The ME Global Chronicle

www.let-me.be

 # 17 – June 2016

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Scientific reviews: ***Richard Podell***
Advisory board: ***Leonard A. Jason***
Cartoons: ***Djanko***
Editor/Editorial team: ***Eddy Keuninckx, Rob Wijbenga***

With thanks to:

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Bente Stenfalk
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Carolien van Leijen
Dr. Charles Shepherd
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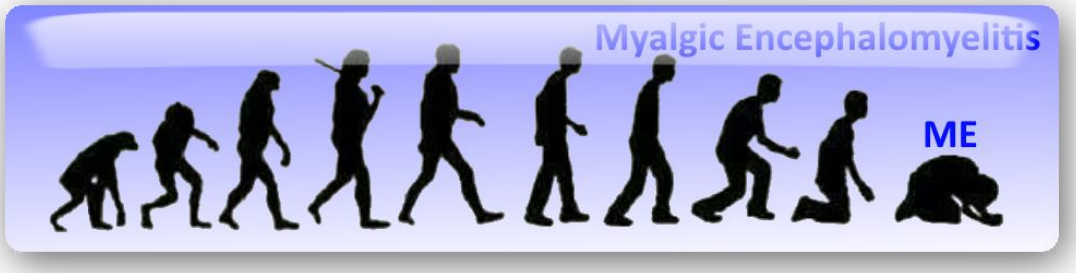
Subscribe to this newsletter.
We are no association or society, just a bunch of idealists who want to give our best efforts towards recognition of this terrible disease. By trying to help connecting to each other all patients all over the world. Anyone who expresses the wish to receive the Newsletter 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 http://let-me.be –
Contact us at info@let-me.be

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

2. Table of Contents

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



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

3. Introduction

Dear friends,

Somewhat later than usual, the June-issue of the ME Global Chronicle with attention to two petitions: one in Germany and one in the Netherlands. You don't have to read all the background information: important is that everyone from everywhere is able to sign. The German and Dutch communities desperately need your support!

David Egan withdrew as editor. We are grateful for his text contributions since the start of this magazine.

Little news about **Karina Hansen**, but the news is good.

In the Netherlands, the citizen initiative is moving in the wrong direction. This is due to the members' choice by the board of the Health Council for its ad hoc ME/CFS commission, which has to evaluate ME. Three of them affiliated to the British group of **Wesseley**, **Sharpe** and **White** with a biopsychosocial approach to ME, are joining. The recipe to maintain and even consolidate the Dutch CFS guidelines of 2013, based on the NICE-guidelines.

Missing Millions is that campaigning approach that we all have to pick up in the future. Mark 27th September as the next global action day. There is a movement growing, like the AIDS movement, but everyone needs to join. Everywhere the exponents of the current disease-approach are consolidating their monopolies. And a powerful patient's protest movement is the only answer. Alongside with research discoveries of course.

Furthermore, much contributions of many readers, a pleasing sign: we especially would like to hear your comment on the contributions of retired **Dr. Wardle** from the UK on his unique approach of research-funding - and a report about the 11th Invest in ME-conference in London, 3rd June of this year.

This magazine becomes more and more a meeting spot for patients from everywhere. We are going to desperately need it in the future, so make full use of it.

Text contributions for the August-issue can be sent before August 10th to contribute@let-me.be

Feed-back and reactions to articles? Mail it to info@let-me.be

Have a good summer, take care and be kind to yourself and all others

The editors

4. NIH/CDC/HHS


NIH
National Institutes of Health
CDC
Centers for Disease Control and Prevention

Silence

Twice a year, HHS gives some of us three minutes to comment—only to ignore the solutions proposed by patients and continue to disenfranchise them.

Therefore, rather than provide substantive comments, I would like to use my time to ask the committee and those on the call to observe a moment of silence to honor and acknowledge all those who—over decades—have suffered gravely with this disease and even died from it.

Let's please use one minute of the remainder of my time to reflect in silence, starting now.

Thank you.

Jeannette Burmeister

Staying The Course To Where?

Dr. Francis Collins, Director of the National Institutes of Health, made a request of the ME/CFS community. During the March 8, 2016 NIH telebriefing (http://1.usa.gov/28QMz1P), **Dr. Collins** said:

So please take our commitment with great seriousness. **Please also stay the course with us** as we seek to identify the most compelling research questions and how we could address those. (emphasis added)

But what precisely is the course **Dr. Collins** has asked us to stay on? We cannot answer that question yet, but we can begin to sketch out the map. We can also identify the elements we expect. Looking across the various communications from NIH to the public in the last several months, here is the outline I see:

Clinical Care Study

The NIH has already designed and has begun executing a study at its Clinical Care Center. There are so many issues and questions about this study, including the risk of bias, the design of the exercise test, patient selection, and more. I refer you to the webinar (http://bit.ly/28NpHPa) with **Dr. Avi Nath**, the principal investigator, in which he addresses some of these issues.

I hope to cover the study in more detail in a future post. But one thing to keep in mind is how long this study will take. Data collection for phase one will take approximately two years. Analysis and writing up results will take longer. And there are two additional phases after that. I don't think we'll see even preliminary data until the end of 2017, at the earliest.

Short term plan to activate research

Dr. Vicky Whittemore made general references to a short-term plan for research on the NIH telebriefing. She said, "We are in the process of putting together . . . both a short-term plan, where we can try to activate some research on the shorter-term as well as initiative that would put in place better infrastructure as well as research funding for longer-term research projects." **Dr. Whittemore** also said that the research plan would be presented "to the appropriate council for approval in the May time frame."

