The ME Global Chronicle

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5 - June 2014

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Textual contributions for the August issue need to be supplied in Word by August,10th and sent to: contribute@let-me.be
The next issue will come out on August, 27th,2014.

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We are no association or society, just a bunch of idealists who want to give our best efforts towards recognition of this terrible disease. By trying to help connecting to each other all patients all over the world. Anyone who expresses the wish to receive the Newsletter will be added to the list: that's the only formality and thing to be done. subscribe@let-me.be –
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Cartoon page 42: ***Djanko***

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Abolishing and obliterating all frontiers
Because **Sophia's** death has hardly changed a thing

Or maybe things unseen
Let's make them visible

Let's use this Chronicle for it, it is at your disposal.
Let's use any tool for it, they're there for all of us.
As long as we stand in unison.

Need a reason?
Just look at this: http://youtu.be/IOflARSgNnE

Good and bad news in the June-issue of the **ME Global Chronicle**.

American **Justina Pelletier** has been released from custody in Boston Children's Hospital and has returned home again on 18th June: however 14 year old German girl **Joanne** is still in custody in a hospital ward and being more or less tortured to death, and around the Danish girl **Karina Hansen** there's dead silence.

The HHS, IOM and P2P are continuing their pathways to a new definition of ME, but are being watched closely by the American ME/CFS community. **Llewellyn King** sent a powerful memo to some 30 patient advocates which is being developed into a powerful initiative. Read all about it in this issue.

Our editorial staff has become twice as large and more and more of you start participating by sending in contributions or drawing our attention to important links and information.

Thank you all so much, and keep doing so!

Next issue will be published towards **27th August**.
Written contributions in Word before **10th August** to contribute@let-me.be

Preface

Dear reader,

We are happy to submit the June 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 Summer is upon us again, in northern Hemisphere countries, and for many patients this is a welcome relief from the cold and damp of Winter and a wet Spring. Bright Summer days and colourful balmy evenings, the warmth of the sun, the intoxicating, sweet flowery, perfumed air, the enchanting sounds of diverse birds and the blossoming of nature bursting forth brings out a sense of optimism in people. It lifts spirits and encourages hope.

There continues to be positive developments in the ME world. The presentations and research results from the IACFS/ME Conference in Stanford University (USA) were impressive, and the Japanese findings on neuro-inflammation have confirmed that ME is indeed a neuro inflammatory illness.

These findings will be replicated in future studies. **Dr. Komaroff** spoke of new findings regarding Leptin and its relationship to many cytokines involved in ME. He also presented a Cytokine-by Cytokine Analyses of the Controls, Mild Cases Moderate Cases and Severe Cases and matching this against symptom severity. These are revolutionary new development in the research of the illness.

The Immunology Primer for Practitioners at the Conference also provided an excellent analysis of immunology and immunological markers in ME and stimulated some good discussions among the doctors and researchers present. Other posters at the conference gave more detailed accounts of post exercise malaise markers in ME, citing some reliable markers. It was a first rate conference and we, ME patients and advocates worldwide express our deep gratitude and appreciation to the conference organisers and to those who presented at the conference.

The Invest in ME Conference held in London will also be reported on here. These conferences also tend to be excellent and first rate. The Rituximab clinical trial in the UK has raised over **£338,000** and is quickly reaching the **£350,000** mark. This is a very important clinical trial, of great strategic importance, which will have a great bearing on patients worldwide. We urge patients and their families and advocates to make a contribution to this worthy project at: http://www.ukrituximabtrial.org/IIMEUKRT%20Donate.htm

One thing we have drawn from these conferences and from the 5,000 research papers is that there are some biomarkers for subgroups, though no one universal biomarker for all subgroups and the illness itself.

Identifying subgroup biomarkers is possible given our present understanding of the illness, and would greatly inform and assist the type of treatments given. I think it would be fair to say that we should work with what we have got.

On this note, some letters have been written into the FDA asking for them to legalise and designate medical drugs for subgroups of ME. For example subgroups which respond to **Ampligen** and subgroups which respond to **Rituximab** and subgroups which respond to **anti-viral** and/or **anti-mycoplasma** and **anti-bacteria** medicines.

There are dissenting voices who say biomarkers do not exist, and cannot exist, and we must wait another 10 or 20 years for biomarkers. In this, they are in agreement with a certain well known, often disliked psychiatrist and his school of psychiatrists.

We could waste another 10 or more years presuming there are no biomarkers and that the scientific research of the last 20 years amounts to nothing, but the list of deaths would increase and grow even more, or we could accept the fact that some subgroup biomarkers do exist for subgroups.

And use this to save the lives of patients in some subgroups. Saving lives, improving lives, giving hope - this needs to be at the core of our ME organisations and group activities worldwide.

A special thanks here to **Rich Podell** and **Lenny Jason** for their contributions and insights. The next edition will be due on August 27th 2014

David Egan

Rich' Reviews: Which CFS-ME Patients (If Any) Should We Treat With Antivirals?

Several prominent CFS specialists are treating selected CFS-ME patients with anti-viral drugs such as Valcyte (valacyclovir), Valtrex or Famvir. This treatment is directed against Herpes class viruses such as Epstein-Barr Virus (EBV) and Human Herpes Virus-6 (HHV-6).

Their anecdotal experience has been encouraging. However, patient selection has been difficult because we lack a well validated lab test to distinguish an inactive asymptomatic latent EBV or HHV-6 from a reactivated virus that might be causing symptoms. After all most healthy people have IgG antibodies against EBV and/or HHV-6. We tend to infer that those with the highest antibody levels are more likely to have active infection; but, we don't really know if this speculation is true.

This month, I will review the best controlled study testing Valcyte as a treatment for CFS-ME. Its senior author, **Jose Montoya, M.D., is professor** in the division of Infectious Disease at Stanford Medical School. The results of this study are encouraging but not conclusive—in part because of the study's small size. However, I am impressed that since the study's completion **Dr. Montoya** has continued to treat patients with Valcyte. He believes that Valcyte helps a substantial proportion of his highly selected patients. A co-author, **Andy Kogelnik, M.D.**, who now practices in Mountain View, California, also uses Valcyte, reporting favorable results.

In 2006 **Montoya**, **Kogelnik** and their Stanford colleagues, treated twelve CFS-ME patients with Valcyte for 6 months.
(http://www.ncbi.nlm.nih.gov/pubmed/17276366).
The encouraging results from this open study allowed them to obtain funding from Roche for a small but well-designed double blind trial of Valcyte.

Twenty Patients received Valcyte for six months. Subjects were selected because they had very high IgG antibody levels against both EBV and HHV-6. Ten patients received placebo. (http://www.ncbi.nlm.nih.gov/pubmed/23959519).

Helpful Hint: To download the full paper first go to PubMed.gov.
From there go to the publisher's site (**Wiley**).

Click on "View Full Article With Supporting Information HTML".

Unlike the usual procedure, **Dr. Montoya** arranged with **Wiley** that this download is **FREE!**

The primary end point of the study was a 20 question self-report questionnaire, the MFI-20. (The MFI-20 questions and other supplemental information are available with the **Wiley** download. But the supplements are not included if you request the paper from PubMed.gov.)

The MFI-20 answers were analyzed in two distinct ways. One way used standard statistical analysis. The other used the identical data points from the MIF-20 for review by four blinded physicians. The physicians were asked to judge which patients had significantly improved. The distinction between these two different methods of analysis turns out to be very important.

Using standard statistical methods the total MIF-20 score documents a trend towards improvement with Valcyte compared to placebo; but this difference was not statistically significant.

In contrast, the blinded physicians' interpretation was very encouraging. Using the same MFI-20 questionnaire answers, the blinded physicians judged that subjects treated with Valcyte were 7.4 times more likely to be classified as "responders" compared to those on placebo (P=.029).

Also encouraging: The MFI-20 contains a subgroup of questions that focuses on mental/cognitive fatigue. The mental /cognitive scale, when analyzed by itself, showed significant improvement for those taking Valcyte. (P=.039). A secondary end point, the Fatigue Severity Scale (FSS) also showed significant improvement.

Dr. Montoya was kind enough to discuss the study with me. He believes that the blinded physicians' judgments gave relatively more weight to the mental/cognitive related questions of the MFI-20. His educated guess is that patients who felt better cognitively tended to become more active physically. This, in turn, could have reduced their degree of improvement on the physical fatigue scores.

Side effects: Valcyte is FDA approved to treat Cytomegalovirus (CMV) in the context of HIV or Organ transplants. In these populations serious side effects from Valcyte are very frequent.

In contrast, in the CFS-ME study, Valcyte was well tolerated. No patients had to be dropped due to adverse hematologic or hepatic events.

Other key points:
Dr. Montoya's clinical sense is that treatment longer than six months may give better results than the six month cut-off used in the Study. Clinically, with longer treatment a substantial number of patients appear to improve, in some cases dramatically.

Dr. Montoya's current monitoring protocol includes CBC, CMP, urinalysis and physician visit at baseline, and then monthly. During the study he required weekly labs during the first month. However, because early lab abnormalities did not occur during the study, he now requires labs only at baseline and then monthly.

In contrast to the study, which used an initial "loading dose" of Valcyte 900 mg bid, and then 450 mg bid, **Dr. Montoya's** current clinical practice starts with Valcyte at only 450 mg once daily for the first 2 to 4 weeks and then continues at 450 mg bid.

Clinicians should note that many of the CFS patients got worse during the first month or two on Valcyte. Among these a substantial proportion improved as the study went on.

Physicians using Valcyte for CFS-ME should offer patients a detailed written informed consent. This should include the fact that Valcyte can cause cancer in animals. It is not known whether Valcyte increases cancer risk in humans. CFS by itself has been associated with increased risk of lymphoma. **Epstein-Barr virus** has been associated with lymphoma. Might treating EBV reduce the risk of lymphoma among patients with CFS-ME? This has not been studied.

Please note: the patients in **Dr. Montoya's** study had very high IgG G antibody levels against both EBV and HHV-6. Only about 15-20% of the CFS-ME population has antibody levels this high.

I have not treated any patients with Valcyte. However, considering my work on this essay and discussions with **Dr. Montoya** and **Dr. Kogelnik**, I am likely to treat selected patients—if they fully understand the limitations of current data and the potential risks involved. However, even so, Valcyte is very expensive, It is not FDA approved as a treatment for EBV or HHV-6. Therefore, obtaining coverage from insurance is likely to be difficult.

Please note that **Dr. Montoya**, **Dr. Kogelnik** use Valcyte or Famvir on some patients, although they prefer to use Valcyte when they can. Valcyte and Famvir tend to be less expensive and are perhaps more likely to be covered.

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

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

http://www.DrPodell.org

9th Invest in ME Conference
A Short Survey

London, May 30, 2014

The English non-profit patient organization Invest in ME invited leading ME scientists and researchers from all over the world to speak at a one day conference in Westminster, London, on May 30, 2014.

After showing the trailer of a brand new Norwegian documentary on very ill patients, panel chairman **Dr. Ian Gibson** opened the Conference shortly after 8 a.m., announcing **Prof. Jonathan Edwards** of the University College, London.

He and his team completed trials on inflammation with RA-patients, many of whom had suffered over 20 years from Rheumatoid Arthritis. With a new combination of drugs he scored significant improvements for 20 out of 22 patients. As **Rituximab** is being used in RA, **Prof. Edwards** has been striving for two years to get a replica study done amongst sufferers of ME/CFS in the United Kingdom, to verify the findings of **Profs. Mell**a and **Fluge** in Norway.

Prof. Angela Vincent, Emeritus Professor of Neuroimmunology at the University of Oxford, talked about the finding of antibodies in neurological diseases, such as Myasthenis gravis, a B-cell mediated autoimmune disease with dysfunction of the acetylcholine, which is involved in the chemical signaling between nerves and muscles. She found that after changing plasma a significant improvement occurred

Prof. Jonas Blomberg, Emeritus Professor of Clinical Virology at the Uppsala University in Sweden, is looking specifically for antibodies to cellular bacteria and their relationship with the mitochondria. In his research for ME-triggers he concentrates on the role of IgM, and especially the occurrence of Chlamydia pneumonia.

He's looking at the genes involved in the immunity against infectious diseases, the HLA. Dysfunctions in the HLA DR1 for example cause Myasthenis gravis. A cross reaction between bacteria and viruses is possible. It's customary to study antibodies against bacteria than the microbes themselves.

Prof. Mady Hornig, from the Center for Infection and Immunity at Columbia University, New York, told us the blood brain barrier has the function of protection, but that it may not be effective for blood from the ventricles circulating through the organs.

Many signs indicate an autoimmune response in ME subgroups and some evidence of antibodies attacking the brain. There may be major dysfunctions in the gut in many diseases, and changes in the microbiome may be significant in illness or disease development / progression.

Autoimmune dysfunctions may be caused by deficient absorption of dietary precursors of antioxidants in the terminal ileum. Microbiota are important in the degradation of tryptophan, and also influence the melatonin production.

Prof. Carmen Scheibenbogen from the Institute of Medical Immunology of the Charité Hospital in Berlin, is specialized in the EBV-pathways. Its DNA can be traced in the blood. Part of the infection subsides from treatment with antivirals, but it is a lifelong mostly latent infection, which can reactivate in future. B-cells with a specific EBV-memory are less prevalent in many ME-patients, or not at all. Her second research is directed towards measuring the reactions of antibodies to over 200 peptides on activation of the EBV.

Compared to controls, ME patients show an increased level of antibody response against EBV-peptides. All this might well be the basis for developing diagnostic tests and treatments.

Prof. Simon Carding of the University of East Anglia and the Institute of Food Research used Powerpoint slides to describe the structure and barrier function of the gut, which with their length of nine meters form the longest immune system of the body, and are also described as our 'second brain'. The gut is home to a hundred trillion microbes, from bacteria to viruses to fungi. 99% of our DNA in origin is microbial.

