or no respect, where many kill themselves not from despair or depression but from sheer physical torment and medical neglect or die from severity of symptoms, underlyingly because of a lack of interest and input from the research and medical community, from the cover up that has gone on for the last three decades of a neurological disease, where life is desperate in every moment of every day, yet health care and services are weighed on the balance of belief: whether an individual practitioner, shockingly, believes the person is physically ill or not:

Greg has represented us down all the decades of my tormenting physical disease. He has witnessed first hand the misinterpretation, arrogance, harm, abuse, neglect, denial, mistreatment, misinformation, because he has cared for me full time day and night through all this time and come to have a unique and intense experience of the truth of the disease Myalgic Encephalomyelitis and its cover up and misdirection by fatigue interpretation, all the time fighting for change and hope for myself and everyone else.

FEW know the true nature of the suffering of Very Severe ME, where too quick a movement, a quiet noise wrongly timed, an action, even slightly wrongly executed, can have devastating physical consequence, leading to increased symptoms and deterioration. **Greg Crowhurst** is one of the people who absolutely does know and has not been afraid to do something about it. He has always promoted a pathway of partnership and respect. He has learned the only way to support and be with someone very hypersensitive with Severe ME, is to approach with profound flexibility and patience, waiting for the right MOMENT to interact and help meet needs gently and tenderly.

Many people backed **Greg**, not just nationally, but internationally, both organisations and individuals. His application was moving and humbling in the breadth and depth of comments supporting his work. We are so grateful to them all, especially knowing the effort it will have taken those who are most severely ill, yet even so, came to his aid. The whole ME community can be proud of this acknowledgement. It demonstrates the true meaning of a partnership approach. Together, speaking the truth, we can be seen, heard and recognised.

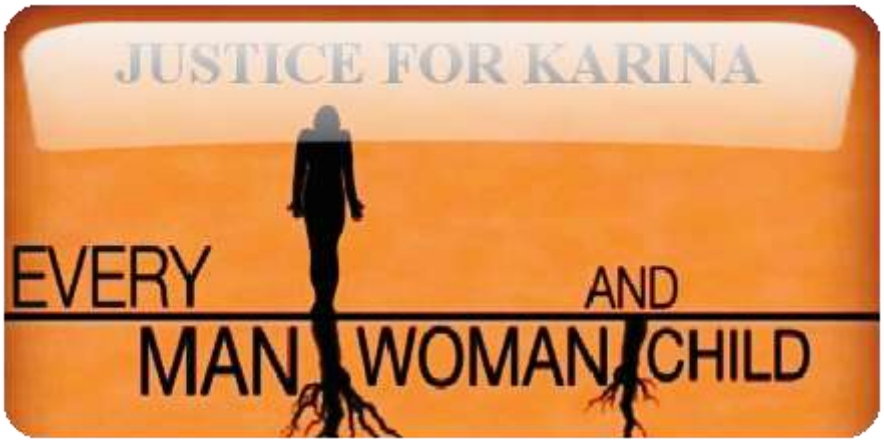
Let us all celebrate that third place in a major Award ceremony is a huge achievement. Let us all be inspired by this and aim to reach higher still in getting our voices heard.

Let us not forget that **Greg** represents the unseen, the hidden, the ignored, those unable to be reached, often without help or misunderstood and continually shows he cares, he knows, he sees, he understands and he fights for a better system, founded on the truth and true nursing practices inspired and initiated by **Florence Nightingale** herself. **Greg** is a true nurse who deserved acknowledging for his total and utter commitment to nursing and to people with Severe ME.

Well done **Greg** and thank you. I am so proud of you!

Linda

12. Vote For…



https://secure.avaaz.org/en/petition/Justice_for_Karina/share/

Karina suffers with severe Myalgic Encephalomyelitis meaning muscle pain with inflammation of the brain and spinal cord.

ME is a neurological disease as noted with the World Health Organization (WHO) G93.3. Every country who belongs to the United Nations must abide by the WHO description of what is a physical disease as well as the United Nations Human Rights.