The specifics of what this plan will include is anybody's guess. **Dr. Whittemore** did note that the Trans-NIH ME/CFS Working Group has been discussing the importance of biomarkers, understanding the underlying causes of ME/CFS, and understanding the cognitive dysfunction associated with the disease.

But there are so many more areas that need investigation, including characterization and evaluation of post-exertional malaise, investigating the possible autoimmune connection, expanding the systems analysis of neurological and immunological gene expression, genome wide association studies, and clinical trials. In fact, the P2P report includes a long list of areas of inquiry (http://bit.ly/28PGQJg).

It is also important to note that this plan appears to have been put together by NIH alone. It is unclear if NIH has consulted anyone outside the Institutes for advice and direction. And there has certainly been no systematic collection of public input (although advocates have been offering their thoughts). We also don't know if the plan will be released in its entirety, or if announcements will be limited to specific initiatives. The last time the Trans-NIH Working Group created any kind of plan was after the State of the Knowledge meeting in 2011, and NIH steadfastly refused all requests to see that plan.

Requests For Applications (RFAs)

RFAs are a big deal (http://bit.ly/1QoMEo4) to us because they set aside funds for particular projects or areas of inquiry. The last RFA for ME/CFS was 10 years ago. Advocates and researchers have been clamoring for another ever since. It seems like we will, at last, get our wish.

Dr. Walter Koroshetz would not commit to RFAs on the telebriefing, but he said, "I think as a short-term process that we definitely have to stimulate with funds that are particularly for ME/CFS and **Dr. Collins** is clearly behind that." Afterwards, NIH issued revised responses to CFSAC's August 2015 recommendations (http://1.usa.gov/1ST5KHv), stating, "The Trans-NIH ME/CFS Working Group is in the final stages of putting together a comprehensive research strategy for ME/CFS research that will include new RFAs." (emphasis added)

This is good news! But it is nonspecific news. We will have to wait for the announcement to find out how much money will be allocated and over what period of time.

Long term plan with coordination

It's a bit fuzzier trying to map out what will happen over the long-term. **Dr. Koroshetz** said, "But I would also emphasize once again that this is a stepping stone. . . . what our intention is, is to coordinate it with many of the other pieces that we're going to start initiating across the country."

He talked about organizing researchers around the country, and that the community should work with investigators at universities and clinics. Such groups would then submit funding applications. I think this could take many forms, and not all would be equally helpful.

Common Data Elements and a Data Coordinating Center

In the revised responses to CFSAC, NIH said it will develop Common Data Elements for use in all studies. NIH also said the Trans-NIH Working Group is exploring the feasibility of a Data Coordinating Center. This represents a change from NIH's previous position. In response to CFSAC's recommendations from June 2014, NIH said "developing and maintaining a unique ME/CFS database is cost prohibitive in light of the small number of ME/CFS researchers."

CDEs and a central data repository are much needed, especially given that ME/CFS specialists and researchers are scattered across the country with limited systematization of data collection. Again, we await specifics.

My Roadmap

In order to decide if we will "stay the course" with NIH, we should have a sense of what we think that course should look like. These are the components of a course that I would be glad to stay on with NIH:

First, NIH should share its research plan with the public. Not only does this increase transparency and accountability, but it will be another small signal that NIH wants to improve its relationship with the ME/CFS advocacy and research community.

Second, NIH should begin with a three-year sequence of RFAs. Starting with $10 million this year, and ending with $20 million in 2018, the RFAs should support validation of biomarkers, early clinical trials, and infrastructure. NIH should then evaluate results to appropriately target future RFAs.

A sequence of RFAs is essential. Our last RFA was one and done, and it has taken 10 years to get NIH to agree to do it again. We cannot wait 10 years between RFAs. Furthermore, dedicated funding over several years is necessary to convince researchers that NIH is serious about its focus on ME/CFS and to attract new researchers to the field. As long as the perception lingers that NIH does not really want to invest in this disease, we will not see research move forward with any increased speed.

Finally – and this might be obvious but should be explicitly stated – we need the first RFA to be this year. NIH cannot wait for the completion of phase one of the Clinical Care study to shape RFAs. That means waiting two years or more, and it is completely unacceptable.

Third, NIH must fund Centers of Excellence. This might be what **Dr. Koroshetz** was referring to when he talked about coordinating efforts across the country. NIH should help recruit three major universities within two years to combine ME/CFS expert clinical care, research, and clinical trials under one roof. These Centers should also participate in the creation of Common Data Elements and the Data Coordinating Center. We need NIH's support and a plan of how we will get these Centers up and running.

Fourth, NIH must incorporate public input in planning and executing ME/CFS research initiatives. **Dr. Nath** said during his webinar that the "extramural folks" were "approaching people and putting together a panel." I confirmed with **Dr. Whittemore** that they are working on this, but she had no further information to release at this time. It is absolutely critical that NIH consider the range of views among patients, advocates, clinicians and researchers – and meaningfully incorporate that input into designing RFAs, studies, data elements, and future initiatives.

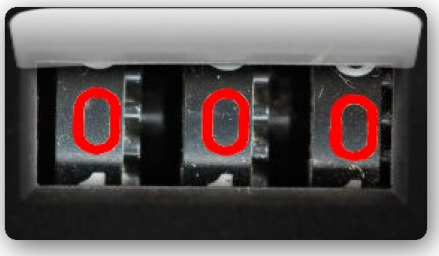
Fifth, NIH must bring stakeholders together to agree upon a basic research case definition, that can then be refined for the needs of particular studies. This is what the P2P Panel recommended, but case definition has been completely absent from NIH communications thus far. NIH says it wants to recruit new researchers to this area, but those researchers need direction on which disease is the target. We need to put a stake in the ground on this issue and move forward.