Prof. Carding explained the gut-brain axis. Dysfunction of the gut microbiome is associated with Autism and Major Depressive Disorders. Treatment with probiotics of mice with autistic features had a great impact. Bacteria can cause a breach in a leaky gut. IBS is quite common in ME, which may be connected with autoimmune reactions. As stated here and in other Conferences and research papers, probiotics may play an important role in ME and other illnesses.

Prof. Sonya Marshall-Gradisnik is one of the foremost researchers in Australia in the field of Neuroimmunology. She has discovered considerable changes in the NK-cells of ME-patients. The severity of the disease seems to be related to these immunological changes.

This has been accompanied by considerable changes in miRNA, which plays an important part in gene expression and bodily reactions to illness or disease. The expression levels of specific miRNAs change in diseases or illnesses and this can be used to differentiate ill people from healthy controls. And also differentiate subgroups. This area will hopefully produce results for ME and CFS in the near future.

Prof. James Baraniuk, Associate Professor, Department of Medicine, Georgetown University, USA presented next. He stated that after the dismantling of a Sarin plant in **Iraq**, **25% of the professional soldiers involved fell ill** in an ever more worsening state. The white matter in the brain is its skeleton, and this was particularly affected. He compared the amount of white matter with the duration of fatigue in ME: within half a year of illness the amount of white matter had already started to decrease. Brain stem atrophies were found also.

Prof. Julia Newton, clinical professor of Ageing and Medicine at Newcastle University, UK, pointed out that the ANS and the vascular system are intertwined. Signs of the ANS go via the brain to the sympathetic nervous system which manages the muscles.

Also in ME there's a dysfunction of the ANS, the so called Dysautonomia which expresses itself e.g. through orthostatic hypotension. This causes a disturbed balance between the sympathetic and the parasympathetic system, the mediators of activity and rest.

She found orthostatic intolerance in 89% of patients, a very high percentage. Doing the Valsalva-test, a simple test based on inhaling and exhaling with mouth and nose closed, she found a decrease of the volume of the liver which is closely connected to the control of the blood pressure.

With ME, high lactic acid levels accumulate within the muscles for prolonged periods after exercise. She measured the intracellular acidity in cultured muscle cells from ME-patients and healthy controls and found a considerable difference in ME patients after exercise. During the pumping of the heart there was exaggerated torsion of the left ventricle.

All her findings affirm that in ME serious abnormalities occur within the brain, the heart and the muscles, although she did find the same within other diseases in which fatigue is experienced. Fatigue is a general concept and may be connected with very specific physiologic abnormalities. Symptoms indicate abnormal functioning of the ANS, dependent on the severity of the fatigue.

Prof. Maureen Hanson from Cornell University, Ithaca NY, is measuring several parameters with a double exercise test, because this really exposes the differences between ME patients and healthy controls.

Some parameters include : Resting exercise rate which is the amount of CO2 exhaled divided by the amount of O2 inhaled, VO2 is the amount of O2 per minute, VO2 max the maximum consummation of oxygen which equates to the level of anaerobic physical fitness.

This survey covers just a few points raised during that long day, packed with information. After **mrs. Hansen** there were speeches of **dr. Amolak Bansal** from the UK, **dr. Andreas Kogelnik** from the USA and **Dr. Julian Blanco** from Spain, a reknown researcher on AIDS.

Much more elaborate information on all this and extracts of their speeches can be read on the high quality Conference Report of **Dr. Rosamund Vallings**, which together with some personal notes also formed the basis of this report, for which we are extremely grateful to her.

Here's the link from the fb-wall of Invest in ME to her report: http://www.investinme.eu/report.html

If you still want to dive deeper into this information, we strongly recommend you'd order the 4-set DVD of all speeches, including **Nigel Speight**'s pre-conference dinner speech, via Invest in ME:

http://www.investinme.eu/2014%20Conference%20DVD%20Order.html

The Underfinanced ME/CFS Research Field Pt II

The Underfinanced ME/CFS Research Field Pt II: Why it Takes 20 Years to Get 1 Year's Research Done

As things stand right now, one could say that it takes 20 years to get 1 year's worth of ME/CFS research done. Why? Because the level of funding allocated for ME/CFS research is 20 times lower than that of comparable diseases.

For example, the NIH spends around $120 million per year on research about MS. The figure for ME/CFS is $5 million per year. (This in spite of the fact that ME/CFS affects at least as many citizens as MS, perhaps even twice as many.) This means that it takes ME/CFS researchers 20-25 years to accomplish what MS researchers can get done in one year.

At this pace, many years of many lives will go by before disease mechanisms, biomarkers and treatment are finally unveiled for ME/CFS. On the other hand, if ME/CFS was granted a level of funding on par with other high-impact diseases, we could quickly see very promising progress.

A case in point illustrating this: In June 2012 the Open Medicine Institute (OMI) convened a round table forum in New York City for 27 international ME/CFS researchers, the OMI-MERIT group. Their goal was to identify and prioritize potential research projects into ME/CFS that could deliver practical results for patients in the shortest amount of time. In 2013 OMI-MERIT published their list of 10 prioritized project that would quickly create ground-breaking progress in the ME/CFS field. They have also estimated costs for these projects.

OMI-MERIT estimates that $13.502 million in total will be needed to complete all of these projects. Some of them are urgently needed, like a confirmatory **Rituximab study**, an international biobank and the search for biomarkers via protein panels and immunologic studies.

At first glance, the figure of $13 million seems large. However, it could easily be covered if the yearly NIH funding for ME/CFS was raised to an equitable level. A budget matching that of MS, $120 million per year, would cover all the OMI-MERIT initiatives ten times over – in just one year!

That way we wouldn't have to wait 20 years for 1 year's worth of research to get done. Keep following this series to find out "What can we do?" in part 3.

Source: **Anne Örtegren**, from Health Rising (www.cortjohnson.org)

Part 3 of this series of articles of Anne will be published in ME Global Chronicle 6. Part 1 has been published in the 3rd issue http://let-me.be/request.php?5, p 32

The OMI to Develop First-ever Biomarkers for CFS

The Open Medicine Institute (OMI) to Develop First-ever Biomarkers for Chronic Fatigue Syndrome and a Range of Complex Diseases

The Open Medicine Institute (OMI), an organization with a mission to improve health care by applying a multi-disciplinary, "big data" approach, today announced that it will begin development of a biomarker for Chronic Fatigue Syndrome (CFS) and other prevalent, chronic but difficult-to-diagnose diseases.

Plans are in place for development of two key tests - a detection biomarker based on RNA expression data from patients and normal volunteers, and a theranostic tool to evaluate treatment efficacy. This is especially critical for CFS as there are no proven diagnostics or treatments and many patients and physicians are currently relying on anecdotal efficacy claims of multiple therapies in their efforts to get well. The proof-of-concept phase of the project has been generously funded by interested Silicon Valley donors and broadly, via the CFS community.

The novel biomarker project will be led by OMI utilizing Affymetrix' microarray technology and platform. "With applications and expertise support from Affymetrix, we are looking forward to developing biomarkers for this enigmatic disease that affects over 8 million people globally," said **Andreas Kogelnik, MD, Ph.D., Founder of the Open Medicine Institute**. "There is so much misinformation about CFS, we need to focus new tools and technologies on this disease to fully understand and treat it."

"Affymetrix is pleased to support OMI on their quest to develop biomarkers for CFS as a model for other chronic diseases – helping to identify difficult to detect conditions and understand and guide treatment decisions," said **David Weaver, Chief Commercial Officer at Affymetrix**.

OMI will also be utilizing the Affymetrix microarray technology on projects covering other complex diseases such as **Autism**.

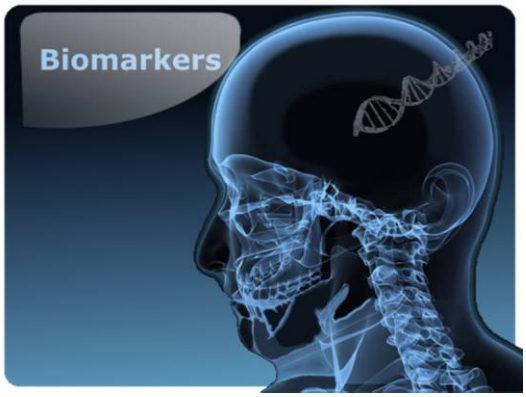
Expanded Core Affymetrix Facility OMI is now an authorized service provider for Affymetrix. In this capacity, OMI will provide research services using Affymetrix tools and technologies to those interested in conducting their own studies. The expanded core facility will also be broadly available to community physicians as a laboratory resource offering research and CLIA-approved testing.

Source: http://on.mktw.net/1lMFTgy

Biomarkers - A Series Of Articles By David Egan

There is no universal biomarker for ME or CFS today, in the present time. The main reason being that both illnesses are very heterogeneous, contain many subgroups, and have yet to be clearly defined and delineated with precision, thus making one universal biomarker almost an impossibility.

In the future, in my view it will be possible to identify universal biomarkers for both illnesses or the constituent illnesses which at present are undiagnosed, with a high level of specificity and sensitivity, at the molecular level and genetic level, and/or through EMF signatures, Spectroscopic signatures, but these areas of science are still in their infancy.



Subgroups and Biomarkers

Many illnesses such as Cancer have subgroups, which means there are slight variations in the illness between sets of patients. This may be due to inherited genetic factors, environmental exposures, interactions of genes with the environment and mutations, polymorphisms and gene expression changes, differing immune systems and reactions, different pathogen exposures, and triggering mechanisms for the illness.

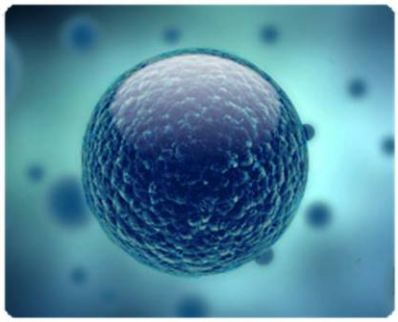
The eminent **Dr. Stephen Holgate** in Britain, stated recently there are 15 subgroups in breast Cancer and he believes that there are many subgroups in ME and CFS. There would be general agreement with him on this by most ME and CFS doctors and scientists and patients. There are some heterogeneous features in a distinct illness such as ME and CFS.

As diagnostic methods and technologies improve over time, including genetic technologies, there will be:

- greater precision attained in the diagnosis of illnesses
- some illnesses will have their subgroups identified, classified and defined with greater precision
- illnesses which were once thought to be just one illness will be found to be a number of undiagnosed illnesses, and they will be split into separate illnesses as a result ; each having their own distinct bio-markers, genetic markers and symptoms. This will bring greater clarity into medical and scientific understandings of chronic physical illnesses such as ME.

There are biomarkers for the subgroups in ME and CFS. New diagnostic technologies can identify these biomarkers. Using biomarkers, patient symptoms and patient responses to certain drugs (**Ampligen**), and Canadian (2003) and ICC (2011) criteria, one can group patients into subgroups.

For example, patients with defective RnaseL pathway and PKR pathway are a subgroup, patients with chronic viral infections such as HHV6a or Enterovirus are another subgroup, patients with mycoplasma infection(s) are another subgroup.



Patients with low natural killer cells and cytotoxicity are another subgroup, patients who respond positively to **Rituximab** are another subgroup.

Patients with chronic inflammatory immune response to molds and mycotoxins are another subgroup, patients with PEM are another subgroup, patients who respond positively to **Ampligen** are another subgroup.

Some subgroups would contain biomarkers from one or more subgroups above.

Identifying subgroups enables us to make use of existing research findings and apply appropriate medical treatments. This can make the difference between life and death in many cases.

In the next issue, we will discuss the RnaseL pathway and PKR pathway biomarker subgroup. This has been the subject of much scientific research.

David Egan

Naked Living

When I first got sick I fought to remain in work. My hobbies had disappeared, evaporating like some rain puddle in spring. My social life took a plunge and my ridiculous pride at keeping a tidy home lay strewn across my kitchen floor.

Every label I had once allowed myself to own was lost. Every label bar one, Employee. And my gosh I fought to keep it, I fought for months.

This society of ours is constantly trying to mould us. There are adverts telling us the products we should buy, pictures showing us what we should look like and then there are the labels. Post its that define us. Wife, sister, runner, employee, home owner, an endless list of nouns supposed to prove who I am.

I clung to that last remaining label, employee, until my brain was floored, my body beyond broken and the tank beyond empty. I no longer had the choice to push and get sicker, I was done for. It was time to throw my hands up in defeat.

Doing so wasn't easy. My husband and I have a mortgage to pay, we are in the middle of a recession but the biggest challenge I faced was losing that last label, my last link to my past. It was as if the world was suddenly throwing down its binoculars. I had nothing left to offer it. It was done with me.

The labels passed through life's shredder. Everything was gone.

Yet, standing naked in front of my mirror of truth I realised this string of words I'd used to define me, could in fact be used to describe millions of people. The post its I'd spent my life accumulating meant nothing.

They were simply a string of random words my life had chanced upon, they weren't me. They didn't define me, they didn't even try to describe who I am.

I knew the outside world looking in thought I was an ME patient, cut off from her past. But what did I think? After all, what everyone thinks really doesn't matter. At the end of each day it's me I lie beside in bed, it's me who must confess and question "did I live today as me?"

So having ditched the labels I've since refused to be labelled. Sure the world can label me, they can call me as they wish but I don't have to accept those labels. Just as I don't buy into marketing campaigns or dress sizes or fad diets.

Living can be as complicated as we make it. Luckily I need simplicity in my life and so living to me is breathing.