Demark is holding Karina against her will and forcing her to take part in treatment which can kill her.

Denmark believes that ME is the same as Insanity which is not how ME is described in WHO G93.3. Denmark is a member of the European Union, United Nations, Human Rights and WHO.

If any of you knows about a petition running or a Group participating in a contest, or any topic worth publishing under this heading, please let us know.
*Next issue will be published on **April 22, 2015**, so the actions which will be brought under our notice should still run by then.*

---

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: $6,840.00 Goal: $20,000.00
Info: http://www.gofundme.com/5yhjdo

Donate to our YouTube channel here: http://www.gofundme.com/MECFSAlert

By donating to our GoFundMe page, you can fund future episodes of ME/CFS Alert and aid us in our goal of comforting the sick, educating the doctors, and shaming the government.

Ian Lipkin study. Raised: **$220,712 from 1,116 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 **£377,000**. 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

http://walkforme.co.uk/how.html

Support the very active Northern Irish **Newry & Mourne group** Please consider supporting Newry and Mourne ME Fibromyalgia Support Group with EveryClick by using the link below. There is a free service and no charge is made to any purchases you make online by signing up to Everyclick! http://bit.ly/1zGUVzj

I am a Trustee for this charity and we are campaigning for a specialist ME & Fibromyalgia clinic in N.Ireland. Trustees were awarded the Patricia Graham 'Shining Light Award' in 2013 for community volunteering.

Joan McParland

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

Since last issue of the ME Global Chronicle an amount of **€ 123,32** has been received from most generous donators. **€ 180,64** has been spent to cover the expenses of a lawyer of the mother of **Joanne**, the 14-year old German girl who is kept in a hospital against her wishes to undergo treatments a psychiatrist is imposing upon her. A credit balance of **€ 188,03** remains, but **Joannes** mother is still proceeding against the forced hospitalization of her daughter, and to retain her rights of visiting her.

As reported in the one but last ME Global (http://let-me.be/download.php?view.10 , p.40) we were no longer in a position to publish details about **Joanne** due to the untimely disclosure of her true identity and the restriction imposed on her mother not to have published anything about her daughter on the internet.

However information has been given recently, which we published in this issue in the article about **Joanne** on page 69.

So please continue to donate, and if any a case like **Joanne**'s is known to you, please let us know via info@let-me.be

We thank those of you who donated from the bottom of our hearts.

The editors

14. Worth Noticing, Watching, Hearing & Reading

Important appeal

Each year we ask for your help to let our elected representatives know about May 12th International Awareness Day and our illnesses. It's important that they know as we depend upon them to arrange for funding for research and services that we required.

Canada has created instructions and a draft email you can use. It's available at http://www.bit.ly/May12th2015EmailCanada.

If you don't live in Canada, feel free to copy their email and amend it for your country. If you draft something for your country, let us know at info@may12th.org and we'll post it for others to use. With your help, we can develop letters and instructions for all countries.

Also, please forward this to as many people as possible. Friends and family can send a note to their representatives on your behalf.

Thanks for your support

Submitted by Jack Elliot on
http://www.facebook.com/events/1687966454755997/ , created by him.

Science to Patients webinars have been viewed 199.999 times on Sunday, April 19, 2015!

New webinars of the Dutch project Science to Patients:

Starting a series of short talks of **Prof. Alan Light**, **University of Utah**, Salt Lake City:

Webinar 58: Fatigue on March 24, 2015
https://youtu.be/OAv3vhCL2pU
Webinar 59: Genes & gene-expression on April 7, 2015
https://youtu.be/ghUtM44yfm0
Webinar 60: Gene expression markers of ME/cfs on April 21, 2015
https://youtu.be/6G4hJDlk-mk
All Science to Patients-webinars to be viewed on http://bit.ly/1sn1pAA

Link to

ME/CFS Alert

all videos:
http://t.co/Cg18CVnwhb

Llewellyn King, ME/cfs Alert, produced by **Llewellyn King** and **Deborah Waroff**:

