The ME Global Chronicle

www.let-me.be

 # 11 – June 2015

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

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

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

2. Table Of Contents

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

3. Introduction

Dear readers,

We hereby present you the eleventh number of the ME Global Chronicle, with news about things passed and news about things going on or about to happen.

Please do not blame us when much, if not everything you find in this issue, is already known. We consider ourselves just as a service-hatch of information from everyone to everyone. Thereby the only criterion is it might be of interest for yourself, but even more for your followers. That is why we continue to emphasize our request to share this magazine as much as possible.

One point of which all of you can think about and can do, we particularly like to draw attention on.

It takes place in a small country, but could have large effects on everywhere, also on your country. We thereby aim at the citizens' initiative 'recognize ME as a biomedical illness', in the Netherlands. We have kept you informed about its developments in previous issues.

The initiator, the Group ME The Hague, has managed to achieve the Dutch parliament has asked the Health Council for advise to revalue the illness ME. The Group ME The Hague is asked by the Health Council to provide input for this process. About twenty global excellent researchers in the ME area expressed their willingness to actively participate to it.

The next step is an appeal to you all: the Group ME The Hague is asked to deliver research papers that contribute to a reliable and up to date view of ME and are evidence-based before mid-August. Anyway double-blind placebo randomized control, preferably with as large as possible cohorts.

If all our efforts result in recognition of ME as a biomedical disease in the Netherlands, and the implementation of that recognition is also recorded in the advice of the Health Council to the parliament, it could very well have a domino effect on other countries.

Therefore everyone's cooperation is of great importance. Mail links to studies that according to you could make the difference to medenhaag@gmail.com, preferably before mid-July.

In the table of contents each name of an article is linked to the article itself: thus you can easily pick out the article of your interest or energy-level. At the bottom of each page there's a link back to the table of contents.

We aim at steering this magazine to independency and a means of exchanging valuable information amongst you all. Hence even more the invitation to mail us anything you deem fit to include in next issue, which will be published on August 22, 2015.

n.b. A new section is introduced in this issue; **Events**

If you want to announce an important event like a conference or an action, or if you want to insert a report of an action or event which took place, please mail to contribute@let-me.be, and we'll try to include it in next issue.

The editors

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

4. 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.

We are now into the Summer season of 2015, and the long hot days of Summer and the cool balmy evenings provide an uplift to the mood of many patients. Controversy continues to plague the illness ME. One recent paper by **Dr. Morton Tavel** was published in a medical journal, it was about SEID, formerly called CFS, and displayed an amazing ignorance of SEID, CFS and Fibromyalgia.

His paper is being challenged and rebutted by letters to the editor. In Britain **Dr. Suzanne O'Sullivan**'s book 'It's all in Your Head – True Stories of Imaginary Illness' pokes fun at ME patients and Fibromyalgia patients, and ignores the scientific facts and medical facts about these illnesses.

It certainly provoked the **Countess of Mar** into replying to her and some reviewers, see http://bit.ly/1G2DM2K The IOM with it's SEID nonsense is largely to blame for this through its denial of known biomarkers established through several research projects, and ignoring the Canadian criteria and ICC criteria.

SEID is now open to the same misinterpretations, lies, denials of facts and evidence stigma and failure as the term 'CFS'. The inability to classify ME as a neurological and immune illness, similar to WHO classification remains a problem in the USA and most European countries.

Yet there are considerable ground for hope and positivity. The Invest in ME Conference was held on May 29th and was another success, exposing some very good research findings and with information on continuing research which will shed new light on the illness.

The conference included top ME researchers such as **Jonathan Edwards**, **Dr. John Chia**, **Dr. Mady Hornig**, **Drs. Fluge** and **Mella**, **Dr. Jo Cambridge**, **Dr. Betsy Keller**, **Dr. Jo Cambridge** and **Dr.Claire Hutchinson**. There is some news about this in our Newsletter. The OMI is continuing with its fund raising for 'The End ME/CFS Project' and this will examine several known genetic markers, biological markers and dysfunctions in ME patients.

This being led by a world famous geneticist **Dr. Ronald W. Davis** in California. The research project includes **3 Nobel Prize winners** and several other leading scientists. It is the top ME research project in the world at present and the one most likely succeed in identifying all the important biological factors.

The Stanford Research Intiative has found evidence of Herpes virus infections in subgroups of ME patients. Research is ongoing to look at brain, nervous system, bone marrow, b-cell, immune cell, muscle infections.

Dr. Montoya is collaborating with **Lipkin** and **Hornig** on these new findings. Certainly, infections are important for some subgroups. There is fund raising for **Dr. Lipkin** and **Dr. Hornig**'s research which will explore the role of immune dysfunctions, infections and gut abnormalities in ME. This is due to begin this year. Other research planned for California include a Lyme study, HPA axis study and a mitochondria study in 2015 -2016.

Jen Brea has launched a mass advocacy platform which will help millions of patients (http://www.meaction.net/news/). Her ME documentary film is being developed at present. We wish her continued success in this.

We will be discussing these successes and more in this June edition. We hope you enjoy our offering.

A special thanks to **Rich Podell** and **Lenny Jason** for their contributions and insights.

David Egan

5. Grassroot

Cartoon Djanko

Citizen Initiative Of The Netherlands

- Fall 2011: a group of ten independent patients starts collecting signatures to request the government to recognize ME as biomedical disease, knowledge about which should be disseminated among practitioners and in medical education, and to redefine ME and look for possible treatments. Currently there's only a CFS-guideline for practitioners which advises CBT and GET as the only possibly effective treatments of the symptoms of ME.

- While 40.000 signatures are needed, in October 2013 a delegation of the Dutch dHHS is presented with **56.000** ones.

- Fall 2014: the parliament commissions the Health Council of the Netherlands to evaluate the current state of knowledge about ME, with special attention to:
  - The definition of ME and diagnosing the disease Start, progress and prevalence
  - Possibilities to prevent and treat ME
  - Impact of ME on the patient, his environments and participation in society
  - Organization of treatment and support of patients with ME in the Netherlands
  - Current scientific developments and perspectives

The Health Council is requested to at least start working on this commitment during 2015, in spite of not having it on its agenda. A final advice is expected in the spring of 2016.

The Health Council has asked the Group ME Den Haag to present them with names of researchers in the field who are able to contribute to the fact we're talking of a serious disease with physical and not psychological causes and/or triggers. As well as its opinion about the IOM-report, and which research-papers would be important to form a legitimate base to recognize and handle ME as a physical illness.

The Groep made an appeal on a number of worldwide renowned ME-clinicians and researchers, keeping an eye on the different specialist fields, ME being a multi systemic disease. The response was huge.

Apart from two of them who did not react for unknown reasons, there was unanimous enthusiasm and all were willing to cooperate in one form or another (almost always in a desired form).

It became clear that 'our' scientists –at least as far as approached by the Groep – were and are fully aware the impact this Citizen Initiative may have, and which positive part they may be able to play in it. And that in itself is a very promising and hopeful sign.

The gratefulness of the Groep ME Den Haag towards them is big. It is a privilege to be instrumental in one way or another in the attempt to close the ranks on a global scale.

Info about the Groep ME Den Haag (only in Dutch): http://www.dezieketeme.nl/

Or mail to info@let-me.be

This is a unique opportunity to change the treatment of at least 20.000 patients in the Netherlands for better and enhance research into ME, which may not occur again for years, and may have an impact on the global community.

Forgotten Plague

Honored to be a part of a seminar on ME. **Professor Alan Goodman**, a medical anthropologist at **Hampshire College**, hosted about a dozen professors for a full week of discussions on this disease, with researchers from the fields of communications, immunology, neurology, economics, and more.

The professors were treated to a private pre-release screening of Forgotten Plague and it was great fun engaging with them afterwards in a robust, interdisciplinary dialogue about this disease and what needs to be done about it.

The professors, all of whom hailed from the **Massachusetts**' "**Five College Consortium**" (**Mt. Holyoake**, **Smith**, **Amherst**, **Hampshire**, and **UMass-Amherst**) will now shift toward publishing a paper on ME in an academic journal related to his/her prospective field.

Thanks so much to **Dr. Alan Goodman** for organizing the seminar. It'll be fascinating to see what larger ripples emanate into the world as a result of the conference!

In case you missed it, here is our fist trailer for Forgotten Plague:

Forgotten Plague is the story of an afflicted journalist who embarks on a journey to find out why the CDC and medical system have neglected his disease, leaving millions sidelined from life.

The film tells the great under-reported medical story of our times. With threads detailing the politics, science, history, and deep human suffering associated with the disease, the film strives to give a panoramic picture of ME/CFS.
https://m.youtube.com/watch?feature=youtu.be&v=VsQcmKT3zSo

http://mecfsdocumentary.com/fundraising/

Quotes

"My H.I.V. patients for the most part are hale and hearty thanks to three decades of intense and excellent research and billions of dollars invested. Many of my C.F.S. patients, on the other hand, are terribly ill and unable to work or participate in the care of their families.

I split my clinical time between the two illnesses, and I can tell you if I had to choose between the two illnesses (in 2009) I would rather have H.I.V. But C.F.S., which impacts a million people in the United States alone, has had a small fraction of the research dollars directed towards it."

Dr. Nancy Klimas,
AIDS and CFS Researcher and Clinician,
University of Miami

Jeannette Burmeister
Taken from Thoughts about ME, http://thoughtsaboutme.com/quotes/

*Thanks **Jeannette** and **John***

Institute Of Medicine To Become National Academy Of Medicine

WASHINGTON - Today (April 28, 2015 ed.), at its 152nd annual meeting, the membership of the National Academy of Sciences voted to change the name of the **Institute of Medicine** to the **National Academy of Medicine**. The newly named **National Academy of Medicine** will continue to be an honorific society and will inherit the more than 1,900 current elected members and foreign associates of the **IOM**. The **National Academy of Medicine** will join the **National Academy of Sciences** and **National Academy of Engineering** in advising the nation on matters of science, technology, and health.

Today's vote amends the **NAS** constitution to change the name of the **Institute of Medicine** to the **National Academy of Medicine**, effective July 1, 2015. This change is part of a broader internal reorganization to more effectively integrate the work of the **National Academies of Sciences**, **Engineering**, and **Medicine**. Reports and studies on health and medicine will continue uninterrupted as activities of the Institute of Medicine, which will become one of the six program units operating under the direction of the integrated academies.

"Today, science, engineering, and medicine share many common areas of interest in the pursuit of discoveries, advancing knowledge, and solving problems of people and society," added National Academy of Engineering President C.D. "**Dan**" **Mote Jr.** "Having three national academies under one roof shows the ongoing collaboration among the people who are tackling today's grand challenges."

The **National Academy of Sciences** was founded in 1863 under a congressional charter signed by **President Lincoln**, which created a body that would operate outside of government to advise the nation "whenever called upon." The **National Academy of Engineering** was founded in 1964. The **Institute of Medicine** was established as the health arm of the NAS in 1970.

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Flickr: http://www.flickr.com/photos/nationalacademyofsciences/sets

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

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

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

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

Sign up here**:** **http://meactionnetwork.org/**
Follow us on Twitter: **https://twitter.com/MEActNet**
Like us on Facebook: **http://facebook.com/MEActNet**

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

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

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

#MEAction

Jennifer Brea

In Memoriam

Beverly Terwilliger, who was known on MECFSForums as **Sp!ndrift**, died on June 7, 2015.

She was a longtime member of MECFSForums, and entertained us often with her wild sense of humor. She will be missed.

Information, posts about her, lifestories, pictures and other remembrances to be found on the memorial site:
http://ocean.terwilliger.muchloved.com/

Thanks to Patricia Carter for posting this on ME/CFS Memorial Page
www.facebook.com/groups/MEMemorial/

Canary in a Coalmine

Dear Canary Community,

I am thrilled to announce that Canary in a Coal Mine has been chosen as one of eight films to participate in **Britdoc**'s Good Pitch New York!!!

"Good Pitch brings together documentary filmmakers with foundations, NGOs, campaigners, philanthropists, policy makers, brands and media around leading social and environmental issues - to forge coalitions and campaigns that are good for all these partners, good for the films and good for society."

BRITDOC is all helping documentaries achieve the broadest reach and greatest impact on the world. We are so excited to have the opportunity these next many months to work with them on developing a killer outreach campaign and expanding our circle of allies.

You can see the full lineup of **Good Pitch New York films** here: http://bit.ly/1BZ0V4u

And learn more about **BRITDOC** here: https://britdoc.org

Here's how you can help:

1) Head on over to the **BRITDOC** Facebook page to say THANK YOU for this amazing opportunity to broaden the film's reach beyond the #mecfs community and find new allies and audiences: https://www.facebook.com/C4BRITDOC What impact do you hope the film will have on the world?

2) Please share your ideas here: http://on.fb.me/1Kq5T1o or in the comments below about who those allies could be. We get to invite anyone we think might be a potential partner for the film's outreach campaign.

What organizations, foundations, or individual activists working in science, health, human rights, women's rights, disability rights, patient's rights, or the environment could be natural allies for Canary in a Coal Mine? How do we best connect the disease and the film to the broader issues they represent represent?

THANK YOU **BRITDOC**!!! We're really big fans of your work.

Jen

Disabled, Chronically Ill To Occupy US Dept. Of Justice

Groups of chronically disabled patients, victims of medical abuse, will be assembling for a peaceful but passionate protest on the steps of USDOJ, 950 Pennsylvania Avenue NW, Washington, DC 20530, from June 1 until July 4.