Finally – and I realize this is not the nature of government – we need a sense of urgency. NIH announced its renewed focus on ME/CFS in October 2015. We're hoping to hear a plan in May 2016 (although no announcement date has been set). The Clinical Care Center study will not yield data for several years. RFAs take time to produce grants, and those grants take time to produce results. I want to see the NIH move much more quickly and with a greater recognition of the urgent need for progress. We've already waited thirty years. That's long enough.

Jennie Spotila, May 3, 2016

Source : Occupy CFS, http://bit.ly/28NtRp9

RFA Ticker, 6/20/16



Another week, another $20,000,000+ in RFAs, and nothing for ME/CFS. It's an unfortunate routine.

But it bears repeating that we have an opportunity to speak up, and tell NIH what priorities should be the focus of future ME/CFS research.

The deadline for response is June 24th, and I offer some ideas and inspiration in this post. (http://bit.ly/28QZzVk)

- **Total RFAs Issued by NIH**: 245 (October 2015 to date)
- **Total Dollars Committed to RFAs**: $2,114,715,000 (October 2015 to date)
- **Total RFAs for ME/CFS:** ZERO (October 2015 to date)

Week Beginning	RFAs Issued	Total Commitment	RFAs for ME/CFS
6/13/16	5	$21,475,000	Zero
6/6/16	5	$7,100,000	Zero
5/30/16	4	$6,900,000	Zero
5/23/16	8	$42,400,000	Zero
5/16/16	2	$7,800,000	Zero
5/9/16	11	$32,100,000	Zero
5/2/16	8	$32,485,000	Zero
4/25/16	4	$7,500,000	Zero
4/18/16	10	$42,230,000	Zero
4/18/16	10	$42,230,000	Zero
4/11/16	4	$6,825,000	Zero
4/4/16	8	$27,000,000	Zero
3/28/16	13	$161,000,000	Zero
3/21/16	1	$2,700,000	Zero
3/14/16	5	$23,650,000	Zero
3/7/16	9	$82,710,000	Zero
2/29/16	1	$1,890,000	Zero
2/22/16	9	$30,100,000	Zero
2/15/16	4	$26,500,000	Zero
2/8/16	5	$9,500,000	Zero
2/1/16	8	$26,000,000	Zero
1/25/16	4	$9,300,000	Zero
1/18/16	2	$4,500,000	Zero

1/11/16	10	$71,200,000	Zero
1/4/16	0	$0	Zero
12/28/15	0	$0	Zero
12/21/15	3	$10,260,000	Zero
12/18/15	5	$20,260,000	Zero
12/11/15	27	$765,090,000	Zero
12/4/15	6	$26,600,000	Zero
11/27/15	4	$21,000,000	Zero
11/20/15	15	$134,400,000	Zero
11/13/15	2	$16,100,000	Zero
11/6/15	10	$22,850,000	Zero
10/30/15	7	$49,800,000	Zero
10/23/15	10	$33,200,000	Zero
10/16/15	0	$0	Zero
10/9/15	13	$332,450,000	Zero

If you want more background on the RFA Ticker, read the inaugural post (http://bit.ly/1QoMEo4).

Source: http://www.occupycfs.com/2016/06/20/rfa-ticker-62016/

(Unfortunately this issue has been published after the 24th June. **The editors**)

5. Dutch Citizen Initiative

Beware Of The Dutch

The Netherlands is a small country, but in the shadows of the ME-related cases in America, something very unique and important is happening. Something that is capable of also affecting the community in America. First off, a short historical description:

In the Fall of 2011, a group of ten independent patients, calling themselves the Groep ME Den Haag (Group ME The Hague), started a petition requesting the Dutch Ministry of Health to: recognize ME as a biomedical neuroimmune disease (separate from CFS); disseminate information about ME to medical practitioners and in medical education; use the ME ICC criteria for diagnostic purposes; increase ME biomedical research. They successfully collected 56,000 signatures and delivered the petition to the Dutch Ministry of Health. (They only needed 40,000 for a responsive action)

Text citizen initiative:

We,

The patients with ME and their sympathizers in the Netherlands. State that diagnostics and treatment of ME-patients isn't adequate. ME is being wrongly considered to be a psychosomatic disorder and being treated likewise. About 5,000 papers, amongst which the ICC for ME (Carruthers et al) show that ME is a severe neuro-immune disease and is requiring thorough diagnostics and biomedical treatment. The ICC also show that ME and CFS are two different disorders.

And request

- ME and CFS to be considered as two different diseases
- Recognition and registration of ME as a biomedical neuro-immune disease
- Diagnostics and treatment based on the ICC ME-criteria (Carruthers, 2011)
- Increased biomedical research into the causes of ME
- Adaption of the tuition and retraining of medical practitioners
- Drafting a health insurance protocol for ME based on the ICC

On February 25, 2015 the Dutch Parliament requested the Health Council of the Netherlands to:
"produce a survey of the state of affairs re. Myalgic Encephalomyelitis, with special attention to include the following aspects in the advice to be given:"

- The definition of ME and its diagnostic criteria
- The onset, course and prevalence
- The possibilities to prevent and treat ME
- The impact of ME on the patient and his setting and social participation
- The organization of treatment and support of patients with ME in the Netherlands
- The current scientific developments and perspectives"

The Health Council of the Netherlands has given its own spin to the request for advice by:

- Referring to the committee as "ME/CFS committee" instead of "ME committee";
- Taking the IOM-report as a starting point instead of the ICC, as desired by the petition.
- Install four members who are savvy when it comes to MUPS culture and approaching the illness, of which one is the recently appointed head of the Nijmegen Center for Knowledge of Chronic Illnesses (**Dr. Hans Knoop**). He and his predecessor (**Prof. Gijs Bleijenberg**) and a different member of the committee (**Prof. Judith Rosmalen**) regularly publish and have close relations with the British psychiatrists **Wesseley**, **White**, **Sharpe** and **Chalder**, who are responsible for the NICE guidelines and the controversial PACE trial publications. It is thus no wonder that the Dutch CFS guidelines are rooted in the NICE guidelines. Three out of four of these people partook in an afternoon conference in Sweden on 17th June together with amongst others the Danish psychiatrist **Per Fink**, who is held responsible for the eviction and forced hospitalization of the young ME patient **Karina Hansen**.