Breathing in the sunlight, the birds, the trees, the fields. Watching the colours change as each season falls in. Smelling summer rain, touching winter snow, standing under budding trees of spring and watching autumn sunsets closing in.

We humans can be incredibly egotistical! To think I had to get sick to realise just how small of a paper clip I am in this vast, vast universe.

As for that question, who am I? I'm a woman in love with life, in love with people, in love with nature. I'm acutely aware of my tiny microscopic footprint, a print that will someday be left behind, hidden in the long grasses of this earth.

Marie H Curran

http://currankentucky.wordpress.com/author/currankentucky/

Llewellyn's Memo

Since I wrote and spoke about the need for a Washington presence for ME/CFS I've received many e-mails which ask, in essence, what next?

Here is a modest proposal of what I think should be done, and what can be done with a minimum of effort and a big impact: schedule a Mothers March at the U.S. Capitol on May 12, 2015.

I envisage about 100 mothers of ME/CFS sufferers walking through the Capitol wearing distinctive sashes; a very dignified demonstration -- with lots of handouts for anyone who wants one.

Marchers don't have to be confined to mothers. But if mothers predominate, there will more media attention than if it is just a general demonstration. I think if everyone is wearing, say, white with a blue sash, and women far outnumber men, that will have impact.

There is a long and effective history of mothers en masse changing history: South Africa and Northern Ireland are two examples.

The aim of this demonstration should be to inform the 113th Congress and serve notice on the agencies of government that the ME/CFS community wants parity in research dollars with other diseases that are more in the public eye – and right now.

This demonstration – and there is nearly a year in which to plan it -- should be seen as the beginning of something big and enduring, not just a one-time or even an annual event.

My thinking is: If we can generate the right publicity in the major media (and I mean across the spectrum, from NPR to the big newspapers), we may attract the patronage of a major foundation. This would support the creation of a national association for ME/CFS, devoted to lobbying and educating on behalf of the disease until it is established as a medical priority in Congress, the administration and the media. The need is urgent.

I was once sent a wise saying by the mystic Rabbi Nathan of Bratislav which said, in effect, "You will never leave Egypt, any Egypt, if you start by asking how will I make provision for the journey?" There is a life lesson in that -- and a lesson for the ME/CFS community.

Maybe a benefactor with time and resources will emerge to organize this mothers demonstration. But, if not ,why not do it anyway?

Suppose right now you decide to go to Washingon, and make your way to Capitol Hill, wearing white with a blue sash (I choose blue because it stands out against white) and walk the halls of Congress, handing out literature that you have downloaded. That is the bare minimum, and it'll have an impact.

If an organization emerges before then, so much the better, but it is not essential. But as a general proposition, a Committee of 100 is a well-tested, public-pressure device.

The thing is to commit, as individuals, to doing it now.

There is nearly a year to build passion, to get the local CFIDS associations engaged and to make the grand, seminal event of the Mothers March happen. If not en masse, go alone. But go. Start the movement with your white outfit and a blue sash, scarf or shawl.

The best organizations start with determined, committed, like-minded individuals. The power of one is awesome once that person empowers herself or himself. A leaderless demonstration is not leaderless if everyone agrees.

You asked me what should happen next, and my answer always is "Start something, if you are well enough or if you are an advocate. Just start.

Llewellyn King

Executive Producer and Host of "**White House Chronicle**" on PBS;
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Commentator, SiriusXM Satellite Radio
He is the creator and co-host of ME/CFS Alert on YouTube.

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May 2015 - The Great Blue March to Capitol Hill

The memo of **Llewellyn King** you just read on the page before, has been sent by him to a group of some 30 patients and patient advocates all over.

None of them thought the idea strange or unrealistic: all of them commented that it was a great one.

Immediately the exchange of a stream of ideas on how to effectuate of what has been written in the memo was triggered. This is a summary of what has been proposed up till now:

- March on the Capitol in Washington
- May 2015 or shortly after.
- Whom: most opted to organize a "Mothers against ME" march, as that might have the greatest emotional impact. The other option is to have a "Families against ME" march. What's important is the message – ME/CFS is a devastating disease that can strike men, women and children but that affects the entire family.
- How: to be determined the upcoming months, preferably by as many persons as possible.
- Where: not only in Washington DC, maybe also in other states of the USA and countries all over the globe, simultaneously.
- Initial thoughts on the purpose: Nothing will change with the public policy toward ME until we enlist the support of government and the public. A March on ME is intended to help achieve that by
    - Build awareness with Congress, the media and the public about the devastation caused by ME and its impact on families and our country.
    - Inform the public and Congress about the failures in research, how abysmal medical care is, and how stigmatized patients are.
    - Request a congressional committee to investigate the public health policy failings that have devastated the lives of one million Americans and 17 million patients world-wide
- Extra's: lifestream the march, billboard size poster, Banner of Hope-quilt, three to four simple statements to be repeated again and again.
- Follow up/embedding in:
    - Via press and congressional committee to Congress, via Congress to HHS for vastly more funding for research and for centers of excellence and appropriate clinical guidelines. ME costs the USA an estimated 18- 23 billion dollars a year.

This needs a clear, concise message.
You as a reader are invited to mail your ideas to: MarchOnME@gmail.com

Kindly note that the title Great Blue March.. is just the title of this article.

Dutch International Project - Science to Patients

The first two webinars by **British professor Julia Newton** were posted online on 3 June, following the successful webinars by **Belgian researcher/physician Kenny de Meirleir**, Dutch **researcher/cardiologist Frans Visser**, **British pediatrician Nigel Speight** and **general doctor Charles Shepherd**, the latter two both being advisors of the British ME Association.

In the webinars that have been posted **Newton** introduces herself and discusses neuro cognitive problems and ME. You have received the transcripts of these webinars, but you can also find them on:
http://www.me-cvsvereniging.nl/english-page,
where you can watch all prior webinars.

On 17 June a webinar by **Julia Newton** about ME and the blood flow has been posted online (http://youtu.be/km-BPrffMOY) , after which she was available for answering questions during a chat session on 20 June. You will receive the transcripts of both the webinar and the chat session next week.

On Tuesday 1 **Julia Newton**'s webinar on The metabolism and the muscles will be posted online, followed by webinars on ME and Sleep on Tuesday 15 July, Ageing and ME on Tuesday 29 July and finally ME and the future on Tuesday 5 August.

During an international Q&A session on Friday 1 August, everyone has the opportunity to ask **Newton** questions from 5.00 until 5.30 pm ECT (11 am EMT in the USA) (http://chatwing.com/mecvsvereniging.wvp)

During the months September, October and November, eight webinars by **Professor Leonard Jason** from Chicago will be posted online. He too will give two international Q&A sessions: on Friday 26 September and on Friday 21 November, both at 5.00 pm ECT.

At the end of 2014, new recordings will be made for the first half of 2015, however, we do not yet know with whom. There are a number of candidates. You can state your preference via wvp@me-cvsvereniging.nl

The webinars that have been posted so far, have more than **145,000 views**. This project has resulted in the establishment of the **ME Global Chronicle**. We hope it will also lead to a good cooperation between English speaking researchers and Dutch researchers.

The ME children's foundation **Save4Children** (see next page) has in fact evolved from this project's magazine. We hope and expect this to be a continuing process.

In short, this project continues to help demolishing the borders that have kept patient communities over the world isolated during the past few decades. We are seeing a wind of change. Let's freshen this wind into a storm.

Please email your questions and suggestions to mwvp@me-cvsvereniging.nl.
Let this become a project by us all, for us all.

Rob Wijbenga
Coordinator team Science to Patients
Chairman ME/cvs Vereniging, the Netherlands
Editor in chief ME Global Chronicle

Save for Children

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

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

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

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

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

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

So please continue to donate:
http://bit.ly/1qwwmz0

The Lipkin Microbiome Study

We still have a way to go to reach the $1.27m target by the end of the year, but with your help we can and will do it. The need is still there for cutting-edge hunt for the causes of ME/CFS in the gut "microbiome", and it will be led by 'the world's most celebrated virus hunter', **Dr W. Ian Lipkin**.

In the news

Journalist **David Tuller**, who has written about ME/CFS for the New York Times, highlighted the crowdfunding appeal with a piece on **Buzzfeed** that attracted nearly 50,000 views. http://bit.ly/1nATOKl

New findings are encouraging in the fight against chronic fatigue syndrome. But the government still provides funding so minimal, one researcher is turning to crowdfunding… "there has to be some way to get this done.

There is no NIH funding to support this at present", said **Lipkin**. Thanks to **David Tuller** for his coverage who wrote again about the appeal in April. http://bit.ly/1joytQ3

On ME/CFS Awareness Day, 12 May, Columbia University (where the microbiome study is based) put out a press release about the appeal: More Than a Gut Feeling. Patients, many who have gastrointestinal symptoms, are convinced that the microbiome will bring answers. http://bit.ly/Uz98NX

Amy, a former occupational therapist from New Zealand and member of the fundraising team, says, "I don't think the gut and immune system connections have been looked into enough in general and also the gut-brain axis. This is an exciting area of research and we get to be part of it."

Gone global

At the last count donations had already come from 20 countries and 33 US states. Those figures are a little out of date and we'll post a new total as soon as we have it.

The Big Interview

Also for ME/CFS Awareness Day, **Ian Lipkin** did a barnstorming interview with **Mindy Ketei** at CFS Central. http://bit.ly/1joyKSY

Mindy Kitei: Where can people donate to your research?
Dr. Ian Lipkin: Donate to our research. We're all in the same boat. We're trying to find solutions to an important problem, so I want to be very clear to your readers that it is their project. It was organically developed in response to their needs, and their wishes, and we're eager to serve.

Cort Johnson wrote a fascinating commentary on the **Lipkin**/**Kitei** interview at Health Rising and wholeheartedly endorsed the campaign: http://bit.ly/1sbuFLk

The **Ian Lipkins** of the world don't come around very often for ME/CFS. He's an opportunity we don't want to miss… a resource we can't afford to waste.. He's a busy man. He's in demand. Something is always popping up. Support the crowdfunding project!

Thanks, **Cort**!

Medal winner

As if to emphasise the point about **Ian Lipkin**'s worth, he was recently awarded the prestigious **Mendel Medal** to honour his ground-breaking work in the development of genetic methods for microbial surveillance and discovery. http://bit.ly/1nAVHqr

Conference Action

Dr Ian Lipkin was a headline speaker at IACFS/ME in March, with his talk "Small Game Hunter", about his work discovering microbes including his work on the human microbiome (so far in autism), as well as his work as part of the Chronic Fatigue Initiative (CFI) looking for pathogens and markers of immune dysfunction.

Ian Lipkin will also be speaking on Infection and Immunity at the inaugural UK CFS/ME Research Collaborative Conference in September.

Dr Mady Hornig, who will be the lead researcher on the crowdfunded microbiome project, also spoke at IACFS/ME about the CFI work, including a fascinating finding that one cytokine is correlated with cognitive problems in severely-affected patients. **Drs Lipkin** and **Hornig** are keen to pursue the microbiome research as they believe problems in the microbiome could well be driving the elevated cytokines that are associated with symptoms.

Drs Lipkin and **Hornig** are world-class scientists who have done great work in many fields, and we are lucky to have them on board.

http://www.microbediscovery.org/

On The Brain – Quote By Dr. Amolak Bansal

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

How this occurs is unknown but there are counterparts in certain newly described autoimmune conditions and viral infections of the nervous system. In addition to a direct stimulation of neurones in different parts of the brain and spinal cord there is also an impaired filtering function of the brain stem and a reduced threshold for neurones to fire off. This allows external stimuli such as movement, light, sounds, touch and sometimes even worrying thoughts to produce widespread neuronal activation with ultimate excitotoxic damage to these cells.

The consequence is impaired activity of the brain generally but particularly the **hypothalamus** and **prefrontal cortex** leading to fatigue, disordered sleep, impaired memory, attention, faintness, palpitations, disordered respiration, temperature dysregulation etc. Outwardly many patients appear well and routine blood and other investigations are normal.

Internally there are severe symptoms which, if unchecked, escalate leading ultimately to immobility and increasing pain and spasms in a proportion of patients. Clearly a greater understanding of this highly disabling condition is required with a greater focus on disrupted immune and neural pathways and not just psychosocial factors as has previously been the case."

Dr. Amolak Bansal

The Journal of IiME. Vol. 8, issue 1

http://bit.ly/1joAFXH

Sleep-specific phenotypes in patients with chronic fatigue syndrome

A cross-sectional polysomnography analysis.

Summary of the research study:

Despite 85–90% of patients with chronic fatigue syndrome (CFS) reporting unrefreshing sleep, previous research has been unable to reliably identify specific irregularities in objective sleep of patients with CFS. Symptoms such as unrefreshing sleep may not only be markers of ME/CFS; they may also serve to maintain it.

For instance, there may be links between sleep quality, sleep-wake regulation and fatigue. There is evidence of this from studies that have shown adopting activity and sleep management strategies improves HPA axis functioning as measured by cortisol levels.

This suggests that further investigation of sleep disturbance of ME/CFS is of more than academic importance but may highlight new avenues for intervention. From a clinical perspective, it is also important to study sleep more thoroughly in ME/CFS as it may highlight some areas of diagnostic ambiguity.

For instance, previous studies have shown that sleep disorders (notably obstructive-sleep apnoea) are occasionally identified during polysomnographic (PSG) assessments with CFS patient cohorts.

To clarify the specific characterisation of sleep in ME/CFS patients objectively, our study examined PSG data for a single night of sleep in a large group of ME/CFS patients. The aim of this research study was to determine whether specific sleep disturbances exist in this group, and if so, whether they are consistent across all patients.

