The ME Global Chronicle

www.let-me.be

 # 24 –August 2017

1. Colofon / Personalia

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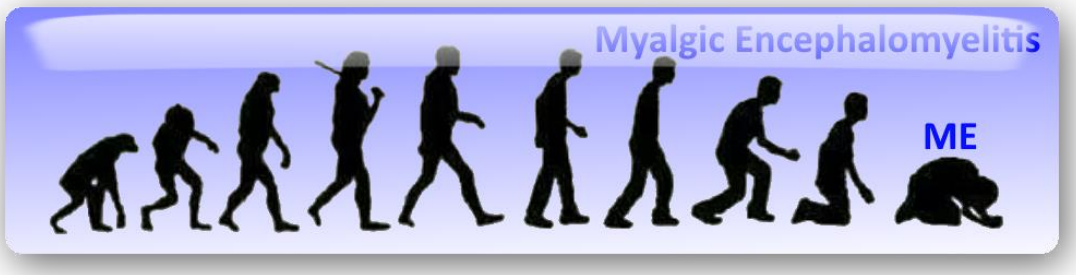
Subscribe to this newsletter.
We are no association or society, just a bunch of idealists who want to give our best efforts towards recognition of this terrible disease. By trying to help connecting to each other all patients all over the world. Anyone who expresses the wish to receive the Newsletter 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 issues https://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.



At all times remember Severe ME: https://youtu.be/BoVvJzmmVWg

3. Editorial

Dear friends,

It is really amazing how we sincerely intend time and again to shorten this magazine to 40-50 pages and how it gets thicker and thicker. In a way that´s a good sign, as so much of importance is happening in the World of ME - on the negative in the stubborn denial of the BPS-scientists the affliction they´re researching is at the best chronic fatigue and has nothing to do with ME, and on the positive in almost daily new discoveries of the biomedical aspects of this horror-disease.

But first of all a sincere and very urgent request.
We started the fund **Save4Children** some three years ago to support (parents of) children with ME who became or were to become victim of the ME-stigmatizing bureaucracy in almost all countries. From its very formation, the financial processing has been done apparently without much effort by the Dutch ME/cvs Vereniging. However, a week ago we were informed that its members recently unanimously decided not to continue this cooperation, from November 1, 2017 onwards. The advantage of this cooperation was that gifts were tax-deductible.

We are looking for a construction to maintain that status, and make an urgent appeal on all of you to let us know (info@let-me.be) if you have any idea how to proceed. Worst case scenario is that from 1st November onwards gifts to the fund are not deductible anymore.

About this issue of the MEGC: just pick your choice in the table of contents and click the article(s) you may be interested in. Also have a peek at our fb-wall https://www.facebook.com/groups/TheMEGlobalChronicle/ which is becoming more and more interactive by the week. We'd like to thank all of you who contributed to the contents of this issue and dare to say the quality of your contributions is of increasingly high standards and invaluable.

The October 2017 issue is to be published ± 25 October, its deadline for contributions being the 10th. However, don´t hesitate to start mailing important issues to include from right now, preferably in word-docs not exceeding some 600-800 words.

We do hope you will find something to your liking in this issue and wish all the friends on the southern hemisphere a bright spring and those on the northern hemisphere a most colourful autumn and of course the possibility to enjoy them, even in the slightest measure.

Thank you so much for your persistent support which is really building up focus.

The editors, August, 2017

4. PACE

MAIMES (Medical Abuse Of ME's)

The Time Has Come To End The Abuse

In this moving and eloquent short film (http://bit.ly/2v2TPQ5), **Dr Sarah Myhill**, a world-leader in the field of treating patients with ME/CFS, describes why she has started MAIMES, a pressure group that intends to ensure a public inquiry into the British medical system's treatment of patients with ME/CFS.

She describes the distressing and hostile environment in which doctors must practice if they want to treat people with ME, using anything other than the deeply-flawed NICE recommendations. NICE, one of the advisory bodies that oversees treatment guidelines for clinical practice in the UK, is basing its recommendations on the flawed and fraudulent data of the now notorious PACE trial carried out in 2011.

This trial involved 641 patients and cost an estimated £8 million. It became part of the orthodoxy in treating people with ME around the world and was widely reported in the media. Its conclusions that Graded Exercise Therapy and Cognitive Behavioural Therapy were the treatments of choice for this patient group reflected the biases of its designers - that people with ME were not ill, but had a 'fear of exercise' and 'faulty belief systems'.

Scientists and patients fought for many years to get the raw data for the study released, and when it was, it was savaged by the scientific community. **Rebecca Goldin**, Director of http://stats.org and Professor of Mathematical Science at George Mason University, methodically unpicked the study.

Professor Goldin found PACE was flawed in design, in execution and in interpretation. There were no blind controls. It wasn't randomised. The participants were cherry picked as likely to succeed, and the criteria for success was changed dramatically during the course of the trial. In the end, if a participant regained the functioning of a seventy-five-year-old, that was deemed a success.

Given the average age of participants was thirty-nine, this is hardly encouraging. But this dishonest piece of manipulated data continues to determine the treatment of millions of people with ME around the world. In the UK, it may also be a factor in whether very ill and vulnerable people receive sickness benefits and support.

But the British medical establishment isn't ready to back down. Doctors such as **Dr Myhill** are demonised and driven out of practice. She has been investigated by the General Medical Council thirty times - and thirty times she's won. Other doctors haven't been so lucky, and have been struck off, had their practice restricted, or even driven to an early death by the constant harassment. **Dr Myhill** also asks why there is this overwhelming attachment to the idea of ME/CFS as a psychiatric illness?

Could it be that to face up to the occupational hazards of groups as diverse as soldiers (Gulf War Syndrome), fireman (9/11 syndrome) and farmers (sheep dippers' 'flu'), all of whom have been exposed to highly toxic chemicals, means we have to rethink how and why people become sick with these syndromes?

So MAIMES is for both doctors and patients. People with ME/CFS deserve proper medical help. Doctors treating them deserve accurate information and treatment guidelines. Please, **Dr Myhill** urges, join the campaign, get your MP on board, and ensure there is a public inquiry into this scandal.

For more on MAIMES, including information on what you can do to help, please see: http://bit.ly/2vU1ocY

For more on **Dr Myhill**'s work visit http://drmyhill.co.uk
To purchase **Dr Myhill**'s books, please see http://bit.ly/2uUk5A2

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http://bit.ly/2iiXWps
http://bit.ly/2uUyg8j
http://bit.ly/2vU28im

FITNET Is Ineffective

FITNET's Internet-Based Cognitive Behavioural Therapy Is Ineffective and May Impede Natural Recovery in Adolescents with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome.

A Review

Simin Ghatineh and **Mark Vink**
Published: 11 August 2017

Abstract

The Dutch Fatigue In Teenagers on the interNET (FITNET) study claimed that after 6 months, internet based cognitive behaviour therapy in adolescents with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), led to a 63% recovery rate compared to 8% after usual care, and that this was maintained at long term follow up (LTFU).

Our reanalysis shows that their post-hoc definition of recovery included the severely ill, the unblinded trial had no adequate control group and it used lax selection criteria as well as outcomes assessed via questionnaires rather than objective outcomes, further contributing to exaggerated recovery figures.

Their decision not to publish the actometer results might suggest that these did not back their recovery claims. Despite these bias creating methodological faults, the trial still found no significant difference in recovery rates ("~60%") at LTFU, the trial's primary goal.

This is similar to or worse than the documented 54–94% spontaneous recovery rates within 3–4 years, suggesting that both FITNET and usual care (consisting of cognitive behaviour and graded exercise therapies) are ineffective and might even impede natural recovery in adolescents with ME/CFS.

This has implications for the upcoming costly NHS FITNET trial which is a blueprint of the Dutch study, exposing it to similar biases.

Source:
http://www.mdpi.com/2076-328X/7/3/52/htm

Journal Of Health Psychology

Journal of Health Psychology, issue 9 (August 2017), vol. 22
The Special of the monthly Journal of Health Psychology, completely dedicated to comments on the PACE-trial, has been published online on July 31, 2017: http://bit.ly/2hgmn68

BPS-exponents, whose names publisher SAGE didn't want to disclose, tried IN VAIN until the 29th of July to prevent its publication. It contains the following, already published articles on PACE:

Special issue on the PACE Trial (http://bit.ly/2tQKbPW)
Introduction by **David F Marks**, editor
First Published July 31, 2017; pp. 1103–1105

'PACE-Gate' (http://bit.ly/2nNkpfa):
When clinical trial evidence meets open data access - **Keith J Geraghty**
First Published November 1, 2016; pp. 1106–1112

Response to the editorial (http://bit.ly/2vaugju) by **Dr Geraghty**
Peter D White, **Trudie Chalder**, **Michael Sharpe**, **Brian J Angus**, **Hannah L Baber**, **Jessica Bavinton**, **Mary Burgess**, **Lucy V Clark**, **Diane L Cox**, **Julia C DeCesare**, **Kimberley A Goldsmith**, **Anthony L Johnson**, **Paul McCrone**, **Gabrielle Murphy**, **Maurice Murphy**, **Hazel O'Dowd**, **Laura Potts**, **Rebacca Walwyn**, **David Wilks**
First Published January 24, 2017; pp. 1113–1117

Once again (http://bit.ly/2ubWeXp), the PACE authors respond to concerns with empty answers - **David Tuller**
First Published April 27, 2017; pp. 1118–1122

Investigator bias and the PACE trial (http://bit.ly/2ucsgCI) - **Steven Lubet**
First Published March 7, 2017; pp. 1123–1127

The problem of bias in behavioural intervention studies (http://bit.ly/2tW2fMI): Lessons from the PACE trial - **Carolyn Wilshire**
First Published March 23, 2017; pp. 1128–1133

PACE trial authors continue to ignore their own null effect (http://bit.ly/2uNlMh5) - **Mark Vink**
First Published April 27, 2017; pp. 1134–1140

The PACE trial missteps on pacing and patient selection (http://bit.ly/2f09IU8) - **Leonard A Jason**
First Published February 1, 2017; pp. 1141–1145

Do graded activity therapies cause harm in chronic fatigue syndrome? (http://bit.ly/2f18QyF) - **Tom Kindlon**
First Published March 20, 2017; pp. 1146–1154

PACE team response shows a disregard for the principles of science (http://bit.ly/2ngoq85) - **Jonathan Edwards**
First Published March 28, 2017; pp. 1155–1158

Bias, misleading information and lack of respect for alternative views have distorted perceptions of myalgic encephalomyelitis/chronic fatigue syndrome and its treatment (http://bit.ly/2uNbRZ0) - **Ellen Goudsmit**, **Sandra Howes**
First Published May 29, 2017; pp. 1159–1167

PACE investigators' response is misleading regarding patient survey results (http://bit.ly/2f0e121) - **Karen D Kirke**
First Published May 11, 2017; pp. 1168–1176

Distress signals (http://bit.ly/2tQpvYi): Does cognitive behavioural therapy reduce or increase distress in chronic fatigue syndrome/myalgic encephalomyelitis? - **Keith R Laws**
First Published May 17, 2017; pp. 1177–1180

Cognitive behaviour therapy and objective assessments in chronic fatigue syndrome (http://bit.ly/2vkUYXc) - **Graham McPhee**
First Published June 19, 2017; pp. 1181–1186

PACE trial claims for recovery in myalgic encephalomyelitis/chronic fatigue syndrome – true or false? It's time for an independent review of the methodology and results (http://bit.ly/2vavtaw)- **Charles Bernard Shepherd**
First Published April 9, 2017; pp. 1187–1191

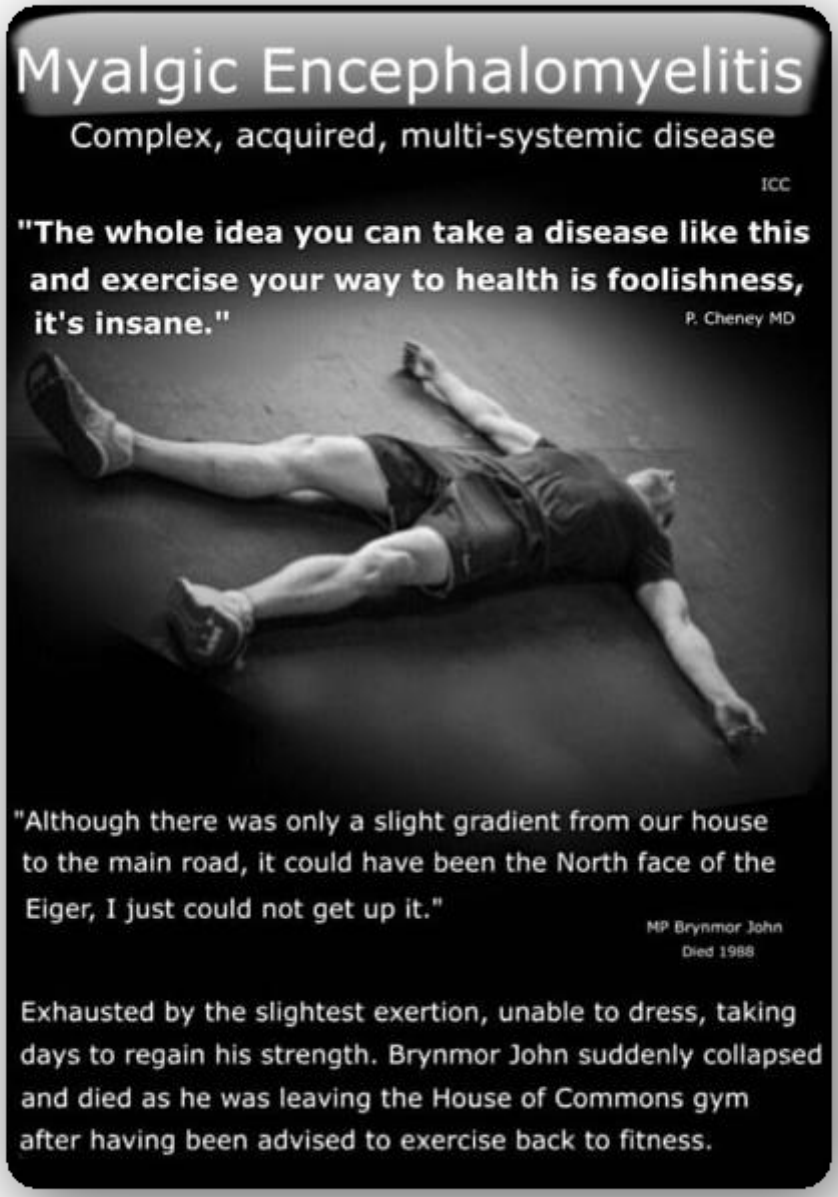
PACE-GATE (http://bit.ly/2vkTsnI): An alternative view on a study with a poor trial protocol - **Bart Stouten**
First Published May 12, 2017; pp. 1192–1197

The PACE trial: It's time to broaden perceptions and move on - **Keith J Petrie**, **John Weinman**
First Published April 10, 2017; pp. 1198–1200

Defense of the PACE trial is based on argumentation fallacies (http://bit.ly/2vXQwuk) - **Steven Lubet**
First Published June 14, 2017; pp. 1201–1205

Chronic fatigue syndrome patients have no reason to accept the PACE trial results (http://bit.ly/2veFrHu): Response to **Keith J Petrie** and **John Weinman** - **Susanna Agardy**
First Published June 27, 2017; pp. 1206–1208

Further commentary on the PACE trial: Biased methods and unreliable outcomes (http://bit.ly/2ubZj9Z) - **Keith J Geraghty**
First Published June 14, 2017; pp. 1209–1216



5. Dutch Citizen Initiative

ME Is Not MUPS

ME Is Not MUPS: Change Dutch Health Council Committee and adhere to the advisory report assignment

Please please continue to sign!

http://bit.ly/2e2Nsq7

Among ME patients there is no public support for a Dutch Health Council Committee with members denying ME as a chronic, complex, multisystem disease (ICD G93.3) or equating it to "MUPS", (Medically Unexplained Physical Symptoms), a functional syndrome, a somatoform disorder (ICD F45), neurasthenia (ICD F48) or unexplained fatigue (ICD R53).

- **We**, Myalgic Encephalomyelitis (ME) patients and all those who recognize the severity and nature of this biomedical disease

- **Observe** that the Dutch Health Council Committee composition is incompatible with the state of the scientific knowledge, of which the Dutch Health Council is aware (WHO recognition ME 1969, ICD G93.3, the Institute of Medicine refers to a chronic, complex, multisystem disease with symptoms that can be explained by objectifiable physical abnormalities as described in thousands of scientific publications),

    - nor does it fit the advisory report assignment given by Parliament (an advisory report about ME),

    - ME is not MUPS! The Dutch Health Council should select the best available expertise, relevant to this disease, but fails to do so

- **And request** to adjust the composition of the Dutch Health Council Committee. Input of patients should be taken as the guiding principle. After all, the Citizen's Initiative "Recognize ME" was the direct reason for the advisory report assignment. They together with the patient organizations have submitted, at the request of the Dutch Health Council, names of (international) ME experts, who are willing to participate (none of them from the MUPS/Mental Health Care field!). The fact that the Dutch Health Council nonetheless prefers irrelevant MUPS and Mental Health Care professionals, that were not suggested to them, over international ME expertise, is unacceptable.

The Dutch Health Council must adhere to its advisory report assignment!