Who are against the enunciation of the above four members have their voices stifled by **Prof. Van Gool**, the chairman of the Health Council, using the argument that "we shouldn't be thought-policing". Even though it has exactly been the MUPS-approach that continuously has been frustrating a biomedical approach to the illness of ME for decades.

During a hearing process on Wednesday July 15th, organized by the congressional committee of the Ministery of Health and the Health Council, **Prof. Van Gool** repeated his thought-policing argument, and made a second remark which is also very controversial and downright untrue. It pertains to the IOM, which he called "a little bit like the Dutch Health Council" and about which he said:

"It is not entirely comparable. From our perception, they take less care handling the participants' interests. You could, for example, buy a chair there to consult with. That is an interesting business model, but we don't use such a model."

This statement also made its way through Twitter to the members of the IOM panel, who have staunchly denied that this point is based on truthful principles.

The father of a severe ME-patient asked for confirmation of **Clyde Behney**, Executive Director Health and Medicine Division National Academies of Sciences, and received the following reaction:

From: **Behney**, **Clyde** <CBehney@nas.edu>
Sunday 19 juni 2016 22:40
Aan: **Lou Corsius**

RE: Questions about scrutiny IOM, claims posed by president of Health Council of the Netherlands

Dear **Mr. Corsius**,
Thank you for bringing this matter to our attention. The National Academies of Sciences, Engineering, and Medicine (the Academies) stand behind the Institute of Medicine (IOM) report, which was prepared by experts in the subject matter and was subjected to our rigorous peer review process before it was released, as we do for each of our studies.

I can assure you that the only way one can become a member of the National Academy of Medicine (NAM, formerly IOM) is by being elected by the members of the National Academy of Medicine based on distinguished professional achievement in a field related to medicine and health. One must first be nominated by two members of the NAM who are required to document how a nominee meets the criteria for membership and then be subsequently elected by the full membership of the NAM.

One cannot buy a membership in the NAM, nor can one buy a role as a member of one of the committees that conduct studies and produce our reports.

Additionally, all members, including the chairs, of our study committees undergo a very strict review for conflicts of interest prior to their appointment, and we also notify the public about the proposed members for each of our committees twenty days before the first committee meeting so that the public can identify any potential conflicts of interest before the committee begins its work.

Thank you again for making us aware of the statements.

Very best regards,
Clyde
Clyde J. Behney
Executive Director
Health and Medicine Division
National Academies of Sciences,
Engineering, and Medicine

Clyde J. Behney

Consequently, patients and patient organizations no longer confide in the committee of the Health Council for a beneficial advice and outcome.

What could you, as a reader, do?
A petition has been created to expel the aforementioned four members from the Committee:
ME is not MUPS http://bit.ly/22r5cKN

Please sign it, if you didn´t yet. Negative developments in the Netherlands could adversely affect our hope for progress in the field of bio-medical ME research all over, already because the dominance of the biopsychosocial model is at risk to be implemented and even strengthened. Thanks to the Health Council of the Netherlands.

Don’t let your fellow Dutch ME patients behind.

Dutch Petition Please Sign

DUTCH PETITION: PLEASE SIGN IF YOU DIDN'T YET!

The petition to protest against MUPS-members of the panel of the Health Council of the Netherlands in support of the Dutch ME community can be signed by anyone reading this. (You don't need to be Dutch to sign.)

Click on this link to sign the Dutch ME-community's petition: http://bit.ly/22r5cKN