They are charging the USDOJ with failure to act on a whistleblower's complaint accusing of research fraud and falsification of information for personal financial benefit as outlined below. Facts sheets reveal rampant fraud and racketeering within the CDC and private entities.

The Occupy leaders state in their criminal charge sheets that there is a common disease mechanism linking Myalgic Encephalomyelitis (ME), Chronic Fatigue Syndrome (CFS), Lyme Disease, Gulf War Illness, Fibromyalgia and Autism. Exposing this mechanism reveals rampant fraud and racketeering within the CDC and other entities, as well as the cause of the autism pandemic.

Through a massive compilation of published scientific research and public-record documents, a group known as the Society for Advancement of Scientific Hermeneutics (SASH), makes a convincing case for these illnesses sharing a common mechanism of fungal-induced immunosuppression, known to the National Institutes of Health (NIH) as "Post-Sepsis Syndrome."

They report that such immunosuppression leads to the chronic reactivation in the central nervous system of multiple viruses such as Epstein-Barr Virus (EBV), Cytomegalovirus (CMV), and HHV-6, leading to cancers and an AIDS-like disease. SASH further shares evidence that the interaction of fungi with attenuated viruses in vaccine vials causes the reactivation of those viruses and ultimately, the diseases they are meant to prevent.

The group's primary charge centers on the USDOJ's failure to take action on a whistleblower complaint that was filed in July 2003 by **Kathleen Dickson**, a former analytical chemist at pharmaceutical giant Pfizer. Her complaint alleged that CDC officers, Yale University medical faculty and others committed research fraud to falsify the current, Dearborn case definition (2-tiered) in order to falsify the outcomes of the OspA vaccines, namely LYMErix, which was pulled from the market after an FDA ultimatum to the manufacturer.

Ms. Dickson's complaint further alleged that the very same government employees who committed these crimes stood to gain substantial financial rewards from a monopoly on all tick-borne diseases, vaccines and test kits. Additionally, their falsification of the Lyme disease case definition and treatment guidelines have left 85% of actual Lyme sufferers unable to obtain diagnosis, treatment, or insurance coverage for their AIDS and cancer-like illness.

An abundance of scientific and historical evidence is presented in the charge sheets. Many of the citations refer to the alleged criminals' own peer-reviewed, published research papers and patent documents, which paint a chilling picture of the extreme effort that SASH says has been made by the alleged criminals to deny basic healthcare to an estimated 30 million sufferers in the United States.

They say that the extent of deceit and corruption, with intent to deny an illness, goes far beyond anything that occurred in the early days of AIDS activism.

The group is calling on USDOJ to prosecute for the fraud and racketeering charges. These criminal acts have left millions of people to suffer in isolation while being ridiculed by doctors, family members and employers as psychosomatic or lazy.

The victims, often bankrupted by the high cost of out-of-pocket medical expenses, and unable to work due to illness, and many suffering with such unmanageable severe pain; frequently commit suicide to escape their continuous denial of basic human rights and lack of basic care and pain management.

For additional information and to view the charge sheets, visit http://ohioactionlyme.org

http://May12.org is endorsing this protest, and is dedicated to raising awareness of complex immunological diseases such as Myalgic Encephalomyelitis, Chronic Fatigue Syndrome (ME/CFS) and Chronic Lyme disease.

E-mail: info@may12.org

Contact Person:
Joni Comstock
Phone number: 515.209.9495

Mike's EU Marathons: Raising Myalgic Encephalomyelitis Awareness across Europe

I'll be running a marathon in each of the 28 EU member countries to raise awareness and much needed funds for biomedical research into ME & for the charity Invest In ME.

I'm aiming to raise funds and awareness for biomedical ME research across the 28 countries within the European Union by running a marathon in each. I've now completed 2 of my marathons; **UK** (April 22, 2001) and **Czech Republic** (March 5, 2015) Next up is **Helsinki**, **Finland** on August 15th!

One of my best friends has had ME for 8 years and been unable to work or lead a normal life, this is the only way I feel I can help him and the other 250,000 sufferers in the UK.

I'm working with Invest In ME (http://www.investinme.org) to unite European ME sufferers and associations to raise the profile of research projects. I aim to run 4-5 marathons a year and am aiming to finish the challenge by 2020.

In 2014 with a group of friends, I took part in a very different challenge for the charity (92 football grounds in 92 hrs) managing to reach over 10 million people (through TV, Press and the football community) and raising nearly £5K for the Rituximab trial.

Throughout this project I met and talked to ME sufferers and their families which has had a very profound effect on my decision to attempt this challenge.

I'm looking for sponsorship for races and travel/flight costs as well as press/media contacts in the countries I'm visiting. If you know anyone who can help please get in touch!

Donate to **Mike**'s EU Marathons: http://bit.ly/1BdhrD6

Follow along:
Mike's EU Marathons Website: http://bit.ly/1GEZ0HO
Facebook: http://on.fb.me/1cUJITg

Source: **ME Action** http://bit.ly/1FUFO59

6. Science

Rich' Reviews: A Promising (NEW!) Medicine For Fibromyalgia Pain

Three drugs—Cymbalta, Savella and Lyrica—are FDA approved in the U.S. to treat Fibromyalgia. These medicines are useful, but not all patients respond and side effects are frequent-especially for **Lyrica**.

Namenda (memantine) is currently approved to treat Alzheimer's disease. Memantine improves several systems of the brain that relate to Fibromyalgia. Therefore, in theory, memantine might be a useful treatment. Unfortunately, no one was willing to fund a Fibromyalgia related study. Not until now.

Happily, Fibromyalgia researchers in Spain have addressed the challenge. They've presented an excellent double blind study comparing memantine to placebo.

Subjects were selected to meet the 1990 American College of Rheumatology case definition. During the six month trial subjects taking memantine had substantially less pain, improved cognitive ability, and better day to day function than patients treated with placebo. Statistically significant improvement occurred within the first month and persisted throughout the six months.

Memantine's side effects tend to be mild. So, if these encouraging results are confirmed by further studies, Namenda (memantine) could quickly become a mainstay treatment.

Why are fibromyalgia researchers interested in memantine? One of the mechanisms causing fibromyalgia pain is increased activity of a set of receptors in the brain and spinal cord. These are called NMDA receptors. Overstimulation of NMDA receptors causes increased sensitivity to pain. Memantine reduces the activity of NMDA receptors.

The research study: **Dr. Barbara Olivan-Blazquez** , **Dr. Javier Garcia-Campayo** and their team recruited 60 long term fibromyalgia patients. Half received memantine, the others placebo.

Pain status was measured in two ways. First, they used a visual analogue scale where patient rate their subjective sense of pain on a scale of zero to ten. Zero means no pain. Ten is the worst pain possible.

After one month on memantine, the average visual analogue score decreased from 6.56 to 4.83. After one month on placebo, the visual analogue score increased from 6.48 to 6.64. The difference favoring the memantine group was highly

significant (P=0.001). Significant differences favoring the memantine group continued throughout the study.

A second way to measure pain was by pumping up a blood pressure cuff. At baseline, the memantine group subjects complained of pain when the blood pressure cuff average reading was 97.9 millimeters of Mercury (mmHg). One month later, pain sensitivity decrease. Pain reporting occurred at an average of 112 mmHg. For patients on placebo, pain sensitivity mildly increased.

Improvement in pain with memantine seems to be at a level that is clinically significant, but for most subjects not dramatic. Only 16% of the memantine treated subjects achieved a 50% improvement in pain (5 of 31subjects). BUT none (0%) of the subjects on placebo had 50% improvement.

Subjects on memantine also did significantly better than those on placebo for the mini-mental status test of cognitive function, and on several measures of functional activity. The bottom line: Subjects taking memantine tended to feel better while also being more active.

Is it reasonable to consider using memantine as an "of label" treatment for fibromyalgia? We have only one fairly small study. So we cannot say for sure if memantine "really works".

Still, as medicines go, memantine is considered to be relatively safe. Among patients with Alzheimer's the most common side effects are dizziness, headache, confusion and constipation. No major drug interactions have been reported. But one should avoid mixing memantine with other NMDA receptor antagonist medicines including amantadine, ketamine and dextromethorphan (the cough suppressant in Delsym).

The Spanish researchers started treating at 5 mg once daily. They titrated over one month to a final dose of 10 mg twice daily. Since people with fibromyalgia tend to be very sensitive to medicine side effects, I would advise physicians to start with a low dose e.g. 5 mg memantine once daily or even less. Then increase as tolerated - even if it takes more than 4 weeks to reach the 10 mg twice daily goal.

The Spanish government provided major financial support for this research study. One obstacle to further research is that Namenda (Forest Laboratories) is now available as a generic. This reduces the incentive for any manufacturer to spend the multi millions of dollars required to seek FDA approval to promote memantine as a treatment for fibromyalgia.

Congratulations and thanks to **Dr Olivan-Blazquez**, **Dr. Garcia-Campayo** and their group for this first rate double blind study.

The Key Article:
Olivan-Blazquez, **B. Garcia-Campayo**, **J**, Efficacy of memantine in the treatment of fibromyalgia: A double-blind randomized, controlled trial with 6-month follow-up. Pain 155 (2014): 2517-2515.

To read the complete article:
http://www.biomedcentral.com/content/pdf/1745-6215-14-3.pdf

Additional references:
Fayed, N. **Garcia-Campayo**, **J**, Changes in Metabolites after Treatment with Memantine in Fibromyalgia. A double-blind randomized Controlled Trial with Magnetic Resonance Spectroscopy with a 6-month follow-up, CNS Neuroscience & Therapeutics, 20(2014): 999-1007
Abstract: http://www.ncbi.nlm.nih.gov/pubmed/25218600

Serra, **G**, …**Kahn**, **D**, Memantine in the Treatment and Prophylaxis of Bipolar II Disorder and Comorbid Fibromyalgia: A case Report, Journal of Psychiatric Practice 20 (2014): 232-6

Abstract:
http://www.ncbi.nlm.nih.gov/pubmed/24847998

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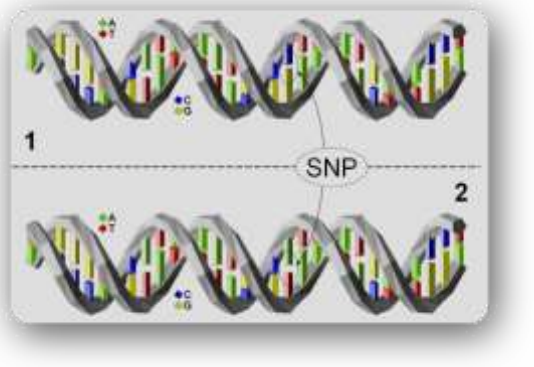
Gene SNPs in ME/CFS

DNA molecule 1 differs from DNA molecule 2 at a single base-pair location (a C/A polymorphism).



Human beings are 99.5% identical as regards their DNA gene sequences. The remaining 0.5% mainly consists of single nucleotide polymorphisms (SNPs, pronounced "snips"), which are small genetic changes in DNA that vary between individuals.

Most SNPs are silent, but others have important consequences; a single SNP mutation in the APOE gene, for example, is associated with an increased risk of Alzheimer's disease. At the moment, scientists across the world are involved in identifying particular SNPs and linking them with particular diseases.

To date, only a handful of studies have attempted to examine individual SNPs or patterns of SNPs in ME/CFS patients. One was an ME Research UK-funded investigation at the **University of London**, which found significant differences in the distribution of a small number of gene SNPs between ME/CFS patients and healthy people (http://bit.ly/1Mkt7Es).

Another study, from **Japan**, examined SNPs in genes involved in the monoaminergic system but did not find an association overall (http://1.usa.gov/1IrTSGo), while an investigation by the **Center for Disease Control** in **Atlanta**, **Georgia** found that genes associated with glutamatergic neurotransmission and circadian rhythm might be associated with ME/CFS (http://1.usa.gov/1JBnW5o).

The latest report on SNPs (http://bit.ly/1BVOmH8) in ME/CFS is a pilot study from **Griffith University**, **Australia**, and it focuses on the transient receptor potential (TRP) 'superfamily' of ion channels (http://bit.ly/1IrUgES) involved in many key biological processes. TRPs are known to be impaired in a range of diseases, including chronic pain and motor neuropathy, so it is certainly feasible that there might be specific variations in SNPs associated with TRP ion channel genes in people with ME/CFS.

When the Australian researchers compared 115 ME/CFS patients and 90 'non-fatigued' controls, they found that 13 SNPs were present at significantly different frequencies. Nine of these SNPs were associated with the TRPM3 gene, located on chromosome number 9, which makes a protein involved in cellular calcium signalling and in maintaining physiologically stable conditions (homeostasis).

Of the others, two were associated with TRPA1 (a sensor for pain, stretch and environmental irritants) and two with TRPC4 which plays a part in the regulation of blood vessels and cell division.

As the researchers point out, the results of this pilot study are essentially preliminary, though they do imply that genetic alterations at TRP ion channels have a role in the development or maintenance of ME/CFS.

All the investigations on SNPs in ME/CFS that have been published to date can best be described as 'hypothesis-generating' rather than conclusive in themselves. Their aim is to pin-point specific areas of the genome that future investigations might examine more closely. However, complex chronic illnesses like ME/CFS are most likely to be the result of very large numbers of SNP variants working in concert.