ME Is Not MUPS - Dutch Petition Approaching 10.000 Signatures

2nd Update: The countdown to our final goal has begun, only 900 signatures needed to reach 10,000. Please be one of these signatures. And ask your friends to sign and share.
https://meisgeensolk.petities.nl/?locale=en

This is what Invest in ME wrote in their newsletter about the Dutch Petition.
(Please sign and share as much as you can)

"Petition to the Dutch Health Council, Invest in ME Research invited the Dutch Health Council to the 2017 conference events in London - and, sharing much in common with UK establishment organisations, they did not reply. Perhaps this may get their attention - https://meisgeensolk.petities.nl/?locale=en

A Dutch petition - ME is not MUPS: Change Dutch Health Council Committee and adhere to the advisory report assignment

The Dutch Guidelines are based on NICE - and have been made part of a broader Medically Unexplained Physical Symptoms (MUPS) guideline. As the Dutch advocates state –

'BPS proponents/Dutch PACE colleagues with vested interests, who are still advocating CBT/GET as safe and effective and as the only "evidence based" treatment, should have no place in deciding future health policy for ME patients and how to spend valuable research money.'

The Dutch Health Council report will go to parliament and determine the care and research spending for the next decade - a similar corrupted scenario being shaped as was planned for the UK.

The Dutch are suffering in the same way as UK patients by the negligence and flaws in establishment organisations – and the apathy of government departments who should be demonstrating responsible management of the problem.

1200 signatures are needed to reach the goal of 10,000.
https://meisgeensolk.petities.nl/?locale=en"

(One can sign from any country with name or anonymous, but do not forget to click on the confirmation link in the email after signing, once you have done that, your signature counts).

Text taken from Invest in ME July newsletter page 8/9
(http://bit.ly/2wdLRas)

ANP-Press-Release Groep ME Den Haag

Given the fact that the week of 8th August 2017 saw two important publications – the Special of the Journal of Health Psychology on PACE and the Montoya-study on cytokines with ME – the Groep ME Den Haag decided to present the ANP (comparable to Reuters, but a lot smaller of course) with an article on both sides of approaching ME: BPS and biomedical.

The Groep Den Haag managed to collect 56.000 signatures in a citizen's initiative to get the parliament recognize ME as a biomedical disease according to the ICCriteria. As a consequence, the parliament ordered the Health Council of the Netherlands to research the current scientific state of affairs re. ME, a process which is to be concluded towards the end of 2017, but doesn't show very hopeful.

Unfortunately, only two newspapers picked up the press-release, which depicts who still hold the reins of power on ME in the Netherlands. The entire text of the press-release ran as follows:

Bio-medical research reveals a road to effective treatment of ME

Current psychological treatments prove to be ineffective.

Currently, an ad-hoc ME/CFS committee of the Dutch Health Council is examining the position of science regarding Myalgic Encephalomyelitis (ME) at the behest of the parliament. In opposition to the patients' representatives supporters of the psychosocial approach and psychogenic treatments such as CGT and GET are over-represented in the said committee, both in number and in influence.

It has already been demonstrated (through bio-medical studies) that ME is a physical illness with Post Exertional Malaise (PEM) as its core symptom: exacerbation of all physical conditions after even the slightest amount of physical activity. Measures such as CGT and GET not only prove to be ineffective to ME patients, they might even have adverse results.

July 31st saw two important publications which refuted this approach to treatment in their own way.

- Connection cytokines/ME

  A large new study, led by Stanford ME expert **Jose Montoya** and in collaboration with **Dr. Mark Davis** (1987 nominate for Nobel Prize in Physiology or Medicine) links the illness of ME to variations in 17 immune system proteins (cytokines), in which a correlation is drawn between the level of concentration in blood and the visible severity of the illness. The findings once again confirm that ME is a physical condition in which inflammation plays a key role.

- Refutation of the psychological approach to ME

  A special edition of the Journal of Health Psychology (JHP), entirely dedicated to the controversial British PACE trial, allegedly to ME/CFS but actually just to chronic fatigue. In this special: peer-reviewed commentaries by scientists and scientifically supported patients. "PACE is a school's example of a poorly performed study" concludes JHP editor **David Marks**.

In terms of methodology, many critical mistakes were made. After an independent repeat analysis of the date, it appeared the earlier conclusions of the authors couldn't be drawn from their own data.

Myalgic Encephalomyelitis is a chronic and complex multi-system illness, for which a remedial cure hasn't been discovered yet, as concluded by the Institute of Medicine (IOM, aka NAM) in a 2015 report, after a systematic literature review of all available publications at that time, including PEM as one of its core symptoms.

Montoya (on Reuters): "There exists no doubt that ME has roots in biology. This is not an illness that can be cured with psychological treatments, counseling or antidepressants." "Patients have been humiliated, separated and ignored."

The results of the PACE trial from 2011 had a large impact on the guidelines and recommendations for treatment, worldwide, also in the Netherlands. The underlying hypothesis of the study: patients ostensibly suffered from 'wrong thoughts about the illness' and 'deconditioning' Cognitive behavioral therapy (CGT) and Graded Exercise Therapy (GET) would be the designated 'evidence-based' treatments. This led to a skewed perception of ME in the minds of the population and successfully prevented acknowledgement of the severity of the condition, bio-medical research and the availability of adequate knowledge and care for those suffering from ME.

Mark Vink, family doctor, insurance doctor and ME patients wrote one of the commentaries in JHP's special PACE edition, concluding:
"Patients want their health and self-sufficiency to return, so they will no longer have to be dependent on welfare and are able to work again."

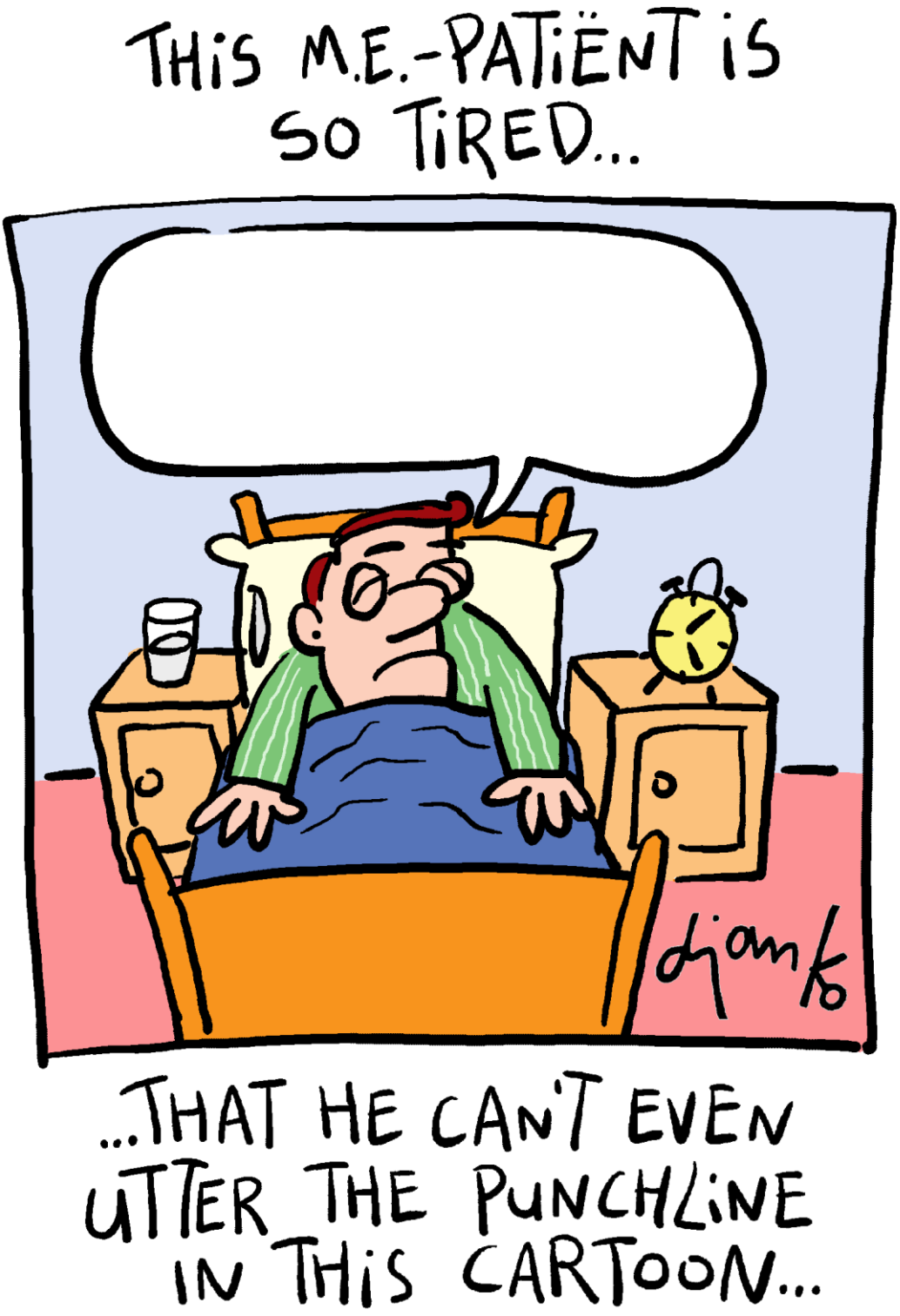
"The PACE trial has shown how CGT and GET are ineffective in helping patients accomplish this."

The CDC (American Centers for Disease Control and Prevention) recently removed their recommendations for CGT and GET as treatments from their web site, given the current scientific situation. Internationally, there's no doubt that bio-medical research is the only way to come to an effective way of treating ME and its patients in the long run.

When will the government, physicians and other governmental institutions in the Netherlands follow suit?

IOM report 2015: http://bit.ly/2wljkMG
PACE study: http://bit.ly/2v2L34E
Montoya/**Davis** study: http://bit.ly/2tY29nF - http://stan.md/2w7fyHw
Special Journal of Health Psychology: http://bit.ly/2hgmn68

Cartoon Djanko



6. Grassroot

The Goose Story

Next fall, when you see geese heading south for the winter... flying along in a "V" formation, you might consider what science has discovered.

As each bird flaps its wings, it creates an uplift for the bird immediately following. By flying in "V" formation the whole flock adds at least 71% greater flying range, than if each bird flew on its own.

People who share a common direction and sense of community can get where they are going more quickly and easily, because they are traveling on the thrust of one another.

When a goose falls out of formation, it suddenly feels the drag and resistance of having to go it alone and quickly gets back into formation to take advantage of the lifting power of the bird in front.

If we have as much sense as a goose, we will stay in formation with tho
se who are headed the same way we are.

When the head goose gets tired it rotates back in the wing and another goose flies point.

It is sensible to take turns doing demanding jobs with people or with geese flying south.

Geese honk from behind to encourage those up front to keep up their speed. What do we say when we honk from behind?

Finally, and this is important, when a goose gets sick, or is wounded by gunshots, and falls out of formation, two other geese fall out with that goose and follow it down to lend help and protection. They stay with the fallen goose until it is able to fly or until it dies; and only then do they launch out on their own or with another formation to catch up with their group.

If we have the sense of a goose, we will stand by each other like that!

Author Unknown

Source: http://bit.ly/2tjY7ov

National ME/FM Action Network, Canada
Whose logo are geese flying in formation

Opinion – Time For #MEICC

As the ME Global Chronicle's August 2017 issue is published, I will mark 28 years being ill with sudden onset ME. While I find it hard to imagine I could feel this ill for so long and still be alive, I know I'm not alone in having been ill without real treatments for over 2 decades.

Being ill this long also means I've watched the morphing of my original diagnosis of Chronic Fatigue Immune Dysfunction Syndrome (CFIDS) change to a vague fatiguing illness called CFS and the growing disdain by doctors toward my ongoing state of ill health.

In my opinion, it is time to find out how many patients fit the International Consensus Criteria (ICC) definition. We can then unify as an MEICC patient group to confront the health professionals in all countries and insist they recognize that the MEICC patients do not belong lumped in with patients not fitting that criteria. I am suggesting this group use the hashtag #MEICC.

We now have the science to back our claims that we are not "just fatigued". We know definitively that activity outside of our limited envelope is dangerous and leads to setbacks and deterioration.

I think it's also time we recognize that the Severe ME patients have been completely ignored by health agencies around the world as well as too many advocate groups, and that it is time they all include information specifically geared for the severe patients. #SevereME awareness day is August 8th.

In reviewing the July 3, 2017 update to the CDC website, which many have applauded as a step forward, I want to point out that the changes I see are cosmetic. The links for the doctors continue to push for graded exercise as a treatment option.

Following are some of what I see is missing from the CDC website and from too many "CFS" conversations:

- Paralysis of patients
- Muscle malfunctions leaving patients bedbound and/or needing wheelchairs that is NOT from deconditioning.
- Cardiac abnormalities which can lead to premature death.
- Heart rate abnormalities that should be seen by an EP Cardiologist and CAN be treated with medications like Corlanor.
- Immune system dysfunction leading to reactivation of viruses, food and medication intolerances, and higher risk of cancer.
- Energy production malfunction at the cellular level leaving patients unable to care for themselves.
- Broken oxygen exchange system as described by the Workwell Foundation which can cause toxicity issues that need to be addressed to improve quality of life.
- How truly disabling this disease is. The continued statements about "tired after shopping" coming out of the CDC needs to be confronted. Those of us who are on the lower end of the function scale can seldom go shopping and if we do it's not just "tired", it causes a disabling crash.

Do you fit the International Consensus Criteria?

Here is an easy questionnaire you can use as a guide: http://bit.ly/2gsuEhM

Colleen Steckel
Founder North Carolina & Ohio M.E./FM Support Group
http://bit.ly/2uuy3IB

An Introduction

Hello, my name is **Lydia Neilson** and I am the Chief Executive Officer and Founder of the National ME/FM Action Network, a Canadian registered charitable organization. I was born and raised in Rotterdam, Holland but came to Canada as a teenager.

I also have ME and the last day I worked for a living was October 17, 1986. One of my co-workers at the law firm I worked became ill but she thought it was the flu so kept working. However, as she was getting worse, she eventually went to see her doctor who advised her she had mononucleosis with a high titres of EBV. There were about ten of us in the law firm and we all got ill but everyone recovered except me. I just started getting worse and worse. My boss had an office up some stairs and I could no longer get up them.

For the next five years I became severely ill to the point I was bedridden but I still did not know what illness I had. I was told I was burned out and given antidepressants and when I did not get better it was because I did not want to return to work. I eventually got a good-news-bad-news report that I had ME but there was nothing he could do for me. I started first a local support group and it was filled and I felt that if I could fill a hall up, then how many more other people are there who are ill across Canada. I then founded the National Group which has been active since 1993.

I will tell you more about what we have accomplished over the years but for this first introduction I will tell you how I have found a way to keep my crashes less and that is by knowing how long I can go before I crash. This is vitally important. When you get up in the morning and doing things, watch the clock and notice what time you got up and how long you go before you start feeling that overtired sensation. Let's say it is 2 hours. That means you should not go for that length of time but stop at about 1 ½ hours then rest. If what you did was physical, then switch over and do something mental like reading. Again, stop at 1 ½ hours and rest. Continue that all during the day.

That schedule would be for a more or less ordinary day. However, you also have to plan for the severe ME days. The schedule may be less awake time so you need to keep track of that kind of day too. Once you have that down pat, stick to it.
If you have to plan for something special, ignore the schedule and rest as much as you can so that you can use all your energy for that event but when at all possible, keep in mind your limits.

Lydia E. Neilson, MSM
Founder NATIONAL ME/FM ACTION NETWORK, Canada

The Pocket Guide To Chronic Fatigue Syndrome/ME

The Pocket Guide to Chronic Fatigue Syndrome/ME - **Dr Rosamund Vallings**

East Auckland GP, **Dr Rosamund Vallings**, has published a new book, The Pocket Guide to Chronic Fatigue Syndrome/ME.

Howick physician **Rosamund Vallings** is continuing her quest to demystify a debilitating illness affecting tens of thousands of New Zealanders with her new book, The Pocket Guide to Chronic Fatigue Syndrome/ME.

Internationally recognised for her pioneering work, **Dr Vallings** is using her encyclopedic knowledge of the illness to produce a text that simplifies and explains everything for sufferers and carers alike.

Featuring the latest research, the book explains the illness carefully, offers strategies for dealing with specific symptoms, and details possible treatment options. It also offers guidance on talking to others about the disorder and caring for CFS/ME sufferers, including the severely ill.

"One thing that happens is a lot of people go on the internet to search for this information and sometimes what they're finding isn't especially accurate," she says. "This book gives them a basic, down-to-earth accurate overview which is really important."

Dr Vallings has more than three decades of experience in the field of CFS/ME, having first come across the illness as a student at The Royal London Hospital in the 1950s. "I remember seeing these patients when I was a student and learning all about this, which was then called Royal Free Disease," she says.

"I eventually came to New Zealand and got involved with some research with one of the rheumatologists at Middlemore Hospital and as a result I became very interested.

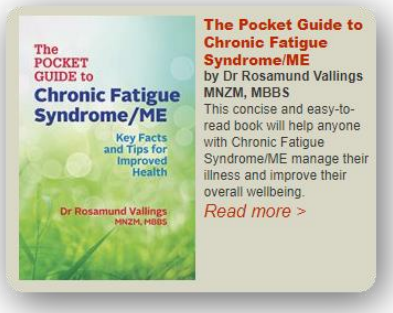
"I started to see some patients and diagnose them, and of course word gets around and I started getting patients from all over the place. It's just grown from there."

She's also received a NZ Order of Merit, was a recipient of the Nelson Gantz Award for Outstanding Clinician by the International Association of CFS/ME, and was nominated for NZ Woman of the Year. She says the disorder has baffled experts and patients for many years, but research is getting to a very exciting stage.

"People from all around the world are coming up with similar conclusions and integrating their research, which is a really good thing to happen.

"The biomarker is the one big thing. Having a reliable test is good both from the doctor and the patient's point of view, because you can reassure the patient that yes this is the right diagnosis or no it's not and we need to investigate further.