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),

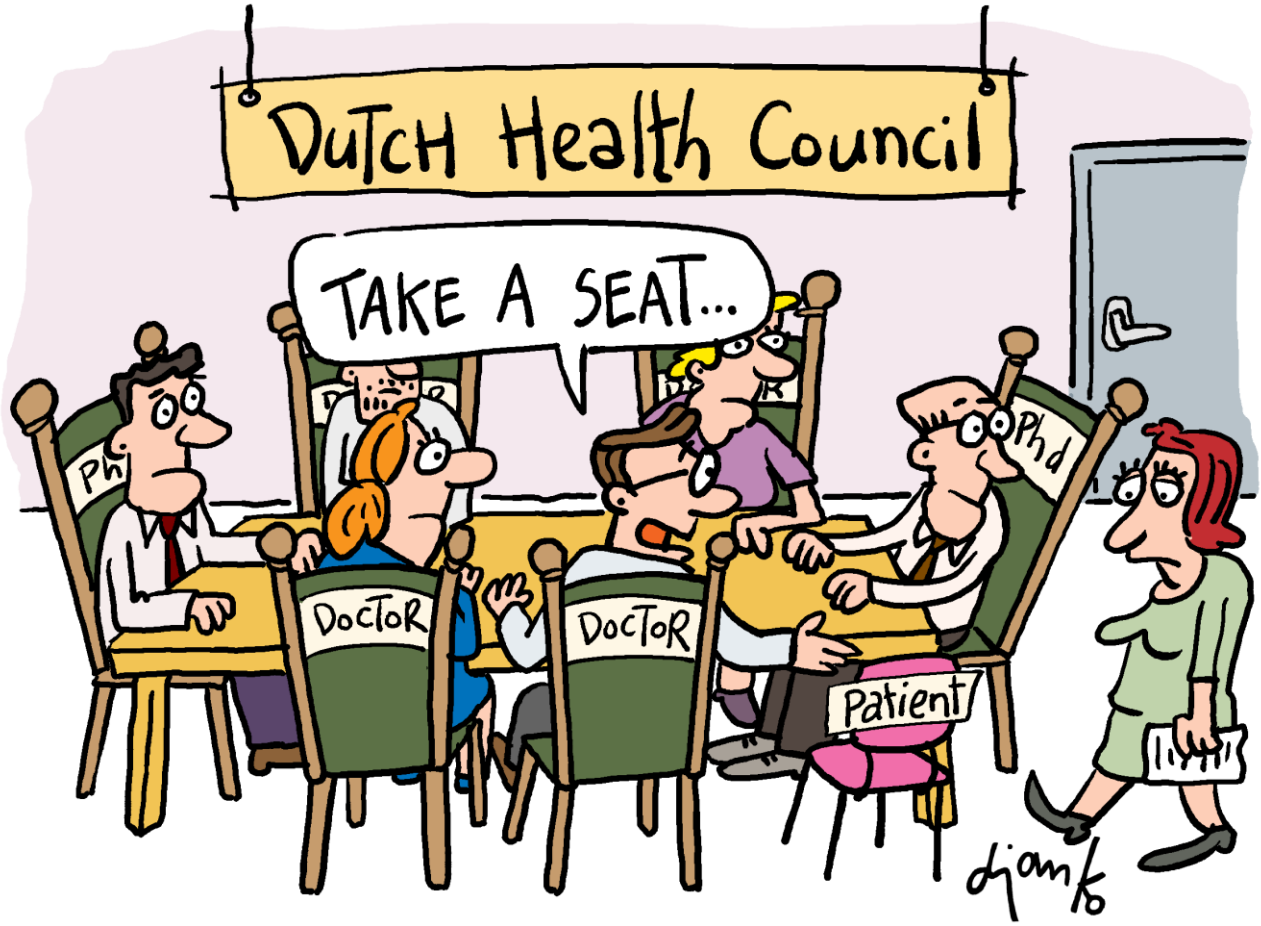
- nor does it fit the advisory report assignment given by Parliament (an advisory report about ME),
- ME is not MUPS! The Dutch Health Council should select the best available expertise, relevant to this disease, but fails to do so.

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!

Want to read more about the background of this petition and the frightening implementations by the Health Council of the Netherlands?
See: http://bit.ly/28V0m8f

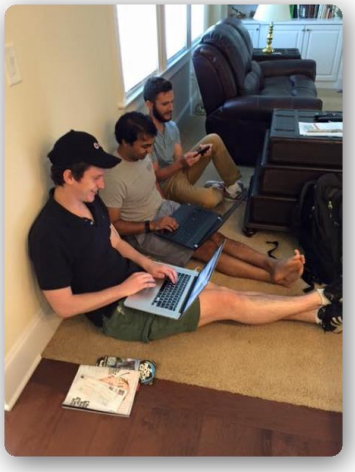
Cartoon Djanko



6. Grassroot

Forgotten Plague

Working on the Congressional Packs, international distribution, and The Blue Ribbon Foundation. By the way, couches are so last year.



Another big announcement this week is that the film is now officially available in iTunes in 80 countries, particularly many European countries that we've been fighting hard to get into.

The translations are downloadable via iTunes in Norwegian, Spanish, Dutch, and Italian.

All the Congressional Packs have now been shipped. We expect all Congressional offices to have received them in 3 weeks (following a 2-week security screening).

You can have your very own DVD copy of Forgotten Plague (http://bit.ly/1QAbuom), the film that tells the great under-reported medical story of our time.

Ryan Prior

MEadvocacy Reaches Members of Congress

Appropriations Submissions

Each year the Senate and House appropriations committees take submissions for planning the federal budget and expenditures. This includes funding for federal disease research. This spring, MEadvocacy once again (http://bit.ly/1YwtLXZ) sent in submissions outlining the devastating nature of myalgic encephalomyelitis (ME) and the need for research.

Submissions were sent to the House and Senate appropriations subcommittees with jurisdiction over the Department of Health and Human Services. We educated the committees on myalgic encephalomyelitis, the plight of severe ME patients due to lack of research funding, and asked for $250 million in federal research funding.

In Person Deliveries

In early June, thanks to volunteers (including relatives of Tom C., featured on our home page (http://bit.ly/1HUjM7X)), MEadvocacy has been able to distribute dozens of packets of information to Congress. The members of several health committees with jurisdiction over the Department of Health and Human Services (HHS) were targeted.

The information explained the disease, included stories of the devastating impact of the disease on severe ME patients, and how HHS has consistently neglected and underfunded the disease for decades.

We are asking that the members of Congress require the following from Health and Human Services:

- Use the historic name myalgic encephalomyelitis
- Use ME expert authored criteria - the Canadian Consensus Criteria or International Consensus Criteria
- Cease using the overly broad CDC criteria (Oxford, Fukuda, Reeves)
- $250 million in federal research annually to bring ME on par with similar diseases
- Provide correct and unified medical education from HHS agencies
- HHS to partner openly and transparently with stakeholders

Patients and activists in our community have been asking Health and Human Services departments for more than 30 years to do what is expected of them. Their mandate is to do research, find treatments, and disseminate accurate information about myalgic encephalomyelitis so patients can get the care needed to improve quality of life.