So, in reality, large studies using genome-wide scanning methodologies and complex analytical methods will be required to obtain definitive results (see a recent review). At present, the 'SNP500Cancer' project is examining samples to locate SNPs of immediate importance to molecular epidemiology studies in cancer, and there are many such examples in a range of illnesses. Ideally, there would be a 'SNPMEproject' using state-of-the-art techniques to do the same for ME/CFS.

Further reading

Examination of single nucleotide polymorphisms (SNPs) in transient receptor potential (TRP) ion channels in chronic fatigue syndrome patients. **Marshall-Gradisnik SM**, et al. Immunology and Immunogenetics Insights, 2015 May 10.

Read more (full text)
http://bit.ly/1BVOmH8

Use of single-nucleotide polymorphisms (SNPs) to distinguish gene expression subtypes of chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME).
Read more: http://bit.ly/1Mkt7Es

SNPs – A shortcut to personalized medicine (http://bit.ly/1JFKosG), by **Bruce Carlson**, Genomics in Cardiovascular Disease. **Roberts R**, et al. Journal of the American College of Cardiology, 2013 May 21
Read more: http://1.usa.gov/1IAKRxG

Photo credit: "Dna-SNP" by SNP model by **David Eccles** (gringer)
http://bit.ly/1cIaqyl

Source: **ME Research UK**
http://www.meresearch.org.uk/news/gene-snps-in-mecfs/

Science to Patients

Webinars 61, 62, 63 and 64 have been broadcast since the April-issue of the ME Global Chronicle.
All these lectures were given by **Prof. Alan Light**, about the following subjects:

May 18, 2015: # 61. Fatigue & pain in ME/cfs
https://youtu.be/HkMBIkNGCqA

0.23 How do you define 'fatigue'?
2.10 Why do ME/cfs patients suffer both pain and fatigue?
3.22 Why do pain and fatigue increase after exercise?
5.20 Is pain related to heaping up of lactic acid in muscles?
6.44 Why do pain and fatigue increase after stress?
7.55 Why don't some patients suffer (much) pain?
9.09 Why is there a time-gap between activity and pain/fatigue?
11.57 Is an inflammatory factor involved in pain/fatigue?

May 30, 2015: # 62. ME/cfs and exclusive conditions
https://youtu.be/6-RMY1nSPBQ
0:24 How do ME/cfs and fibromyalgia differ?
4.09 How do ME/cfs differ from fatigue in cancer and MS?

June 6, 2015: #63. Effects of ME/cfs on the brain
https://youtu.be/McH2GJobOuk
0.24 How does the brain's fatigue detection system work?
1.55 Similarities in control bloodflow brain-other tissues
5.13 How does ME/cfs affect global and regional blood flow in the brain?

June 17, 2015: # 64: ME/cfs, the immune system and cell functioning
https://youtu.be/qo5Z93YFbc0 0.24 Which dysfunctions did you find in the immune system
1.23 What role do immune cells play in ME/cfs
2.53 Differences immune system between men and women
3.49 Which current research is most promising and why?

These four broadcasts constitute the last webinars of **Prof. Light**. On **June 19, 2015** a last Q&A session with **Prof. Light** has been held.

An extract will be published in the next issue of the ME Global Chronicle.

We owe our utter gratitude for his willingness and superb cooperation all through, in spite of his own extremely heavy time schedule. It has been a great pleasure and privilege working with him.

The team Science to Patients currently is working on the subtitles of three webinars from (Dutch) patients' perspective, which will hopefully be broadcast next month.

After the summer seven webinars of **Dr. Bateman** will be broadcast.

Four Q&A sessions will be held with her via chatwing.

All webinars together have been watched over **213.000 times** by now.

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

Antiviral Compound May Protect Brain From Pathogens, West Nile Virus, Study Shows

Researchers have found that an antiviral compound may protect the brain from invading pathogens.

Studying West Nile virus infection in mice, scientists at **Washington University School of Medicine** in **St. Louis** showed that interferon-lambda tightens the blood-brain barrier, making it harder for the virus to invade the brain.

The blood-brain barrier is a natural defense system that is supposed to keep pathogens out of the brain. Sometimes, however, bacteria or viruses circulating in the blood slip past the blood-brain barrier, turning routine illnesses into serious infections.

Interferon-lambda is produced naturally in the body in response to infection, but the new research suggests that larger amounts of the antiviral compound may tighten the blood-brain barrier against pathogens or possibly even faulty immune cells that can attack the brain and cause conditions such as multiple sclerosis.

By blocking interferon-lambda's receptors in the brain, it may be possible one day to open the barrier to chemotherapies to treat specific diseases in the brain, such as tumors. Such tumors now are not optimally treated with chemotherapy drugs because the drugs can't cross the blood-brain barrier.

The findings are available online in Science Translational Medicine.
"We have identified a new antiviral function of interferon-lambda that doesn't involve directly attacking a virus but stems viral invasion into the brain," said co-senior author **Robyn Klein**, **MD**, **PhD**, **Professor Of Medicine**. "This suggests the possibility of multiple new applications. We're testing one of these right now, conducting studies in mice to see if interferon-lambda can help prevent brain inflammation in a mouse model of multiple sclerosis."

Other forms of interferon have shown potential for influencing the blood-brain barrier, but interferon-lambda may have significantly fewer side effects.
Infections with West Nile virus occur globally. No treatments exist for the virus, which crosses the blood-brain barrier in an estimated 1 percent of infected people, causing a debilitating neurological condition that can be fatal.

Klein and co-senior author **Michael Diamond**, **MD**, **PhD**, **Professor Of Medicine**, looked closely at West Nile virus infections in mice to learn more about how viruses cross the blood-brain barrier. This barrier typically keeps large

molecules, such as immune cells, drugs and pathogens, out of the brain while letting in essential nutrients such as glucose.

In earlier research, **Klein** showed that West Nile virus can open the blood-brain barrier to enter the central nervous system, but that the barrier usually quickly closes, preventing immune molecules from following to attack the virus.

In the new study, the scientists studied mice that lacked the interferon-lambda receptor. Compared with normal mice, the mice without the receptor had higher levels of West Nile virus in the brain. The researchers found the blood-brain barrier was much more permeable to the virus in these mice, suggesting that loss of the receptor through which interferon-lambda acts had loosened the barrier.

The scientists then gave normal mice West Nile virus along with interferon-lambda. The mice received the antiviral compound at the start of the infection and two and four days later. Typically less than 20 percent of normal mice survive such a high dose of the virus, but survival rates rose to more than 40 percent after treatment with interferon-lambda.

"Viruses are most dangerous when they enter the brain," said **Diamond**. "Compared with untreated mice, we found significantly lower concentrations of the virus in the brain among mice treated with interferon-lambda."

If further studies of interferon-lambda prove fruitful in stemming the spread of viruses to the brain, a major hurdle remains. By the time symptoms of viral infections are serious, the virus is already in the brain. This reality suggests earlier diagnosis is critical.

But, the researchers note, interferon-lambda may be a better way to influence what gets into the brain than other forms of interferon, which are associated with significant side effects such as fever, chills and fatigue.

"Interferon-lambda has significantly fewer receptors in the body, which may mean using it as a treatment is likely to have fewer side effects," **Diamond** said. "It's also possible that interferon-lambda may influence other protective barriers in the body, such as those in the skin and the gut, an area of research my laboratory is investigating."

Story Source: Science Daily, http://bit.ly/1AZy9WB

The IOM-Report, Heredity, NK Cells, Neurotoxins, Viruses And Fever

In a Q & A- session on Friday March 27, 2015 via chatwing **Prof Alan Light** discussed i.a. these topics

Q: Are you able to estimate whether the IOM-definition is a step forward to broader knowledge about ME, and if it has the potential to lead to discoveries of the roots of this horrendous disease?

A: The IOM-definition really added little if anything to the knowledge those of us in the field already had. However, we do hope that it attracts the attention of those not in the field—particularly physicians in a variety of disciplines—general practice, arthritis, medicine, cardiovascular, etc., who have been ignoring this debilitating disease, and dismissing it as a psychiatric disorder, that therefore, they can do nothing for.

Q: How do you view your findings in the context of heredity? I ask this because in my family several members have ME as well

A: We have tried to look at this issue. We have worked with an expert in this area, **Dr. Cannon-Albright** who discovered the breast cancer gene. She used the Utah Population data base to research this and found that there is a familial connection in CFS/ME and it is hereditary, in a small proportion of the patients. We have been trying to get the funds to follow up on this, but have been unsuccessful so far.

Q: Is a dysfunctional or poor immune system also heritable? Because all of my family has an autoimmune disease or cancer. Is there a link?

A: Yes, a poor immune system is heritable. However, environmental factors such as diet, pollution, toxins, etc. can also destroy your immune system.

Q: The Natural Killer cells are often low in ME patients. What is causing this and how to increase those NK cells?

A.: This is a very good question. We believe that the NK cells are giving us big clues as to the cause of ME in at least some patients. We believe that the immune system is very likely the culprit in at least some patients, possibly because auto-antibodies that attack the Fatigue pathways are responsible.

Q: Do you know a way to increase the NK cells?

A: Increasing NK cells is easy. Viruses do it nicely in normal people. The problem is to do it in patients who need them. Not all ME patients do. Some of them might do better without the T cells that are making autoantibodies which attack their fatigue system, if that is the cause of their condition.

Q: Do neurotoxins cause fatigue, or do they just cause a lot of damage?

A: We don't have definite answers for this. Our current hypothesis is that humans build up the same sorts of metabolites in the parts of their brains they use more when they focus on that particular mental task.

For example, if you are using your brain to type, you build up the amounts of ATP, lactate, and acid in the motor region of the brain used for typing, and in the visual part of the brain used for vision and for generating language.

These metabolites activate neurons in the brain specialized to detect these metabolites, and these neurons send signals to your fatigue processing centers (likely in the insula of the brain) which generates the sensation of mental fatigue, making you want to stop typing.

This protects you from using any one part of your brain for too long, which is very important, because unlike your skeletal muscle, in which you can increase the blood flow 100 times when you exercise, your brain is always using all of the blood that it can get.

You only shift the blood around to various parts as you use that part of your brain, stealing away blood from other parts of your brain. If you permanently did that, the part of your brain that you are stealing the blood from would die.

Neurotoxins could cause fatigue if they interrupt the ability to shift your attention around or if they interrupt the blood supply to your brain. In either case, these could also cause a lot of damage to your brain both directly by killing cells, and indirectly by not allowing you to rest parts of your brain, therefore killing cells in the parts of your brain you are stealing the blood from.

Q: If a lack of a neurotransmitter would be responsible for both fatigue and pain, which one would it be? Or several?

A: Epinephrine and norepinephrine (would affect both your fatigue neurons and your autonomic control of your blood flow) and serotonin.

Q: And could that be caused by a virus, maybe from the herpes family, which hides itself in nerve cells?

A: Directly—yes. If these viruses damage the fatigue and pain detecting neurons, they could cause pain and fatigue (the reason is complicated, but involves upregulation of central pathways because of the peripheral damage—this is intended to fill in for the lost neurons, but in fact overshoots and causes more pain and fatigue than it should).

Indirectly, yes, and it could be caused by other viruses as well which you don't need to harbor. If these viruses have a protein sequence similar to part of the fatigue systems proteins, autoantibodies that cause a gain in function (more pain, more fatigue) might be induced by these viruses. Thus, the virus might be long gone, but the autoantibodies might continue to cause pain and fatigue.

Q: What role does fever play in relation to ME/CFS? I never hear about it.
A: Normal fatigue can be increases by increasing core temperature. Fever - when you have a virus or other infection - can cause the sensation of fatigue. Heat may be thought of as one of the metabolites that signals fatigue to the brain.

CFS/ME patients often feel too cold and then feel too warm, and they do show abnormal fluctuations in their core temperatures. We have seen fluctuations in the amount of TRPV1 in CFS/ME patients - one of the receptors that detect heat.

http://www.me-cvsvereniging.nl
contact@me-cvsvereniging.nl
http://www.me-cvsvereniging.nl/english-page

7. Research

The ME Association Illness Management Report "No decisions about me, without me" May 2015

"This is the largest and most comprehensive 'patient evidence' report covering ALL aspects of CBT, GET and Pacing – i.e. efficacy, safety and acceptability – that has ever been produced."
Dr Charles Shepherd, Medical Advisor, ME Association

On 28th May, The ME Association published **Part 1** of the report for public consultation. It is a 294 page document focusing on courses delivered mainly in clinical settings and includes an executive summary, a complete and detailed analysis, relevant patient comments, and extensive conclusions and recommendations.

Part 1 can be downloaded here: http://bit.ly/1L8UJPG
Part 2 will focus on self-management and will be published in the near future.

Introduction
Large numbers of patients with ME/CFS consistently report that prescribed management approaches are not as acceptable, effective, or safe in practice as is often claimed they ought to be.

In 2012 the ME Association decided that a new and more detailed patient survey was required to try and better explain the factors contributing to patient reported outcomes, and this report provides quantitative and qualitative evidence of the patient experience.

The report will be used to lobby the UK National Institute for Health and Care Excellence (NICE) and other authorities including NHS ME/CFS specialist services, to effect improvements which will hopefully lead to better outcomes for patients in the future.

The Survey
The survey was split into three sections, one each for CBT, GET and Pacing, it asked 228 questions in total and was completed by 1428 respondents. 493 respondents had been on a CBT course, 233 on a GET course and 226 on a Pacing course. Some had been on separate courses for one or more of the interventions; others had been on courses comprising multiple interventions.