"There are also some fairly good studies going on in Europe looking at treatment options which are very encouraging, but the results of those trials are not going to be unwrapped until about October so everyone is waiting with baited breathe."



* The Pocket Guide to Chronic Fatigue Syndrome/ME has been published on August 8, with books available worldwide from http://www.calicopublishing.co.nz

Dr Vallings has written two previous books, Chronic Fatigue Syndrome/ME: Symptoms, Diagnosis, Management and Managing ME/CFS: A Guide for Young People.

Meghan Lawrence, **Stuf**

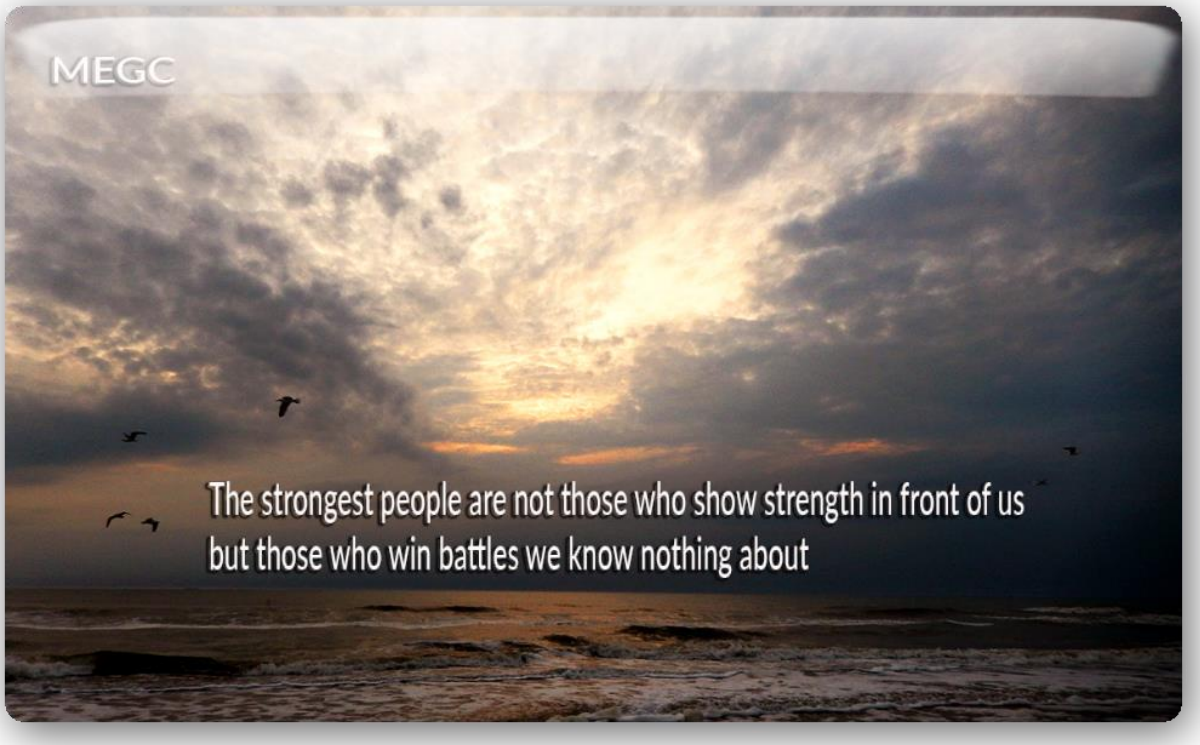
Dr. Nigel Speight

Many of you will have known that the British Paediatrician **Dr Nigel Speight** has for the last two years been under investigation by the British General Medical Council in relation to his work supporting patients and families with ME

We are delighted to be able to tell you that finally the GMC have closed the case against him with no action taken. This means that he is free to continue his work with ME families without restrictions.

Dr Speight has asked us to thank all those in the ME community worldwide who gave him such strong moral support and helpful testimonials, which his lawyers were able to use with good effect.

The editors



Tell Congress "Don't Defund ME/CFS!"

Call to action to American patients and advocates

Last week (of July ed.), the House Appropriations Subcommittee on Labor-HHS zeroed out the $5.4 million line item for Chronic Fatigue Syndrome at the CDC....again.

Tell your members of congress to restore the funding for ME/CFS for next year's budget.

We cannot abandon the progress we've made so far!

http://bit.ly/2w3vRZ7

Along with the prepared message you can add a personal message as well

Submitted by **Emily Taylor**, SMCI

We Need To Tell Our Story!

I usually feel proud of what I have achieved in the past 19 years; how I manage to live my life despite living with M.E. How my focus is on the positive and what I have learned from this experience of life on the other side. The side of life nobody wants to find themselves living in ...

In my Into the Light Artist book (of which you see some of the pages here) I broach many subjects such as the good and bad of living illness, society's views, the power of silence, moments of gratitude, but also of the danger of giving people with a physical illness a psychiatric diagnosis.

In order to give people the right information, we need to tell our own story.

An experience:
In 2013, I was in hospital for a planned five-day stay, to re-evaluate the state of my health/illness, as I had become more ill again during previous months. That week the main focus seems to be physiotherapy. I appreciated this as the therapist was understanding, although a little too adventurous perhaps with suggested exercises.

But one of the main questions I was asked that week from two neurologists and other doctors was: "How's the form?"

After the then fifteen years of illness I was yet again (as I was in 1998) referred to a psychiatrist.

I was asked did I mind? No, not really, I know my life. I understand my illness.

I had a very, very long meeting with a Liaison officer for unexplained neurological illnesses. (Some title!). This young woman dug as deep as she possibly could to find a reason for my long illness. Childhood fears? Bullying during teenage years? School experiences? Family circumstance? Anything she could possibly think of. She also asked me: "Why do you think you have ME? It does not exist."

I found this a very dangerous statement. One I can cope with, but I was thinking about other, more vulnerable people, who might be ill for a shorter time, and feel under tremendous pressure to be told that their illness does not exist. Suicide is not uncommon.

I told her of my life, how I deal with illness, that I have beautiful garden, a lovely home, that I create art and publish books.

The following day I met with the psychiatrist himself. The liaison officer was there too, and one other person, who's role I do not know.

The psychiatrist was intrigued (his words) by my story, and concluded that he saw no psychological illness, no depression, could not suggest any medication, and felt that if I wanted to achieve something/anything I obviously have the skills to do that. He did not prescribe me to come to the CBT clinic at the hospital, but if I ever had the opportunity to do this in my hometown, than maybe go for it. (My GP threw that out the window.) Case dismissed. Although of course the liaison officer's notes are in my file and that was very much evident during subsequent hospital stays...

The controversy surrounding the publication and awarding of the Wellcome Book Prize 2016, for **O'Sullivan**'s book "It's all in your head: True stories of Imaginary illness" last year brought the need to speak up and tell our own story, to the fore again. I am not so much worried about my own wellbeing, but am concerned for the mental wellbeing of the many people living with M.E, or other unexplained illnesses.

Worried that the already minimal care and understanding would be further curtailed, and financial support being questioned. And most of all that society had yet again a reason to disbelieve the experience of so many.

At the time, the Dutch health committee charged with defining M.E. as an unexplained illness re-tweeted a tweet in support of **O'Sullivans** book.

In Ireland the Irish Small and Medium Enterprise Association (ISME) jumped on **Sullivan**'s bandwagon (no idea why) with the headline 'Can this book save HSE €3.5 billion?':

"**Dr. O'Sullivan** claims the modern healthcare system is collapsing because of people experiencing physical illnesses that have no physical causes. The suffering is real; the causes may be subconscious and therefore the cures are wholly ineffective and wasteful. ... it could be costing the Irish system €3.5 billion or a full quarter of the health budget."

At the time I wondered if this was really just the story of one woman? Or is there some kind of lobby group behind her? I was rather baffled by her power.

Since this time there has been a lot in the media about the misinformation (to put it mildly) of the 'PACE' trial (http://bit.ly/2d8wnse). Maybe our time has come to be heard? To be believed by the public and the medical profession?

Let's hope that from now on the majority of people will listen to the real stories and not the stories in the likes of **O'Sullivan**'s head.

Be well.

Corina Duyn, Ireland http://www.corinaduyn.com
version of this story on http://bit.ly/2wdXK06

In Rituximab Treatment – Part 1

A Danish patient's-report

Due to the lack of understanding of disease causes in ME with Danish doctors, some Danish ME patients have, on their own initiative and on their own account initiated a Rituximab treatment at a Norwegian private clinic. Here, ME-patient Lisa (56) tells about her treatment with Rituximab in Norway after a preliminary 8 months.

I have been ill at the better end since autumn 2011. In 2015, I read a long, long thread on the Norwegian meforum.info about people who started a Rituximab treatment at the Kolibri clinic at Stavanger. After six months of reporting time, I contacted the clinic and went to the inaugural consultation with oncologist **Dagfinn Øgreid** in spring 2016. I had to bring my files from my GP about my illness with information about which studies and specialist doctors I had attended, As well as an ME diagnosis, which in my case is called neurastics.

First meeting at the clinic

At the clinic I received a very basic medical examination, as well as taking a larger battery of blood samples to exclude other diseases as a cause of my symptoms as well as diseases that would collide with the intake of Rituximab. In addition, I was told about the preparation (MabThera), which has been tested. Medication that has been used for 30 years for example with certain types of lymphoma, and what I could expect from side effects (a few weeks of increased ME symptoms after the main course where I had 2-3 months!) And what the prognosis was (1/3 symptom-free, 1/3 radically reduced symptoms, 1/3 nothing - a division that also applied to Kolibris 150 patients). Consultation and blood tests cost about 4.300 dkr. And took an hour's time. One must be approved for treatment.

Finally, I was told that I could start treatment in September, with the main course of 2 x 1.000 mg given every 14 days. So I went by plane from Copenhagen to Stavanger (return $ 1,200-1,500 if you are not too late) together with my daughter as it is advisable to have someone with you for the first time because you do not know how you will respond to the medicine.

First treatment

The whole day is set aside for the first time, as you do not know how you will respond and whether the infusion rate should be lowered to counteract allergic reactions. So we had to leave the day before and stay close to the clinic to be there at 8 next morning (double stay at Smart Hotel Forus 550 dkr.). I had no reactions, and the subsequent sessions were started every time at 12, so I could go back and forth the same day.

Treatment at your own risk

Before starting the first treatment, you must sign a declaration of consent that you've been informed about the medication, its side effects and complications, and that it is an experimental treatment. You also commit to send the clinic a brief summary of any effects and side effects once a month.

Prices and information

At the clinic you are in a bedroom along with 2-3 other patients.
A couple of nurses constantly monitor you with blood pressure, oxygen saturation and temperature and ask you how you're doing. You will first get a medication through drops, which will be countered if necessary in case of allergic reactions, and then you get Rituximab, which you should bring yourself. I think the simplest way is to retrieve it from the clinic's prescription (after pre-ordering) at a nearby pharmacy on the way from the airport.

Apart from that I don't know what it could involve complications it could involve when importing it from Denmark (Customs, Cold Storage), it is also approx. 1,500 dkr. per 500 mg cheaper in Norway (approximately 11,200 dkr) incl. visa fee. In addition, the clinic charges 8,500 dkr for the infusion each time at the 2 main treatments and 6,000 dkr per subsequent booster. Extra are 600 dkr for taxi return airport/ pharmacy/clinic per visit). The 2 main courses take about 4 hours if no complications occur and the subsequent boosters (500 mg every 3 months with a total of 5 times) 2-3 hours. **Dr. Øgreid** told me at the start of thetreatment that only 2 patients out of 150 had demonstrated such significant reactions that they had to significantly slow down the rate of infusion and to beg the patients to complete the treatment at a slower pace.

Treatment process

After each treatment, you talk to **Dr. Øgreid** shortly before returning home and one of the things which they have also found at Haukeland is that it takes a longer and longer response time. There is a positive ruling on the Rituxi regime. Currently, most treatments are effective between 6 and 12 months. I have been running for 8½ months myself and have got 2 boosters now.Until now no positive results are worth talking about. I sleep a little better at night and have had less bowel air, but that is not something that changes my overall well-being. Most importantly, in fact, I started to get a cold again and have had them 2 times over the last 5 months after over 3 years of not having caught a cold or the flu or anything else that has bothered me.

Are these signs of improvement? That I can fall ill again could indicate that the immune system is at stake and that the Rituximab makes a difference to this. So I just have to be patient and hope that within too long there will be some progress.

Lisa

The editorial board of ME Nyt will continue to follow Lisa's treatment and review it in the magazine.
Source: ME nyt 2 /2017 - Medlemsblad for ME FORENINGEN

In Memoriam - Dr. Bruce Carruthers

Bruce Magoffin Carruthers May 7, 1933- July 21, 2017

Dr. Bruce M. Carruthers, M.D., C.M., F.R.C.P. (C), was born in Mahableshwar and raised in Miraj, India. He was the only son and middle child of missionary parents, a Canadian father and American mother. Like many missionary children, he attended the Kodaikanal International School in Tamil Nadu, graduating in 1950.

Bruce then came to Canada for medical school at Queen's University in Kingston, his father's alma mater. While at Queen's he met his first wife, **Janet Greenhow**, the mother of his three children and a nursing student at the time. He continued his medical education with an internship at Charity Hospital in New Orleans and a residency at the Hospital of the University of Pennsylvania in Philadelphia, and then settled with his family in Vancouver in 1961.

Early in his career, he specialized in internal medicine and the treatment of metabolic diseases like diabetes, and for many years practiced at Shaughnessy and St Vincent's Hospitals, and was on faculty at UBC. He developed a deep interest in Iyengar yoga in the late 1960s, and was a pioneer in incorporating yoga as part of a preventive approach to patient health.

As his thinking on comprehensive care evolved he turned his attention to fibromyalgia syndrome, and myalgic encephalomyelitis/chronic fatigue syndrome, co-authoring the Canadian Consensus Documents for each of these and advancing their medical understanding and treatment. He was also an avid student of philosophy, history of science, non-Western medicine, social commentary, and for decades was a particularly good customer at Duthie Books.

For a time, he resided with his second wife Maureen Carruthers on Galiano Island in semi-retirement, but returned to Vancouver. In a lifetime of devoted medical practice, he treated and helped thousands of patients and strove to fulfill in full measure his Hippocratic Oath.

After a debilitating stroke in 2012, he moved to the Arbutus Care Center in Vancouver, where he received superb care. His children wish to thank the ACC staff for their professionalism and compassion, and to thank Sharon Shiels, his good friend and former patient, for her unending kindness.

The staff at VGH provided excellent medical treatment during his final days. To the end of his life, he enjoyed music, art, and a good Indian curry.

He is survived by his three children, **Bruce**, **Elspeth** and **Andrew**, three grandchildren, **Samuel**, **Esther** and **Gladys**, two former wives, **Janet Greenhow** and **Maureen Carruthers**, and his two sisters, **Mary Carruthers** and **Virginia Hegseth**. His wife, **Janella Fleming**, pre-deceased him.

A memorial service will be set at a future date. In lieu of flowers, please consider donating to the medical charity of your choice.

Source: The Province http://bit.ly/2uZgMYs

Not mentioned in this obituary is that **Bruce Carruthers** also co-authored the International Consensus Criteria (2011) and its primer (2012), apart from lecturing on ME all over the world.

In a guestbook, you can leave a message of appreciation and gratitude for all Bruce has done for the ME-community http://bit.ly/2vdmbb3

In Memoriam - Julia Browell

It is with heavy hearts that we post this sad news. Our ME community has lost an advocate and precious soul. **Julia Browell** passed away on Monday evening July 24, aged 61. She died of multiple organ failure in hospital, her daughter and grandchildren by her side. **Julia** lived with severe Myalgic Encephalomyelitis (ME) for most of her adult life, and made a lifelong commitment to advocating for people with ME.

A loyal, tenacious, intelligent, grateful and resilient person, **Julia** was diagnosed in early adulthood by a rare Australian doctor knowledgeable about Ramsay's Definition for ME (well before the term Chronic Fatigue Syndrome [CFS] had been conceived). She became involved in ME advocacy efforts in Australia and the UK decades before the internet, relying on paper and pen and her forthright voice.

And **Julia** used her voice well. She spoke and wrote candidly, and didn't mince words. Her motto was: "Nothing about me, without me! You can't walk in my shoes, so don't presume to be my voice." **Julia**'s commitment to ME advocacy meant she was an active part of the first international Yahoo support groups for severe ME patients, providing comfort and resources to scared newly diagnosed patients and supporting long-term online friends. Later, she became an active participant and administrator in Facebook advocacy and support groups both in Australia and internationally, particularly the UK.

Julia hated injustice of any kind and had a strong social conscience. She was interested in global social justice issues, as well as concerns pertaining to her local area, the Latrobe Valley region of Gippsland in Victoria, Australia. But **Julia** didn't just spectate and speculate; she walked her talk.

She was a community representative on a Disability Reference Committee at local council level. She was also involved in a community group called Voices of the Valley, who made submissions to government during the Hazelwood Mine Fire Inquiry regarding the fire's impact on the health and wellbeing of her community. She often popped into the offices of her local members of parliament for a cuppa and to talk to them about local concerns, and also the many challenges facing ME patients in Australia and beyond. She was always excited when Greens Party politicians came to town, and took as many opportunities to meet with her favourite, **Senator Richard Di Natale**, as her health allowed.

More recently, **Julia** was one of the first Australians to join the global advocacy network #MEAction, and was a stalwart supporter of grassroots activism for ME. Despite living two hours from Melbourne, **Julia** travelled by train to the #MillionsMissing Melbourne ME protests in both May and October 2016, meeting online friends for the first time, donating shoes, holding up placards, and talking to the public. Who could fathom that, just weeks before the October #MillionsMissing protest, she had suffered a heart attack, such was her commitment to ME activism.