We conducted an analysis of 343 polysomnography (PSG) recordings (measures of brain and body function during sleep) from ME/CFS patients collected by colleagues in a fatigue clinic in the **Netherlands**. The PSG was carried out over a single night and the referral criteria for PSG investigation were that the patient

- met diagnostic criteria for CFS according to the Fukuda definition,
- they were drug-free for at least 2 weeks prior to the overnight study and
- their symptoms could not be explained by a physical or psychological illness.

The first finding was that over 30% of patients fulfilled the criteria for a Primary Sleep Disorder (PSD; sleep apnoea or PLMD). This is important and underscores the need to assess for sleep disorders in ME/CFS populations.

Of the remaining 239 patients (without a primary sleep disorder), 89.1% met quantitative criteria for at least one objective sleep problem.

Importantly, this analysis has also led to the classification of four distinct sleep phenotypes in people with ME/CFS. For full details of this study, see Gotts et al, 2013.

However in brief the sleep profiles identified are as follows:

- Type 1. are characterised by having problems in getting to sleep
- Type 2. appear to have normal sleep but are spending a longer than normal time in the lighter stages of sleep
- Type 3. are sleeping more than any of the other three groups
- Type 4. are having the most disturbed sleep as marked by night-time awakenings.

Overall, the results from this study confirm objective sleep difficulties in patients with ME/CFS and suggest a significant overlap between ME/CFS and a variety of symptoms of sleep disturbance.

Importantly it demonstrates that one night of PSG is sufficient to tease apart, and exclude, those with apnoea and PLM disorders from four other distinct sleep phenotypes in patients with ME/CFS.

Interestingly, these four phenotypes tend to mirror symptoms related to sleep quality and quantity that are amenable to different evidence-based treatment approaches.

The findings from the study highlight the need to routinely screen for Primary Sleep Disorders in clinical practice and tailor sleep interventions, based on phenotype, to patients presenting with ME/CFS.

Gotts, Z. M., **Deary**, **V.**, **Newton**, **J.**, **Van der Dussen**, **D.**, **De Roy**, **P.**, & **Ellis**, **J. G.** (2013). Are there sleep-specific phenotypes in patients with chronic fatigue syndrome? A cross-sectional polysomnography analysis. BMJ open, 3(6).

Submitted by **Zoe Gotts**, Postgraduate Researcher
Northumbria Centre for Sleep Research (**NCSR**)
Faculty of Health & Life Sciences, Northumberland Building (NB431)
Northumbria University,Newcastle upon Tyne, **Great Britain**

The role of Mitochondria in ME and CFS.

A neglected area in medical practice & scientific research?

Dr. Sarah Myhill (see picture) is a distinguished and highly regarded medical doctor and researcher based in Wales. She runs the famous Myhill Clinic there.

Dr. Myhill has been treating ME patients and researching the illness since the mid 1990's. Her team's collaboration with Oxford University researchers into Mitochondria has been revolutionary and provided important new medical insights into Mitochondria and their role in illness and disease. This has particular relevance to ME and CFS and other illnesses involving mitochondria disorders.

The following video lecture was presented by **Dr. Sarah Myhill** in 2014. Her areas of speciality are the mitochondria, oxidative stress, toxins, and the immune system, and the inter-relationship between them in ME/CFS patients.
She provides a brilliant analysis of these areas and provides some useful diagnostics and treatments for patients.
http://www.youtube.com/watch?v=BG_v6-U1a8g

Dr. Myhill has also written a new book about ME and CFS this year, titled "Diagnosing and treating Chronic Fatigue Syndrome: its mitochondria, not hypochondria" which is in Kindle and paperback format.

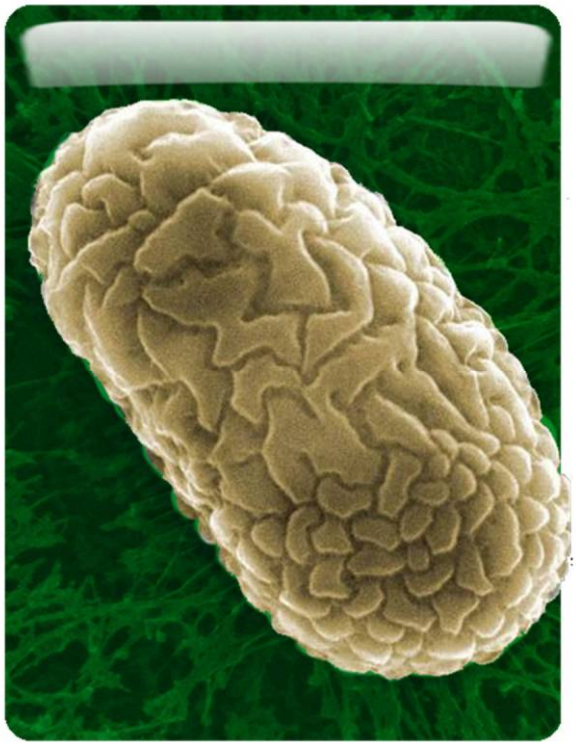
This is a brilliant book which sums up her medical and research work and findings into the illness so far. Some research listings can be found here at http://www.me-ireland.com/scientific/3.htm

Her work is validated by scientists in a few countries who have consistently found abnormal mitochondria degeneration and destruction and mitochondria dysfunctions in ME/CFS patients. It is worth noting that the mitochondria and the Krebs cycle are involved in ATP production and the recycling of it, and that ATP is the energy fuel of all cells, all tissues, and all organs and glands in the body.

It is the fuel of the body, and governs the energy state of a person. Even minor reductions in ATP or ATP production will slow down the body and cause fatigue.

Many leading medical doctors and scientists believe mitochondria dysfunction lies at the root of ME and many other illnesses involving fatigue. The mitochondria and the Krebs cycle require essential nutrients, minerals, biochemicals, methylation end-products, SOD and glutathione in order to function effectively AND they are also susceptible to disruption / blockage / attack by pathogens, parasites, environmental toxins, free radicals, excess inflammation, poor detoxification status, poor antioxidant defences, excess metabolites (from exercise) and deprivation of the aforementioned essential nutrients.

Dr. Edward Conley who runs the famous Fatigue, Fibromyalgia and Autoimmune Clinic, Michigan, USA has publically stated that solving the ATP, mitochondria and Krebs cycle problem in ME/CFS resolves the ME/CFS illness.



The mitochondria have been overlooked by many researchers and medical doctors, and thus there continues to be an incomplete understanding of the illness.

Certainly, measuring mitochondria damage and dysfunctions in combination with measuring immune system subset changes, chronic viral, mycoplasma, Lyme and other pathogen infections, neurological dysfunctions, HPA axis dysfunctions, ANS dysfunctions and cardiac dysfunctions in research projects and clinical trials would greatly increase our understanding of ME and CFS, and inevitably lead to innovative and effective new treatments.

The mitochondria damage and dysfunctions in ME and CFS be categorised into the following:

- Mitochondria Function Profile test and Micro-Respiratory studies test (Acumen Laboratory, Devon) - highly recommended by **Dr. Myhill**
- The level of ATP in cells, and rate of ATP production and recycling in cells. Including the efficiency with which ATP is made from ADP and the level of oxidative phosphorylation. Level of mitochondria nutrients. Superoxide Dismustase and Glutathione tests and Cell free DNA test. These are all included in the Mitochondria Function Profile test and Micro-Respiratory studies test (**Acumen Laboratory, Devon**).
- Translocator protein studies test - highly recommended by **Dr. Myhill**
- Impairment of the protein which transports ATP and ADP across mitochondrial membranes. This is called the Translocator protein. Mitochondrial numbers, mitochondrial structure and mitochondrial DNA. Identify toxins blocking the three main areas (oxidative phosphorylation, translocator protein and mitochondrial DNA), and the levels of calcium, magnesium, zinc, potassium (and the pH) associated with mitochondrial membranes.
- Cardiolipin Profile test (**Acumen Laboratory, Devon**) - highly recommended by **Dr. Myhill**
- This measures damage to the mitochondria membranes. This can affect mitochondria function and ATP production and transport.
- Mitochondrial (Leucocyte) Respiration Studies (**Acumen Laboratory, Devon**).
- This test can identify when oxidative phosphorylation is uncoupled from the electron transport chain. Uncoupling can be caused by toxins.
- Full Intracellular Calcium Studies (Acumen Laboratory) - highly recommended by **Dr. Myhill**
- High calcium levels can block mitochondria functions.

- Toxins which block mitochondria functions and destroy mitochondria - highly recommended by **Dr. Myhil**
    - DNA adducts test
    - Fat biopsy for pesticides or Volatile Organic Compounds tests
    - Lymphocyte sensitivity to metals and chemicals test
- Methylation Cycle Blockage and Defects, and its effects on Immune system function and the Mitochondria - highly recommended by **Dr. Myhill**. The Methylation cycle provides Co-Q10 and carnitine and substrates and co-factors to the mitochondria. Methylation is vital to the mitochondria and to the immune system, the nervous system and detoxification systems.

Acumen Laboratory has no web site currently but can be contacted directly via email at acumenlab@hotmail.co.uk or
telephone on +44 (0)7707 877175.

Postal address is
Acumen,
PO Box 129,
Tiverton, Devon
EX16 0AJ, UK or through

Dr. Sarah Myhill's clinic

These are reliable biomarkers for ME and CFS, and provide a good report of one's biological status. There is room to include these in medical practise and in all research projects into ME and CFS.

We congratulate and express our deep gratitude to **Dr. Sarah Myhill** and the staff at her clinic and **Dr. John Mclaren-Howard**, **Dr. Norman Booth**, **Dr. Peter Behan**, **Dr. Gow**, **Dr. Dowsett**, **Dr. Nijs**, **Dr. Meeus**, **Dr. Conley**, **Dr. Paul Cheney** and all the other dedicated scientists and doctors who have researched the role of mitochondria in ME and CFS over many years.

David Egan

Study on severely affected ME/CFS patients

Around 10 to 25% of ME/CFS patients are housebound or bedbound, yet very little is known about the origin and outcome of their severe illness. So, when ME Research UK awarded a large programme grant (http://bit.ly/1kJVzV1) to the researchers in Newcastle in 2014, it was decided to initiate a specific project investigating housebound or bedbound individuals who are unable to attend clinics or take part in research projects. The two-year investigation will be conducted day-to-day by the newly funded ME Research UK Research Associate – more information at http://bit.ly/S2yeDx

Research Overview

Our special 32-page edition of Breakthrough magazine entitled, "£1 million of biomedical research: an overview of the projects you have funded" is now available on-line http://bit.ly/1mNZkvM. Several thousand hard copies have already been sent to our friends and supporters. Written in a clear, simple style, and describes some of the 35 projects (and 55 published scientific papers) we've helped to fund, classified into subject areas, such as circulation, muscle, diagnosis etc.

"Breakthrough" magazine

The electronic version of our Spring 2014 "Breakthrough" magazine is now available on our website http://bit.ly/1oHZELa. This issue contains coverage of ME Research UK-funded research on the brain (laser-evoked potentials and cerebral blood flow), the impaired movement of the eyes, weakness in the upper limbs, and much more…

CFSRF

Farewell to the Chronic Fatigue Syndrome Research Foundation (CFSRF)
The impending closure of the CFSRF following the death of its driving force **Anne Faulkner** on 7th November 2013, marks the end of a chapter in the history of ME/CFS research. Read our short essay http://bit.ly/1kol9i7

Weekly research updates
Every Friday, we produce a weekly round-up of all ME/CFS-related scientific publications in the past week, with links to the relevant publications or commentaries. Have a look on our website next Friday!

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My June 2014 CFSAC Testimony

First, I 'd like to congratulate the newly appointed committee members. The patient community is particularly excited about the addition of **Dr. Jose' Montoya**, a true ME/CFS expert with crucial clinical and research experience in our disease, something HHS committees desperately need a lot more of.

I also would like to thank the committee members who recently rotated off CFSAC. I want to dedicate my comments to advocate extraordinaire, **Eileen Holderman**, the outgoing patient advocate. [for camera: behind me to my left wearing black] **Eileen** has not asked me to make the following comments nor is she aware of them.

She has never sought the spotlight for her countless contributions, having turned down many offers for interviews and feature stories. She is not in this for the glory. In fact, few are aware of her many efforts and she rarely gets credit for her hard-hitting and strategically smart advocacy.

Despite being quite sick with ME/CFS, **Eileen** is a force of nature. Her experience, intelligence, dedication, professionalism, hard work, strength of character and strong relationships with researchers, clinicians and advocates make her easily the most effective advocate of our time.

I have been in awe of, and inspired by, **Eileen**'s unshakable and unparalleled integrity, especially in the face of public and behind-the-scenes hostility and palpable lack of respect from HHS. When she went public last year with intimidation attempts by HHS, she was brushed off without an adequate investigation or even as much as an official response to her from **Dr. Koh**, Assistant Secretary of Health, let alone an apology or assurances of refraining from further intimidation on the part of HHS.

Eileen cannot be intimidated nor can she be co-opted and that is crucial for effective advocacy that does not sacrifice the good of the community for personal gain. **Eileen** is not interested in financial favors, seats at tables of rigged games, rubbing elbows with the perceived powerful, prominence or anything else that is so often wrong with advocacy.

Three minutes are not nearly enough to go into any meaningful detail. But remember, **Eileen** called out HHS, on the record, for hijacking CFSAC's recommendation and hiring the IOM. She has been unflinching in her opposition to the IOM effort.

Eileen is the one who has continually reminded this committee that its shameful practice of calling our disease "chronic fatigue" is unacceptable and unscientific, sadly to no avail for the most part.

We have to thank **Eileen** for the inclusion of the Canadian Consensus Criteria in this committee's recommendations at the last meeting. She made her motions so swiftly that HHS was unable to mount enough opposition.