ME/cfs Alert, episode 73
March 16th, 2015
https://youtu.be/Ny6MPUCtwjs

Llewellyn King sits down with **Dr. Mady Hornig**, Director of Translational Research, Center for Infection and Immunity, to discuss the latest developments in MECFS research. **Dr. Hornig** talks about the possibility of diagnosing ME with blood tests; differences in immune system responses across early and late-stage ME patients; her input on where ME research should be better funded; and further insight into the psychiatric/somatic divide within and beyond the ME community.

http://youtu.be/X4Tnt2d-5S8
Dr. Lucinda Bateman on SEID & Fibromyalgia, followed by questions & answers

Quality not too good

Neurology Today on S.E.I.D

http://bit.ly/1EDCTyM

SMCI 2015 Webinar Series

The Solve ME/CFS Initiative (SMCI) will be bringing you a free webinar series throughout 2015

The first webinar with **Dr. Lucinda Bateman** has been broadcast on 17th April: https://www.youtube.com/watch?v=359XmpNBHM8

All sessions take place at 1 p.m. Eastern/10 a.m. Pacific and will be less than an hour long.

The 2015 schedule includes:

Friday, April 17
Lucinda Bateman, MD: Director, Fatigue Consultation Clinic and Co-Founder, Organization for Fatigue and Fibromyalgia Education and Research (OFFER)
"Will SEID Diagnostic Criteria Improve Diagnosis and Treatment?"
View **Dr. Bateman**'s presentation on our YouTube channel.http://bit.ly/1G6Q5Ql

View **Dr. Bateman**'s PowerPoint here: http://bit.ly/1zFGbO7
Will SEID Criteria Improve Dx

Thursday, June 18
Lily Chu, MD, Co-Vice President, International Association for ME/CFS

Thursday, July 16
Peter Rowe, MD, Director, Chronic Fatigue Clinic, Johns Hopkins Children's Center

Thursday, October 15
Alan Light, PhD, Research Professor of Anesthesiology, University of Utah

Thursday, December 17
Solve ME/CFS Initiative Year-End Research Review
Additional dates and speakers will be added, so check back frequently.
Anyone can RSVP (http://bit.ly/1D9hGJg) to participate, but space is limited so register now.
Each webinar will be recorded and posted to our website and YouTube channel within a week of the live date, so you will have access to the great content at your convenience.
Source: http://solvecfs.org/smci-2015-webinar-series/

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

Is ME Stable?
M.E. is not a stable illness. One can probably observe people with some illnesses carefully for an hour or so and collect a lot of good information about what they can and can't do, how severe their illness is, and what their usual symptoms are from day to day, and so on. However M.E. is not one of those illnesses.
Listen to this audio-message of the Hummingbird Foundation, and let others who are unfamiliar with ME listen to it:
http://youtu.be/k4FPLTHrpe4

If you're suffering from **food intolerances** or for other reasons may have to take good care of your diet it might be interesting to take a look at this new site of the ME research UK: http://bit.ly/16LswMS

Understanding M.E - A Guide For Friends, Family & Carers
A practical paperback

Being an 'invisible' illness, makes ME even more difficult. This book aims to help a non-sufferer understand the nature of the illness, in plain English.

Not really expensive (£2.75 from Amazon, excl. p&p), and as the author, British ME-patient **Hayley Green** writes: "I have seen time and time again, and experienced myself, people we know not understanding our illness. I have published a guide suitable for friends, family and carers to help them understand.

It has been written specifically and in such a way for non-ME sufferers to see how our symptoms and limits affect us.

25% of all Royalties to Invest In ME! "Let's do it for ME!"

Contains five chapters, logically built up:
1. What is ME?
2. Understanding symptoms
3. Understanding Limits
4. How to help
5. Facts & Quotes

To be ordered at Amazon: http://amzn.to/1M9BTH6

15. Poem – It's okay

It's okay
for me
to be kind
to myself.

It's okay
to be wrong.

It's okay
to get mad.

It's okay
to be flawed.

It's okay
to be happy.

It’s okay
to move on.

Hayley Williams

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."