During her life, **Julia** experienced almost unthinkable injustices related to living with a poorly understood and stigmatised illness. She lived through almost unbearable losses. During the last months and weeks of her life, she again suffered the impact of a medical system that fails to acknowledge and appropriately treat ME. But, even in her final days, she never ceased her efforts to educate medical staff about ME and its appropriate management.

Julia appreciated the simple things: the warmth of winter sun on her back, watching her vegetable garden change through the seasons, her favourite Chinese takeaway, a good belly laugh, small gestures of kindness. Our thoughts go out to **Julia**'s family and friends, especially her sister, brothers, daughters and grandchildren. Her beloved partner **Bob** died four years ago.

Today, let us light a candle for **Julia Browell**.

Farewell, our magnificent Spinifex Dreaming. You will be greatly missed.

Source: **Millions Missing Australia** http://bit.ly/2whDYkG

In Memoriam - Peter Holbrook

Peter Holbrook was an ME- and cancer patient of Northern Ireland. He passed away on the morning of Monday, June 3rd. He was diagnosed with lung cancer in February.

Peter has had an amazingly eventful life traveling the world, including his happy years growing up living in Hong Kong, to where he ended up in his little corner of 'Tranquillity' where he could jump in the car and travel to any part of Northern Ireland or Ireland with his trusty Camera at any time and take the images we came to know him for.

Peter entered a Photography Competition to design a Christmas Card for Invest in ME, and out of the many entries his was one of the few chosen, and it was made into a pack of cards sold to raise money and awareness for the Charity, which he was very proud of which is how he came to know the charity chosen.

He was a very talented Photographer, Artist, DJ, Singer - A man of many talents and many stories which entertained everyone he met.

He will be VERY sadly missed, and will hate the fuss being made of him on Facebook, but at the same time would love the attention (especially from the ladies!!)

He has been laid to rest with his Parents, on Friday morning July 7, 2017 at 11am

A fundraising page to his memory for research funded by Invest in ME has been set up http://bit.ly/2v7Dg5q

Marathon Mike

It's been a busy 3 months on the challenge where I've run my hottest/worst marathon, attended my first ME research conference and secured a donation of 250 pies from a national retailer....

September 10, Vilnius Marathon (Lithuania #12) (http://bit.ly/2uXQbLx)
October 15, Amsterdam Marathon (Netherlands, #13)

I also booked my 2nd marathon for next year which will be Vienna Marathon! I passed through Vienna on my honeymoon and had 2 days to explore, it'll be great to go back to the city once again to run this race.

Total Sponsorship Raised: £7360 (http://bit.ly/2myjzmi)
Social Media Followers: 1614 (http://bit.ly/2uXQbLx)
Miles Covered: 227
Average Temp: 18C
Lessons Learned: To keep reading, learning and asking for running advice.

Mike

Read more:
https://mikeseumarathons.blogspot.be/2017/07/mayjunjuly-update.html

Unrest

We're thrilled to announce the theatrical release of Unrest!

The U.S. premiere is September 22 at New York's IFC Center, followed by select theaters around the country. Our U.K. theatrical tour launches October 20 in London, in partnership with Picturehouse Cinemas. We can't wait for more of our amazing supporters around the world to have the chance to see Unrest on the big screen!

We aim to bring Unrest to many more countries and cities – at theaters and through our community screenings initiative. (For more, see below!)

Watch our theatrical trailer: http://bit.ly/2fxpiHl

Here are the *Unrest* theatrical opening dates:

NEW YORK	-September 22	- IFC Center
LOS ANGELES	-September 29	- Laemmle Monica & Pasadena
SAN FRANCISCO	-September 29	- Vogue Theatre
BERKELEY	-September 29	- Rialto Cinemas Elmwood
CHICAGO	-September 29	- Facets Cinematheque
SEATTLE	-October 4	- Northwest Film Forum
LONDON	-October 20	- Picturehouse Cinemas

More to come!

If you don't see your hometown on this list, don't worry – it's #TimeForUnrest around the world! You can help bring the film to your community by signing up to host a screening (http://bit.ly/2hRclsm) or contributing to our global social impact Kickstarter campaign (http://bit.ly/2hQwS0s).

Read Variety's official announcement of our theatrical release here (http://bit.ly/2hQMUYf).

Learn about how Unrest is one of the very first films to be released with the support of the Sundance Institute Creative Distribution Fellowship (http://bit.ly/2fxy9IZ).

Please share widely and help us spread the word about our release — and thanks, as ever, for being on this journey with us! (**Alysa Nahmias**, Producer of Unrest)

Jen

https://www.facebook.com/unrestfilm

7. Karina Hansen, On Her Way

The psychiatric coercive treatments have caused **Karina Hansen** PTSD with subsequent flashbacks, but after returning home and after the Olanzapine dose she received at the institution in Hammel has been reduced, **Karina Hansen** has gotten much better and now gets fewer flashbacks.

The medication

At the institution in Hammel, **Karina Hansen** received 2 x 10 mg olanzapine = 20 mg per day. **Doctor Stig Gerdes** reduced the dose at **Karina Hansen**'s return to her parents at the end of 2016, so that **Karina Hansen** received 7.5 mg + 5 mg olanzapine = 12.5 mg per day. At a consultation with **psychiatrist Mogens Undén** at the end of May 2017, the dose was further reduced to 10 mg per day.

After that, **Mogens Undén** has reduced the Olanzapine dose, first to 7½ mg per day, and again to 5 mg per day. So now, hopefully, it will not take long before **Karina** can get totally rid of the medication.

Incorrect treatment

Blood samples from d. 03.05.17 showed that the olanzapine concentration at **Stig Gerdes**' reduced dose of 12.5 mg per day was at 141 in plasma, which was still very high. The therapeutic level is 25 to 150. If you convert **Karina**'s level of medication to the dosage at the institution in Hammel, she got 225 in plasma, which could have been fatal.

Doctor Stig Gerdes's authorization was taken from him by the Board of Patient Safety because he reduced the Olanzapine dose without first discussing with the guard, **Kaj Stendorf** and with **psychiatrist Nils Balle Christensen**, although **Nils Balle Christensen** was no longer **Karina**'s psychiatrist at that moment.

The Patient Safety Board has failed

The psychiatrists at Risskov Hospital recommended a rapid withdrawal from the medicine, and **Mogens Undén** also believes that weaning is the right thing to do. The Board for Patient Safety thus stands alone in its assessment that the slight cut down of the medication doctor **Stig Gerdes** introduced to protect **Karina** from stiffened muscles and life hazard, has been irresponsible.

Access

Psychiatrist Mogens Undén now has access to **Karina**'s medical files from Hammel Neurocenter. It took quite some time to get the files and more than one way to prevent delivering them has been attempted, but **Mogens Undén** stood for his rights as the attending physician and finally succeeded.

(I don’t know anything about the contents of the files; I’m not entitled to know it but most important is that **Mogens Undén** has been granted access for the sake of further treatment of **Karina**)

Karina Hansen, on her way
Karina Hansen now lives where she wants to live and she is slowly recovering in her loving home and in the hands of a clever and skilled psychiatrist who is slowly taking her from the meds she never should have been taken.

Bente Stenfalk
Vice-President of the Civil Rights Movement Denmark

Slightly edited by the MEGC editors

Karina Hansen, Save4Children

Karina Hansen is the second child the fund Save4Children is focusing on.

Though free and at home with her parents once more, **Karina**'s freedom is still being threatened by 'her' psychiatrist **Nils Balle Christensen** of Aarhus and her guardian. As long she's not completely out of danger, she will remain our main focus, to help her and her parents with legal procedures to get her unhelpful guardian off her case.

As explained in earlier issues, it is of great importance donations will continue for obvious reasons. A proficient lawyer in such a complicated case doesn't work pro deo.

For more detailed information read **Valerie Eliot Smith**'s in-depth blogs about **Karina** (https://valerieeliotsmith.com/)

Since last issue € 35,= has been received. Thanks to both givers!

Please continue to donate via https://let-me.be/page.php?11 as the effects of your donations are obvious, helping to give back already two young ME-patients their freedom instead of an uncertain institutionalized life at the hands of 'caregivers' who only care for their own career and wages.

The editors

N.B. Please read the introduction to this edition about donations to the fund. Until the end of October donations can be made as before. Through a mailing and on the wall of the ME Global Chronicle we will inform you in time how the situation will be from 1 November onwards: your gifts may not be tax deductible after that date.

8. Science

Drug Discovery: Alzheimer's And Parkinson's Spurred By Same Enzyme

AEP protease acts on amyloid, tau and now alpha-synuclein

Editorial note: although it's just speculation at the present stage, it is not unthinkable this has correlation to possibly a subgroup of ME. That's why we thought it worthwhile including

Alzheimer's disease and Parkinson's disease are not the same. They affect different regions of the brain and have distinct genetic and environmental risk factors.

But at the biochemical level, these two neurodegenerative diseases start to look similar. That's how Emory scientists led by **Keqiang Ye**, **PhD**, landed on a potential drug target for Parkinson's.

In both Alzheimer's (AD) and Parkinson's (PD), a sticky protein forms toxic clumps in brain cells. In AD, the troublemaker inside cells is called tau, making up neurofibrillary tangles. In PD, the sticky protein is alpha-synuclein, forming Lewy bodies.

Ye and his colleagues had previously identified an enzyme (asparagine endopeptidase or AEP) that trims tau in a way that makes it more sticky and toxic. Drugs that inhibit AEP have beneficial effects in Alzheimer's animal models.

In a new Nature Structural and Molecular Biology paper, Emory researchers show that AEP acts in the same way toward alpha-synuclein.

"In Parkinson's, alpha-synuclein behaves much like Tau in Alzheimer's," **Ye** says. "We reasoned that if AEP cuts Tau, it's very likely that it will cut alpha-synuclein too."

A particular chunk of alpha-synuclein produced by AEP's scissors can be found in samples of brain tissue from patients with PD, but not in control samples, Ye's team found.

In control brain samples AEP was confined to lysosomes, parts of the cell with a garbage disposal function. But in PD samples, AEP was leaking out of the lysosomes to the rest of the cell.

The researchers also observed that the chunk of alpha-synuclein generated by AEP is more likely to aggregate into clumps than the full-length protein, and is more toxic when introduced into cells or mouse brains. In addition, alpha-synuclein mutated so that AEP can't cut it is less toxic.

Ye cautions that AEP is not the only enzyme that cuts alpha-synuclein into various toxic pieces, and the full-length alpha-synuclein protein is still able to aggregate and cause harm. Nevertheless, he says his team is moving on to testing drugs that inhibit AEP in Parkinson's animal models.

Source: **Science Daily** http://bit.ly/2sS5nUd

Journal Reference:
Zhentao Zhang, Seong Su Kang, **Xia Liu**, **Eun Hee Ahn**, **Zhaohui Zhang**, **Li He**, **P Michael Iuvone**, **Duc M Duong**, **Nicholas T Seyfried**, **Matthew J Benskey**, **Fredric P Manfredsson**, **Lingjing Jin**, **Yi E Sun**, **Jian-Zhi Wang**, **Keqiang Ye**.

Asparagine endopeptidase cleaves α-synuclein and mediates pathologic activities in Parkinson's disease. Nature Structural & Molecular Biology, 2017; DOI: 10.1038/nsmb.3433 (http://dx.doi.org/10.1038/nsmb.3433)

Membrane Lipid Replacement For Chronic Illnesses

Membrane Lipid Replacement for chronic illnesses, aging and cancer using oral glycerolphospholipid formulations with fructooligosaccharides to restore phospholipid function in cellular membranes, organelles, cells and tissues, **Garth L. Nicolson**, **Michael E. Ash**

Membrane Lipid Replacement is the use of functional, oral supplements containing mixtures of cell membrane glycerolphospholipids, plus fructooligosaccharides (for protection against oxidative, bile acid and enzymatic damage) and antioxidants, in order to safely replace damaged, oxidized, membrane phospholipids and restore membrane, organelle, cellular and organ function. Defects in cellular and intracellular membranes are characteristic of all chronic medical conditions, including cancer, and normal processes, such as aging.

Once the replacement glycerolphospholipids have been ingested, dispersed, complexed and transported, while being protected by fructooligosaccharides and several natural mechanisms, they can be inserted into cell membranes, lipoproteins, lipid globules, lipid droplets, liposomes and other carriers. They are conveyed by the lymphatics and blood circulation to cellular sites where they are endocytosed or incorporated into or transported by cell membranes. Inside cells the glycerolphospholipids can be transferred to various intracellular membranes by lipid globules, liposomes, membrane-membrane contact or by lipid carrier transfer.

Eventually they arrive at their membrane destinations due to 'bulk flow' principles, and there they can stimulate the natural removal and replacement of damaged membrane lipids while undergoing further enzymatic alterations. Clinical trials have shown the benefits of Membrane Lipid Replacement in restoring mitochondrial function and reducing fatigue in aged subjects and chronically ill patients. Recently Membrane Lipid Replacement has been used to reduce pain and other symptoms as well as removing hydrophobic chemical contaminants, suggesting that there are additional new uses for this safe, natural medicine supplement.

Highlight

- Oxidative damage to membrane phospholipids occurs in essentially all chronic and acute medical conditions, cancer and aging.
- Membrane Lipid Replacement with glycerolphospholipids replaces damaged phospholipids and restores membrane and cellular functions.
- Clinical trials have shown the benefits of Membrane Lipid Replacement in restoring mitochondrial function and reducing symptoms.
- Membrane Lipid Replacement can also be used to remove toxic chemicals and other substances due to a 'bulk flow' mechanism.
- Oral Membrane Lipid Replacement supplements are safe, inexpensive, effective and convenient.

For example, membrane glycerolphospholipids form the matrix for all cellular membranes and provide separation of enzymatic and chemical reactions into discrete cellular compartments and organelles. They are also essential for the function of a variety of membrane-intercalated and membrane-bound enzymes, and they afford cells with an important energy storage system [(http://bit.ly/2wAB1bV); (http://bit.ly/2uvfbcQ);(http://bit.ly/2uuHOa5). Moreover, they provide precursors for bioactive molecules that function in signalling and recognition pathways

Normally, natural cellular anti-oxidants neutralize these free radical and other oxidants, but in various illnesses the concentrations of free radical and other oxidants are so high that the cellular anti-oxidants are unable to neutralize all of them. Thus, excess free radical and other oxidants can damage cellular components (oxidatieve en nitrosatieve stress)

Membrane lipids are vitally important to life, mainly because they fullfill four major requirements for cellular health (http://bit.ly/2vVswLI); (http://bit.ly/2wOPPDr). They provide: (a) the matrix for all cellular membranes, permitting separation of enzymatic and chemical reactions into discrete cellular compartments; (b) energy storage reservoirs; (c) bioactive molecules that are used in certain signal transduction and molecular recognition pathways; and (d) functional molecules that interact with other membrane constituents, such as proteins and glycoproteins (http://bit.ly/2voNd0W); (http://bit.ly/2vLmgpg). This last characteristic is an absolute requirement for the formation, structure and activities of cellular membranes

Mitochondria

Mitochondria have a dual membrane structure reminiscent of bacterial membranes. Between the membranes of mitochondria is an intermembrane space, and inside the inner membrane is the mitochondrial matrix compartment. The inner mitochondrial membrane (MIM) is the most metabolically active membrane of mitochondria. It is a highly complex structure that is freely permeable to oxygen, carbon dioxide, and water. Embedded in the MIM are the four respiratory chain complexes, plus ATP-synthase (complex V), ubiquinone, and carnitine-palmitoyl-transferase II, most of which makes up the electron transport chain (ETC). The ETC accounts for about 90% of cellular oxygen consumption and provides more than 80% of cellular energy.

Mitochondria provide other critical functions for cells, including the modulation of calcium signaling, regulation of cell death, the maintenance of cellular redox balance, and innate immune signaling (http://bit.ly/2uvfIvm). Mitochondria also contain important biosynthetic pathways, especially for certain lipids (http://bit.ly/2uMy99U). Because of their role in apoptosis, it is reasonable to claim that mitochondria function as gatekeepers of cell life and death. inflammatory immune responses are closely linked to mitochondria.

Using a combination of protected glycerolphospholipids and antioxidants MLR studies have shown that mitochondrial bioenergetics can be improved in animals and humans. It also has the added benefit of potentially reducing inflammation (http://bit.ly/2vWylrj). Unfortunately, western diets with excessive sugar and saturated fats along with environmental insults can lead to mitochondrial dysfunction and higher susceptibilities to inflammation, apoptosis, NCDs, cancers and premature aging

The use of MLR phospholipids for repairing and replacing membrane glycerolphospholipids requires a long-term approach. Similar to other nutritional supplements, MLR is not a quick fix for cellular damage. In most cases, and especially in chronic conditions, the damages to cellular membranes and other structures are not temporary and continue for an unpredictable period of time.

Thus, dietary and behavior modifications must continue, and in order to maintain health MLR supplementation may be a lifelong requirement, especially in individuals with a typically modern sedentary lifestyle.

Although most contributions in this area have concentrated on mitochondrial function and some obvious links to cellular energy balance, such as fatigue and other issues, recent studies have focused on the effects of MLR supplements on pain, gastrointestinal and other symptoms

Source: http://bit.ly/2u1qMMN

Epigenetic Modifications And Glucocorticoid Sensitivity

Epigenetic modifications and glucocorticoid sensitivity in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)
De Vega, **Herrera**, **Vernon**, **McGowan**

Abstract

Despite a heterogeneous patient population, immune and hypothalamic-pituitary-adrenal (HPA) axis function differences, such as enhanced negative feedback to glucocorticoids, are recurring findings in ME/CFS studies. Epigenetic modifications, such as CpG methylation, are known to regulate long-term phenotypic differences and previous work by our group found DNA methylome differences in ME/CFS, however the relationship between DNA methylome modifications, clinical and functional characteristics associated with ME/CFS has not been examined.