Ironically, it probably would have been easier to shut down **Eileens**' effort if the meeting had been in person instead of a teleconference with slides.

I look forward to seeing a lot more from Eileen in the future. This community is blessed to have her and owes a tremendous debt of gratitude to **Eileen Holderman**!

Thank you **Eileen**!

Jeannette Burmeister

(*The editors of the ME Global Chronicle share Jeannette Burmeisters gratefulness*)

Please Cancel P2P

At the end of May, **Mary Dimmock** and I sent a letter to **Dr. Francis Collins**, Director of NIH, requesting that he cancel the P2P Workshop on ME/CFS and reexamine how to best collaborate with the ME/CFS research and clinical community.

We offered five reasons why we believe the P2P Workshop is not the right way to move forward. You can read the letter below, and that was not the only thing we sent. With attachments and supporting documentation, the package came to 38 pages total. I believe that we have provided ample reasoning and evidence in support of our request to **Dr. Collins**.

Many people have asked me what they can do to try and stop P2P. I believe this request to **Dr. Collins** is the first step, and there is a very easy way for you to join in.

If you have questions or comments, post them here or email me at jspotila@yahoo.com

Dear **Dr. Collins**:

We are writing to request that you cancel the Office of Disease Prevention's Pathways to Prevention Workshop on ME/CFS ("P2P Workshop").

Your immediate action is required to ensure that ME/CFS research and policy is based on the best scientific evidence and processes.

In your April 16, 2014 letter to Representative **Zoe Lofgren** and colleagues, you said that the P2P Workshop would produce recommendations to move the field forward.

We believe that this is not the case, and we offer the following documentation to support our conclusion:

- The Workshop is unnecessary and redundant given the recommendations of disease experts and other NIH efforts to advance ME/CFS research and clinical care. See Attachment 1.
- The Workshop has been structured to address the problem of medically unexplained fatigue, and not the disease(s) known as ME/CFS. See Attachment 2.
- NIH has paid lip service to collecting input from stakeholders, but in reality has not involved them in a meaningful way. See Attachment 3.
- The P2P Workshop process is inappropriate for this disease, particularly because the decision makers will be non-ME/CFS experts. See Attachment 4.

- The goal of this Workshop is unclear as a result of numerous contradictory and confusing public statements by HHS about the purpose of the Workshop. See Attachment 5.

Dr. Collins, we are not objecting to the P2P Workshop simply to make a political point or for the sake of criticizing federal efforts to address the challenges of this disease.

We are appealing for your help because we know you recognize that ME/CFS is a serious public health issue that needs the best of what science can offer.

We sincerely believe that the evidence included with this letter raises genuine concerns that the P2P Workshop does not represent the best of what science can offer, and may very well take us in the opposite direction.

For all of these reasons, we request that you cancel the P2P Workshop.

Further, we request that NIH reexamine how to best collaborate with the ME/CFS research and clinical community to achieve the goals of a research definition and strategy.

Those who are researching and treating this disease are in the best position to define how to move forward.

We thank you for your consideration of this issue, and we look forward to your reply.

Sincerely,

Jennifer M. Spotila, JD
Mary E. Dimmock

Source: http://www.occupycfs.com/2014/06/02/collins-please-cancel-p2p/

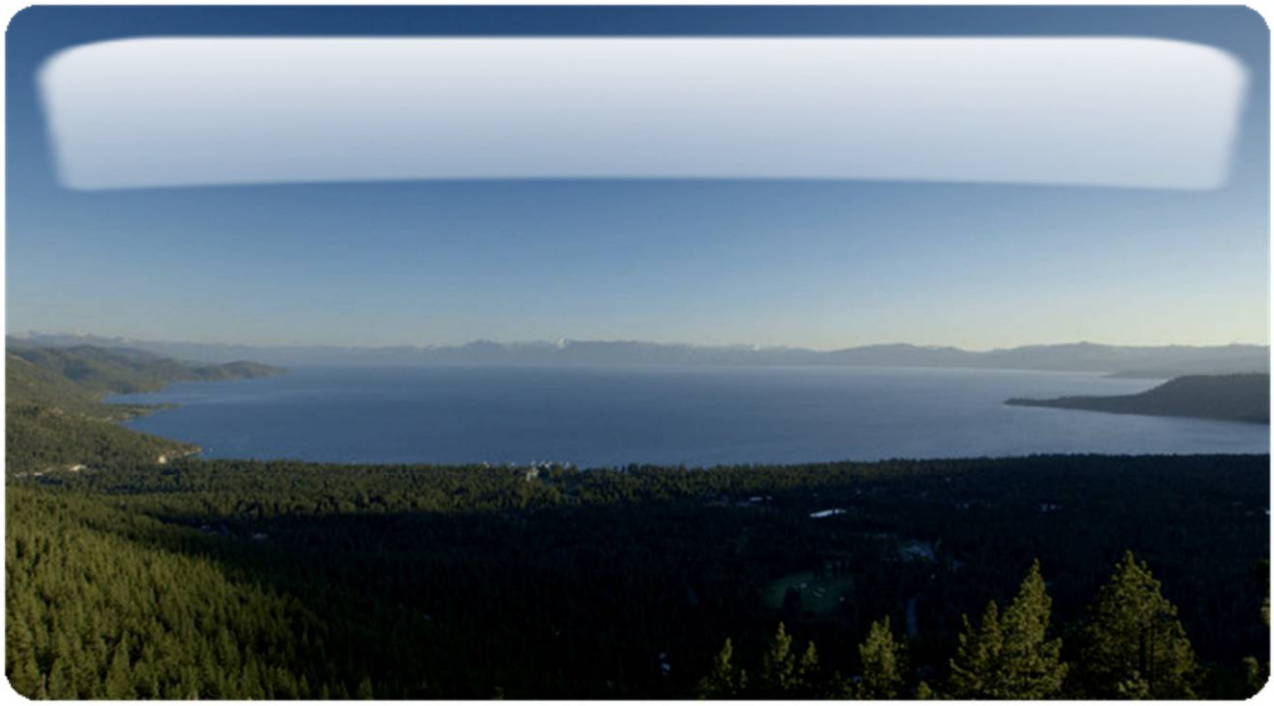
Jennie Spotila

Canary in a Coalmine

Greetings from Lake Tahoe! (and London and Princeton)

We have been in Nevada all this week interviewing local residents about their memory of the 1980s Incline Village outbreak, where hundreds of residents fell ill with ME.

ME patient **Leslie**, whose daughter is bedridden with the disease, spoke about the dark early days of the outbreak, and gave an inspiring message of hope for the severely ill.



The best and worst of times:
This week, we also shot a miraculous moment at a hospital south of London.
Jessica Taylor, with her mother, **Kate**, standing again after eight years in bed.

And a heartbreaking one in Princeton:
Celebrating the miracle of being able to attend my 10th college reunion, without any concept of the cost.

While we still have a long way to go in the production of the film, we have in the can some stunning footage and many amazing moments – beautiful, terrifying, heartbreaking, joyous, and lovely. In other words, what I believe is a picture of all of our lives, whether or not we have ME.

Jen

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.

Check with me in a few months and some of that is a bit dependent on where we end up after we finish development.

We aren't really aiming to be an advocacy organization. We want to be a platform: decentralized, organic, and with a few basic guiding principles but no unifying stance or position. We don't aspire to speak with one voice or to be united. We aspire to help our diverse community become more connected and to do what they're already doing, better.

We aim to provide tools and training that help people to become even more effective advocates and activists, and to leverage the virtual and dispersed nature of our community as a strength, rather than a weakness.

To analogize to the conference world, we're not **TED** or **Davos**. We're more like an un-conference (http://en.wikipedia.org/wiki/Unconference).
Both approaches to organization have their comparative strengths and I think our community needs both.

We're not really the people, we're not the ideas, we're not the plan. We're just the infrastructure. (Although, I'm pretty sure I will use that infrastructure to hatch one or two schemes of my own, and hope others decide it will be useful to them as well.)

I know that all sounds rather vague, but showing is much better than explaining at this point! We hope to launch this fall.

We will eventually hire software developers/designers who will be healthy professionals. And I imagine some of the elements will be in-kind donations of skills and/or time from diverse, non-ME people from different fields.

Yes, this is very early days yet! We just wanted to do this soft launch as I know so many folks were jazzed by the May12th + **Peter Staley** shows. And I just want to say that there's something coming down the pike, and that I hope to take the best of what we've learned from those conversations, and future conversations we'll have, to better understand why other social movements worked, and what tools and strategies we need to make it work for our community.

Ideally, users will be able to choose and customize their email subscriptions (e.g., all actions, actions in their country, international actions, local actions, actions by topic, actions by specific groups, featured actions, actions of a certain size or type). We'll be able to mobilize the entire network as well as parts of it.

And every time someone executing a local action brings more people into the network, the strength and size of the entire network grows. Each of our successes is all our success.

With 4,000+ likes on FB and 2500+ emails for the film, I am something of a gatekeeper and I don't want to be. I don't think each of us should have to try to build up that kind of following every time we start something new. Hopefully, by two years from now, we'll have 10,000 members in the #MEAction community.

Then if you're a patient starting something new, you don't need to spend years building a following in order to get the word out. All you need is a really good idea, a few good collaborators, and that idea will propagate.

Sorry for the mystery. These are just very early days. My instinct was and still is to try to be low key about my part in this because while I am very much front and center in the film (since it documents in part my personal experiences), #MEAction is much more an idea, a we, and will ultimately be and become what the folks who use it/join it choose to make it.

However, I completely understand how hard it is to know who or what to trust in this space (there are still some who think I am part of a vast conspiracy!) The best answer I can give to folks who are uncertain about whether to join at this stage is to wait until we launch – then see how the website is set up, what we're about, and whether that looks like something you'd like to be a part of.

Jennifer Brea
http://meactionnetwork.org/

Political/Legal Developments

Grassroots movements

A new organisation called ME Action Network, http://meactionnetwork.org/ has been set up by some North American ME activists. The purpose of this organisation is to unify all ME and CFS organisations and advocates in all countries worldwide. They would present a unified front for

- Protesting in individual countries
- Building public awareness about ME in all countries
- Lobbying government and state agencies to implement Canadian (2003) and ICC criteria (2011) and build or set up ME clinics
- Lobbying government and state research bodies for increased research funding into ME
- Crowd-funding for important private research into ME
- Protect the rights of ME patients. This would include protection against the malpractises of psychiatrists
- Crowd-funding for legal cases, involving abuse of the human rights of ME patients.
- International cooperation and assistance between ME patients and ME organisations around the world.
- Education and training of medical doctors and civil servants about ME and CFS, and their biological based diagnostics and treatments in all countries.

We strongly urge all ME patients, in all countries to join this organisation, ME Action Network, http://meactionnetwork.org/ and build a united front, and work together in this united front.

The ME and CFS Documentary Project

Blue Ribbon Foundation

We are so happy to report that we are receiving funding to initiate the Blue Ribbon Fellowship by June 1, 2015. We are partnering with the Wisconsin ME/CFS Association, which has generously agreed to provide $8,000-$10,000 to fund at least two fellowships.

The first two fellows will likely be working at the Whittemore-Peterson Institute in Reno, NV and the Institute for Neuro-Immune Medicine in Fort Lauderdale, FL. We will make the application go live in October and will advertise the program at medical schools around the United States.

Students will have the opportunity to view which of the institutes have ongoing research in the areas in which they're interested. Students will likely be able to apply directly to a specific research project. The application will close by December and the Blue Ribbon Foundation will do the preliminary review of applications. From there, the local institutes will be able to interview candidates and select the candidate(s) they feel are the best fit.

The fellows will all be medical students in between their first and second years of medical school. They will work at top neuro-immune institutes as research assistants and would likely have opportunities to shadow top doctors during clinical rounds.

Step Up for M.E.

The Blue Ribbon Foundation is also working around the clock to plan and execute our Step Up for M.E. 5K on Saturday, June 21st in Marietta, GA. We have attracted about 9 sponsors from the local business community. All are eager to assist in pulling off an exciting, high-energy event to benefit local charity. The Step Up for M.E. 5K effort is ably led by our Race Director **Nicole Castillo**.

We ultimately envision the Step Up for M.E. 5K to spread to other cities, states, and nations. We are looking to partner with a race management company capable of managing Step Up for M.E. as a nationwide or a worldwide initiative similar to what Relay for Life has accomplished for cancer. Already, we are taking steps in that direction. For instance, Pandora Org, all the way from Michigan, has committed to sending a big banner to support our event in Georgia.

A basic formula for success is easy to outline. If 50 cities organize 5K events and each event raises $20,000, then the result would be $1,000,000 in funds raised each year. Many other diseases have national or international branded fitness events and ME/CFS should be no different. Let's get it going! It's so very exciting to see the growing consciousness and unity of the global ME/CFS community and to think what we'll all be able to accomplish in years to come.

Forgotten Plague

We are very excited to announce that we have received about $20,000 in additional funding from a new Executive Producer to complete post-production on our film. This will ultimately bring the full funding for our film to about $71,000.

The additional funding will enable us to partner with veterans in the Atlanta motion-picture industry (For perspective, Atlanta is perhaps the 3rd largest producer of films, behind only the perennial heavyweights Los Angeles and New York).

Atlanta has been a major rising leader in feature films in the past half-decade, playing host to such major productions as The Walking Dead, X-Men First Class, Anchorman 2 and a host of others. We're so blessed to be able to attract personnel from that high caliber of production value and to negotiate terms at non-profit rates.

We have partnered with **Electric Puzzle Productions** for a portion of the editing and post-production services. So far we have created a 28-minute rough cut of what will ultimately be a 90-minute feature film.