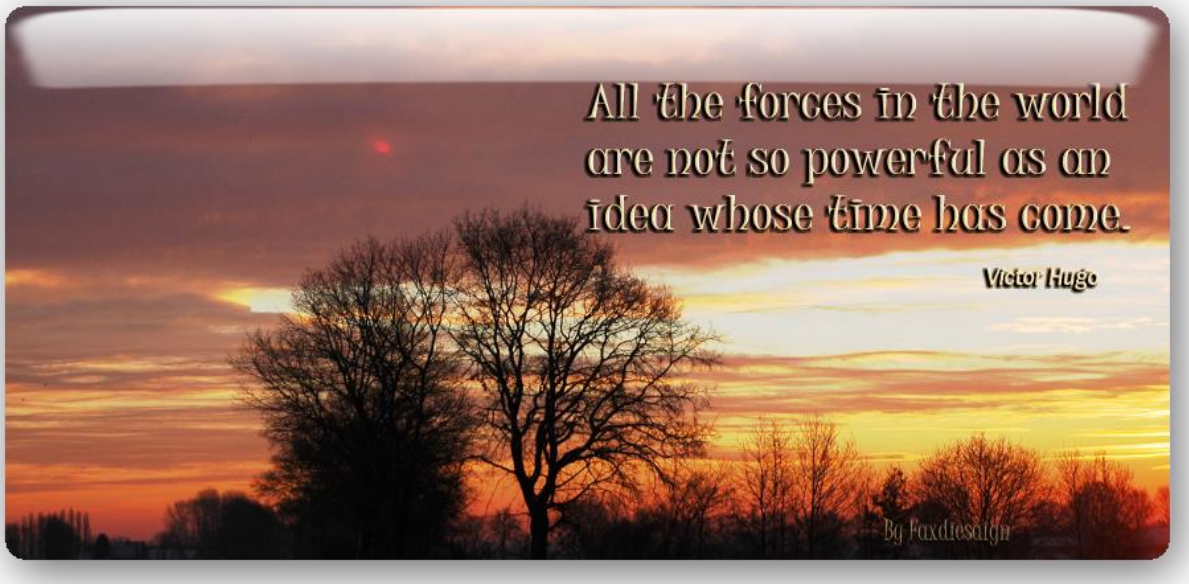
Showing a pattern of institutional bias against our disease, HHS has neglected to fulfill their duties. So we are imploring members of Congress to see that the future is not a repeat of the past.

What Can You Do?

Contact your member of Congress and ask if they received a packet about myalgic encephalomyelitis and let them know this directly affects you and your family. If they didn't receive one, ask them to go to http://www.MEadvocacy.org to read about ME and learn more on the resources page (http://bit.ly/1rtgyBO).

Together we can be heard.

Mary Ann Kindel
MEAdvocacy
http://bit.ly/1S8YN0y



Marathon Mike - Sweden

Stockholm Marathon was my 6th of 28 on the challenge and it was a truly memorable one. Prior to the race I was in close contact with RME (the National Society for ME patients in Sweden) and I interviewed them to find out more about what it was like for the 40,000 or so people with ME in the country (interview here: http://www.mikeseumarathons.eu/sweden.html).

I didn't know before I flew out but I was also to meet up with two ME patients (**Susanne Froroth** and **Catharina Rosenberg**) after the race for drinks and a chat, this I enjoyed very much.

I flew off from Gatwick arriving in Stockholm late afternoon and able to just about check in at the rather quiet Expo to pick up my race number and register.

I went to visit Skansen Park and the island of Fjaderholmarna the day before (doing a lot of ill-advised walking) in temperatures that almost hit 30C, I must admit I was concerned I was going to melt and struggle in the heat. I woke up pretty early even though I wasn't due to race until midday and was delighted to see that we'd just about topped £3500 raised over the 5 marathons so far for Invest In ME.

I had a breakfast of mostly cereal and bananas, a fight almost broke out for those trying to grab the latter much to the dismay of the staff, runners eh?! After some stretching and a short walk up to the stadium I saw lots of Brits and had a nice chat with a few, all of which were suitably worried about the Vasterbron bridge and the rising heat.