Methods

We examined the DNA methylome in peripheral blood mononuclear cells (PBMCs) of a larger cohort of female ME/CFS patients using the Illumina HumanMethylation450 BeadChip Array. In parallel to the DNA methylome analysis, we investigated in vitro glucocorticoid sensitivity differences by stimulating PBMCs with phytohaemagglutinin and suppressed growth with dexamethasone. We explored DNA methylation differences using bisulfite pyrosequencing and statistical permutation. Linear regression was implemented to discover epigenomic regions associated with self-reported quality of life and network analysis of gene ontology terms to biologically contextualize results.

Results

We detected 12,608 differentially methylated sites between ME/CFS patients and healthy controls predominantly localized to cellular metabolism genes, some of which were also related to self-reported quality of life health scores. Among ME/CFS patients, glucocorticoid sensitivity was associated with differential methylation at 13 loci. Conclusions Our results indicate DNA methylation modifications in cellular metabolism in ME/CFS despite a heterogeneous patient population, implicating these processes in immune and HPA axis dysfunction in ME/CFS. Modifications to epigenetic loci associated with differences in glucocorticoid sensitivity may be important as biomarkers for future clinical testing. Overall, these findings align with recent ME/CFS work that point towards impairment in cellular energy production in this patient population.

Source: http://bit.ly/2vdhr7w accessed Jul 31, 2017

Cytokine Signature Associated With Disease Severity In Chronic Fatigue Syndrome Patients

Authors
Montoya, **Holmes**, **Anderson**, **Maecker**, **Rosenberg-Hasson**, **Valencia**. **Chu**, **Younger**, **Tato** & **M. Davis**
Contributed by **Mark M. Davis**, June 28, 2017 (sent for review November 16, 2016; reviewed by **Gordon Broderick**, **Ben Katz**, and **Anthony L. Komaroff**)

Significance

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) devastates the lives of millions of people and has remained a mystery illness despite decades of research. It has long been suspected that inflammation is central to its pathogenesis. Although only two cytokines were found to be different (TGF-β higher and resistin lower) in ME/CFS patients compared with controls, 17 cytokines correlated with ME/CFS severity. Thirteen of these cytokines are proinflammatory and may contribute to many of the symptoms these patients experience for several years. Only CXCL9 (MIG) inversely correlated with fatigue duration.

Abstract

Although some signs of inflammation have been reported previously in patients with myalgic encephalomyelitis or chronic fatigue syndrome (ME/CFS), the data are limited and contradictory. High-throughput methods now allow us to interrogate the human immune system for multiple markers of inflammation at a scale that was not previously possible. To determine whether a signature of serum cytokines could be associated with ME/CFS and correlated with disease severity and fatigue duration, cytokines of 192 ME/CFS patients and 392 healthy controls were measured using a 51-multiplex array on a Luminex system. Each cytokine's preprocessed data were regressed on ME/CFS severity plus covariates for age, sex, race, and an assay property of newly discovered importance: nonspecific binding.

On average, TGF-β was elevated ($P = 0.0052$) and resistin was lower ($P = 0.0052$) in patients compared with controls. Seventeen cytokines had a statistically significant upward linear trend that correlated with ME/CFS severity: CCL11 (Eotaxin-1), CXCL1 (GROα), CXCL10 (IP-10), IFN-γ, IL-4, IL-5, IL-7, IL-12p70, IL-13, IL-17F, leptin, G-CSF, GM-CSF, LIF, NGF, SCF, and TGF-α.

Of the 17 cytokines that correlated with severity, 13 are proinflammatory, likely contributing to many of the symptoms experienced by patients and establishing a strong immune system component of the disease. Only CXCL9 (MIG) inversely correlated with fatigue duration.

Full text: http://m.pnas.org/content/early/2017/07/25/1710519114.full

News From NCNED/Griffith

NCNED is continuously expanding its collection areas of samples of both ME patients and healthy controls:

July 18, 2017: NCNED is again looking to expand our collection areas to include Melbourne, Sydney and Canberra for studies in August. We are recruiting people who have CFS/ME as well as healthy people with no fatigue issues.

Participation will involve answering a few short questions by email or over the phone, and then if eligible, attend one of our collection centres to donate 10mL of blood.

If you are interested, please contact us on
ncned@griffith.edu.au or
give us a call on (07) 5678 9283.

August 3, 2017: Expanding to the Sunshine Coast
NCNED is again looking to visit the Sunshine Coast area as part of our research studies. We are recruiting people who have CFS/ME as well as healthy people with no fatigue issues (same contact data as above).

August 15, 2017: Expanding to Canberra
NCNED is coming to the Canberra area as part of our research studies. We are recruiting people who have CFS/ME as well as unrelated healthy people with no fatigue issues.
(ibid)

Promising findings from Neuroimaging in NCNED
Chronic fatigue syndrome (CFS) is also known as myalgic encephalomyelitis (ME). The term encephalomyelitis implies involvement of the brain. However, previous studies that focused on brain structural changes in CFS have yielded inconsistent findings.

The neuroimaging team at the NCNED, **Leighton Barnden** and **Zack Shan**, has undertaken a new approach to investigate brain functional changes in CFS. This study which was commenced in 2016, utilised the most advanced functional magnetic resonance imaging (fMRI) techniques on a state-of-the-art MRI scanner. A series of brain functional images, each taken in less than a second, was collected both while the subject was engaging in a cognitive task, and also in a resting state.

Thousands of functional brain images were acquired for each individual in two 15-minute collections. The fMRI scans from 83 individuals, both CFS patients and normal controls, were successfully acquired.

Leighton and **Zack** are focusing on analysis of this data and promising new results have already been found. The initial results were presented at the recent 2017 Organization of Human Brain Mapping (OHBM) annual conference and received much positive feedback. They have already submitted one scientific report that is currently under peer review and two additional manuscripts are under preparation.

More details will be provided when each manuscript has been published.

NCNED would like to thank all participants involved in this study, The Stafford Fox Medical Research Foundation, **Mr Douglas Stutt** and The Blake Beckett Foundation for supporting this research.

Source: wall of NCNED http://bit.ly/2lVUbnD

OMF-End ME/CFS Symposium At Stanford

OMF-End ME/CFS Symposium at Stanford, August 12, 2017

Ron Davis Gets Standing Ovation!

Very rare for a scientific presentation!

August 12 was an amazing day at OMF's Community Symposium on the Molecular Basis of ME/CFS at Stanford University. The room was buzzing with positive energy. The researchers' presentations were incredible and showed great insights into this disease.

There were renowned scientists from all over the world, and from related fields revealing interesting new insights into ME/CFS research. Patients, caregivers, clinicians, and other researchers attending interacted with these scientists during breaks, lunch and an evening reception, and there was so much excitement and optimism in the room.

Here are some of the highlights from this amazing meeting (stay tuned for more!):

- Additional comprehensive evidence that ME/CFS is a molecular disease was presented. (Yet another nail in the PACE coffin!)
- Experts in metabolism, immunology, genomics, neurophysiology, electrical engineering and bioinformatics presented data.
- We learned about innovative ways to find new pain drugs and saw elegant evidence of a clear connection between the immune system and the brain.
- The scientists decided to continue as a "Working Group", and are already planning multiple new ways to work together to facilitate and accelerate progress.
- Nobel laureate Mario Capecchi noted how important patient participation is in studying any disease, and how impressed he was with the amount of ME/CFS patient participation!
- In Ron Davis' concluding remarks he stated that it is clear that what is missing is funding. He described ME/CFS as "a horribly underfunded disease". Progress has been impressive despite the limited resources, but it is clear that more funding is needed to unravel this mystery and find treatments and a cure fast.

We need your help to accelerate the pace!

Every Donation of Every Size Brings Us Closer to A Cure.

To End ME/CFS, the world is counting on brilliant researchers working collaboratively. If you have ever thought to donate to our End ME/CFS project, NOW IS THE TIME!

We need to keep the momentum going and leverage the expanding interest in finding a cure.

Thank you for giving what you can today. (http://bit.ly/2vMYDM8)

Sincerely,

Linda Tannenbaum
CEO/President

PS - Please forward this message to family and friends. Encourage them to join you in your support of OMF's research for treatments and a cure

Watch the symposium again:
https://livestream.com/accounts/1973198/events/7610236/videos/161149931

Dysregulation Of Cytokine Pathways

Dysregulation of cytokine pathways in chronic fatigue syndrome and multiple sclerosis

Matthew Sorenson, **Jacob Furst**, **Herbert Mathews** & **Leonard A. Jason**
Published online: 07 Jun 2017

Abstract
Background: Cytokine studies in chronic fatigue syndrome (CFS) have yielded mixed findings.

Purpose: This investigation evaluated whether network analysis of cytokine production differs between patients with CFS and multiple sclerosis (MS) as compared to a reference group of healthy controls.

Methods: Three subgroups (N = 109) were included: 15 participants who met diagnostic criteria for CFS, 57 participants meeting criteria for MS, and 37 controls. Peripheral blood was obtained and production of a select cytokine profile was determined from stimulated and unstimulated mononuclear cells. Data were generated through the use of a multi-analyte bead suspension array. Pairwise associations were determined for each group, and these associations were used to create a graphical representation of the data. The graph was clustered using an eigenvector community algorithm and results visualized using edges to model the correlations by color and thickness to show direction and strength.

Results: The control and MS groups produced a three-neighborhood relationship regardless of cell condition. While producing a three-neighborhood relationship, the MS group differed significantly from the control group as it displayed stronger relationships among pro-inflammatory cytokines. In contrast, the CFS group displayed a three-neighborhood solution when unstimulated. However, when cells from the CFS group were stimulated, a two-neighborhood model was found that exhibited stronger inter-cytokine correlations. The model found in CFS was significantly different from that found in the control and MS groups.

Conclusion: CFS was characterized by a pattern of global immunologic activation using network analysis, fundamentally different from those found for either MS or control groups.

Source: http://bit.ly/2w4VSH0
Submitted by **Prof. Leonard Jason**

Chronic Fatigue Syndrome Prevalence Is Grossly Overestimated

Chronic fatigue syndrome prevalence is grossly overestimated using Oxford criteria compared to Centers for Disease Control (Fukuda) criteria in a U.S. population study - **James N. Baraniuk**
Published online: 21 Jul 2017

Abstract:
Background: Results from treatment studies using the low-threshold Oxford criteria for recruitment may have been overgeneralized to patients diagnosed by more stringent chronic fatigue syndrome (CFS) criteria.

Purpose: To compare the selectivity of Oxford and Fukuda criteria in a U.S. population.

Methods:
Fukuda (Center for Disease Control (CDC)) criteria, as operationalized with the CFS Severity Questionnaire (CFSQ), were included in the nationwide rc2004 HealthStyles survey mailed to 6175 participants who were representative of the U.S. 2003 Census population. The 9 questionnaire items (CFS symptoms) were crafted into proxies for Oxford criteria (mild fatigue, minimal exclusions) and Fukuda criteria (fatigue plus ≥4 of 8 ancillary criteria at moderate or severe levels with exclusions). The comparative prevalence estimates of CFS were then determined. Severity scores for fatigue were plotted against the sum of severities for the eight ancillary criteria. The four quadrants of scatter diagrams assessed putative healthy controls, CFS, chronic idiopathic fatigue (CIF), and CFS-like with insufficient fatigue subjects.

Results:
The Oxford criteria designated CFS in 25.5% of 2004 males and 19.9% of 1954 females. Based on quadrant analysis, 85% of Oxford-defined cases were inappropriately classified as CFS. Fukuda criteria identified CFS in 2.3% of males and 1.8% of females.

Discussion:
CFS prevalence using Fukuda criteria and quadrant analysis was near the upper limits of previous epidemiology studies. The CFSQ may have utility for on-line and outpatient screening. The Oxford criteria were untenable because they inappropriately selected healthy subjects with mild fatigue and CIF and mislabeled them as CFS.

Source: http://bit.ly/2x7ecwh

Scientific Progress Stumbles Without A Valid Case Definition

Current estimates from the Centers for Disease Control and Prevention (CDC) of the number of people in the United States with chronic fatigue syndrome (CFS) increased from about 20,000 (http://bit.ly/2wgSZTx) to as many as four million (http://nyti.ms/2vRUnei) within a ten-year period (http://bit.ly/2wpFdi6). If this were true, we would be amidst an epidemic of unprecedented proportions. I believe that these increases in prevalence rates can be explained by unreliable case definitions. For example, in 1994 (http://bit.ly/2wgmrJs), the CDC's case definition did not require patients to have core symptoms of the CFS. Making matters worse, in 2005 (http://bit.ly/2v6fE1n), in an effort to operationalize their inadequate case definition, the CDC broadened the case definition so that ten times as many patients would be identified. Even though these estimates were challenged (http://bit.ly/2x5GdVM) as bringing into the CFS case definition many who did not have this illness such as Major Depressive Disorder, as late as 2016, the CDC re-affirmed the merit (http://bit.ly/2wgAn69) in this broader (http://bit.ly/2fXQSh1) case definition.

Another misguided effort occurred in 2015, when the Institute of Medicine (IOM) developed a revised clinical case definition (http://bit.ly/2dorrj5) that at least did specify core symptoms, but unfortunately also eliminated almost all exclusionary conditions, so those who had had previously been diagnosed with other illnesses such as Melancholic Depressive Disorders, could now be classified as meeting the new IOM criteria. This case definition has the unfortunate consequence of again broadening the types of patients that will now be identified, thus their effort also will inappropriately select (http://bit.ly/1IKxeXw) many patients with other diseases as meeting the new IOM criteria. Making matters even worse, the clinical case definition was not designed to be used for research purposes, but it is clearly being used in this way, and one group of researchers (http://bit.ly/2uY8AYs) has already inaccurately reported (http://bit.ly/2xjykv7) that the new clinical case definition is as effective at selecting patients as research case definitions.

Increases in prevalence rates [of CFS] can be explained by unreliable case definitions.

This comedy of errors becomes even more tragic with the recent development of a new pediatric case definition (http://bit.ly/2topevV). As with past efforts, data were not collected to field test this new set of criteria. Even worse, medical personnel are asked to make decisions regarding symptoms without being providing any validated questionnaires, and this has the effect of introducing unacceptable levels of diagnostic unreliability. Scoring rules are so poorly developed that guidelines indicate that a child needs to have most symptoms at a moderate or severe level, but in reality, according to the flawed scoring rules of this case definition, youth can be classified as having the illness even if they report all symptoms as mild. These criteria further suggest that "personality disorders" should be assessed in children, as these disorders are listed as psychiatric exclusionary conditions; however, personality disorders cannot be diagnosed (or

reliably assessed) prior to the age of 18, as personality characteristics are not fully developed until adulthood. Finally, these authors also require the youth to have at least six months of illness duration, whereas the Canadian criteria (http://bit.ly/2vhcp6p) and others (http://bit.ly/2vWXbW3) suggest that children with three months duration can be diagnosed with the illness. Other significant limitation (http://bit.ly/2fY1ooD) of this primer have been mentioned by others. In summary, these authors failed to incorporate standard psychometric procedures that include first specifying symptoms and logical scoring rules, developing consistent ways to reliably assess these symptoms, and then collecting data to ensure that the proposed criteria are reliable and valid.

When a field of inquiry is either unable or unwilling to develop a valid case definition, as has occurred with CFS, the repercussions are catastrophic for the research and patient community. In a sense like a house of cards, if the bottom level is not established with a sturdy foundation, all upper levels of cards are vulnerable to collapse. Science is based on having sound case definitions that allow investigators to determine who has and does not have an illness. Having porous and invalid case definitions, whether clinical or research, affects not only prevalence estimates of CFS, but also has dire consequences for treatment approaches, as when individuals who have solely affective disorders are misclassified as having CFS, and when they improve from psychological interventions, it is easy to erroneously conclude that CFS is a psychiatric illness, which further stigmatizes patients.

Submitted by **Prof. Leonard Jason**

Source: Oxford University Press blog http://bit.ly/2vGVg9t

9. Severe ME

Ten Golden Rules

- You shall not call ME "CFS".
- You shall not presume that ME is a fatigue illness.
- You shall not ignore people with ME and pretend that their illness does not exist.
- You shall not back the psychosocial misinterpretation of ME.
- You shall honour people with ME and their carers and advocates.
- You shall not bear false witness against people with ME using psychosocial jargon to misinterpret the truth of their illness.
- You shall not be careless around people with ME, for your carelessness will cause harm and deterioration.
- You shall not be complacent or compromise away the truth of ME by any means.
- You shall pro-actively make a stand and contest all untruth.
- 10.You shall never accept inferior, dismissive or inadequate treatment.

Source: Stonebird http://bit.ly/2wqJNcK

Case Study - Hay Green

Severe ME day 2017 - Case study; **Hay Green**
Hay Green, author of "101 tips for coping with ME" and also runs the Facebook page named after it, kindly allowed me to interview her for Severe ME day. She has recently deteriorated to being severely affected, having been mildly and then moderately affected since 2007.