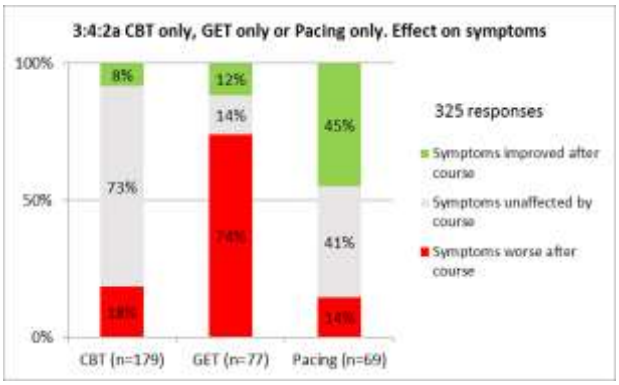
The Report

An examination was made of the effect courses were deemed to have had on illness severity, on symptoms, disability benefits, employment and education, the appropriateness of courses in relation to individual patient need, and the effect CBT has on anxiety, depression and stress.

Also considered was course availability within the NHS, suitability of session length, reasons why courses were not completed in full, the provision of course information to patients, the impact of the NICE Guideline on course delivery, effectiveness of courses led by specialists and non-specialists, and a comparison was made between these results and those from previous patient surveys.
Note: The full results can be read in the 294 page report, here are just 3 examples:

Example 1:

Where patients attended a CBT, GET or Pacing course which had no overlapping elements of the other two interventions, more reported an improvement in symptoms following their Pacing course than did those who attended either of the other courses.

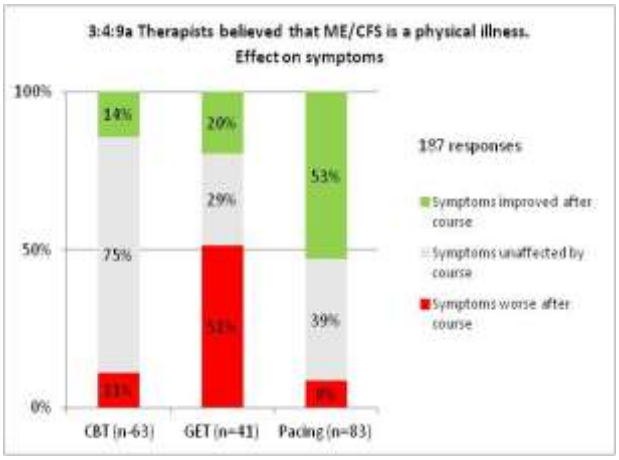


CBT resulted in 91% of participants feeling their ME/CFS symptoms were unaffected or made worse, GET 88%, and Pacing 55%.

Example 2:

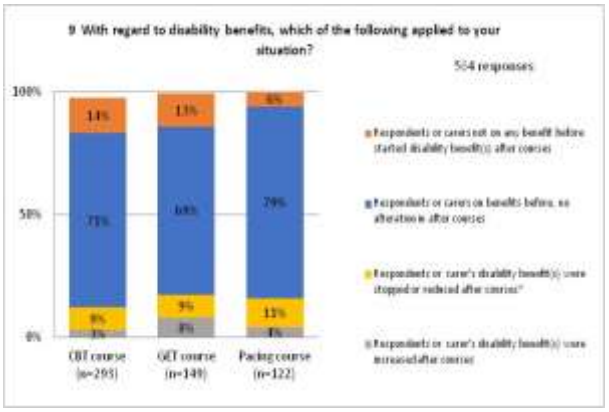
Symptoms were reported as having improved or as remaining unaffected by more patients where therapists leading a course recognised ME/CFS to be a physical illness than where therapists believed the illness was psychological.

Symptoms were deemed to have been made notably worse where courses were led by therapists holding this psychological belief even for Pacing.



Example 3:

For those who were on benefits, it was most notable that irrespective of the course undertaken, claims remained largely the same with few reducing or stopping their benefits.



However, net overall increases were seen in benefits following courses in CBT and GET compared to a slight decrease from those attending Pacing courses.

Conclusions and Recommendations

Note: Please see Sections 4 and 5 of the report for the full conclusions and recommendations, what follows is a summary:

Cognitive Behavioural Therapy (CBT)

The ME Association concludes that CBT in its current delivered form should not be recommended as a primary intervention for people with ME/CFS.

CBT courses based on the model that abnormal beliefs and behaviours are responsible for maintaining the illness, have no role to play in the management of ME/CFS and increase the risk of symptoms becoming worse.

The belief of some CBT practitioners that ME/CFS is a psychological illness was the main factor which led to less symptoms improving, less courses being appropriate to needs, more symptoms becoming worse and more courses being seen as inappropriate.

Results also indicate that graded exercise therapy should form no part of any activity management advice employed in the delivery of CBT, as this also had a negative effect on outcomes.

However, the results did indicate that, when used appropriately, the practical coping component of CBT can have a positive effect in helping some patients come to terms with their diagnosis and adapt their lives to best accommodate it.

CBT was also seen to have a positive effect in helping some patients deal with comorbid issues – anxiety, depression, stress – which may occur at any time for someone with a long-term disabling illness.

Graded Exercise Therapy (GET)

The ME Association concludes that GET should be withdrawn with immediate effect as a primary intervention for everyone with ME/CFS.

One of the main factors that led to patients reporting that GET was inappropriate was the very nature of GET itself, especially when it was used on the basis that there is no underlying physical cause for symptoms, and that patients are basically ill because of inactivity and deconditioning.

A significant number of patients had been given advice on exercise and activity management that was judged harmful with symptoms becoming worse or much worse and leading to relapse. And it is worth noting that despite current NICE recommendations, a significant number of severe-to-very severe patients were recommended GET by practitioners and/or had taken part in GET courses.

The ME Association recognises that it is impossible for all treatments for a disease to be free from side-effects, but if GET was a licensed medication, it believes the number of people reporting significant adverse effects would lead to a review of the use of GET by regulatory authorities.

Pacing

The ME Association concludes that Pacing is the most effective, safe, acceptable and preferred form of activity management for people with ME/CFS and recommends that it should be a key component of any illness management programme.

For some, improvement may be a slow process so, whilst they may be somewhat better by the end of a course, the improvement is not enough to take them into a better category of severity for some time, perhaps not until they have self-managed their illness for a few years.

The benefit of Pacing may relate to helping people cope and adapt to their illness rather than contributing to a significant improvement in functional status.

Learning coping strategies can help make courses more appropriate to needs even if they do not lead to immediate or even longer term improvement in symptoms. Importantly, it ***can*** prevent symptoms from becoming worse.

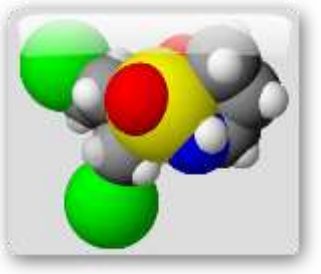
Next steps...
The ME Association will prepare a paper on illness management that better reflects the patient experience and which utilises the evidence obtained from the results of the 2012 patient survey, and from the ME Association's 2010 Management Report. It will also reflect those aspects of the 2007 NICE guideline that are felt to be supported by patient evidence but have not found their way into delivered patient care.

The paper will detail a recommended illness management approach for ME/CFS and will focus on issues such as personalised patient care, improved professional education, course accessibility and home visits, and better provision of course information, as well as shared decision making.

The aim is to improve patient reported outcomes with a more encompassing and sympathetic approach to illness management in the absence of a specific treatment.

Extract produced and submitted by **Russell Fleming**

Phase II Cyclophosphamide Trial For ME Gets Under Way



Norwegian researchers have commenced phase II trials (http://1.usa.gov/1fc1piT) of the anti-cancer drug cyclophosphamide (http://bit.ly/1cVH1kk) on ME patients.

Led by senior consultant **Dr. Øystein Fluge** and **Prof. Olav Mella**, the team is focusing on non-responders and those patients who have relapsed after treatment with rituximab (http://bit.ly/1L9Uwfi), a B-cell depleting drug.

Forty patients with moderate to serious myalgic encephalomyelitis (ME) (sometimes referred to as me/cfs or chronic fatigue syndrome) are taking part in the cyclophosphamide trial, which began in March this year and is scheduled for completion by September 2016.

Twenty-five participants have not received previous treatment with rituximab, are either rituximab non-responders, or have relapsed following rituximab treatment.

Fluge and **Mella**'s work is bringing hope to millions of ME sufferers, worldwide. Their research into the use of rituximab to treat ME is considered a real breakthrough after the success of an earlier trial (http://1.usa.gov/1HJ5bvl), and they are currently undertaking a large phase III trial (http://1.usa.gov/1IeF9vQ) of rituximab on 152 ME patients running over over three years.

Mella and **Fluge** believe that ME is a form of autoimmune illness where the body comes under attack from its own defence system.

Patients in the cyclophosphamide study have been selected according to the Canadian criteria (http://bit.ly/1TniLJj) (2003) from those who have had the illness for at least 2 years.

In this latest study, six intravenous infusions of cyclophosphamide will be administered at four-week intervals with the first at 600 mg/m2 and subsequent infusions at 700 mg/m2.

Side effects at these levels are expected to be minimal. Similar dosages are administered in the treatment of breast cancer and lymphoma as part of a multiple drugs regimen.

Investigations into possible large vessel endothelial dysfunction and skin microvascular dysfunction will also be performed at the start of the study and during follow-up.

The **Kavli Trust** (http://bit.ly/1GGzGBb) is contributing to funding a nursing position for 12 months and is financing laboratory work related to both the rituximab and the cyclophosphamide studies.

Autoimmune response theory

Mella and **Fluge** believe that ME is a form of autoimmune illness where the body comes under attack from its own defence system. "We think an autoimmune response, often after an infection, somehow disrupts the body's ability to micro-manage the bloodstream," said **Fluge**. One indication that this might be the case is that blood vessels in ME patients do not enlarge as far as in healthy people after they have been compressed.

The researchers also believe that sufferers have a genetic predisposition to develop ME. **Fluge** notes that the condition tends to run in certain families. "Members in the immediate family of 45 per cent of the participants in our first study had autoimmune illnesses. That's a higher proportion than in the general population."

The Nitric Oxide connection

Recent findings by **Fluge** and **Mella** have supported anecdotal evidence of ME patients receiving immediate relief after treatment with nitric oxide.

In 2014 **Fluge** and **Mella** filed a European Patent Application (http://bit.ly/1fc2tU2) for the use of a nitric oxide donor in combination with a B-cell depleting agent to treat ME.

The application details a case where an ME patient experienced immediate relief from symptoms after treatment with an NO donor.

The researchers outline a strategy for the use of a B-cell depleting agent, such as rituximab, together with relatively high doses of L-Arginine 5 g twice daily and L-Citrulline 200 mg twice daily.

What is cyclophosphamide?

Cyclophosphamide dampens the immune system's response and is used in chemotherapy to treat some forms of cancer. It is also an important treatment for serious autoimmune diseases such as systemic lupus erythematosus with severe lupus nephritis, severe rheumatoid arthritis, granulomatosis with polyangiitis and multiple sclerosis.

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

Sleep Study

The SAFFE study using Fukuda and the Canadian criteria is ongoing but needs more participants

It is a voluntary study with all meals and refreshments provided, and reimbursement of reasonable travel costs. You must be between 25-65 and be able to speak English. If you are travelling by car a voucher is provided for free parking right outside the facility. The research hospital is a secure facility in the grounds of the Imperial Hospital.

A private room is provided for your stay. You will be required to have a telephone call to assess if you are suitable and if so you will travel to the facility for a one night stay during which you will be assessed, blood taken, weight, BP and blood sample, and the usual medical history.

Once this is done you are free to rest on your bed. Early evening the team will put sleep monitoring equipment on you and leave you to sleep. You have the choice of a community room if you are able or you can just stay on your bed and rest.

The team are very experienced in dealing with people with M.E so are mindful of limitations and need to rest. The ward and rooms are very quite.

If you are successful you need to travel again to the facility for the research to take place. This is done over three weeks, a Monday to Friday (four nights) stay one week where you will be given either the drug or the placebo, and then a week's break before you return to complete another Monday to Friday stay and are given the drug or the placebo.

The trail is about monitoring slow wave sleep using sodium oxybate. If you want to participate in the study but are unsure of the effects of this drug on your health, or interaction on current medication or any other query you may have then please contact the research facility on the email below.

During the day you are free to do whatever you wish once you have taken a few cognitive tests, for example remembering where items were on a screen before they disappear and are reordered. The tests take a few minutes.

If you have any questions about the study please direct them to the team.

The study is being undertaken by;
Professor David J Nutt
Dr Sue Wilson
Professor Basant K. Puri
Dr Claire F Durant
Dr Louise Paterson

All of which you can read about on the link below. Some of you will recognise **Prof. Puri** from previous research and his involvement with M.E over many years. **Prof. David Nutt** was the drug advisor to the Government amongst many other roles.

The study is located here and will reimburse you for reasonable travelling costs:

Centre for Neuropsychopharmacology
Division of Brain Sciences
Imperial College London
Burlington Danes Building
Hammersmith Hospital campus
160 Du Cane Road
London W12 0NN

Any enquiries please email: saffe@imperial.ac.uk
Or call: 07599 948053

More info: http://bit.ly/1Ld2Cnb

Posted by **Ali Head** on the IiME-fb wall

Griffith Research Sheds New Light On Cause Of CFS

New research findings may shed light on the potential cause of Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME).