Time Completed: 4hrs 05 mins

Mike

Read more here:
http://www.mikeseumarathons.eu/stockholm-sweden-june-2016.html

#MEPedia

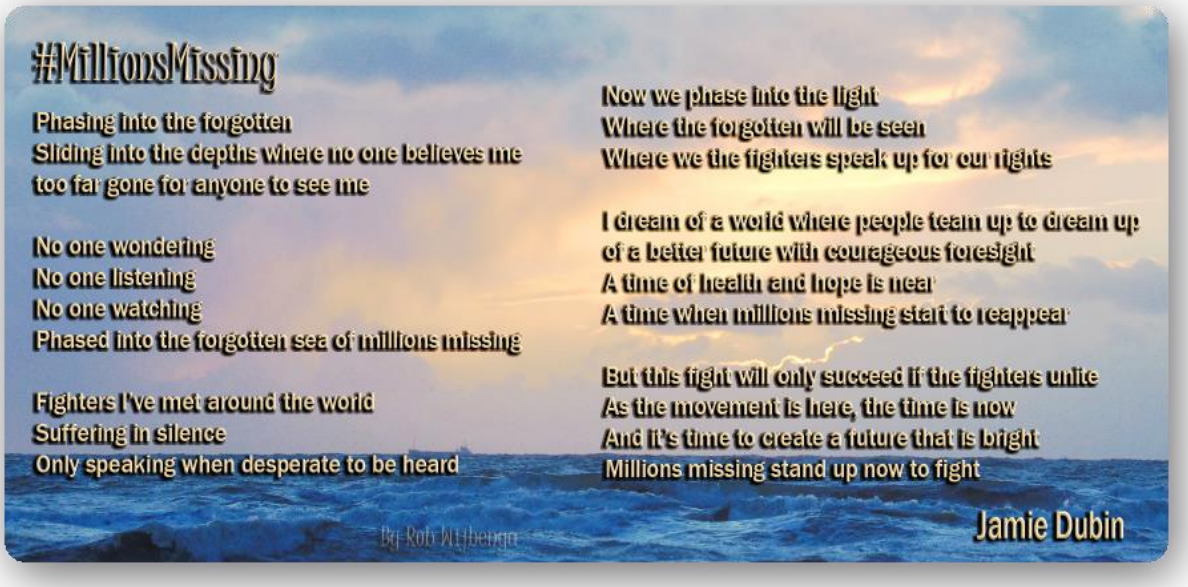
How to contribute

Contribute to MEpedia Today!

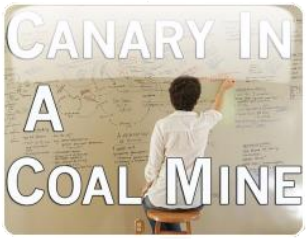
Anyone can contribute, and everyone has something to offer, whatever your skills & experience, even if you have never edited a wiki (like Wikipedia) before. All we ask is that you read the guidelines before you edit (http://me-pedia.org/wiki/How_to_contribute).

Please also join our group of authors and editors
https://my.meaction.net/local_chapters/mepedia

Jennifer Brea



Canary in a Coalmine



It's been such a busy but incredible spring. I'm delighted to share this update with you because your support for Canary means so much. Without it, none of this would be possible.

First, we have been selected as one of eight documentaries to participate in the Sundance Edit & Story Lab, a unique opportunity to workshop the film with Oscar-winning directors and editors. And I've been to Banff, Canada to give my first TED talk!

I believe we have a unique opportunity, on a scale our community has rarely had, to make ME visible.

But we need your help. Although the film is not yet finished, we are just months away from picture lock – that moment in post-production when the edit is final and we move on to music, color and sound. In order to finish the edit by September, in time to submit the film to festivals, we need to raise $40,000. Every amount helps. Consider making a donation today.

Learn more about our team: http://www.canaryinacoalminefilm.com/team/

Our UK-based producer Lindsey Dryden and associate producer Alex Usborne from 104 Films, a British production company focusing on disability, have had an amazing few days pitching Canary at Sheffield Doc/Fest!

This was our first time pitching at a European market. We had some exciting meetings with broadcasters and distributors in Canada, the UK, France, Germany and more, and continued our conversations with industry and supporters in the US.

We came away with new ideas about how to Canary can reach a global audience, and are so excited about bringing the film to Europe next year.

Thank you Sheffield Doc/Fest!!!

Read more about Little by Little: http://www.lblfilms.com/
Read more about 104 Films: http://www.104films.com/

I am thrilled to announce that in a few weeks' time, I'll be speaking at the TED Summit in Banff, Canada!! The theme is "It's About Time," which is exactly how I feel about the treatment of this disease.

It's also how I feel about the importance of listening to patients' stories and embracing uncertainty.

Check out the full program here: https://tedsummit2016.ted.com/program

I'd love to hear from you in the comments below what messages and stories you think we should be taking to the TED Summit.

Support Canary:
The film: http://www.canaryinacoalminefilm.com/donate
The impact campaign: http://j.mp/canaryimpact
Partners: http://www.canaryinacoalminefilm.com/partners/

Jen

It Didn’t Take Me Very Long

“It didn’t take me very long to figure out that we are repeating history with ME. I’m having a déjà vu. AIDS patients were made invisible and their real-world knowledge about the changes that needed to be made to end the crisis was ignored.”

Terri Wilder,
an ME/CFS patient and member of AIDS advocacy organization,
ACT UP New York.

“… no charismatic leader headed ACT UP, an action group committed to ending the AIDS crisis…. Over 25 years ago, these activists learned that being polite was not going to change discrimination towards those afflicted with HIV..

… they were specific in their demands for basic human rights. More importantly, they were persistent in keeping pressure on those who were unwilling to change the status quo. They stayed focused on critical issues and made it clear to those in power that they would not be defeated.”

Leonard Jason,
Principles of Social Change

Too Much Ugliness

In this world there is often too much ugliness, judgment and strife. In the ME/CFS and FM community, there is far too much misunderstanding, dismissive attitudes, and suffering. Yet through it all, BHC (Bateman Horne Center) stands for compassion, kindness, integrity and commitment. And we know that we are not alone in that!

We want to focus on the stories of radical kindness and unexpected compassion.

Take a moment to tell us about a time when someone treated you with unexpected care, showed a kindness you didn't expect, or simply spread some joy in the face of your chronic illness.

Perhaps you want to write a short story, submit a poem, or send a short blog post? Or maybe you have artwork, photography or a piece of music that reminds you of this? The Patient Voice (http://bit.ly/28SdlHX) is about lifting your voice a little higher and sharing your inspiring message, so be creative.