Back then she was like any other woman in their early 20s with a zest for life, plenty of friends and a career she loved. She would go to the gym after work, them home to cook. She was looking forward to everything a 20 year old expects in life – developing her career, marriage, children. However in 2011 at the age of 23, after a bout of tonsillitis, she was diagnosed with ME. She'd been suffering from it, mildly and unknowingly, since 2007. Life was never the same again

She is now 18-20 hours a day bedbound. She manages to leave her house only about once a month. Usually for medical appointments which she says are a lifeline. She is fortunate in having a very sympathetic and understanding GP which is the most helpful thing for her. Unfortunately there is little apart from symptomatic relief her GP can offer her though as we don't currently know the cause or have cures for ME. On other occasions, if she hasn't a medical appointment, she might leave the house to do something fun like a short visit to a garden centre or to feed the ducks

Her symptoms are;
- Severe Muscle, joint and bone pain
- Vertigo / nausea
- Orthostatic intolerance
- Tremor of limbs and hands
- Post-exertional malaise
- Severe Fatigue
- Reverse Sleep disorder
- Muscle weakness and fatigue
- Parasthesia (Parasthesia is numbness and tingling in the hands and feet)

She is on morphine for pain and uses a commode as she suffers from bladder issues

Despite all this Hay remains upbeat. To occupy herself whilst in bed she reads, writes, meditates, manages her facebook page "101 tips for coping with M.E" which has over 1.5k followers and keeps five cats; 3 adults and two kittens. Like many women with ME she has been forced to accept she will never have children so her cats are her closest thing to them.

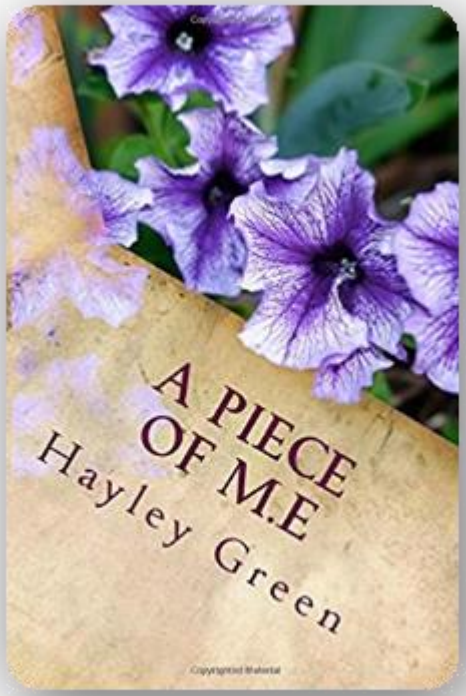
She says they're much more independent than children. Her female cat **Mia** is particularly intuitive and will come to lie at **Hay**'s feet for hours when she is crashing. When **Hay**'s been very bad she has even according to Hay "sat on my pillow and put her paw on my head as if to say 'there there, its going to be okay!"

In 2013 she began writing her debut book "101 tips for coping with ME". She says she's always loved writing and was inspired to write her first book when she realized there was a gap in the market for a simple, easy to understand, non medical jargon orientated book about how to live with ME.

He has since written several others to continue to raise awareness, all with differing percentages of the proceeds from each book going towards Invest in ME Research, as well as setting up and running the Facebook page named after her first book. She now has an amazon author page, **Hayley Green**. She's also a member of the Let's do it for ME planning group. She confesses she can only do very little at a time though and has to pace very carefully indeed. Even visiting Facebook can exhaust her.

When I asked what her dreams/aspirations for the future were she replied;
"I dream of being able to move freely again without pain, to work full time hours, to be able to leave the house at the drop of a hat. To be able to dress, cook, eat and bath all in one day. I would love to set up a charity to provide tailored support to M.E sufferers. To pick up where I left off at 23 when I became so ill."

Hayley Green's new book "A piece of ME" is out now in paperback. It is an anthology of poetry written by ME sufferers. Priced at £3.75 with all proceeds going towards Invest in ME Research. Buy now!



Source: Let's do it for ME http://bit.ly/2umagGS
Interview by **M.Amor**

The Sickest Among Us

A project with the hope to be of some avail to the sickest among us

This is an ongoing project to find items that are specific to help Severe ME patients. While many of the tips in the other files are good for everyone, Severe ME patients have unique challenges. Please help me find more things that can improve the quality of life of those who live in the most difficult of circumstances imaginable.

Severe ME Distractions

- "Focusing on beauty is something, sometimes, perhaps, being very still and pure and comforting, profoundly uplifting, if possible , either externally or internally though the extreme blankness of mind, the dulling of vision, the extreme pain, the tirade of symptoms, etc may block even this and no thought or distraction may be possible. xxxxx" ~**Greg Crowhurst**

I recommend for anyone dealing with Severe ME or someone who is a carer of someone with Severe ME to look for these books by **Greg Crowhurst**:
Severe ME: Notes for Carers Severe ME

Facebook page: https://www.facebook.com/severeme
Website: http://www.stonebird.co.uk/

Audio / Videos That Are Easy To Listen To.
These are not easy to find as many include music background or a jarring bell at the end.

You are not alone - "Art in Suffering" by **Greg Crowhurst**
A silent video about the suffering of Severe ME http://bit.ly/2wdLXyU

Audio guided meditation that goes through the body. Modifying to only imagine tensing the muscles might work for severe patients. http://bit.ly/1COlg05

Other Suggestions For Distraction:

- Smooth stones or other small objects that are easy to hold that can be focused on while resting in the dark.

- While avoiding chemical scents, perfumes, deodorants, laundry soap, etc. smells is recommended there are some essential oils that can be a pleasant distraction. Diluted in a spritz bottle makes it easy to freshen the air. Lavender is a good one to try.

- Wall hangings with soft colors and gentle scenes are a nice way to give variety to surroundings. Cloth hangings may soften the sounds in the room.

- Try to get in contact with nature in some way. Open window if able to tolerate noise. A grounding mat is an option to check out. Can put it into the bed and it provides a way to ground similar to standing in bare feet outside.

- Daydreaming and fantasizing.

- Focusing on things of beauty. Beauty is in the eye of the beholder, so putting things within eyesight that bring pleasure can bring pleasure in the midst of suffering.

Submitted by **Colleen Steckel**
http://bit.ly/2wIRvOw

If anyone has suggestions or links to audio files they think might work, please email myalgicenc@gmail.com

Perversely Dark

It is perverse that many formerly able bodied persons have to lie in complete darkness and isolation.

And, indefinitely so.

In each of their respective rooms, in two different places around the greater Oslo, Norway area lie ME/CF'S patients Kristine and Bjørnar sequestered in protective total darkness. In both cases, the tiniest amount of mental, social, or physical effort is detrimental and can completely overwhelm their bodies' minimal energy reserves and function.

Consequently, only health care assistants and immediate family are permitted whispered access into their isolation in order to feed, medicate, and tend them.

Film maker **Paal Winsents** and Fenomen Film remarkably were consented entrance into these patients' dark realms and permitted to 'siphon' some of **Kristine** and **Bjørnar**'s stories and their precious infinitesimal life energy for the making of this important and unusual film.

While medical experts in Norway and internationally debate and test their many theories in attempt to understand and discover a cure for ME/CF'S to get its patient group up and out into light and life again, many such lives wither way as the many years roll by.

During the six years of filming **Kristine** and **Bjørnar**, the Fenomen Film crew was astounded by these patients' non-despairing fortitude, courage, and level of intellectual reflection despite the lack of proper stimuli or external battery life recharging them when confined to be in the dark with a great unknown.

Without giving away too much, Perversely Dark is also a film about love, perseverance soccer, presents, and Christmas songs, as well as a human transformation one would not believe it if not seen with one's own eyes.

"Perversely Dark" is a 58 minutes documentary by **Pål Winsents**, produced by Fenomen Film, tom@fenomen.no and can be watched freely on the internet here: http://bit.ly/2w6dP7E
The film is 58 minutes long and deeply moving…

Film trailer: https://vimeo.com/95673314

Tom Camenzind's Story

Tom Camenzind's Story.
ME/CFS Alert Episode 93 - https://youtu.be/7Ck9oWJilP0

Tom Camenzind is a handsome young man who should be in the joyous throes of youth. A popular and gifted student at Stanford University, **Tom** was clearing the hurdles of academia with ease and grace. In January of his sophomore year, he caught a cold on campus. ME walked through some door, and stole his promising life.

Today **Tom** lies conscious but prone in his parents' home in San Ramon, Calif. He is totally paralyzed and can only communicate with his parents, **Mark** and **Dorothy**, by pressure from his fingers on sensors. He cannot tolerate everyday sounds, light or touch.

When the sensor-activated bell sounds, **Tom**'s parents come rushing to his side. **Mark** is an engineer and **Dorothy** is a physician, and the strain of their son's affliction on them is palpable. **Tom** cannot do anything, anything whatsoever, for himself. At 23 years old, he is on the threshold of life, but he cannot cross it. He breathes and thinks, but he cannot live his life.

Recently, I filmed the **Camenzinds** for a special edition of "White House Chronicle," a weekly program that I produce and host for PBS and other broadcast outlets. It was made in conjunction with the Solve ME/CFS Initiative, a Los Angeles-based charity.

Tom's agony, and that of 1 million in America and 17 million around the world, predominantly women, cries out in terrible, silent eloquence for a national research effort with international cooperation on ME/CFS – so that those who suffer, like **Tom**, can dare to hope.

Tom's paralysis is extreme, but others suffer daily with extreme fatigue, headaches, muscle pain, dysphasia and light and sound intolerance. Normal work is impossible, as is maintaining ordinary family life. Precious few ME/CFS patients make a full recovery. My files contain letters from sufferers who beg for death. Suicide is common.

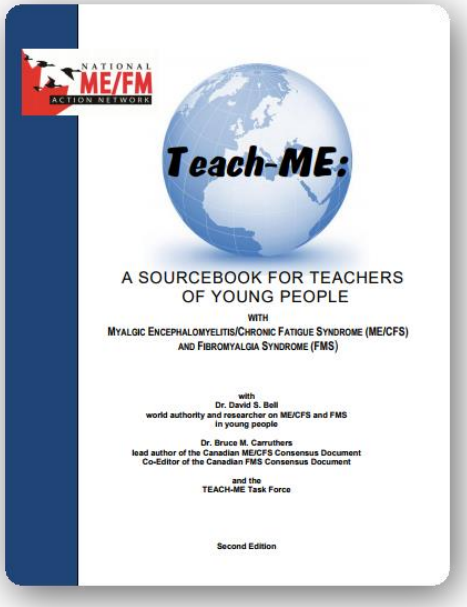
Sadly, ME has no celebrity champions. AIDS had **Elizabeth Taylor**, Muscular Dystrophy has **Jerry Lewis** and Parkinson's Disease has **Michael J. Fox**.

For **Tom** to come back to his life one day, money and research are needed now. Oh, so needed.

Llewellyn King is executive producer and host of "White House Chronicle" on PBS. Taken from http://bit.ly/2wgDhrQ

ME And Children

Teach ME



A Sourcebook For Teachers Of Young People With ME/CFS Aand FM
2nd edition 2005, reprinted in 2012

This is a Guide for teachers published by the ME/FM action Network so that they will be alert and understand that perhaps the child they think is lazy and absent a lot may have ME or FM. (http://bit.ly/2tjY7ov)

With **Dr. David S. Bell** and **Dr. Bruce M.** Carruthers, lead author of the Canadian ME/CFS Consensus Document and Co-|Editor of FMS Consensus Document – Second Edition.

From the introduction of the first edition: Canadian teachers are becoming more aware of children and adolescents with ME/CFS and/or FMS. It has not always been this way, partly because ME/CFS and/or FMS have had a controversial history. Although the number of adults being diagnosed with these illnesses seemed to grow rapidly in the mid-eighties, official recognition of the illness in adults has been slow.

Tragically, recognition of the prevalence and devastation of ME/CFS and/or FMS in children has been even slower, leading to many heartbreaking situations. Fortunately, all that is changing. Research on ME/CFS and/or FMS has been increasing rapidly, including research on children and adolescents. We can expect that in the next few years we will understand these illnesses much better - in people of all ages. While we arewaiting for that new knowledge, there is much that the classroom teacher can do for the young person diagnosed with ME/CFS and/or FMS.

The authors are Canadian teachers, disabled with ME/CFS and/or FMS, who are members of the National ME/FM Action Network.

Mary Ellen, Chairperson, TEACH-ME Task Force, National ME/FM Action Network, 2002

Source: http://bit.ly/2hLi9ns

Submitted by **Lydia Neilson**

I Went For Walks In The Evening

I went for walks in the evening and cried

When **Stine**'s daughter was at the sickest, she could not walk to the toilet alone. The mother juggled her job with sole responsibility for her ill daughter, and became increasingly tired.

Stine Aasheim

Interview of Norwegian ME-patient **Stine Aasheim** by **Cecilie Skjerdal**, journalist.

– For a long period she did not tolerate daylight. We had the blinds shut for about two years.

Eight years old, **Stine Aasheim**'s daughter became ill. Often she was too ill to go to school or play with friends. It hurt to be touched. She was so dizzy that she needed assistance when she walked.

Sometimes she lacked the strength to say more than two words in a row. Movements within her sight, sounds or odours could cause intense headaches and make the symptoms worse.

On better days, **Stine** drove her to school, but often had to pick her up before the day was over. She slept at her mother's office. After three such years they were worn out, and both broke into tears at the doctor's office.

– The doctor responded by saying that they would have to use anti depressive medicine for the rest of their lives. But we were not depressed. The girl was sick and we did not understand what it was, says **Stine**.

After changing GP, a medical investigation was initiated. Pediatrician and neurologist diagnosed the girl with Myalgic Encephalopathy (ME). The energetic **Stine**, once a salsa teacher, amateur theater player and arranger of opera balls, who used to be a prime engine for projects both at work and private, had to put everything on hold. Now she had to focus on the most important: her daughter and her job.

Constantly **Stine** had a bad conscience. Absence from work had consequences for colleagues. And when she was at the office, she thought about the girl who was home alone. – «Twice she lay on the floor when I got home, unable to get up by herself."

Stine did not know what help could be had and wasn't able to figure it out. All the energy was spent in making everyday life go on. After long days of concern, she went for walks and cried. She read everything she came across about ME. The research was spread – doctors disagreed with each other, and there was no treatment.

She joined a network of ME-moms, which could provide support and help. Everyone was tired. Frustrated over doctors being sceptical of the diagnosis. Economically exposed. Many had high education, but their career was put on hold. Life was on hold. For such is life with a child with ME.

Daily life is influenced by the overall grief of what could have been, and the struggle against a system that mistrusts them. It's an eternal «fingers-crossed» project: anniversaries are planned, but when the day comes, the child lies in the dark in its room. Holidays are booked in a hopeful moment, but must be cancelled.

– "Occasionally we can go visit someone. If her condition gets bad, it's easier to go home than suddenly chasing out guests you've invited.

She started blogging about everyday life with a child with ME. Together with other ME mothers, **Stine** created a blog. She needed to express herself and wanted to give hope and support to children with ME and their parents.

"My wishes for you are skinned knees and getting sunburnt. Exam stress and a broken heart. Not because I wish you harm, but because I with all my heart wish for you to live through every part of the life kids should live. My beloved child. I love you higher than heaven and from here to eternity. I hate ME", Stine wrote in a blog.

Today her daughter is 18 years old. During the last year they have seen some improvement. But ten years of having a sick child have left their traces in **Stine**: now she is on sick leave. Fortunately, during these years, she has learned to live in the moment and find pleasure in the little things: walks with the dog, beautiful scenery, a few minutes at a coffee shop. She tries to meet friends a couple of times a month.

"I create small quality-moments. It's nice to talk to someone from what I call 'the healthy world', she laughs. **Stine** says humor is what keeps her going. Gallows humour. "That's how I really am, I've always used humor. Something bad and sad I give a humorous twist, then I move the focus a bit. It is so lovely to smile!"

She nurtures faith in better times and keeps an eye on the research. Recently, the government gave NOK 30 million for research on ME. "There is reason for hope!"

Translated by The ME Parents

Norwegian original in KK

Submitted by **Stine Aasheim**

Accused Of Fabrication

Carers of children with ME 'accused of fabrication'

A "significant number" of those caring for children with ME have been accused of fabricating their child's illness, a survey has found.The charity Action for ME said a safeguarding referral to a child protection team had been made against one in five respondents. Its chief executive said children and their carers faced the "double whammy" of an ME diagnosis and not being believed about their condition. NHS England has been asked to comment.

Myalgic Encephalomyelitis (ME), also known as Chronic Fatigue Syndrome, is a debilitating disease that has a major impact on the lives of those affected. It causes persistent fatigue that does not go away with rest or sleep. It affects about 25,000 children in the UK.

Out of 270 respondents to the survey, one in five said they had had a safeguarding referral to a child protection team made against them. Half of the referrals involved allegations that parents had fabricated or induced their child's illness, although 70% of all the cases referred to social services were dropped within a year.

'Lives stolen'
Sonya Chowdhury, CEO of Action for ME, which is based in Keynsham, near Bristol, said: "*Ninety-six per cent of the parents felt that their children's care had been affected by a lack of understanding of ME and nearly 100% of parents were concerned their child had not been believed. If people are not believing a child about an illness even when there is a diagnosis, those children are facing a double whammy. Not only have they had their lives stolen as a result of illness, they've had their lives affected and traumatised as a result of the system.*"

She said the charity would be carrying out further investigations into the claims.

England's chief social worker **Isabelle Trowler** said: "It's important that all the professionals who work with young people have a firm understanding of conditions like ME and the impact these can have on their daily lives, so they can access the same opportunities as their peers.

"I have met and continue to meet with groups and organisations including Forward-ME, and will work collaboratively with them and a national network of social workers to further professional understanding of children with ME."

Source: **BBC News**
http://www.bbc.com/news/uk-england-40407174

10. News from

Australia

Brisbane

Indooroopilly Uniting Church invite you to attend a screening of Unrest, an award-winning documentary on ME/CFS (Myalgic Encephalomyelitis /Chronic Fatigue Syndrome) by **Jennifer Brea**.