Researchers from **Griffith University's National Centre for Neuroimmunology and Emerging Diseases** (**NCNED**) – part of the new Menzies Health Institute Queensland – have uncovered significant factors contributing to the pathology of this illness.

The results reveal genetic changes in important receptors associated with immunological and cellular function and contribute to the development of this complex illness.

"These findings have been achieved through a team effort involving researchers, patients, funding bodies, clinicians and the support of Griffith University and the Queensland Government," say chief investigators **Professor Sonya Marshall-Gradisnik** and **Professor Donald Staines**.

Co-researcher and consultant immunologist **Professor Pete Smith** said that important signalling mechanisms are disrupted as a result of these genetic changes involving the detection and response to threats.

"These are primitive genes that are involved in many cellular signals in the brain, gut, cardiovascular and immune systems, as well as in the mediation of pain".

CFS/ME is a highly debilitating disorder characterised by profound fatigue, muscle and joint pain, cerebral symptoms of impaired memory and concentration, impaired cardiovascular function, gut disorder and sensory dysfunction such as noise intolerance and balance disturbance.

Many cases can continue for months or years. It is believed to affect around 250,000 Australians.

The research findings were presented by **Prof. Marshall-Gradisnik** at the international IiME-conference in London on May 29,2015.

Louise Durack

8. ME And Children

Mourning Is Love With No Place To Go

There are lots of reasons we may mourn and all of them are to do with loss; of love, of people who matter, of time and secret things we never speak about, of longings and leavings.

We all have shadows that steal over our hearts sometimes, weighted with what ifs and goodbyes we wish we'd never had to make.

This quote makes sense to me. We are great gallon drums full of love, we are mighty rivers of it and if that love has no waterfall to leap over on the way to the ocean, it is going to be painful.

So, it follows that the path to healing must involve finding somewhere for love to go. That in order to honor our own mourning, we must recognize that we only feel so deeply because we have so much feeling left to offer.

This world needs people who care. It needs people who, despite their own hurting, reach out always to give that love in them, to the others they know.

We can't guard our hearts against pain, because the only way to do so would be to empty them of love. Instead, we can join our love to other people's and make something courageously tender and monumentally important.

Sarah-Louise Feather

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

Part 2
British **Tanya Mawer** is a mother to a.o. two girls with ME. In her blog of Saturday, 21 February 2015 under her penname **Crazy Purple Mama** she writes about the kind of life they are forced to live and what they do encounter. We split it up into three parts.

The first part was published in the ME Global Chronicle of April 2015
Tanya introduces her family and herself in this blog:
http://crazypurplemama.blogspot.co.uk/2014/01/introduction.html

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

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

So, in a bid to try and help raise awareness about chronic illnesses both girls have completed this "Chronic Illness Challenge". Originally it was designed as a instagram or facebook challenge and the idea was to answer a question a day for a month.

However, for someone who suffers from cognitive issues this isn't always possible and there may be days go by when typing or texting isn't possible. Which is why the girls decided to take their time and compose a blog post to have it posted altogether as a comprehensive post about their specific journey with this illness. They have both provided their answers beneath each question to explain how it affects them.

Day 11. Why do you believe you have this illness? Bad luck, a higher power or something else?
It's just bad luck.. If it is a 'higher power' whatever it is can fuck off. I definitely got this from bad luck.

Day 12. Briefly explain to a healthy person what it is like to live with this illness.
There is no brief way to explain this. it is so complicated and affects absolutely everything in my life that it just is too much to explain.

You always feel fatigued and ill no matter what you're doing, you always feel sleep deprived and in pain, basically like a zombie that 'doesn't look like a zombie'.

Day 13. Has your physical illness had any effect on your mental health? Explain.
Is that a joke? Of course it has, how can you be in constant pain and not become angry/depressed?

Yes, my ME caused me to come out of school at the age of 10 which had given me social anxiety, I've been recently going to CBT to help this but was on the waiting list for years.

Day 14. Give 5 things you are grateful for.
1. My bed
2. My PC
3. My ipad
4. My boyfriend
5. My family & friends.
1. My family,
2. My dogs,
3. The health care we receive,

4. My osteopath (I always email her whenever I have a new symptom because she has ME herself and knows how to help usually).
5. My bedroom. Weird thing to be grateful for, but we decorated it specifically to be a calm environment for me to rest.

Day 15. What would you say to people newly diagnosed with this illness?
Fuck off physiotherapy, don't do GET, look after yourself, focus on getting yourself better and nothing else, education can wait, medical professionals don't always know best. If you feel poorly rest, please don't try to push through it.

I'd tell newly diagnosed people to NOT go into anything too quickly, to rest and to pace.

Day 16. What is your favourite inspirational quote?
The three I love aren't exactly inspirational but hey ho
"Not all those who wander are lost"

Cobain once wrote "Art that has long lasting value cannot be appreciated by majorities , only the same small percent will value arts patience as they have always have. This is good."

"I have met many minds able to store and translate a pregnantly large amount of information, yet they haven't an ounce of talent for wisdom or the appreciation of passion."

I don't have a favourite inspirational quote..

Tanya Mawer

Karina Hansen

The Danish Minister of Health has probably allowed psychiatrist **Per Fink** and psychiatrist **Nils Balle Christensen** to get **Karina Hansen** from her home.

The Ministry of Health denies it, but we have it on a sound-file from the Symposium of **Per Finks** birthday, where **Ole Thomsen**, manager of the Region Midtjylland, said it.. "With help for the police and the Minister, you dared to do it," he said in his speech for **Per Fink**.

That means, that the **Karina**-case has been on highest level in Denmark.. which they now deny.. He said it in English, so you can hear it yourself.
I sent the sound-file to the Ministry of Health so that they could hear it themselves, but they still say they do not know anything about it...

In Denmark the clinic that has taken **Karina Hansen** 'in custody', **Per Finks** psychiatric Clinic for Functional Diseases, now wants to treat all the girls who have been ill from HPV-vaccines…

Physical illness treated by psychiatrists !!!

Bente Stenfalk as posted by **Michael Evison** on **Bring Karina** home
http://on.fb.me/1CayoJq

ME AWARENESS 2015 : EQUALITY AND ME

Statement by Tymes Trust.
Also at http://www.tymestrust.org/tymespublications.htm

"The Equality act 2010 sets out the need to treat people equally who have a protected characteristic such as a disability," wrote Health Minister Earl Howe in 2013. He added: "ME/chronic fatigue syndrome (CFS) falls within the definition of disability."

Why is this statement from one of our Tymes Trust Patrons so important? There are two main reasons:

- Firstly, it was given in the capacity of a Government Minister and so carries a great deal of weight in asserting that people diagnosed with ME/CFS have a protected characteristic under the Act.

- Secondly, any parent with a child diagnosed with ME/CFS can state that their own child has a protected characteristic, because ME/CFS falls within the Act's definition of disability. We hope this knowledge will assist in avoiding some of the worst pitfalls and misunderstandings that ME/CFS commonly engenders when parents are trying to obtain what their child needs.

As you know, one of the worst misunderstandings that can arise is the suspicion that the parent may be neglecting or harming their child. As a result, the child may be further traumatised by social services investigating their family. This is not just an occasional case. To date, we at Tymes Trust have advised 142 such families, none of whom have, to our knowledge, been found guilty of anything.

Childhood ME can cause such a degree of illness and disability that it is the biggest cause of long term sickness absence from school. This was first revealed by a five year study, published in May 1997 by the Journal of Chronic Fatigue Syndrome. I carried out this study with microbiologist **Dr. Elizabeth Dowsett**.

These children suffer the classic effect of deterioration after effort, which typically occurs over the following few days. They are usually unable to attend school because the physical effort of doing so causes a worsening of their condition, so they need education at home.

Why should this be? Using the Workwell 2-day testing protocol, exercise physiologist **Mark Van Ness** has shown that the body cannot use oxygen in the normal way. By measuring gases exhaled during effort, he has demonstrated a long suspected impairment in the aerobic energy system. It means that "to try to use aerobic exercise, such as graded exercise therapy, to improve health in these patients" is "utterly counterproductive".

Forcing sick children into school is just another form of exercise, both mental and physical. Despite all these facts, some parents have been threatened with fines and prison for allegedly allowing truancy, and generally disbelieved.

The Equality Act has Technical Guidance for Schools. It states that Protected Characteristics (which Earl Howe has confirmed includes disability by reason of having ME/CFS) establishes a new form of disability discrimination - "discrimination arising from disability". It states: "The Act protects pupils from discrimination and harassment based on 'protected characteristics".

Under the section "Unfavourable Treatment", paragraph 5.44 states: "For discrimination arising from disability to occur, a disabled pupil must have been treated 'unfavourably'. This means that he or she must be put at a disadvantage.

Often, the disadvantage will be obvious and it will be clear that the treatment has been unfavourable, for example being excluded from school. Being denied a choice or excluded from an opportunity is also likely to be unfavourable treatment.

Sometimes, the unfavourable treatment may be less obvious. Even if a school thinks that it is acting in the best interests of a disabled pupil, it may still be treating that pupil unfavourably."

Paragraph 5.47 states: "As long as the unfavourable treatment is because of something arising as a consequence of the disability, it will be unlawful unless it can be objectively justified, or unless the school did not know, or could not reasonably have been expected to know, that the pupil was disabled."

Naturally, the matter is complicated. The Technical Guidance gives a relevant example of 'substantial disadvantage'.

Example: A pupil with chronic fatigue syndrome finds it harder to concentrate in lessons in the afternoon as a result of an increase in her tiredness.

In practice, pupils with classic ME can often be better in the afternoon than in the morning. This results from the effects of dysfunction in the hypothalamus gland, which commonly leads to sleep reversal; not only may the child be unable to sleep at night, and need to sleep during much of the morning, but the brain may not be at maximum arousal (and thus more able to concentrate) until the latter part of the day.

Whatever the particular disability, if it places the child at a substantial disadvantage "in comparison with non-disabled pupils" then this officially counts as 'substantial disadvantage'.Children with ME must be given a proper chance to recuperate, convalesce, achieve educationally, and get strong again.

Jane Colby
Executive Director The Young ME Sufferers Trust (TYMES)

Joanne

During a hearing in April the judge decided that **Joanne**'s mother could continue to see her for three hours in the afternoon! But as yet he did not give her mother back her parental rights. And he made it clear that the psychologist's report will be the foundation of his decision in the coming main proceedings.

This psychologist states that her mother's fears of wrong treatment would be so huge that she would not be able to agree with a psychological treatment, which implies her absence is required. These fears would be reinforced by sources (ME support groups) that the mother had consulted to build up her "model" of the disease (that is one of an organic disease).

The psychologist therefore comes to the conclusion that the ability of **Joanne**`s mother to make decisions concerning **Joanne**´s health would be restricted at the moment whereas this would not be the case with her father.

A new 'diagnosis' of **Joanne** has been put forward by doctors at the clinic where she is being ´taken care of´ at the moment, namely that she actually would not have CFS anymore but "Pervasive Refusal Syndrome" (mainly because she would "refuse" to eat and drink (she still needs the tube)). But the diagnosis would not matter really: **Joanne** would in any case need psychological treatment.

Father and child protection authorities want to put her on a psychiatric ward and there the mother would not be allowed to see **Joanne** any more. So the contact ban is still on the agenda in the coming main proceedings. The nightmare continues.

Joanne is in a terrible state. Her new psychologist is desperate to get her out of bed, she would be able to do everything, she would just have to believe that she could do it. Now they want to start with a full physical load, it would be time they stop "the gentle way"!

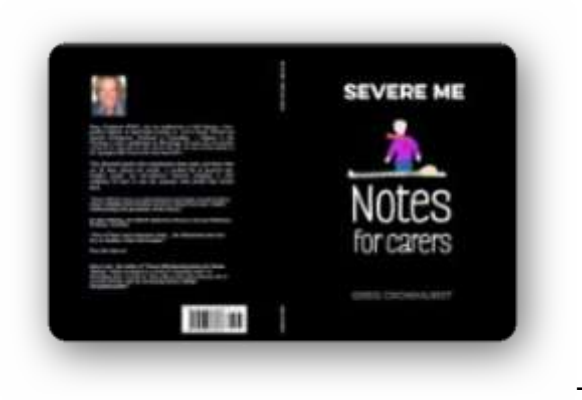
There´s still some hope left for **Joanne**'s mother to get back her parental rights, by thorough preparation of her lawyers for the next hearing in July. But that again involves large expenses, so she´s greatly indebted to the generous donators until now, one of which donated a large sum of money.

Thanks to you, readers, there´s still hope. That´s the power of standing together. **Joanne**´s mother expresses her deep gratitude for the support of all of you.

9. Severe ME

Caring For Someone With Severe ME

A sample chapter from "Severe ME:Notes for Carers" *



How do you offer care to someone in so much physical pain, that even the tip of their nose throbs in agony, who cannot bear light, noise, sound, touch, who is so profoundly hypersensitive that every move you make can be a torment, threatening to push him/her into even more extreme depths of illness?

The care required in Severe ME is complex, multidimensional and holistic. You need to be aware of the other, of the environment – and especially in Severe ME, profoundly aware of the interaction between them.

One thing is for sure, caring for someone with Severe ME is not easy. It demands, as we shall see in this book, much of you, not least massive self-awareness, courage, creativity, gentleness, warmth; so you can see the person, through the suffering and be there for them. Being a carer for someone with Severe ME challenges you to constantly reflect upon your **Value Base**.