One of the most common questions we are asked day in and day out is, "What is the length of your film?" So it's worth repeating one more time. The film will be 90 minutes long, just as most conventional movies are. We are making a movie intended toward a mainstream audience because we want to make ME/CFS a mainstream disease. It's high time to cross over into the full light of day.

However, within the context of the 28-minute rough cut we've completed so far, we have been able to show the edit to 15-20 friends in the motion picture industry, the sciences, and in the ME/CFS community. We've taken the feedback and critiques they've given and are using those comments to influence the future editing and post-production of our feature film.

It's vitally important to take into account every possible perspective so that we can make our ultimate 90-minute feature film as lean, mean, smart, and powerful as we possibly can.

Ryan Prior & **Nicole Castillo**

New drugs and supplements

Important Note
These supplements and treatments can only be undertaken with the permission and supervision of your own medical doctor.

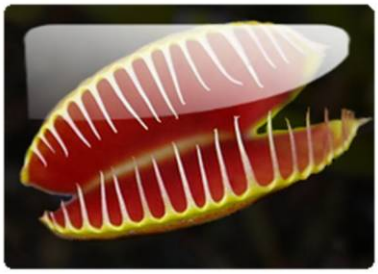
Carnivora

Carnivora has strong immune modulation properties and anti-microbial properties. This has been confirmed in some research studies, see http://www.carnivora.com/scofca.html .

Though no studies of Carnivora use for ME and CFS treatment have been undertaken yet. The scientific findings in relation to ME and CFS suggest immune dysfunctions, autoimmune factors, and chronic microbial infections, and upregulated oxidative and nitrosative stress and damage. Carnivora may be useful for some subgroups in ME and not useful for other subgroups in ME. This has been the experience with leading drugs such as Ampligen, Rituximab and anti-viral drugs, and anti-lyme drugs.

Regrettably most medical doctors and medical authorities refuse to carry out intensive and accurate laboratory tests on ME patients to establish all biological abnormalities, dysfunctions and infections. This has created a field of confusion, fuelled by presumptions and assumptions, and excess heterogeneous groups. And most doctors are content with this ignorance and content to offer some drugs to treat secondary symptoms ; though these drugs cause serious side effects in many cases

Fortunately, Carnivora has many uses, and offers modulation and normalisation of the immune system and targeting of many types of microbes and abnormal cells. And Carnivora has no side effects, which is an added bonus !



For over a century big pharmaceutical companies have synthesised biochemicals from rare plants in the jungles of South America, Eastern Asia, and Africa to create new drugs to treat many illnesses. Carnivora is derived from the Venus Fly trap plant, Dionaea muscipula, a native of the southern states of the USA, and can also be found in South America.

As regards specifics, Carnivora offers the following:

- Homeostasis of T-helper and T-suppressor cells of the immune system
- Inhibition of NF-kappaB
- Inhibition of inflammatory cytokines
- Improve NK cell function
- Nutrients to support antibody activities
- Anti-viral and anti-Bacteria actions
- Strong antioxidant properties
- Some cardio-tonic properties

- Phytohormones / Phytosterols to help balance the endocrine system
- Some possible anti-Cancer properties (ongoing research to establish this)
- Contains many phyto-nutrients, biochemicals and minerals which have significant antioxidant, immune modulating and anti-microbial properties.

It can take 3 months or more for Carnivora to begin to have an effect according to patient reports. We are not saying that Carnivora is a cure for ME. Carnivora may improve some ME patients or some subgroups, but not improve others. But, even a mere 10 - 15% improvement is better than nothing. And for those who improve more, there is the possibility of greater things. At present and for many years, patients had nothing

David Egan

Joanne

Joanne, the 14 year old girl from **Germany** who has severe ME since she was 10, is now in hospital for 7 months. As you may know from the reports in The Global Chronicle issue 2, 3 and 4 she is "treated" with CBT/GET, with all kinds of "activation therapies" and deliberate sensory overload.

Her neurological, cardiologic and overall ME symptoms are much worse due to this "treatment" but still doctors and nurses deny her severe deterioration and declare their "treatment" as successful.

Moreover, in contempt of her explicit and signed declaration to not want an MRI under general anaesthetic they recently made an MRI and even a lumbar puncture, even though it is clearly against the German law to not have informed consent for such invasive procedures.

They simply declared her mentally unfit for giving informed consent. Even the doctors conceded that the lumbar puncture was very dangerous due to her severe scoliosis. Ever since, **Joanne**'s condition is even worse. She is in terrible pain, has cramps, is throwing up all the time and often she can hardly speak or focus her eyes. Sometimes she has problems to breath. The detrimental effects of these medical tests (and the overall "treatment") are denied and the numerous "treatments" are continued.

Her inability to come up to their demands and expectations is still regarded as malingering and/or due to a "psychological blockage", and there are now compelling indications that her room is tapped or even under video surveillance – probably to prove that she would just be a malingerer and well able to turn around in bed and talk and sit up and do all these things they expect from her. Or to prove that her mother is to blame for their lack of success by acting like a Munchhausen by proxy mother. Tapping or video surveillance of hospital rooms is illegal in **Germany**.

Whenever able to speak at all **Joanne** tells her mother about the cruel and threatening behaviour of nurses and doctors alike. "Now start moving for once, you lazy sod!" or "You are like a sack of potatoes!" are still the more harmless verbal assaults she has to endure on a daily basis. Again a doctor threatened to keep her in hospital for three years, if necessary, until she would eat by herself and be well again.

How could this poor girl who has most severe ME and who is paralysed, tube fed and extremely sensitive to all kinds of physical, orthostatic and sensory stress ever become better under such circumstances? **Joanne** clearly said that this would be tantamount to a life sentence, but that she'd rather be in prison because there people are at least left alone. And that they destroyed her and that she'd give up and stop fighting. So how long will she survive this life sentence?

In a second court hearing on April 28 the mother was again denied to get back custody. Again she was blamed to have neglected her child and to be the cause of **Joanne**'s disease or at least of the lack of desired progress. **Joanne**'s father still has sole custody because he supports all the "treatments" and her continued stay in hospital. So at present, **Joanne**'s mother has no influence whatsoever.

Since the insurance company stopped paying for the hospital stay they will most probably admit her to a psychosomatic or psychiatric ward pretty soon, possibly far away from her mother, because then the insurance company is forced to finance a further hospital stay. This, mother says again and again, would clearly be her end.

Nigel Speight who had visited **Joanne** twice to influence her health care team and the social workers and who even testified in the recent court hearing reported on this case during the pre-conference dinner at the Invest in ME conference in London on May 29. He would have a lot of bad cases right now, he wrote in an email, but this would definitely be the worst.

Joanne's mother has still been fighting together with her excellent lawyer but the limits of her financial capacities are exceeded by far and she is not able to pay him any longer. Then their last hope for a turn to the better will be gone and for getting back custody in a still impending court decision and eventually getting her child back home is the only hope left.

So we would be most grateful for any donation to the **Save4Children** fund – which will at present be solely used to support **Joanne** and her mother.

THANK YOU for your support!

On June 24, 2014 a sum total of **€ 988,25** has been received. **€ 695,80** has been transferred to **dr. Speight** to cover the expenses of his first trip to Germany to assess **Joanne**'s position etc. The expenditures of **€ 463**,= for his second trip have not been transferred to him yet.
The current sum balance is **€ 292,45**
Please donate here: http://bit.ly/1qwwmz0

"I can't go on any longer, Mummi! I can't make it any more!
You won't have me for much longer!
I won't make it tomorrow!
Tomorrow it's all over!

[name of physiotherapist], psychologist, cleaning woman, moving my legs, eating training and much more!
That won't work anymore!
I can hardly speak.
Good bye, Mummi, I can't go on any longer!"

That is what Joanne said on Sunday, June 15.
The next day she was unable to speak a single word.

Justina Pelletier Home Again…

Good news from Boston. 16 year old Connecticut teenager

Justina Pelletier spent 16 months and two birthdays in state custody as the central but largely off-stage player in an explosive drama involving parents' rights and the controversial new field of medical child abuse.

On Wednesday June 18, 2014, the 16-year-old girl has returned to her parents' custody and the family's home in West Hartford, Conn., following a ruling by the same Massachusetts juvenile court judge who originally removed her from her parents' care. Read all about it in The Boston Globe: http://bit.ly/1ieYo1K

A survey of those 16 months, as her case didn't get unnoticed:
"Quackery and alleged diagnosis based on presumptions, guesses, superficial judgments and assumptions with no scientific and medical basis, no patient examination and tests, and in many cases involving denigration, blaming and insulting of the patient still exists in the 21st century.

There is a minority of psychiatrists and a minority of medical doctors with psychiatric leanings who wrongly believe ME / CFS to be a psychiatric illness and they interpret patient cases to suit their own preconceived notions and ideas, and thus they mislabel and misdiagnose patients.

While she was incarcerated, the psychiatrists refused to accept a second opinion from doctors, and deprived the child of her treatments for her physical, biological illness, thus depriving her of her legal and human rights.

She deteriorated while being imprisoned in the mental hospital, as her physical illness was completely neglected. It took a number of court cases in the USA and several public protests to get her released from this mental hospital and back to her family. She is now receiving treatment for her physical, biological illness.

Her family will be taking legal actions against the psychiatrists and the hospital involved, and legislators are considering changes to laws to stop this abuse permanently.
- Justina's Story: A Fateful Day in February: http://bit.ly/Ulqrlp
- Justina's Story: What is Mitochondrial Disease?: http://bit.ly/Td9QPH
Source: http://www.me-ireland.com

News from...Australia

There's a short but beautiful, recent interview with **Prof. Sonya Marshall Gradisnik**, who also discoursed in London, during the Invest in ME-conference on May 30, 2014:
http://ab.co/1lxNwGI

Featuring ME-patients **Amity Slockee** & **Lucy Corrigan**, **GP Dr. Greg Schwartz** and **Prof. Sonya Marshall-Gradisnik** on the discovery of biological markers. Including a transcript of the video.

Matt Wordsworth, newsreader: "It (CFS) can be an incredibly debilitating illness but sufferers have often been maligned as malingerers. Identified in the 1980's Chronic Fatigue Syndrome was labelled yuppie flu.

But Queensland Researchers say biological markers show they're on the cusp of a breakthrough.

They're hopeful of developing a quick diagnostic test which would eliminate uncertainty and lead to better treatment."

News from...Belgium

7 May – The WUCB in Mechelen organised an event, during which **Gunther De Bock** (WUCB) gave a short introduction on the history of the illness. After that **Mark Impe** (VPP) gave a video presentation during which he appealed to the entire community of advocates and associations in Belgium to cooperate with one another.

Later on, **Dr. Francis Coucke** stated that nothing is done after patients are diagnosed with ME/CFS. Other diseases, like Diabetes, Cancer, Crohn's disease and so on, are very well supported and patients are assisted in every possible way.

Most doctors in Belgium have no time to investigate CFS. Furthermore, no research is being done on Lupus, a disease that has been growing exponentially over the last twenty years (1 in 200 people suffer from it), even though treatment knowledge is available. The impact on life quality is enormous for patients who have been diagnosed with ME/CFS.

If you live in Antwerp, Balen or Mol, the risk of getting Neuro Lupus is six times higher than if you live elsewhere he said. The most obvious cause for this is pollution. Gammaglobulines (treatment costs 1,000 euros per month), immunity treatment, hormones treatment and so on, can be helpful for some ME/CFS patients.

Dr. Coucke said doctors should more often be practicing functional medicine, as **Dr. Kenny De Meirleir** and **Dr. Richard Horowitz** do.

9 May - A petition was drafted by **Nele Lijnen** and **John Crombez** to include the recognition of the disease of Lyme and ME/CFS into the new coalition agreement. I personally do not agree with the change of name from CVS (CFS) into OLK (Unexplained Physical Symptoms), because every disease deserves its proper name. Furthermore, it is confusing to alter a name which has already been changed from ME to CFS. The petition, which currently has about 20.000 signatures, intimates that Lyme disease is the only actual illness, while CFS is inexplicable. http://bit.ly/1jq5X0n

22 May - **Jan Hautekiet** discussed CFS, Lyme and Fibromyalgia on national radio (Radio 1). Afterwards, the editorial office said to me that there had been an enormous response to the broadcast.
Even though this is a positive signal, it would have been better if the public had been more diverse. The editors had tried to contact me one hour before the broadcast, but unfortunately I missed that tweet. Therefore, I was unable to tell the editorial team what it means to live with this illness.
There is still a lot of work to be done…

Eddy H. Keuninckx

News from...Czechia

To mark the occasion of May – the Myalgic Encephalomyelitis (ME) awareness month – in the Czech Republic in 2013, we began an awareness campaign which involved gifting a DVD of the film Voices from the Shadows. This campaign lasted until February 2014.

The aim of the campaign was to gift the DVD with the documentary about our illness to influential people who can impact the lives of ME/CFS patients in our country.

The campaign has been funded by patients themselves, their families and friends – thanks to them, 45 influential people in the Czech Republic received the DVD of the documentary.

Among the most significant recipients was the presidential couple of our country – **Mr President Miloš Zeman** and the first lady, **Ivana Zemanová**. The Ombudsman, the Public Defender of Rights (http://www.ochrance.cz/en), also received the DVD of the film.

The Head of the Country Office of the World Health Organization in the Czech Republic (http://www.who.cz), **Dr. Alena Šeflová PhD**, and the Dean of the First Faculty of Medicine at the Charles University in Prague (http://www.lf1.cuni.cz/en), **Professor Aleks Šedo**, were also among the recipients of the DVD.

The film was also gifted to leading doctors who chair specialist medical societies (http://www.cls.cz/english-info), to directors and heads of large clinics, editors of specialist medical journals and also to an editor of the state television who has covered the issue of ME/CFS in the past. The film was also gifted to Czech organisations for human rights and to other influential people.