The screening will take place on 26th August and starts at 10.15am.
9.30 am refreshments on arrival for a 10.15am screening, 12 noon Q&A

Q&A featuring researcher **Sonya Marshall-Gradisnik** from the NCNED (National Centre for Neuroimmunology and Emerging Diseases) at Griffith University on the Gold Coast.

Free to book, entry via donation at the door – all money raised will go toward ME/CFS research. Limited seating is available.

The church is located near buses and trains. It has parking at the back via Musgrave Rd. It is wheelchair accessible via a lift from the car park (or by being dropped off at the front of the church on Station Rd.) The seats are padded.

Booking details: http://bit.ly/2vSgTCg

Gold Coast

Josh and **Ketra**, two young Gold Coast residents struck down in the prime of their lives by ME/CFS (Myalgic Encephalomyelitis/Chronic Fatigue Syndrome), would like to invite you to a compelling and informative night with talks and a movie about ME/CFS.

When: Thursday 12 October 2017, at 6:30pm - 9.30pm

Where: The Southport Church of Christ, 1 Griffith Way (Cnr of Olsen Ave), Southport, QLD 4215

Q&A with Gold Coast professionals: ME/CFS-experienced health practitioners have been invited to do a 'questions and answers' around the topic "what we can do for patients now".

Tickets: Seats are limited, bookings essential. We recommend a $10 donation to research per ticket. If you would like to donate but can't attend, click the 'book now' button and choose 'donation only'.

Who should come: Everyone interested in ME/CFS. Medical professionals, teachers, politicians, therapists, disability advocates, students, patients, chronic illness sufferers, and the general public are all encouraged to attend.

Booking details: https://www.trybooking.com/book/event?eid=304268

Sydney

The ME/CFS & FM NSW Support Group are organising community screenings of **Jennifer Brea**'s film Unrest in the Sydney area. If you are interested in attending a screening they need a prompt response to the 6 questions below to help them determine the number and location of the screenings:

(1) Health permitting, are you likely to attend a screening?
(2) Would you attend alone or with a family member, friend or carer?
(3) What suburb do you live in?
(4) We are proposing a mid-morning or early afternoon screening; do you have a preference?
(5) Would you prefer a mid-week or weekend screening or would either suit you?
(6) Would you be able/willing to contribute to the cost of the screening? $5 or $10?

Screening(s) are being planned for mid-September to mid-October, depending on availability of venues. Prices have not been finalised, and will be influenced by the venue costs, but they will be kept to a minimum. Venues will be as accessible as possible. Please be aware that it will be impossible to meet everyone's preferences. At this stage, they are only asking for expressions of interest from those likely to attend. As soon as the venues and dates are finalised tickets will be made available. If you are interested please email your answers to: unrest@mecfsnsw.org.au

Source: newsletter Emerge Australia

Belgium

We're very happy with the latest scientific developments at the University of Stanford. Hopefully, a test can shortly be developed that is able to detect ME at an earlier stage. At the current level, a lot of time is lost ruling out other diagnoses. Not to mention this will open the doors to getting the illness acknowledged.

Nowadays in Belgium, it has become common practice to waive the insurance of CFS patients after a certain period of time, as decided by a computer program. It is therefore very difficult to prove the opposite without airtight laboratory tests. That's also something which we are happy for.

But most importantly, there's finally a focus on a remedy on the horizon, or at least we hope. Because like the Open Medicine Foundation puts it into words "Bound Together in Hope", we hope the three emphasized points will give us the cure we're duly entitled to.

Not a witch hunt like now, but a right to a correct treatment in all aspects.

Eddy H. Keuninckx

Canada

National ME/FM Action Network Bids Farewell To
Dr. Bruce Carruthers, R.I.P.

July 25, 2017
Our **BC Director, Sherri Todd**, has informed us of the passing of **Dr. Bruce Carruthers**. **Dr. Carruthers** is one of the two doctors who did the original drafts of the Canadian Clinical Definitions from which the medical panels worked to make the final definitions which became know as "The Canadian Definitions".

Our **Director, Sherri**, summed up the words and feelings of all of us that were privileged to work with this wonderful man. We are grateful to **Dr. Carruthers** and are saddened by his passing.

"Friends,
I am saddened to share with you, news of the recent passing of Vancouver ME/FM Physician, **Dr. Bruce Carruthers**. **Dr. Carruthers** was a very kind, compassionate and dedicated Physician, who was much loved by all who knew him, most especially his ME/ FM/MCS patients.

Three times he tried to retire, and three times he returned to practice due to the needs his ME and FM Patients presented, when they could not find other knowledgeable and supportive Physicians to treat them. For those most seriously ill, he would make a home visit.

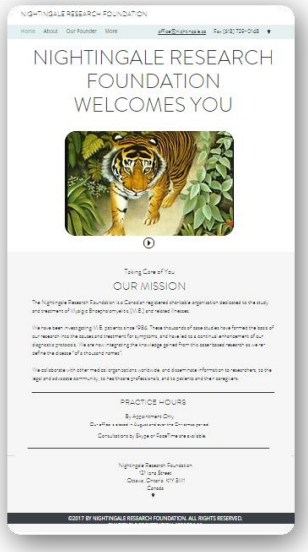
On both a personal and professional note, I had the pleasure of knowing **Bruce** for well over 30 years, and called him my friend. He became a Medical Advisor to the National ME/FM Network, and lectured around the world. He was one of the most exceptional, interesting and intuitive human beings I've ever met.

I'm sure this played a great part in the legend he became to his friends, patients, colleagues and throughout his many years of research into Substance P, his public forums educating Patients and Physicians, in radio and news interviews, and in his many published articles, journal material and in the ME and FM Consensus Documents, which are still used today. Many times I've had patients tell me that when they told him their history and symptoms, he knew and understood them. Patients felt his compassion, and respect for them.

Dr. Carruthers was a-one-of-a-kind, incredible Physician. Those of us fortunate to know him, be his patient or colleague, or who benefit from his published articles, know he will never be forgotten! RIP **Bruce**!"

Sherri Todd, Director for B.C.
NATIONAL ME/FM ACTION NETWORK
Submitted by **Lydia Neilson**

Nightingale website completely re-designed



Good news from the Nightingale Research Foundation! After months of work by **Dr. Hyde** and his volunteers, the Nightingale website has been completely re-designed, made more clear & easy to navigate, and updated.

There you will find information about the Foundation, about **Dr. Hyde**, his qualifications & history, how he works & what he works on, and about the history and definition of M.E. itself.

There are free downloadable PDF definitions of M.E. (which of course include some history), available in English, French, Norwegian, and Danish. You can also order a hard copy of this publication in any of these 4 languages (details on the site).

The site also has a Resources section which covers many things, including

- Historic legal decisions that are of importance to M.E. patients (the public is invited to add to these),
- Links to some of **Dr. Hyde**'s books & articles, and
- Two very important photos : a brain SPECT scan photo showing the damage of M.E. in the brain, and a microscope slide photo showing an active enteroviral infection at the cellular level in a gastric mucosa biopsy.

Also, the Resources section will soon have a list of world-wide M.E. Associations, Societies, Charities, ongoing Research Projects, Facebook Groups, etc.

This list is almost completed (of course it cannot be expected to include every single group, but we are doing our best to include as many as possible !). The list should help patients find both information and support, although the website itself is FULL of valuable and up-to-date M.E. information.

We hope you will take a look – there is lots of help and support to be had, and much to learn. The link is still http://www.nightingale.ca

Submitted by **Allison May**

Denmark

Membership's day ME Foreningen
Valby Kulturhus 7th of October 2017 at. 11-13

Theme: ME, POTS and the autonomic nervous system. Symptoms, investigation and possible treatment

As a former doctor at the Sync Center at Freeriksberg Hospital in Copenhagen, **Dr. Louise Brinth** saw many patients daily with POTS.

Also many ME patients have what is called orthostatic intolerance - ie dizziness symptoms that deteriorate in standing and walking positions - as part of their everyday lives.

In the 2015 report of the Institute of Medicine in the USA about ME, orthostatic intolerance - including the particular POTS (postural orthostatic tachycardia syndrome) diagnosis - is also included in the diagnostic criteria for ME.

Louise Brinth will talk about what POTS is and the possible relationship with ME based on her interest in the autonomic/unconscious nervous system. She also wants to learn how knowledge about POTS can help to investigate and possibly also treat the ME patients who are affected.

Date: 07.10.2017

Location: Valby Kulturhus, Valgårdsvej 4-8, 2500 Valby

Time: 11:00-13:00

Registration And Submission:
Karin Sekretariatet@me-foreningen.dk 44959700

WE LOOK FORWARD TO SEE YOU

Germany

Petitition to recognize ME in Germany http://bit.ly/2bz537S

ME or "CFS" patients ask for:

- Recognition Of The WHO Code G93.3
- Funding Of Biomedical Research On ME ("CFS")
- No More Discrimination By Our Health System

Myalgic Encephalomyelitis? - Never heard of!

Myalgic Encephalomyelitis (ME) is the most common and the most devastating disease your doctor has never heard about. Many doctors believe that this disease exists only in the minds of the patients. However, already in 1969, the WHO classified ME as an organic disease under the diagnostic code G93.3.

In Germany, ME is being played down and incorrectly labelled as "Chronic Fatigue Syndrome". These names are the result of an unprecedented campaign of trivializing and psycho-pathologizing ME, which began shortly after the WHO classified ME as an organic disease. (If you want to learn more about the disease and who might be affected by it, please scroll down.)

In particular, we call for:

- An official acknowledgement of BMG (Federal Department for Health), the G-BA (determines the benefits catalogue of the Statutory Health Insurance), the Bundesärztekammer (German Medical Association), the GKV (Statutory Health Insurance), the MDS (medical advisory service of the German association of statutory health insurance funds), the AWMF (committee of the scientific medical expert associations) and the DRV (German federal pension fund) to classify ME (and "CFS") under the key G93.3 as determined by the WHO.
- An official acknowledgement of all the institutions listed above to bring into line their future actions with regard to the disease ME or "CFS" with Article 2 (2) and Article 3 (2 u. 3) of the Basic Law of the Federal Republic of Germany [Article 2 (2) "Every person shall have the right to life and physical integrity. ... ". Article 3 (2) "Men and women shall have equal rights. The state shall promote the actual implementation of equal rights for women and men and take steps to eliminate disadvantages that now exist." Article 3 (3) "No person shall be disfavoured because of disability."].
- The deletion of all references to "CFS" and ME in the AWMF guideline on p 3 without substitution (http://bit.ly/2wciYM5).
- A new version of a guideline of the AWMF for Myalgic encephalomyelitis based on the International Consensus Criteria of 2011 and the International Consensus primer of 2012.
- The deletion of the chapter "Chronic Fatigue Syndrome (CFS)" and all references to "CFS" and ME in other chapters including the deletion of patient letters from DEGAM guideline no. 2 "tiredness" without substitution.

- A new version of a medical guideline on Myalgic Encephalomyelitis based on the International Consensus Criteria of 2011, and the International Consensus primers 2012.
- The development of patient letters based on the International Consensus Criteria of 2011 and the International Consensus primers 2012.
- Forwarding of information (new guidelines and patient information, see above) to all doctor's offices for general medicine, internal medicine, neurology, infectious diseases, immunology, allergology, rheumatology, cardiology, haematology, endocrinology, environmental medicine, sports medicine, physiotherapy, osteopathy, psychiatric and otolaryngology.
- Information and education campaigns on the disease for doctors, hospitals, emergency rooms, rehabilitation clinics, public health offices, school boards, social services departments, health insurances, pension insurances, disability insurances, medical consultants, job centers and the social association VdK.
- Medical Training on Myalgic Encephalomyelitis based on international biomedical research.
- The establishment of the subject in the curricula of medical schools.
- The deletion of all references to "CFS" and ME and G.93.3 from the DRV "Guidelines for the sociomedical assessment of people with mental disorders" without substitution.
- A nationwide awareness campaign on ME based on the International Consensus Criteria of 2011 and the International Consensus primers 2012 (print and digital media).
- The withdrawal of the deficiently researched RKI report "Erkenntnisstand zum Chronic Fatigue Syndrome (CFS)"
- The establishment of a research budget for biomedical research into ME. The size of the budget should be equivalent to diseases of comparable prevalence and comparable level of disability (eg MS).

We ask for your signature!
http://bit.ly/2bz537S

Northern Ireland

Some welcome media coverage!

We are delighted to have been invited by NVTV, a local television station, to take part in a interview highlighting the lack of specialist NHS services for ME patients in Northern Ireland.

The invited panel included speakers from three separate organisations. Sally Burch, Secretary for Hope 4 ME & Fibro Northern Ireland, was our spokesperson for the event.

Maeve Hully, CEO for the Patient and Client Council NI explained the vital role of the P&CC in supporting our campaign. (We enlisted the help of the P&CC in 2013, and by informing them of the plight of both ME and fibromyalgia patients. The P&CC continue to ensure the patient voice is being heard and have played a leading role in negotiations towards new services for both illnesses.)

Clare Ogden, Head of Communications and Policy for Action for M.E. explained their organisation's findings on the lack of adequate ME services in a recently published UK wide survey, which included Northern Ireland.

In the time allocated to answering questions, it was impossible to cover all the complicated politics surrounding the disease but as usual Sally has done an amazing job to educate viewers. The 30-minute programme (http://bit.ly/2fRE7o9) has been released in the meanwhile.

Special Journal of Health Psychology

As part of our campaign for specialist ME services in Northern Ireland, these booklets (http://bit.ly/2hgmn68) will now be going out to strategic decision makers for NHS commissioning services and key government officials: Special Edition on the PACE Trial from the Journal of Health Psychology.

Available for £6 from the publisher - or book a copy to collect at our September meeting.

Website back on line

The website of Hope4ME & Fibro Northern Ireland underwent a c omplete transformation and is back online since 29th July. Have a look here: https://hope4mefibro.org/

Hope4ME&Fibro NI's reaction to NICE's invitation for input
Extensive response (http://bit.ly/2fUpssh) from Hope 4 ME & Fibro NI to the NICE CG53 surveillance document (which had suggested not reviewing the "CFS/ME" guideline - we disagree), in which only registered stakeholders for the guideline were invited to comment on the provisional decision via this website.

Reasons to disagree were a.o.:
1."Hope 4 ME & Fibro Northern Ireland have been campaigning for some time to have graded exercise therapy (GET) and cognitive behavioural therapy (CBT) removed from the NICE guideline CG53 for "CFS/ME". These therapies, when applied to patients with myalgic encephalomyelitis (ME), are widely reported to cause harm. Many of our members have reported being harmed by medical pressure to exercise. E.g. One young man was put on an exercise bike by a neurologist, and the exertion caused him to collapse, vomiting, on the floor. The NICE guideline CG53

was used as justification for this patient's treatment. This situation cannot be allowed to continue –it is time the CG53 guideline was reviewed and the recommendation for GET removed.

2. Patients worldwide support the removal of CBT and GET from the NICE guideline CG53. At the time of writing the ME Association petition, calling for a review CG53, has collected over 15000 signatures in the few days allocated for the consultation period. This substantial plea should not be ignored by those in control of NICE. CG53 is not working for patients. The guideline should therefore be reviewed immediately.

Source: wall of Hope 4 ME & Fibro Northern Ireland (http://bit.ly/2wbZYNF)

South Africa

We are screening Unrest at 6 venues starting 7 September. We haven't yet confirmed all venues.

The first 2 or 3 will be in Johannesburg and Pretoria. Thereafter we will screen it in Cape Town. The first screening is at a restaurant in a health care centre. Our target audience for this specific screening is medical practitioners. The venue has 80 seats.

Thereafter, we will screen at Universities in order to educate medical students, Head of Departments, the public, local government, the media and patients.

We aim to do many more screenings after the first 6.

A weekly magazine contacted me, they are doing an article on ME and our Foundation, I have received the draft, but it will only be in the magazine 1 December.

Submitted by **Retha Viviers**

The Netherlands

Screening Unrest in Amsterdam

The Dutch screening of **Jen Brea**'s ME-documentary Unrest will take place on Friday October 13, 2017 at 15.00 PM onward. Most probably at the same theatre where in February 2016 Forgotten Plague has been screened, the LAB 111, Arie Biemondstraat 111, Amsterdam. However, check with the organising association, the ME/cvs Vereniging:
http://www.me-cvsvereniging.nl/contact, also to make your reservation.
A survey of all screenings: http://see.unrest.film/showtimes/
trailer Unrest: http://bit.ly/2vHoKCz

Website ME Centraal

ME Centraal which set of as a fb-wall https://www.facebook.com/MECentraal/ to provide Dutch-speaking ME-patients, their caregivers, their families and physicians with current info on the disease on August 8, 2017 has proven to provide in a need, given the fact that at its first year's celebration almost 700 followers are obviously taking an interest in it. One column reached over 22.000 people, many other articles more than 10.000 and there's a continuous lot of interaction on the wall.

Apart from 'celebrating' Severe ME on that day the moderators also started a simple website https://mecentraal.wordpress.com/ to publish longer articles and preserve older ones in a clearer way. Within short they intend to publish articles in English as well. So keep an eye on it.

Press release Groep ME Den Haag

The Groep ME Den Haag which managed to engender over 56.000 signatures in a petition to recognise ME as a biomedical disease as defined by the International Consensus Criteria, two weeks ago published an ANP article on both the Montoya-cytokines study and the special of the Journal of Health Psychology on PACE. More on this and the text of the press release under the heading Dutch Citizen's Initiative in this issue. ANP is the Dutch equivalent of Reuters, although much smaller of course.