Your value base is reflected in the way you communicate with and approach the person you are caring for; that is known as your **Posture**. As carers we strive to adopt a posture of **Partnership** that deeply values the other person, alongside an acute awareness of anything in the environment or in your approach that could cause any harm or deterioration, alongside the ability to react quickly to protect the person.

It is all too easy to adopt other postures. For example **Authoritarian/Cold** postures that do **Not** understand Severe ME. Typically these postures are based upon the wrong belief that the person is just not "trying hard enough", that they "simply have to pull themselves together", "change their thoughts"- many people with Severe ME have suffered this abuse, typically at the hands of those who subscribe to the psychiatric "biopsychosocial" model of thinking, which erroneously ascribes ME to "maladaptive thinking".

It is surprisingly easy to slip into a cold or authoritarian posture - especially when things are difficult! It is when things are at their most difficult that a posture of partnership is most useful as a framework to grasp onto. At these moments we have to be most fully present in a humble, loving and courageous encounter.

What is important is your ability to be fully present, especially through the difficult times and not compromise your value base.

Fundamentally you need to make sure your presence is safe and secure, that you stand by the person through the difficult and good times and work issues out together, with great sensitivity, creativity and immense flexibility, gaining deeper understanding every day.

A posture of partnership is holistic, real and meaningful, it takes account of the whole of the person's situation: mind, body, emotion and spirit; perhaps the greatest contribution a carer can make is to see the other as a whole person.

Being a Facilitator

Those who care for someone with Severe ME/Very Severe ME take on the role of a facilitator. **The carer focuses on what the person needs, not what the carer thinks they need; they are the hands and feet of the person.** They do things for the person that the person wants doing. In ME the issues are extremely complicated in regard to how to help without causing deterioration and aggravating symptoms.

In ME you will always find a post-exertional deterioration, meaning that as a carer you need to be aware of the immediate and long term impact of any intervention.

It is very important that you :

- Know all you can about the physical reality of Severe ME.
- Are acutely aware of the harm you can inadvertently do, at any moment.
- Care about every single thing you do and make sure you get it right for the person.
- Respond straight away.
- Ignore your own personal feelings and opinions, you are there for the person.
- Avoid mistakes, you cannot afford to make any when the person's health is at stake.
- Think all the time about what and how you are doing everything, ensuring it is appropriate.
- **Are exceptionally careful. Ordinary things done in unaware ways can still be harmful.**
- Remember that you are there to do what the person has asked. Only do what you are asked, nothing more, nothing less.
- Do everything in a compassionate and loving way.

This book, which covers a wide range of practical and personal issues, might help bring greater understanding to you as a carer. Ready? Let us make a drink……

Greg Crowhurst

Severe ME: Notes for Carers, a new book by **Greg Crowhurst, is to be released soon*

To Observe


To observe without judging
is the highest form of intelligence
Krishnamurti
By Faxdiesain

Isabel's Story Of A Life Worth Living

Isabel Walter lies in bed, the curtains closed – the light is too much for her to cope with. She is bedbound. Her world is confined to the four walls of her bedroom, limited by the chronic and debilitating condition ME. Every day, she suffers from nausea, headaches, fevers and intense fatigue.

Isabel, who was an academic researcher, is unable to watch TV or to use a computer. She cannot listen to music or the radio.

During her day, she will eat three meals, brought to her by her husband, **Paul Hibbard**.

On a good day, she may write a few notes about her life which she hopes one day, although in several years, may become a book.

She will spend seven minutes listening to a book tape – seven minutes is all she can hope with, but she reckons that in a few months she will have enjoyed another book.

Isabel can make it to the bathroom four times a day without help and can read and talk in the briefest of snatches.

The highlight of her day is to speak to Paul, which she does for 15 minutes. These exertions, as small as they be, will utterly exhaust her.

This is **Isabel**'s life, restricted by ME, a condition which little is understood and for which there is no cure.

Isabel, 43, met **Paul**, 44, when they were both PhD students in London 19 years ago. They moved to Scotland and Isabel worked in social research at St Andrew's University. "I used to go running," she said. "I used to walk up mountains. I loved it. I hardly had a day of illness before getting this."

ME was given the derogatory nickname yuppee flu in the Nineties. It is an invisible illness with indistinct symptoms and no examination findings which can confirm a diagnosis. As such, sufferers were dismissed as hypochondriacs. **Isabel** said: "I used to have that prejudice before I was sick. I used to think people should pull themselves together and get better.

"This is a real and physical illness."

Isabel's ME was triggered, she believes, by a virus in 2007. Two years later, she was using a wheelchair and she has been housebound for the past four years. In 2012, she married **Paul**, a psychology lecturer at the University of Essex. Even their wedding day was planned around **Isabel**'s condition. She explained: "We had the wedding late in the day, so I could rest in the morning and I had a rest in the middle. We also had a quiet room for me to sit. The adrenalin got me through."

The couple moved to Wivenhoe two years ago to be closer to family and in the hopes of getting better health care. But **Isabel**'s condition worsened.
She suffered a relapse after contracting the norovirus and for the past 18 months, has been bedbound.

To live trapped within four walls, living a life so limited, seems cruel beyond belief. But **Isabel** is positive and determined not to be a victim of ME. She said: "You can live a life, even if it is limited, and it is a life which is valid and important.

"I used to do creative writing and I started writing notes about my life. I hear the church bells and I am learning bird songs. You realize the smaller life gets, the more notice you take and the richer it is. You see the smallest of details which other people are missing.

You realize how important certain things in your life are. I can talk to my husband for 15 minutes a day, I can't do any more, but it is so precious. I know people out in the world don't think about talking to their husbands, they just do it automatically.

This illness is awful and difficult, but it is part of the gift of ME that you appreciate and value life incredibly strongly. There is a thought that for people like me, life is not worth living. It is a different life, but it is my life and I am going to hold on to it. You always have hope you will get better.

Isabel has physiotherapy and occupational therapy as her muscles have wasted. The common thinking was being active would help, but now it is acknowledged a key feature of ME is the body's inability to recover after expending even small amounts of energy. So rest and recuperation are vital.

Paul goes to a support group, Colchester MESH, to get information and support for those living with ME.

For **Isabel**, it is a question of managing her condition and hoping for a cure.

Wendy Brading (http://bit.ly/1GJnwJD),
News Editor / Specialist News Reporter
Source: http://bit.ly/1LdwxZt

10. News from

Australia

Queensland

Awareness Week is over for another year and we have:

- Sent out 144 awareness letters to politicians
- 27 Media Releases
- And met with **John McVeigh**

Our monthly support group meeting is now the 1st Wednesday of each month except for January!!!!
The venue has moved to the
DR PRICE ROOMS
Little Street Centre
Toowoomba

Meeting times are from 10.00am to 12.00pm. Tea and coffee will be supplied.

SUPPORT GROUPS, ME/CFS/FM Support Association Qld Inc - Group leaders and other information.

We are always trying to establish more Support Groups in local areas, but this depends heavily on the availability (time. energy etc) of someone in the local community to be able to devote the time to organise the groups.

Even with minimal organisation, to arrange activities that will be attended by those well enough to do so is sometimes not effective. Many leaders report that meetings arranged have not been attended and the energy expended has therefore been wasted. Many areas are telephone support only at this time, and this is still helpful for those who cannot travel about easily.

BRISBANE & LOGAN CITY Fibromyalgia Support Meeting, 3rd Thursday of the month at Logan Hyperdome Library, 66-70 Mandew Street, Shailer Park - 2 pm	**Judy Everett** Info packs, monthly newsletter & phone support	(07) 3806 5601
BRISBANE WEST ME/CFS/FM/MCS Support & Activism	**Sylvie** sj.dakini@hotmail.com	(07) 3876 7938
CROWS NEST Support Group Phone support only	Group Leader: **Berrie Cawthorne**	(07) 4698 4715
FRASER COAST FM/CFS/ME Support Group Maryborough Community Health Centre, Conference Room, inside front door and turn left 167 Neptune Street, Maryborough 1st Monday of each month from 9.30 – 11.30am (except January)	**Judy Vickers** **Anaree Nelson** **Jenni Ghill** CONTACT 9am – 3pm painfatiguefogfc@hotmail.com	(07) 4121 6910 (07) 4123 5518 Mobile: 0409 453 397 (07) 4123 6803 Mobile: 0499 465 229
FIBROMYALGIA, CFS/ME Gold Coast 2nd Thursday of the month 11am – 1pm @ Southport Library	Group Leader: **Carol Baker**	Mobile: 0406 154 766
LOGAN ME/CFS/FM Phone or email only	Group Leader: **Lee Rowe** Telephone between 8.30am -12pm or 7pm – 9pm leeann50@bigpond.net.au	(07) 3200 8223
NORTHERN SUNSHINE COAST (FM/CFS/ME) **Self Help Group** Phone support only	Group Leader: **Sandy Eastman**	(07) 5471 0039
ROCKHAMPTON Phone Support Only	**Marilyn Gavranovic** leviti@bluemaxx.com.au	Mobile: 0403 391 388
ROSEWOOD FMS Support Group 10 am—11.30 am 3rd Thursday of every month	Contact person **Judy Rosewood** Community Centre School St	(07) 5464 2227 (07) 5464 2965
TAMBORINE MOUNTAIN Support Group Phone Support Only	Group Leader: **Jeni Uhlig**	(07) 5545 3134
TROPICAL NORTH QUEENSLAND **CARDWELL** **rdickson@qldnet.com.au** **INNISFAIL** **SMITHFIELD** cfs_me_tnq@yahoo.com.au **TOWNSVILLE (phone support)**	**Joy Gwen** **farnthqldfibromyalgia@bluemaxx.com.au** **Peter Ashley** ahinds@smashman.net **Mara** mmhogan2@bigpond.com	(07) 4066 0178 (07) 4063 2334 (07) 4057 5920 (07) 4778 3560 (07) 4724 1062

*Submitted by **Lyn Wilson** in the Queensland Communicator*

Emerge Australia

Curious and curiouser

While curiosity is not always recommended for cats, if we want to understand the whys and wherefores of ME/CFS, then it's essential.

Research projects undertaken (http://bit.ly/1dHHDe1) into ME/CFS are slowly increasing in number. And as more progress is made, more people are becoming curious and pursuing the elusive cause of this condition.

Questions are being asked all around the world - and some interesting answers are being found. This month we're focussing on the different types of research that is being undertaken and the findings that are being published.

In the meantime, the closing date for Emerge Australia's research project into the Health and Welfare (http://bit.ly/1J1hfK4) of people affected by ME/CFS is looming (31st July 2015) so if you haven't yet completed the survey, then please go ahead and do so (http://bit.ly/1LcLcr5).

The results of this project will help us to advocate for the people who have been impacted by this condition while all the medical research is being undertaken.

Source: Emerge Australia Newsletter
http://bit.ly/1LdUi3E

Belgium

The campaign 'Stop The Diagnosis CFS' from the Wake-Up Call Movement Belgium (**WUCB**, http://www.wakeupcallbeweging.be/) has now truly begun.

The first show on May 6th was well attended.

In the first section a lot of information was shared while in the second part performances of singer **Mira** were followed by the stand-up comedian **Jens Dendoncker**. I personally have experienced that the goal was more than successful. Packages containing flyers, stickers and posters about the event where handed out at the end of the show.

The next shows are planned in **Bruges**, **Hasselt** and **Antwerp**. You can attend the first following show in **Bruges** on 28 October 2015. All information can be found on http://www.stopdediagnosecvs.be.

During the month of May as much attention as possible was paid to ME/cfs by, amongst others by the WUCB association.

I personally have also tried to take action by asking several municipalities whether they would light a building or monument in one of the three colours (blue, green or purple) during the night of May 12th.

For some (like **Ghent**) it proved technically not (yet) feasible, for others there was not yet a framework (like in **Antwerp**). But Leuven and my hometown **Diest** have responded positive.



This has made me much pleasure. Of course I also gave my own garden a colour.


Here is a picture of the public swimming pool in **Diest**.

One of the major newspapers in Belgium has also paid attention to my initiative in Diest (http://bit.ly/1L8Okko). **Diest** will try to put a number of buildings in a tan next year.

We hope for even more support for this initiative next year.

Eddy H. Keuninckx

Malta

Support Meeting + Workshop
When: Wednesday July 1, 2015

Myalgic Encephalomyelitis & Fibromyalgia Alliance Malta

1st half an hour we shall update you on recent events and present to you with the FIRST Awareness campaign for the Maltese Islands.

2nd hour - Workshop shall be on healthy smoothies and yoga therapy.

Info about location and other data: http://on.fb.me/1TpC8kX

Leaflets and posters and membership cards available

Rebecca Camilleri

Massachusetts

The Massachusetts CFIDS/ME & FM Association conducted a survey from March 30 till April 18, on the topic "What were your earliest symptoms of ME/CFS?"

This survey received 800 responses and included many comments. It is not scientific, but the large number of responses makes it significant.

The results suggest that the symptoms in the first few months of the illness (or what later turns into ME/CFS) are quite heterogeneous, with fatigue and cognitive impairment occurring most frequently.

Clearly this is an area that deserves further study. If the disease (or the triggering events, such as infectious mononucleosis or a severe flu-like illness) is recognized early and proper treatment/management is provided (e.g. rest as needed), perhaps fewer people would develop the severe, chronic form which we identify as "ME/CFS."