The response to this campaign was essentially as expected. Interest in the patients' situation, especially of those with the more severe form of ME/CFS, is not a priority.

That's why we really appreciate the willingness of all the influential people who, despite their heavy workloads, found time to watch the documentary, who sent us their comments and who are doing everything they can for ME/CFS patients.

Among all the welcoming responses, let's mention the assurance from the **President's Office** that the information sent to them will not go unnoticed.

Quite the opposite: **Mr President** says thank you and that he will make the most of any opportunity so that he can, within his strictly delineated competencies, alert in the most effective manner possible representatives of the highest organisations of executive power.

A positive response came from the Czech office of the World Health Organization. **Dr Alena Šeflová PhD**, the Head of WHO in the Czech Republic, expressed her understanding of the difficult situation of people affected with the neurological disease ME/CFS – which is classified under the code of G93.3 in WHO's International Classification of Diseases.

Although the Czech office of WHO are trying to find a solution, an attitude change towards the disease in the Czech Republic unfortunately appears to be a long-distance race.

An offer of legal help for ME/CFS patients came from the League of Human Rights (http://llp.cz/en/) as a response to being gifted the DVD.

The League deals with patient rights. An offer of legal help also came from the Czech Helsinki Committee who offered free expert social advice for Czech patients with ME/CFS, for example in the area of welfare benefits.

The film Voices from the Shadows can help to open society's eyes to ME/CFS but only if there is wider awareness about the film. Our awareness campaign tried to do this.

We tried to promote the film especially in expert circles because we believe that change of attitude towards patients with ME/CFS in the Czech Republic can come from these circles and therefore this could also offer most help. More awareness is needed so that there is more funding for medical research.

We thank the filmmakers for making the film and for the opportunity to translate it into Czech. We hope that our awareness campaign can serve as an inspiration to others to try a similar approach.

Nina - Czech Club of ME/CFS Patients (http://www.me-cfs.cz)

Source: https://www.facebook.com/VoicesfromtheShadows

News from...Denmark

There's a new documentary on ME/cfs in the making in Norwegia: Sykt Mørkt, Sick Darkness

The trailer with Norwegian subtitles can be seen with http://vimeo.com/93525737. It shows the daily life of two families with a very ME sick son and daughter and MP **Laila Dåvøy** announcing on tv that the ME riddle may be solved by the Norwegian researchers **Fluge** and **Mella**. The trailer has been subtitled in English as well and has been shown at the very beginning of the IiME-conference in London, May 30,2014: http://www.syktmorkt.no/

About the film:
"How sick is it that young people must lie isolated in total darkness. Indefinitely. The documentary film "Sykt Mørkt" is about the life in the darkness."

Quite unusually, for 6 years the film crew has been able to follow the life of two young people with severe ME, **Kristine** and **Bjørnar**, who both lie isolated in darkness. They were astonished by their calmness, their spirits and their ability to reflect when outer stimuli are reduced to an absolute minimum.

"Without telling too much, "Sykt Mørkt" is a film about football, presents and Christmas carols. And about a human transformation that you will not beleave until you see it."

The film is getting English subtitles at the moment and it should be ready for the IiME conference. **Pål Winsents** is also known as the producer of the documentary film "Få meg frisk!" [Make ME well!].

A crowdfunding for 150,000 NOK is needed to fully finance this new **Norwegian** documentary film about serious ME: Sykt Mørkt [Sick Darkness] by producer **Pål Winsents**.

Please donate here: http://www.syktmorkt.no/#!sttt-filmen/cwoc

On 12th May there has been a special screening of the film at Cinema Victoria in Oslo. Then, in addition to the film screening, there has been input from several of the players in the ME debate, including **Jorgen**.

Researchers **Olav Mella** of Haukeland and **Katarina Lien** from Oslo University have also been giving their views.

The film is on facebook: https://www.facebook.com/syktmorkt?fref=ts

Thanks to **Helle Rasmussen**, **Denmark**

News from...Germany

ME/CFS research in Germany

Dr. Madlen Löbel (left) and Prof. Carmen Scheibenbogen (right) - University Clinic Charité in Berlin, Germany

Prof. Dr. Carmen Scheibenbogen was one of the presenters at this year's IiME conference in London on May 30. She and her team at the Institute of Medical Immunology at the famous university hospital **Charité** in Berlin recently published two remarkable studies on the inability of ME/CFS patients to properly control the reactivation of the Epstein-Barr-Virus.

The first one, titled "Deficient EBV-Specific B- and T-Cell Response in Patients with Chronic Fatigue Syndrome" can be found here. (See also The Global Chronicle No 1, p 26) **Chris Cairns** has written a most interesting comment on this study, including analyses from "anciendaze" who explains the far reaching consequences for understanding the immune deficiency in ME/CFS.

The second study of the **Scheibenbogen** team, titled "Investigation of humoral immune response towards persisting Epstein-Barr virus infections in multiple sclerosis and chronic fatigue syndrome using peptide microarrays (TECH1P.868)" can be found here. She describes the specific antibody microarray test she develops together with a Berlin company which might become the first standardized diagnostic test for ME/CFS. The patterns of antibody responses they found could be of diagnostic value for multiple sclerosis and chronic fatigue syndrome. In a preliminary study more than 90 % of the ME/CFS patients could be identified.

Ever since **Prof. Scheibenbogen** visited the London IiME conferences for the first time she closely cooperates with the Norwegian oncologists **Olaf Mella** and **Øystein Fluge** with regard to their research on **Rituximab** in the treatment of ME/CFS. The B cells which are the target of the monoclonal antibody **Rituximab** also harbor the Epstein-Barr-Virus. The researchers regularly exchange their new research results.

The German ME/CFS community is very grateful that **Prof. Scheibenbogen** is committed to explore the disease mechanisms and possible treatments of ME/CFS and cooperates with many international ME/CFS researchers.

Submitted by **Regina Clos**

http://let-me.be

News from...Ireland

In February and March of 2014, several letters were sent by an ME organisation to the Minister for Health, the Irish Prime Minister, the head of the Irish Medical Council, and the Chief Medical Officer. We asked for the state authorities to immediately accept and implement the Canadian ME/CFS criteria (2003) and ICC criteria (2011) and to build a national clinic to treat ME and CFS and Fibromyalgia, patients in Ireland.

This clinic could be an ME clinic or part of a larger neurological clinic treating many neurological illnesses. The web proposals for an ME clinic were outlined on http://www.me-ireland.com We had some positive feedback from the government and the state medical authorities. There is general agreement that ME is a serious physical, biological illness, requiring medical attention.

However, the confusion created by some psychiatrists in other countries has divided medical opinion here in Ireland, and there is not complete agreement among all medical professionals here. The scientific and medical evidence presented on our web site at http://www.me-ireland.com/scientific.htm is being actively used to convince doctors, medical authorities, legal authorities and political authorities that ME is a physical and biological illness and people have actually died of this illness. We are trying to being ME awareness to the next level of understanding, so that all parties accept that it is physical and biological and deadly in some cases.

We hope that the state authorities will finance the building of an ME clinic and accept the Canadian and ICC criteria. And we hope that state agencies will fund ME research, especially replication studies to confirm some biomarkers. We realise that the Irish state is bankrupt, as a result of the banking crisis and austerity which has gripped the western world since 2008, and that it has experienced great difficulty in sourcing funding on international financial markets.

Yet the provision of an ME clinic would attract in foreign investment and foreign customers and revenues into Ireland, and help the government repay its debts. We hope that the Irish government has the strategic insight to make such a strategic investment for the benefit of all parties. Though, there are indications of 'Dickensian' penny pinching similar to the worst and most depraved austerity policies of the 1930's. One wonders if humanity ever learns ?There are contingency plans to present the ME clinic proposal to private international investors and foundations, complete with capital, revenue, cash flow and profit projections, in the event of the Irish government refusing to build an ME clinic.

In general, the private sector tends to have a more open minded view of strategic planning.We have included links to the letters below. We will keep our readers updated on developments: http://bit.ly/SNlzUF - http://bit.ly/1nJLgAO - http://bit.ly/1qV6wnQ - http://bit.ly/1nJLrMG

News from...The Netherlands

ME patients open up their hearts to Members of Parliament

On Wednesday May 14, 2014 **Prof. Dr. K. De Meirleir** spoke about the disease ME during a public hearing in Parliament. **De Meirleir**, former professor at the Vrije Universiteit of Brussels, is specialized in the treatment of the disorder.

Prof. Dr. Kenny de Meirleir (photo Wordpress.com Marthas Have)

That Wednesday afternoon ME patients opened up their hearts in Parliament. During a committee meeting they were given the opportunity to clarify the bottlenecks they encounter in medical care.

This happened as part of the citizen initiative ME, for which over 56,000 signatures were collected in two years and a half.

ME, short for Myalgic Encephalomyelitis, is also referred to as chronic fatigue syndrome (CFS).

However, according to the ME patients and two medical specialists present at Wednesday, the latter designation is misplaced, and the major cause of the current problems related to ME.

"It's like defining Alzheimer's disease as chronic forgetfulness, Parkinson's disease as chronic trembling and tuberculosis as chronic coughing", according to **Mirande Siem**, ME patient and member of the ME Group Den Haag, applicant of the citizen initiative.

Lawyer Arthur de Groot, who honorarily assists the ME Group, indicated the name debate as 'labelling fraud' to the Members of Parliament present. "The World Health Organisation clearly classified the disease ME as a biomedical disorder in 1969."

As a member of the WHO, the Netherlands are legally bound to this classification, according to **De Groot**. "Therefore the government has a duty to provide for ME patients, which forces it to take measures.

Later on a lot of noise has arisen. The disease has been narrowed down to a mainly psychological or psychiatric problem. This particularly happened in the **Netherlands**, **Belgium** and the **UK**, according to the Belgian ME expert **prof. Dr. Kenny de Meirleir**, working at the Vrije Universiteit of Brussels.

"However, ME is a neuro-immune disease presenting inflammation in the brain and other organs, usually due to infections," **De Meirleir** stated during the hearing.

He pointed out the "International Consensus Criteria" for ME, drawn up in 2011 at the request of the Canadian government by an international workgroup of medical experts, based on data of 110,000 patients. It shows from these criteria that ME and CFS are two different diseases.

As key feature of ME **De Meirleir** mentioned "exercise intolerance", exhaustion after even the smallest physical or mental strain. "I know of patients who had to stay in bed for a week after a walk to the bus stop."

Dr. Hans Klein, a psychiatrist and researcher working at the Universitair Medisch Centrum Groningen, was also on the same wavelength. He characterized ME as a "neuro-inflammatory condition" based on PET-scans, made as part of recent research.

He believes there are indications of chronic inflammation of the brain. "The thalamus is affected in ME, which is a major coordination switchboard for emotions, behaviour and feelings," **Klein** said.

Klein stated that ME research in the Netherlands "seriously runs behind" and "is pushed way too much into the psychological corner". The Dutch medical branche doesn't have any other knowledge about ME, while there have been around 5000 studies into the disease, and the Netherlands count around 30.000 ME patients, according to **Klein**.

Sandra Kouwenhoven, member of the ME Group Den Haag and patient herself, called ME a "multisystem disorder" which leads to neurological, immunological, craniological and gastrointestinal (stomach–gut – WvH) symptoms.

> "It would be best if an ME patient would be treated by a group of specialists with expertise in this area. But such general practitioners and medical specialists are not available."

Another problem is that a diagnostic treatment code (DTC) for people with ME doesn't exist. "Therefore I ask the government to develop a DTC for people with ME. The government has that power."

Member of Parliament **Van Gerwen** (SP) wanted to know whether a knowledge and expertise centre for ME could be a solution. ME Group member **Michelle Ouendag** replied that this knowledge needs to be imported from abroad first.

Kouwenhoven pointed to the forty web lectures by **prof. De Meirleir** in which he considers all kinds of aspects of ME. "We should also get physicians interested in those."

ME Group member **Siem** stated that the very first importance is for the government to recognise ME as a neuro-immune disease. Member of Parliament **Rutte** (VVD) wondered what the Parliament was able to do. "It is being presented like politics should recognise ME as a disease, but this is rather the role of authorities like the Health Council."

Psychiatrist Klein thinks that politics have many possibilities to ensure ME becomes plainly visible. "When things go wrong socially – which is structural in the diagnostics and treatment of ME – it's politics that have to make a move."

De Meirleir pointed to the example of **Norway**, where the Ministry of Health offered public apologies the other day for the way ME patients were treated until recently. The reason for this was the publication of a study in which promising results for a potential treatment of ME were reported.

De Meirleir believes it is possible for over 70 percent of ME patients to reach an acceptable quality of life, if they get a proper diagnosis and treatment.

"This allows them to work again, whether fulltime or parttime. In **Belgium** 7500 euro is available per patient for treatment with cognitive behavioural therapy.

We can offer a much better quality of life for half the price."

Source:
Reformatorisch Dagblad 15-05-2014 **Wim van Hengel**
http://www.rd.nl/1.827440

News from...New-Zealand

Meetings are held in **Wellington** and **Kapiti**

Wellington: 7/7, 8/4, 9/1, 10/6, 11/3 and 12/1, from 12:30-2:30 pm
On 7/7: Lower Hutt Special Venue
On 8/4, 10/6 and 12/1: Johnsonville Community Center
On 9/1 and 11/3: Anvil House

Kapiti: in the Waimea Cafe from 11 am to 1 pm. Exact dates on inquiry.

We welcome new members at any time but would love you to get into contact with our Community Support Worker Claire (support@wellme.org.nz) for more details before attending your first meeting.

If you'd like to get into contact with the group you can ring us (0800 632 847), email us information@wellme.org.nz or if you're looking for immediate support, please click here http://wp.me/PQCHd-4e.