Petition ME isn't MUPS

The petition against the composition of the ad hoc ME/CFS panel of the Dutch Health Council is still running but has almost achieved it's goal of 10.000 signatures, its counter last Monday noon being at 9139
Please help them and in fact all your fellow patients in Holland to reach 10.000 by signing and sharing https://meisgeensolk.petities.nl/?locale=en
More on this petition in the section Dutch Citizen's Iniitiative in this issue

United Kingdom

Euromene: New European ME/CFS Biomarker database project | 31 July 2017

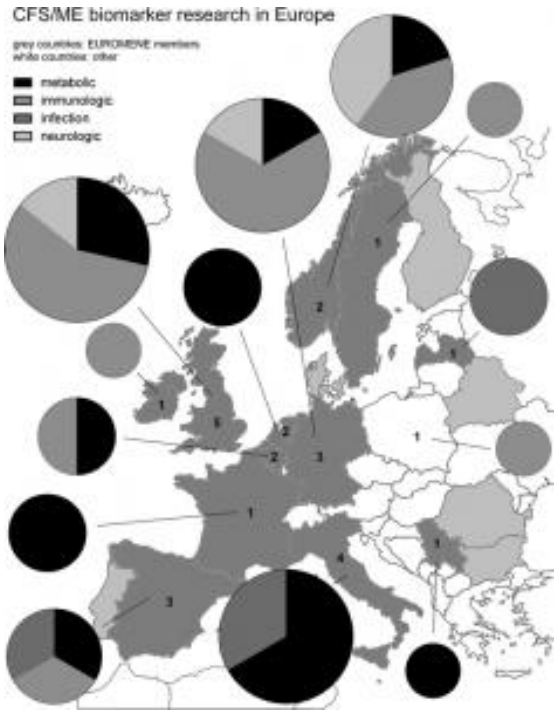
Last week, an inaugural review was published (http://bit.ly/2ihDoO6) that presented a biomarker database initiative by EUROMENE, and will lead to better collaboration between ME/CFS research groups across Europe. The review also highlighted flaws in current research, suggested possible improvements, and drew attention to the significant lack of funding for ME/CFS research in general.

EUROMENE (The European ME network http://bit.ly/2uSNyub) is a collaboration of researchers and clinicians from 17 European countries who aim to promote cooperation and advance research on ME/CFS. They are funded by COST (European Cooperation in Science and Technology http://bit.ly/1M3H34v), a non-profit organization, and this initial study has established a database on all biomarker research relating to ME/CFS within Europe on which they hope future research will build.

Two members of EUROMENE are in receipt of grant funding by the ME Association's Ramsay Research Fund. Dr Eliana Lacerda (http://bit.ly/2uS51TG) is a member of the UK ME/CFS Biobank team at London School Hygiene and Tropical Medicine and Dr Elisa Oltra (http://bit.ly/2vbADib) from Spain is examining micro-RNA in PBMCs and exosome-enriched vesicles in people with severe ME/CFS.

Biomarkers; scientific highlighters

Biomarkers are measurable indicators of a disease state within the body, such as certain metabolites or specific genes, which can be used in diagnosis, classification of subtypes of disease, indicators of prognosis and in predicting response to treatment. A good example of a biomarker would be high blood pressure as an indicator of stroke risk.



The search…

The researchers conducted a vast search of publications on biomarkers from the last 5 years and compiled a total of 39 active ME/CFS studies from 17 different countries.

These studies were then grouped into four categories of biomarkers; Immunological, Infection-related, metabolic and neurological (See Fig. 1). The majority of biomarker studies at the moment seem to be focused mainly on immunological and metabolic markers.

Studies on immune markers explored immunoglobulins, autoantibodies and cytokines. Most of the studies on infection markers were focused on XMRV, confirming the absence of this virus in European ME/CFS cohorts.

Neurological biomarker studies focused on neurotransmitter regulation and those on metabolic markers included mitochondrial dysfunction, oxidative stress and cortisol regulation.

Through the magnifying glass

Most of the studies in this review were exploratory in design, so the number of patients used in each study was low and the control groups were often not properly matched by gender or age, which can have a significant effect on the results.

Some studies also reported inconsistent data, with some findings being reported in one study not able to be confirmed in others. Many of the biomarkers found showed alterations in subgroups of patients, and not in all patients, or had wide overlap with healthy control groups, so were not specific to ME/CFS patients. These subgroups of patients could be a result of differing disease onset (infection- versus non-infection triggered).

These reasons, along with the fact that only a few small studies have been carried out so far, could explain why no useful biomarker has been identified. Therefore, the study concludes, strategies are needed to improve the quality and comparability of these biomarker studies – Table 3.

Table 3
Strategies for development of diagnostic biomarkers in ME/CFS

1. Standardization of sample collection and assay procedures
2. Use of an uniform clinical case definition
3. Use of questionnaires to assess symptoms and severity to define subgroups
4. Stratification of patients according to sex, disease onset, and disease duration
5. Include sex- and age-matched control groups
6. Sufficient sample size and predefined hypotheses (statistical power)
7. Confirmation of results in validation and multi-center cohort studies
8. Study combinations of biomarkers, perform pathway analysis or functional studies

The search is still on…

Although no single biomarker for diagnostic use has been identified, this project provides a platform for advancement of research and the improvement of future studies.

There were, however, some promising initial results which could later develop into something very exciting. Interestingly, metabolic studies consistently revealed different gender-related patterns, which could be an avenue of further exploration.

Furthermore, recent studies analysing multiple metabolites could show specific alterations in ME/CFS patients, pointing to a possible common and specific metabolic profile.

The writers suggest taking a broader approach – instead of looking for a single diagnostic biomarker – to analyse several different pathways together to create a palette of diagnostic markers.

The bottom line

This paper is a fantastic step in the right direction. EUROMENE are bringing ME/CFS researchers together across Europe to collaborate on key issues and are trying to set a higher standard of research – which is desperately needed – and it concludes with a very important message: that the main reason for the scattering of small studies is due to lack of funding.

"To promote research, it is crucial to increase funding for ME/CFS, which is currently still far below the budget funds for most other serious diseases in both the EU and the US funding agencies, such as the National Institutes of Health (NIH)"

You can read the full paper which provides a breakdown of all the published research that has been included in the database, here (http://bit.ly/2ihDoO6).

Submitted by **Russell Fleming**

11. 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

UK CFS/ME Research Collaborative 2017 Conference Programme

#CMRC2017 (quite a mixed company of speakers….)

DAY ONE - WEDNESDAY 13 SEPTEMBER 2017

- 09:30Welcome **Prof Stephen Holgate**
- Plenary Session: Biology of CFS/ME
- 09:40 Post-infectious CFS/ME study at National Institutes of Health - **Dr Avindra Nath**
- 10:15 Imaging in research - **Dr Matt Wall**
- 10.50 The challenge of chronic pain: how neuroscience can help- **Prof Maria Fitzgerald**
- 11:50 Transient receptor potential ion channels and impaired calcium signalling in natural killer (NK) cells in CFS/ME patients-**Prof Don Staines**
- 12:25 Addressing the problem of fatigue in arthritis - **Prof Alan Silman**
- 12:50 Establishing the prevalence of Joint Hypermobility Syndrome (JHS) in a London Fatigue Clinic: A clinical audit - **Gina Wall**
- 14:45 Orthostatic Intolerance in CFS/ME: lessons from the last two decades - **Dr Peter Rowe**
- 15:20 Orthostatic intolerance in CFS/ME - **Prof Dr Frans Visser** and **Dr Linda van Campen**
- 15:55 Investigating altered metabolism associated with ME/CFS using comprehensive metabolic profiling of plasma samples by mass spectrometry - **James McCullagh**
- 17:30 Learning from other illness fields: Dementia Platform - **Prof John Gallacher**
- 19:45 Creating Collaborations (over dinner): An opportunity for researchers to share research and explore new collaborations in a confidential space, enabling data to be shared and new projects to be explored.

This is open to researchers/clinicians/professional and student members only.

DAY TWO - THURSDAY 14SEPTEMBER 2017

Plenary Session: Catalysing Collaboration

- 09:00 What it takes for pharma to engage in a research/drug discovery programme – TBC
- 09:35 **Mike Dalrymple**, LifeArc
- 10:10 MRC-funded researchers: updates on MRC- funded research -
- **Prof Carmine Pariante**; **Prof Esther Crawley**; **Prof Anne McArdle**; **Dr Mark Edwards**; **Sue Wilson**
- 11:45 Infection and mood (Title TBC) - **Prof Carmine Pariante**
- 12:25 Patient and public involvement in research - Speaker TBC
- 14:00
    - Workshop 1 - Managing orthostatic intolerance in CFS/ME: a workshop for practitioners
    - Workshop 2 - How can we work better together to drive scientific breakthrough for people with CFS/ME?
    - Workshop 3 - Daily fluctuations in fatigue: using technology to identify patterns, predictors, and potential solutions - **Dr Peter Rowe**, **Dr Mark Edwards**, **John McBeth** & **Katie Druce**
- 15:30 **Anne Faulkner** Memorial Lecture - **Prof José Montoya**
- 16:15 Conference reflections - **Prof Stephen Holgate**

Source: http://bit.ly/2vLgW4v

Simmaron Research Patient Day

You Are Invited

Simmaron Research Patient Day

Research Update

Saturday, September 9, 2017, 1 to 4 p.m.

At the Donald W. Reynolds Community Building (Parasol)
948 Incline Way
Incline Village
Main Room, First Floor – The Trepp Room

Speakers will be:
Dr. Jan Armstrong - Chairman of the Board,
Dr. Daniel Peterson - Scientific Medical Director,
Courtney Alexander Miller - Simmaron President,
Gunnar Gottschalk – Simmaron Senior Research Fellow attending Rush University,
Dr. Salman Hashmi – George Washington University,
Dr. Mady Hornig – Scientific Board Members and Columbia University,
Dr. Konnie Knox – Scientific Board Member and Coppe Labs
Dr. Maureen Hanson – Scientific Board Member and Cornell University
(more speakers to be announced later)

Please RSVP to: redefiningmecfs@gmail.com or 775-298-0030

*this is a fragrance-free event

October 18, Chronic Exhaustion

Chronic Exhaustion, even on the cellular level
Conferences on ME/CFS in Stockholm & Malmö
Cardinal Symptoms, biomarkers and possible treatment

Registration: http://www.rme.nu/konferens
The conferences are free and are primarily targeting healthcare professionals, politicians and the media. The public is welcome, but there is a limit to how many participants we can accommodate. Registration deadline is September 30. Some of the lectures will be held in English and will be followed by a short Q&A. Coffee/Tea will be served.

In Sweden, around 40 000 people are estimated to suffer from ME/CFS (Myalgic Encephalomyelitis/Chronic Fatigue Syndrome), classified as a neurological disease by WHO (ICD-10 G93.3). The illness is often severely debilitating, but under-diagnosed. Ongoing international biomedical research is in the process of finding diagnostic biomarkers and effective treatment.

The conference program in Stockholm (http://bit.ly/2sUpK4K)
Time: Wednesday Oct 18th, 2017 1 p.m. – 5 p.m.
Venue: Landstingssalen, Landstingshuset (the County Council Hall), Hantverkargatan 45, Stockholm

Subjects & speakers:
Anomalous microbiome and metabolic profiling in ME/CFS-patients.
Professor Maureen Hanson, Cornell University, New York

ME/CFS and the immune system: Where are we now?
Geraldine (**Jo**) Cambridge, PhD, Dep. Medicine, University College, London

Biomarkers for ME/CFS in cerebrospinal fluid
Prof Jonas Bergquist, Uppsala University

Neuroradiological studies in ME/CFS
Dr Per Julin, The ME/CFS unit, Stora Sköndal Neurorehabilitation Clinic, Stockholm

If you have any practical questions about the Stockholm-conference,
contact: stockholm@rme.nu

The conference program in Malmö (http://bit.ly/2rScAGT)
Time: Thursday Oct 19th, 2017 1 p.m. – 5 p.m.
Venue: Kockums Fritid, Västra Varvsgatan 8, Malmö (Room: Bio)

Subjects & speakers:
Infection triggered autoimmunity in ME/CFS. An explanatory model. –
Professor em. Jonas Blomberg, Uppsala University

Anomalous microbiome and metabolic profiling in ME/CFS-patients –
Professor Maureen Hanson, Cornell University, New York
ME/CFS and the immune system:

Where are we now? –
Geraldine (**Jo**) Cambridge, PhD,
Dep. Medicine, University College, London

Aktivitetsförmåga och delaktighet hos personer med ME/CFS (presented in Swedish). Occupational therapist **Ewa Wadhagen** – **Wedlund**,
the ME/CFS unit, Stora Sköndal Neurorehabilitation clinic, Stockholm

Panel discussion.
Healthcare for ME-patients in Region Skåne

If you have any practical questions about the Malmö-conference,

Contact: skane@rme.nu

12. Column – A Call From The Heart To Doctors

Preferably, at that moment, I'd opt to sleep. Not because I was depressed. Not at all. Just completely exhausted. Totally fatigued. Would it be odd, at my age, to succumb to an eternal slumber if I were given the offer? To just be okay with it? Just because the candle is on the brink of burning out?

I know it doesn't stay that way, and if I had more energy, I would think: "are you crazy?!" It's also not something to say out loud. You'd instantly be labeled with a depressive disorder. Although it has nothing to do with this.

Apparently, it feels like somebody on the verge of dying, capitulating to the moment. Such little strength. It's barely believable, as if you're always not dying, yet. There's no other way for me to describe it.

What is even happening to our bodies and why are doctors turning a blind eye? Human lives that are lost, years that never return as a result of the arrogance, incompetence, avarice and perhaps power and money?

I'm sorry when I say that this might be a serious crime, albeit by unwillingness. It is a blatant form of negligence to ignore those who make it clear they're gravely ill, to not treat their complaints with seriousness.

I did not follow an education on your level. But you're doing thousands of us in the Netherlands an injustice by solely basing your advice on what's 'supposedly' known about ME, but which doesn't approach ME from a distance. Chronic fatigue at best. Thinking outside the box is an option, just like rightly and actually listening to the patient, and thinking with them.

A person afflicted with ME doesn't visit a physician just like that. Something is really gone awry. Any energy required to make a 'trip' like that is unavailable, not yet speaking of actual trips. What would you do if your child or significant other fell this severely ill, but would be unable to be diagnosed properly, instead only being able to receive a medically lackluster diagnosis? Would you too insist on designating their illness as a psychological disorder? Or would you delve into the scientific world and seek out the possibilities? Don't your patients deserve this same way of being approached and treated? Or is it an 'away from your bed' type of job?

As a physician, assuming that patients are making up their afflictions is, in my opinion, equally as heinous as claiming all refugees are criminals. It is pure discrimination against a group of your fellow people who are dependent on aid, who aren't self-sufficient. Regardless, it is myopic behavior, unworthy by the Hippocratic Oath.

Yes, I'm aggrieved, angry and frustrated. Should you read this, dear doctor, please understand that this is about my life I have to miss. It boils down to me having to wait for you to gain the proclivity to immerse yourself into the most recent scientific climate surrounding ME, to actually fully dedicate yourself to my concerns and to take action. Nothing more, nothing less.

Dear doctor, dear specialist,

Respect your profession, your patients and yourself. Practice your work every day with a bright look ahead. Use all the knowledge at your disposal, provided it pertains to this illness and, when talking to a patient with Myalgic Encephalomyelitis, assume their experiences to be true.

Thousands of ME patients want their former live to return to them, and in order to make that happen, we need you, the physicians.
A call from the heart.

Rosa
(Pseudonym of a Dutch ME-patient)

13. Column – ME Am Not What It Looks Like

Today I had another conversation with my mom about the invisibility of my illness. How my bubbly appearance may confuse people when they see me. It even confuses my parents at times. Like when I was staying over at their house just after my holiday. My mom said she noticed my exhaustion on my first day back, but that I seemed fine & even radiant on the days after.

When I look back at pictures from those days, I have to agree with her. It must have been the happy memories of my holiday, being able to spend some quality time with my parents & enjoying the sunshine in their garden literally shining through. And this wasn't an act (because I don't have to act around them), but for sure there was also my body crashing, as expected. I felt it big time: the pain, the indescribable exhaustion & eventually the intolerance to any sound. But apparently this was all invisible, even to my parents.

So I can see how this confuses other people even more. I understand that. What I refuse to accept though is the disbelieve of some people. Those thinking that my symptoms can't be all that bad because I'm still able to put on a smile & enjoy our moments together. That's like calling me a liar & one who exaggerates and to me that's a huge insult. Please understand that I tend to downplay my symptoms rather than exaggerate. I do this not only because I don't want to complain all the time but also because I don't always want to admit to myself how bad & scary this illness really is. I would get seriously depressed. But then why do I write about my struggles on Facebook?

Well, first of all writing has always been my way of venting. It helps to clear my mind, to ease my emotions & to not go crazy. And secondly, I'm hoping to create some awareness of living with an invisible chronic illness. It's not much different from people writing a column in a magazine or a newspaper. Like a woman with a multiple handicapped child who used to write a weekly column about their lives, their joys & their struggles. I always enjoyed reading her stories because it gave me a better understanding. And that's what I hope to get out of my posts on Facebook. Not to arouse pity, but a better understanding.

I know there are people who feel that I'm too open at times, or even too negative. Some say I'm a strong, positive person, others find me weak. I'm probably a bit of everything, depending on my mood. Most of all I'm just human & doing the best I can. It's normal to have ups & downs. That's life, my life & that's what I write about.

Written by an anonymous Dutch patient and published on the wall of ME Centraal http://bit.ly/2sQwYp5 where it caused a wave of recognition.

14. 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."