Results are summarized here: http://bit.ly/1MUdqEP

The Massachusetts CFIDS/ME & FM Association thanks the patients who responded to the survey in such detail. The many comments, which are not fully reflected in the summary, add much to the richness of this data.

Submitted by **Charmian Proskauer**

The Netherlands

All news and information about the Citizen Initiative of the Netherlands you find in the section Grassroot, page 11 . This is a major and impressive initiative which with the help of a large group of ME-researchers and clinicians is gaining momentum and is highly promising, not only for Holland.

The ME/cvs Vereniging (ME/cfs Association) is celebrating its tenth anniversary with an impressive conference on September 26, 2015, the first one to be organized by the association. Invited speakers are **Drs. Byron Hyde**, **Nigel Speight**, **Annemie Uyttersprot**, **Neil Harrison**, dietician **Christine Tobback** and **Prof. Frans Visser**. All info available on page 90, section Events.

On 15th June a book has been published written by a Dutch ME-patient, **Francis Verreck**, called ' Ik had nog niet dood gehoeven' (I didn't need to die yet).

Central person is **Denise de Hoop**, an ME patient who developed breast cancer which was untimely diagnosed because she was stigmatized suffering from a somatoform disease (ME). **Denise** died of it in December 2012, with **Francis** promising her to publish the nearly daily updates she posted on the internet forum of ME-net (the present ME-gids, http://www.me-gids.net/index.html) in book form. **Denise** was a very active and militant patient activist.

The book (only in Dutch right now) can be had from bol.com: http://bit.ly/1fe8ijG and costs € 19,95 excl. p&p.

Sweden

A new ME/CFS centre is opening its doors in June in **Stockholm**, Sweden. Since it will have a neurological focus and brings the comeback into the ME/CFS field of the much appreciated physician **Dr Per Julin**, this could potentially be a very positive development for Swedish ME/CFS patients.

The centre is also hoping to be able to set up biomedical research in collaboration with the **Karolinska Institute**. The new unit is a part of the health care system in **Stockholm** and patients from all over Sweden can be referred to the clinic.

Sadly enough the previous years have brought problems in **Stockholm** with ME/CFS patients who were placed in Rehab projects with more and more focus only on CBT.

This new centre gives patients a choice, and the Swedish patient organisation **RME** is hoping that with this novel unit at **Stora Sköndal**, the biomedical approach will take some steps forward.

Submitted by **Henrik Fransson**
Chairman RME Stockholm

11. Vote For...

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

http://bit.ly/1G7kAjw

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

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

Demark is holding **Karina** against her will and forcing her to take part in treatmentwhich can kill her. Denmark believes that ME is the same as Insanity which is not how ME is describedin WHO G93.3.

Denmark is a member of the European Union, United Nations,
Human Rights and WHO.

Petition to the WHO
Off late I created a petition and I hope you will support it, it's called:
Governments must comply to WHO ICD10 G93.3

This issue is very important to us as a family but also concerns many people around the world, and together we can do something about it: to speed up scientific research and give hope.

Please read more about it and support this petition here: http://bit.ly/1GnI3Am

Campaigns like this always start small, but they grow when people like us get involved, please take a second right now to help out by supporting this petition and passing it on.

Would you be so kind as to click the link to AVAAZ, filling in your e-mail address on the site? With doing that, you support my petition to the World Health Organisation in Geneva and all its 164 member states.

Thanks so much,
With Best Regards,
Frits de Bruyn and **Family**

12. Major Fundraising

LLEWELLYN KING IS RAISING FUNDS

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

Raised: $7,397.00 Goal: $20,000.00

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

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

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

Ian Lipkin study. Raised: **$220,712 from 1,116 donations!**

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

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

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

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

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

Join together so that we are stronger; our friends have created "The ME/ CFS crowdfunding campaign" facebook page (http://bit.ly/1GHPQMC) where they will promote the ME/ CFS crowdfunding campaigns. Please visit the page and "like it" to get more information about the ME/ CFS crowdfunding efforts and the current campaigns.

Their first crowdfunding campaign is for Open Medicine Foundation's Severely Ill Big Data Study: http://bit.ly/1JPAkip

"This is a hugely exciting study. The OMF End ME/CFS scientific advisory board includes three Nobel laureates and is headed by world-famous geneticist **Dr. Ronald W. Davis**, whose son is a severely ill patient. The researchers are looking for distinctive molecular biomarkers for ME/CFS and they're going to do this by looking where the disease is burning brightest: in the most severely ill, housebound and bedbound patients.

And they'll bring a powerful 'big data' approach by taking samples of blood, saliva, sweat, urine and feces, running a sophisticated and comprehensive battery of tests, and using powerful data analysis methods to find those biomarkers.

They want to study 40 patients but they've set an initial, interim target to enable them to get the study underway immediately: 15 patients at a cost of $25,000 each, for a highly achievable goal of $375,000 (£240,000, €330,000)." wrote ME/CFS Crowdfunders.

Donate here! Let's all work together to get those 15 patients funded!
http://bit.ly/1IeTYyB

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

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

Since last issue of the ME Global Chronicle an amount of **€ 2,438,64** has been received from most generous donators. **€ 2,611,94** has been spent to cover the expenses of a lawyer of the mother of **Joanne**, the 14-year old German girl who is kept in a hospital against her wishes to undergo treatments a psychiatrist is imposing upon her. No credit balance remains, but **Joannes** mother is still proceeding against the forced hospitalization of her daughter.

However information from Joannes mother shows that because of your generous gifts her lawyer has been capable of securing her right to continue and visit Joanne (see the article about **Joanne** on page 54
So please continue to donate, and if any a case like **Joanne**'s is known to you, please let us know via info@let-me.be

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

The editors

Mike Shepherd's North Pole Challenge.

Mike's wife **Lara** has fibromyalgia, and he has done this amazing challenge for the sake of his teenage daughter **Elizabeth**, as she has had ME for several years of her young life.

Mike's North Pole Challenge Facebook page is here:

https://www.facebook.com/Northpolechallenge

This year in 2015 for the "U.S. & elsewhere" division of #chilliMEchallenge, funds go to the biomedical M.E/CFS research at Columbia University's Center for Infection and Immunity of the Mailman School of Public Health that most closely shares our vision to find the root cause of M.E/CFS, specifically **Mady Hornig**, **MD**, **Ian Lipkin**, **MD**, **Jose Montoya**, **MD**, and colleague's studies.

GET THOSE VIDEOS RECORDED!

THE CHALLENGE:
You or a friend/family member post a hilarious video eating a hot (or pretend hot if you must) chili pepper or tabasco sauce and tag others you nominate/challenge and donate, OR if not, just post the donation page link on your FB and if you donated be sure to say so.

http://www.mailman.columbia.edu/chiliME
http://www.gofundme.com/chillimechallenge

13. Worth Noticing, Watching, Hearing & Reading

Video 74: https://youtu.be/AjrViKJGSUA
Published May 10, 2015
In MECFS Alert Episode 74, **Dr. Mady Hornig** sits down with cohost **Deborah Waroff** to discuss the implications of her groundbreaking research into M.E., or myalgic encephalomyelitis.

Video 75: https://youtu.be/uJEF_gszisY
Published May 15, 2015

In episode 75 **Llewellyn King** does an appeal to all of us to share some of our favorite literature on his channel. If you'd like to submit something, whether it be your favorite quote or a piece you wrote yourself, message us on Facebook at ME CFS Alert, tweet Llewellyn at @LlewellynKing2, or leave a response here on YouTube.

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

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

Appeal to all our readers re. the article of **Rich Podell** in this issue (see p23)

Critical Question Addressed to All Readers: Does anyone know a high executive at Proctor and Gamble—the producer of the Align brand of B infantis 35624? Align has supported several clinical studies. If their product truly helps CFS, psoriasis and or ulcerative colitis that could certainly expand their product.

Impressive video about **Naomi Whittingham** and her super-brother **Tom**

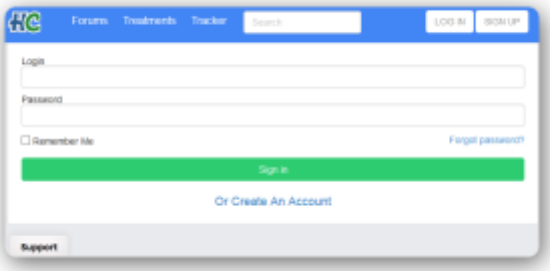
https://youtu.be/dgovI7Q273g

From **Naomi Whittingham**:
My brother has made a video to promote his participation in the Edinburgh marathon (31st May) in aid of ME Research UK.

Although partly a fundraising initiative, the video also delivers a powerful message and can be used as a tool for raising awareness. It has been viewed over 4,000 times in one week, and so far raised roughly the same amount in £.

Please share as widely as possible.
Source: http://meaction.net

Can´t be watched or shown too much:
https://youtu.be/IOflARSgNnE



Healclick
A daily reminder to track your symptoms and treatments. Might be useful.

https://www.healclick.com/users/login

14. Poem – Dear Recruitment Agent

Dear recruitment agent who sent me a lovely e-mail this morning
asking if I'm interested in an Accounts Assistant job currently vacant.

Unfortunately I'll have to decline You see, I haven't worked outside my home
In over three years, And in my home, I work casually:
Sometimes I clean yesterdays dishes, Sweep dirt under my couch with my four day old sock

Sometimes I pick up a sweeping brush, Proudly make my own meals
Sometimes I chop the tops off my fingernails, Forget that a knife is sharp
Sometimes I burn myself, Forget that a grill pan and toaster are HOT
Sometimes I forget what I'm doing, Find myself searching for clues.

As for outside my home? I like to take an amble in my garden
Where I often find my legs stuck.

I rarely leave my four walls alone Don't drive beyond my local town
Only do so after days of rest
Repeating no sooner than a month later.

A visit to a friend leaves me recovering The way an ultra-runner recovers
From a blistering race across the Sahara.
Road trips? They're out too
My body seizes while sitting in the one spot
Nausea swirls easily and the headaches come on
At the slightest sound of noise.

I don't remember the last time I went clothes shopping

I only go food shopping now, joining my husband
He takes care of the list, I mind the trolley
Holding it with both hands, Carefully pulling my legs.
These legs aren't made for walking, They saunter, grump up when asked to move, My hips seize, legs weaken

Don't ask them to take on stairs, Stairs make my legs and heart race, My arms throw tantrums too, Refuse to raise themselves beyond my shoulder, Burn at my shoulder, wrist and hand.

Oh and the exhaustion, that's present everyday, I sleep for twelve to fourteen hours, Spend my days amid avid rest, Either on my trusty couch, or outside On my garden bench.

I can't follow the plots of TV, Or concentrate on the words of a book
I like to read poetry, (Skipping poems more than a page in length)
I re-read poetry, Forgetting which one I've read.

Dear recruitment agent,

Call back again soon.

Marie H. Curran
http://www.mariehcurran.com

15. Column - Me And My ME.. A Pithy Conversation

'I want you to leave; I don't feel happy with you anymore'

- What do you mean? We have been together that long!

'Yes, 13 years and I feel less and less liking it with you.'

- I cannot just leave you.'

'Why not?'

- I am a part of you! We have been through so much together!'

'We don't experience that much together, you hinder me in being able to do what I want to do. It feels like I don't really live with you, not as I would like.'

- What would you do?

'I want to have the freedom to be able to do what I want to, I want to be able to work again, be able to go out, do nice things together with friends, go on vacation.'

-But we can still go on vacation together, can't we?

'Yes, of course, and then we are lying in bed for the whole day, while others have fun.'

- What do you mean; together in bed is still social too, isn't it?

'No, not with you! I lie down in bed too often, lying down in bed is not my idea of a holiday. I want to see things, hike through the mountains, laughing, eating out… That doesn't work when you are with me.'

- But why this so suddenly? We were still happy together?

'I have never been happy with you, you sneaked into my life and you've never asked me anything. You've never asked me if I wanted to be with you, you've never asked me if it was okay to control my life. You've never asked whether I was happy with you, you've never given me the option to leave you. You don't have the rights to hinder me the way you do. I have the rights to live like another, to be happy like another, to be healthy like another. Because of you I'm unhealthy and unhappy.'

- That's quite a lot, what you said right now. I know you had unhappy moments sometimes, but we did still experience great things together? Without me you wouldn't be the beautiful person you are today.

'You mean the 'beautiful' person who lies in bed whole days, too tired to do something and feels worthless because she has nothing to add to life?'

- No, I mean the beautiful, tender person you are now. Do you feel so little worth because of me?
'Yes, for sure.'

- Is there nothing positive to me?
'The only thing I can think of is the amount of friends you've given me, people who are, like me, fixed in a relationship in which they are unhappy. Who feel exactly the same as I do. That's the only positive thing I can think of. I'm grateful for that, really, I don't think I would have had that much friends without you.'

- But you still want to get rid of me? Is there someone else?
'Now that you mention it, indeed, there is someone else. Someone who doesn't hinder me, in fact, I get energy from him. He makes me happy; he makes me feel I'm really someone, someone who matters. But the energy I get from him you take away almost immediately. Therefore you don't hinder just me, but also my relationship with him.'

- I'm happy you have someone, but can't we live together? I mean all three of us? You know that leaving is not an option for me, but maybe we can make a kind of a deal, the three of us.
'Maybe you can try to be less present for a while. Let us do our thing. When leaving is not an option for you, then make sure you come to me just now and then, but I don't want you anymore to be around me for 24 hours a day, seven days a week. That frightens me. Allow me that little bit of luck and the freedom I'm so up to. I deserve that after thirteen years together with you.'