Alternatively, you can find us on

Facebook here: https://www.facebook.com/wellme.mecfs
and on twitter here: https://twitter.com/WellMeNZ

News from...Northern Ireland

Members of the committee were invited to a civic reception hosted by **Banbridge District Council** to acknowledge the formation of a new patient support group in the area. The event was attended by **The Health Minister** for Northern Ireland, **Mr. Edwin Poots**. **Mrs. Joan McParland** took this unexpected opportunity to hand deliver an information pack to **Mr. Poots** which included a copy of Canadian Consensus Criteria and the educational documentary **'Voices from the Shadows'**. An invitation was also extended to **Mr. Poots** to attend a support group meeting in Newry to listen to patients concerns but unfortunately this was rather rudely ignored!

A petition was launched in April requesting that **Health Minister**, **Mr.Edwin Poots**, adopt the CCC as Northern Ireland's official clinical guideline for M.E. We believe this move would allow N.I. to take the lead in developing a more sympathetic and paced approach to the understand, diagnoses and treatment of M.E. The petition has attracted over 1200 names including prominent MLAs, doctors, researches and patient advocates from around the globe. A date for presentation has been requested.

Written confirmation has been obtained from Northern Ireland Blood Transfusion Services (NIBTS) that a lifetime ban is in force for blood and organ donations from patients with a diagnoses of M.E. and CFS.

The official reason, from NIBTS, states this ban is to protect patients from suffering relapse after blood donation. Blood and organ donations are accepted from patients with a diagnoses of Fibromyalgia. We feel this is a situation for concern due to gross misdiagnoses and clinicians who are unwilling to give patients a formal diagnoses of M.E. A number of medical professionals have verbally stated they prefer to give a suspected M.E. patient, a diagnoses of Fibromyalgia, due to the stigma and misunderstanding surround the disease.

May 12th Awareness Day in Newry was celebrated by the lighting up of three prominent buildings, **The City Hall**, **Newry Arts Centre** and **Craigavon Civic Building**. Other organised events included three churches giving out blue ribbons and offering prayers for the sick. Members of the support group also enjoyed a celebration meal to mark the occasion along with invited local MLAs and **The Lord Mayor** who all voiced their support for more public awareness.

In reply to a written request from the support group, **Newry Lord Mayor Michael Ruane**, made an official proclamation that from this year 2014, May 12th is Newry ME/FMS Awareness Day! The proclamation appeared and remains on Newry & Mourne District Council's official webpage.
We are delighted and grateful to **Mr. Ruane** for this recognition for patients and hope this move will encourage other towns and cities to follow his lead for the future. A fundraiser for bio-medical research also took place after the meal and all proceeds will be forwarded in due course.

After a slow start in 2013, May 12th Awareness Day certainly attracted much attention this year. A friendly global challenge was set by a colleague in Canada for all countries to light up as many buildings as possible.

The result was indeed global and N.I. progressed from just one spectacular lighting up event last year to a grand total of 16 prominent buildings around the province. We were delighted that other supports groups joined us for the team effort which resulted in N.I. winning the friendly challenge!

We were honoured to welcome **Mary Schweitzer** to the June monthly support group meeting! This very welcome and unexpected speaker shared her journey from severe M.E to near recovery while continuing treatment with **Ampligen**. All patient members were delighted to have this opportunity to meet with **Mary** and thanks to **Horace Reid** for organising her travel arrangements in N.I.

We are currently liaising with **Mr. Dominic Bradley MLA** and preparing for a meeting with The Health Minister when we will officially hand over the petition for the adoption of CCC.

Change will not happen overnight but we are committed and pledge to continue our campaign for adequate NHS services for M.E. patients in N.I.

Joan McParland

Major fundraisings

Llewellyn King is raising funds

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

Raised: $4,675.00 Goal: $20,000.00

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

Ian Lipkin study. Raised: $70,004

The initial target has been set at $1 million.

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

http://www.microbediscovery.org/

Raising Funds for the UK Rituximab Trial

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

Thanks to an amazing effort across many countries the Biomedical Research Fund for the IiME/UCL UK rituximab clinical trial has now reached **£338,000**. The goal is **£350,000**.

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

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

http://theblueribbon.storenvy.com/

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

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

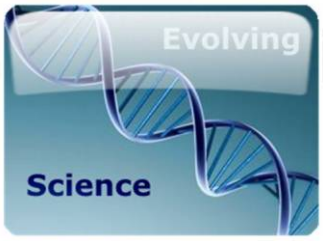
To Donate: http://bit.ly/1qwwmz0

Select your language at the bottom

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

Worth reading & watching

Just a reminder that this was started earlier this year. We were hoping to be a united advocacy group for M.E.
http://www.meadvocacy.org/



Evolving Science
Don't tell us you never stuck upon the high quality fb-wall Evolving Science from Belgian ME-patient **Linda**. You missed a lot, but still can make up for it by clicking right now
http://on.fb.me/QEG4T0

Examining case definition criteria for chronic fatigue syndrome and myalgic encephalomyelitis
Leonard A. Jason, **Madison Sunnquist**, **Abigail Brown**, **Meredyth Evans**, **Suzanne D. Vernon**, **Jacob D. Furst** & **Valerie Simonis**
http://bit.ly/1l73rRM

Poems from Conflicted Hearts:
Poems of Kentuckycurran. **Tayen Lane** Publishing / Smooth Stones Press
Published March 1st, 2014
eBook: $4.99 (Amazon, Barnes & Noble, iTunes & Tayen Lane).
To request a review copy, schedule a contributor interview, or obtain more information regarding publishing an excerpt, please send an email to info@tayenlane.com

Prof. dr. Julia Newton
on ME and the bloodflow

http://www.youtube.com/playlist?list=UUPZtpMdUGvQblEJ3IfgYQ8Q

High time to join forces, all over the world:
Need a reason?
Over 51,000 views
Watch this: http://youtu.be/IOflARSgNnE

Llewellyn King, ME/cfs Alert, produced by **Llewellyn King** and **Deborah Waroff**, broadcast five new videos since the last issue of the ME Global Chronicle:

Episode 59 http://youtu.be/R7JtNImePlY
What is needed: a presence in Washington
April 17, 2014
Llewellyn King: ME/CFS Alert, Episode 59, April 17, 2014

Episode 60 http://youtu.be/xuiZbrIQ6Ko
Interview **Llewelyn King** with **prof. Anthony Komaroff**, Harvard Medical School, part 1
On funding for research on ME/cfs & the disease itself
April 25, 2014

Episode 61 http://youtu.be/bgmffj4ItZo
Interview **Deborah Waroff** with **prof. Anthony Komaroff**, Harvard Medical School, part 1
On biomarkers, treatments and state of the art
May 22,2014

Episode 62 http://youtu.be/eMosC6O1VZc
Interview **Llewellyn King** with **prof. Anthony Komaroff** Harvard Medical School, part 2
On contagion, outbreaks, **ampligen** & **rituximab**, brain research, gender & ME/cfs
June 3, 2014

Episode 63 http://youtu.be/HiUCoIoybUw
Interview **Deborah Waroff** with **prof. Anthony Komaroff**, Harvard Medical School, part 2
On a new secretary of health,
June 14, 2014

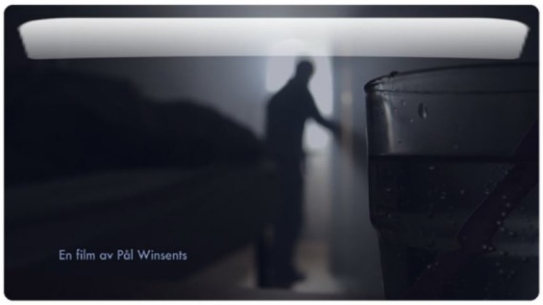
A Good Practice Guide to Education for Children with ME for GPs, Schools and Families is also available online:

http://www.tymestrust.org/pdfs/gpguidev2.pdf

Source: www.tymestrust.org

If you're living in the Worcestershire, UK-area and are looking to make new friends and have support when you need it: there's a brandnew group facebook page for sufferers of ME and FM in Worcestershire, UK: https://www.facebook.com/groups/556279061149706/

Kelly Williams Set It Up



Norwegian docu **Sykt Morkt** (**Sick Darkness**)
Trailer with English subtitles
http://www.syktmorkt.no/

A small group of us have created a series of short videos mostly showing the errors in the PACE trial reports. The latest two have just been released, concerning the claims that CBT promotes recovery in people with ME/CFS.

6: ME Recovery Song http://youtu.be/QbKTBMyZfX0
7: How's That Recovery? http://youtu.be/d_7J5ELjArU

The complete set can be found here:
http://www.youtube.com/user/MEAnalysis/videos

I hope that there is something there that interests you.

Graham McPhee

Shocking video on severe ME
http://youtu.be/35oviFjxYHY

shown in Japan on May 12, 2014

submitted by **Masako**

Appeal from **Rich Podell**, see article on page 8.

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

Invest in ME conference, May 30, 2014

Conference Brochure IiME 30 May, 2014 online now:
http://bit.ly/1joAFXH

With many valuable articles and descriptions of the speakers and their topics on May 30, 2014

Full set of 4 dvd's, covering all presentations including **dr. Nigel Speight**'s pre-conference dinner speech, to be ordered through: http://bit.ly/1ivrbiI

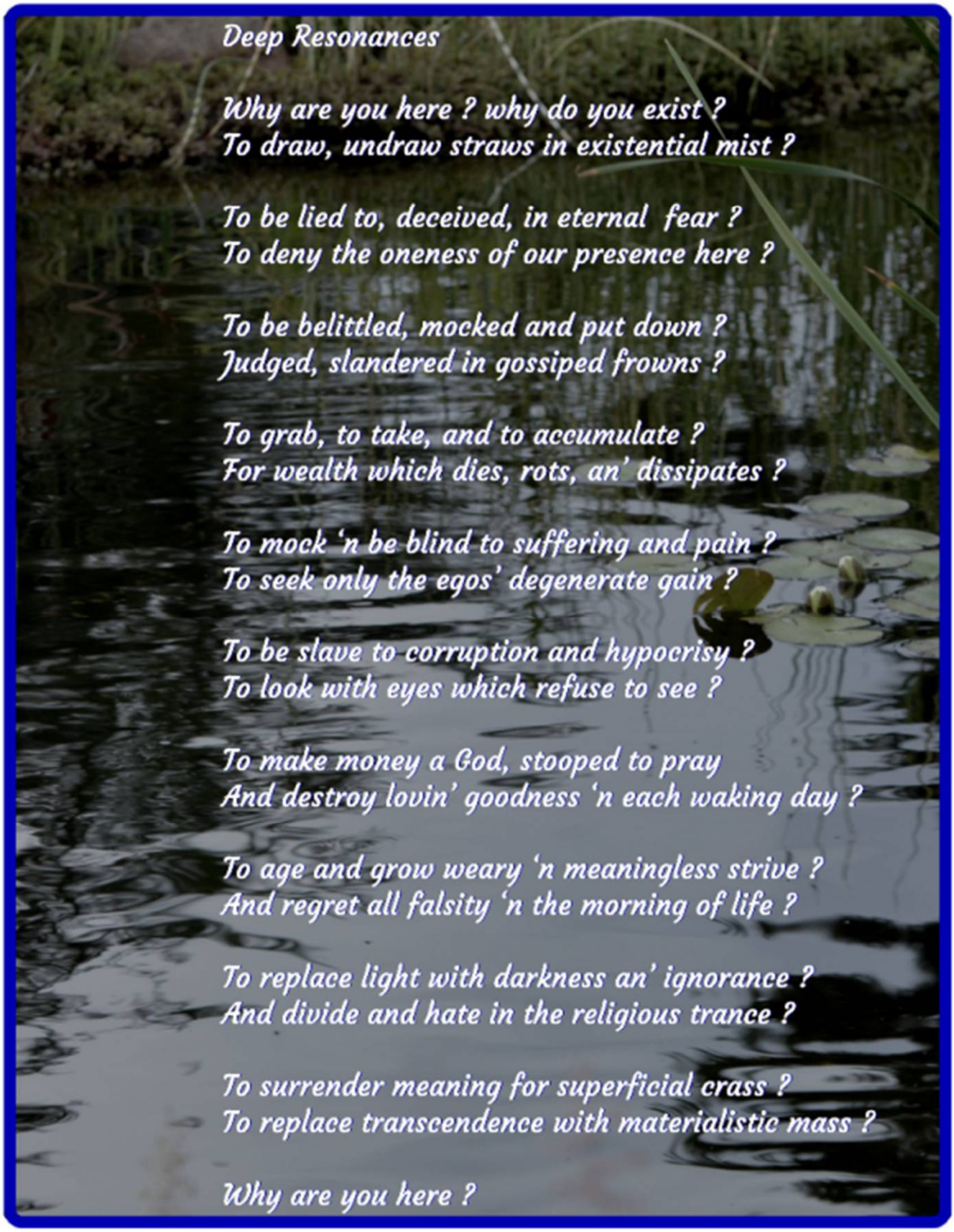
A better vision on ME?
Watch this video:
http://youtu.be/2rVrlD34H7I
Action For ME's CEO **Sonya Chowdhury** observing and reflecting on what's currently happening in the world of ME. Especially listen from 6:26 onwards.

Thanks to **Joan Parland** for posting this on https://www.facebook.com/groups/newryandmourne.me.fms/

"Aliveness is:
Loving each other
Being in relationship
Standing together in partnership
Fighting together for the righ service
Being bold
Being happy
Trusting in goodness to prevail"

Taken from:
Severe ME
Featuring "Justice to **Karina Hansen**", p.337 - **Greg Crowhurst**
To be ordered via http://bit.ly/1wwcDlN

Poem From An Irish Poet



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."