- Does that make you happy?
'I know for sure it does. Ideally I'd see you completely leave, but I know that's impossible. I'll try to accept you'll always be there, but that's only possible when you're not continuously with me. When you give me some more freedom, you can stay, but modestly!!'

-I'll try to; sorry you're that unhappy because of me.
'Make sure I became happy again! Then everything will be all right..'

Marloes

16. Events


Calendar
SUNDAY MONDAY TUESDAY
4 5 6 7 8 9 10
11 12 13 14 15 16 17
18 19 20 21 22 23 24
25 26 27 28 29 30 31

The Invisible Ones

A Conference on Severe ME/CFS and the way forward

The **Swedish National Society for ME Patients** (RME) is arranging two conferences on severe ME/CFS, one in **Stockholm** on 19th October and one in **Gothenburg** on 22nd October.

The conference will be held in English excepting the welcoming introduction.

In connection with the conference in Gothenburg we are also arranging a closed researcher's meetings on Wednesday 21st October in which those giving the presentations at the conferences will be attending too.

The conference is free of charge and is aimed towards healthcare professionals and politicians. Seats are limited. The general public may attend space allowing.

Last day for registration **30th September**.
Please contact info@rme.nu for registration or questions.
Web: http://www.rme.nu

Program in Stockholm:

- ME/CFS background, symptoms and research: **Daniel L. Peterson**, **MD**, **Simmaron Research**, USA.
- Distinct differences in plasma immune signatures between early and late stage of ME/CFS: **Mady Hornig**, **MA**, **MD**, **Director of Translational Research**, **Center for Infection & Immunity** and **Associate Professor of Epidemiology**, **Columbia University Medical Center**, USA.
- ME/CFS case definitions and the importance of a name: **Leonard Jason**, **PhD**, **Professor of psychology** and **Director of the Center for Community Research**, **DePaul University**, **Chicago**, **Illinois**, USA.
- Presentation of the newly opened ME/CFS clinic at the Stora Sköndal Foundation: **Lena Nilsson**, **Manager Neurological rehab clinic**, and **Ulla Lindbom**, **Neurologist**, **Stora Sköndal**.

Program in Gothenborg:

- First three speakers and subjects: see Stockholm
- Infections and autoimmunity with ME/CFS: **Jonas Blomberg**, **Professor Emeritus of the Klinisk virologi**, **Uppsala Universitet**
- Diagnostics and treatment of ME/CFS at the Gottfries Clinic: **Olof Zachrisson**

A snapshot of Invest in ME's 10th annual conference

On Friday 29 May 2015, the British charity, Invest in ME (http://bit.ly/1MUrE8F), held its 10th annual conference at the Institution of Mechanical Engineers in central London (http://bit.ly/1G5AbAa). It followed on from the two-day Biomedical Research Colloquium (http://bit.ly/1QYve2e) on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (http://bit.ly/1C77m5y) (ME/CFS).

Conference highlights

The whole day was a highlight but these were my particular favourites:

Professor Ian Charles kicked off the proceedings with information on the research park – the Institute of Food Research at Norwich - and its possibilities in resolving chronic diseases like ME. Research is going on in alterations in the intestinal barrier integrity and microbiota (dysbiosis) in ME. Personalized nutrition may constitute one of the future weapons to cope with some ME-symptoms. He wore a very beautiful necktie.

Professor Mady Hornig took over with her abundant energy, charm and formidable intellect. She outlined her "three strikes hypothesis" ie. the intersection of genes, environment, and timing causing chronic illnesses such as ME/CFS.

The work of **Professor Hornig** and her colleagues at NYC's **Center for Infection and Immunity at Columbia University's Mailman School of Public Health** has recently produced ground-breaking research in the understanding of this disease. Details of the two recent studies can be found here (http://bit.ly/1GGXXsE) and here (http://bit.ly/1dFeXSY).

Prof. Hornig researches cytokines and discovered that levels of several IL's and IFN gamma are higher than in controls at the onset of the disease but lower in long-term ME.

The cerebrospinal fluid signatures differ in ME from those in MS and healthy controls. A large number of metabolites (180) and cytokines have a mutual influence.

Professor Jonas Bergquist from Sweden talked on proteomics in ME. Which proteins are expressed when and where, why and how. There's an increased cell-activation in ME. Altered protein-levels could serve as diagnostic markers of ME.

Dr. Amolak Bansal talked about the different diagnostic criteria and gave some examples of overlapping disorders like borderline, in which there are cold peripheries as well, an alcohol intolerance, drug hypersensitivity, altered pupil reflexes and a sighing respiration.

Autonomic neuropathy is the only disease which shares the strong variations in eye-reflexes with ME. In ME there are often reverse reactions on antidepressants. Contrary to sufferers from depression an ME-patient starts tasks but has great difficulties in finishing them.

In England there are many urban regions and as a consequence Lyme is much less found to be a comorbidity than e.g. in the USA or in Canada.

Dr. Luis Nacul stated that 'inappropriate behaviour' as well loss of taste may be part of the symptoms of ME. The Biobanl in London in March 2015 had stored already as many as 17.000 aliquots. These comprise i.a. blood, serum, plasma, red blood cells (peripheral blood) and blood for RNA-research.

Later in the morning, **Professor Sonia Marshall-Gradisnik** took the podium. She and her team at Australia's **National Centre for Neuroimmunology and Emerging Diseases** (NCNED), located at **Griffith University** on Queensland's Gold Coast, have also been coming out with a series of studies, revealing differences in immune function between subsets of ME/CFS patients and healthy controls.

The NCNED has been building on years of work in the field which demonstrates a reassuring maturity; full details of their most recent publication can be viewed here (http://bit.ly/1SfReIr).

Professor Marshall-Gradisnik's commitment and compassion shone through as she spoke. She and her team found acetylcholine to be a vital activator and talked about cells, genes and SNP's (single nucleotide polymorphisms, playing a part in DNA-research), illustrating her talk with a lot of powerpoints.

With ME there are deviations in TRPM3 which plays a role in the thermoregulation of the body, and in TRPC4, playing a part in memory and attention.

Moving on: pre-lunch, **Professor Simon Carding** of the UK's University of East Anglia (UEA) introduced a group of researchers who are working on projects supported by Invest In ME.

These young academics are of vital importance to the future of UK research into ME/CFS.

They are:-
Daniel Vipond, **PhD candidate** at **UEA**, working on the UK Gut Microbiota Project at the **Institute of Food Research** (IFR)
Navena Navaneetharaja, **UEA medical student** studying for a Masters in Research degree at **IFR**
Bharat Harbham, **UEA medical student** studying for a Masters in Research degree at IFR
Fane Mensah, **PhD candidate** at **University College**, **London** (UCL) in the laboratory of **Dr Jo Cambridge** working on the Rituximab project

After lunch **Dr. Jo Cambridge** talked about the Rituximab-study in the UK. With a photo of a B-cell he mentioned three antibodies, an antibody being a soluble form of a certain B-cell receptor: IgM with 10 binders, IgA with 4 binders and IgG with 2 binders.

Dr. Neil Harrison is rather new in the field of ME-research but he's determined to proceed with it, and will be one of the speakers at the 26 September-conference in the Netherlands. He has published a research in cooperation with two researchers of the **Radboud UMC** in Nijmegen, Holland: good to know that not only harmful impulses come from that city. His speech was about the inter-relationship immune system-brain-inflammation, a very important field in ME.

Dr. John Chia gave us an update on his specific area: enteroviruses. There's a difficulty recognizing enteroviruses. Until more recently there were no rapid diagnostic tests to detect them.

With new technologies much more is possible. Proof of the part ev's play with ME is not so new however: **L Cunningham**, **RJM Lane**, **LC Archard** et al. published a research in the Journal of General Virology 1990 in which the enteroviral RNA in muscle biopsies occurred to be 1:1 with ME-patients and 100:1 in healthy controls. I takes a while…

Dr Claire Hutchinson of the UK's **University of Leicester** talked about visual processing and ME re. biomarkers. This is the link to a description of her work here (http://bit.ly/1SfRk2G).

The final session of the day was from **Professor Olav Mella** from **Haukeland University Hospital** in Norway. **Professor Mella** and **Dr Fluge** are conducting a clinical trial of the immunomodulatory drug Rituximab as a possible treatment for ME/CFS, having stumbled upon its potential in 2007 whilst treating cancer patients.

The results of Phase 2 of the trial will be published within the next few weeks; Phase 3 is expected to be completed in mid-2017.
The utter simplicity and clarity of **Professor Mella**'s presentation was stunning; the design of the trial demonstrates the utmost transparency, integrity and scientific rigour. And again we were treated to that special ingredient: care and concern for patients and their welfare.

So – highlights of the highlight which was **Professor's Mella**'s session:

- There will be sub-studies within the trial including endothelial dysfunction and gastro-intestinal issues
- They are considering the possibility of testing Cyclophosphamide (http://bit.ly/1eewK4s) for those who can't tolerate Rituximab, which is highly toxic. Cyclophosphamide is cheaper than Rituximab so could be the drug of choice. They have recently commenced a 40-patient study. Very sick patients could be included in that trial (at last!)
- Objective measures included to monitor changes in activity levels (electronic armbands to be worn for 7 days pre- and post- treatment)
- He addressed the political significance and impact of this trial worldwide for patients
- He concluded by thanking Invest in ME for inviting him; he then thanked patients because "most of our ideas come from listening to what the patients tell us"
- Finally, and best of all: not once did **Professor Mella** refer to the illness as anything other than "ME". He gets it.

Sources: the basis of this report has been written by **Valerie Eliot Smith**: http://bit.ly/1QYs3HJ and has been added with notes taken at the conference by one of the editors

Dutch ME conference

Saturday September 26, 2015

Biomedical research and treatment
The ME/cfs association of the Netherlands holds a conference in Amsterdam to celebrate its 10th anniversary on Saturday September 26th. The conference is intended for physicians and specialists, medical students/PhD students, patients and interested.

A number of known national and international speakers in the ME field will give a lecture this day:

- **Prof. Dr. Frans C. Visser**: ME, POTS, orthostatic intolerance and pain (in Dutch)
- **Dr. Nigel Speight**: Paediatric ME/CFS and The challenge posed by the Very Severe Case
- **Dr. Byron Hyde**: Biomarkers & possible treatments of ME
- **Christine Tobback**: The role of multiple food sensitivities in ME and fibromyalgia (in Dutch)
- **Dr. A. Uyttersprot**: Diagnosis (in Dutch)
- **Dr. Neil Harrison**: Immune-Brain communication: Relevance to Inflammation induced Fatigue

Prof. Dr Frans Visser: Cardiologist, Cardiovascular Care Foundation, Amsterdam. Study medicine at the University of Leiden and the study for cardiologist in the VUMC. Cardiologist and Professor by special appointment in the VUMS and ad interim tutor of the A training of cardiologists in the VUMC. Working in the Independent Treatment Centre Foundation Cardio Care in the Parkstad Clinic in Amsterdam since 2008.

Dr Nigel Speight: Paediatrician, The University Hospital of North Durham, United Kingdom. Expert on the ME/cfs field in children. Medical advisor at The ME Association. Member of the international expert panel about ME, co-author International Consensus Criteria and Primer for ME.

Dr Byron Hyde: Chemist, physician and researcher, Ottawa, Canada. Senior Fellow of the Canadian Royal College. Founder of the Nightingale Research Foundation, which specializes in ME.

Christine Tobback: Nutritionist, Himmunitas, Brussels, Belgium. As a nutritionist she coaches among others patients with chronic fatigue and fibromyalgia in the health centre Himmunitas and in various centres abroad. Was also working for the first (football)team of R.S.C. Anderlecht.

Dr A. Uyttersprot: Neuropsychiatrist, Vilvoorde and Meise, Belgium. Studied medicine at the RUG Gent and studied to neurologist and neurophysiolologist at the Academic Hospital Leiden and specialised further in psychiatry at the University Hospital Ghent and institution psychiatry at the Psychiatric Institute Sancta Maria. Works as neuropsychiatrist specialized in ME/cfs in the CFS-centre AZ Jan Portaels in Vilvoorde and in a private clinic in the Atlas clinic in Meise.

Dr Neil Harrison: Neuropsychiatrist, Brightono and Sussex Medical School, United Kingdom. Specialized in psycho-neuro-immunology. Researching on infections, inflammations, psychiatric and immunology and investigating the neurobiological basis of among others autism.

More information about the conference can be found on http://www.mecongres.nl
Mail to: congres@me-cvsvereniging.nl

Dr. Myhill Seminar In London And Book

As part of Biocare's Summer 2015 Advanced Education programme, **Dr Myhill** is to deliver a seminar detailing her views on the causes of CFS, the assessment techniques she uses, and her unique 'sustainable medicine' approach to treatment.

This seminar will take place **on Monday 13 July 2015** from 10.00am to 4.30pm at the Cavendish Conference Centre in London. The cost is £70 plus VAT. The first half of this seminar will investigate chronic fatigue syndrome and the second will focus on the critical roles that inflammation and the immune system play.

Dr Myhill will also be launching her new book 'Sustainable Medicine' which empowers us all to achieve the above.To book your place, please contact Jacqui at education@biocare.co.uk or call 0121 433 8774. Full details are given on the flyer.

Submitted by **Helle Rasmussen**

17. 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."