Send your submission to PatientVoice@BatemanHorneCenter.org

Find details on making a submission here: http://bit.ly/28SdlHX

In Memoriam - Jodi Bassett

In Memory Of Our Founder, Jodi Bassett Sept. 01, 1976-Jun. 11, 2016
A tribute

I'd venture a guess that those patients fortunate enough to make their way to http://HFME.org all followed roughly the same route. We got very sick, very suddenly. We saw a lot of doctors. We were stunned to discover that most of them didn't know what was wrong with us, didn't care what was wrong with us, or didn't believe there was anything wrong with us at all. Some of us were herded into that vast holding pen labelled 'Chronic Fatigue Syndrome', where we were either forgotten or harassed. Some of us wandered aimlessly, wondering if we'd ever get a diagnosis.

And that's when we heard, from a friend of a friend, about the Hummingbird's Foundation for M.E. It was not like anything else we had encountered in the wasteland of online resources. It was written by a patient, not a physician. Nobody there was trying to sell us a magical remedy, or sign us up for punishing treatments like Graded Exercise or Cognitive Behavioural therapies. At long last, we'd stumbled across the corner of the internet where all the science was hiding.

At the heart of HFME was its fearless founder, **Jodi Bassett**. Her output was prodigious. The hummingbird motif couldn't have been more apt – she was always busy, always working. I envied the way her mind worked despite her malfunctioning brain. She was the critical thinker we all aspire to be, with an uncanny ability to crystallise her thoughts. She penned articles, reviewed books, collated data, and democratised M.E. research in a way that empowered patients and pulled the rug out from under the CFS lobby.

If **Jodi** had one ambition, it was for neurological M.E. to be recognised as distinct from what is commonly called 'Chronic Fatigue Syndrome', a label she regarded as bogus and dangerous. Her stand made her unpopular in some circles. In a political landscape where many are pushing for unity, **Jodi** was not afraid to stand alone.

One day people will understand that her goal was not to alienate the vast numbers of people diagnosed with CFS, but to make sure each and every one of them was issued the accurate diagnosis they deserved, whether M.E. or something else.

Our fearless ambassador passed away on June 11, 2016. In recent months, her battle with M.E. was complicated by breast cancer. **Jodi** dealt with these new challenges privately, under the care of her loving family.

I trust her wishes for privacy will be respected now also. The grief is still very raw for all who loved her.

For now, http://HFME.org stands as a testament to her conviction, her limitless compassion, her wry sense of humour and brilliant mind. I'll never cease to be amazed that **Jodi** used her illness to help others. It is hard for us to understand how and why we've lost our dear friend and mentor. My hope, though, is that **Jodi** will be remembered not for what she suffered, but for who she was in spite of her suffering.

Emma Searle, hfmesupporter

http://www.facebook.com/HummingbirdsFoundationforME/?fref=nf
http://bit.ly/28Plvj2, Obituary & Guest Book, which can be signed until July 18, 2016.

In Memoriam - Louise Ramage

Louise was a long-term Canadian ME-patient who died in her fifties.

This is what her daughter wrote:
"It is with the most sadness that I tell you all that my mom **Louise Ramage** has passed away.

We are completely devastated.

If there is one thing she would want from me, she would want me to tell you about her disease M.E.

This took her life and we can't even handle it.

We wish she was back here with us but know that she is in heaven with my dad and watching over us.

We are dying inside. Love you so much and I'm sorry I couldn't do more for you.

Xo"

Thanks to **Paul Kayes** for informing all

May she be surrounded with peace, love and light, free from a body with such a devastating disease

In Memoriam - Tink Bastian

Tink Bastian died on Thursday, 23 June 2016. We have lost another lovely creative soul to M.E..

RIP **Tink** and as you said in Twitter, of **Jodi**, "*Fly and be free*."

I have her beloved **W**'s permission to share with others that **Tink**'s death was not suicide, though she may have eventually come to that decision because she was so ill.

Donations in her memory can go to
http://www.thepongofund.org/ or
http://www.dovelewis.org/
two charities dear to **Tink**.

Katheen Fatooh

In Memoriam - Pam Carmichel

I wish to acknowledge the passing of the beautiful **Pam Carmichel**.

Born 18 September 1956, she became a friend of mine because of ME/CFS in 2010. She introduced me to her family and every time I was in Melbourne I took the time to meet with her.

She was a dedicated teacher who fell ill in the mid noughties. She fought hard against her insurer and she struggled to get the medical assistance she needed. She repeatedly asked for assistance from medical personnel and was repeatedly let down. On Thursday 19 May 2016 she lost her fight.

I wish to acknowledge this beautiful and brave woman who was subject to the many insults that came with this disease. She faced them with strength and dignity and with the protective bravery of a mother who put her children ahead of herself.

RIP **Pam Carmichel** ... You will be missed.

Geoffrey Hallmann

Letter To The Editors

We received the following letter with attachments and were in doubt whether to publish them or not. We decided we also couldn't withhold this information to you all, but would very much like to know your opinion about this, especially from those of you who are more or less well-informed on this. ***Dr. Wardles*** *article on the Orphan Drugs Act is here as well, his longer article "Things have never looked brighter for M.E." you will find here http://let-me.be/request.php?32*
Please mail any reaction to info@let-me.be
The editors

Dear Editors.

I would like to congratulate you all on the layout and design of the ME Global Chronicle, it's a particularly good production. I also like way you have set out your priority areas. I believe that I can help with one of these; "The (wrong or inadequate) financing of research on ME in the USA". This is a particular interest of mine.

In 2015, of 2,750 biomedical research papers published in the last ten years only one was a clinical trial involving the treatment of M.E. This was the study using rituximab published by **Drs Fluge** and **Mella** in Norway. In a study involving 30 patents they achieved remission rates of 64%. They are now carrying out a second study involving 150 patents. That's great news but…

Why are there no more enthusiastic follow-ups? ME sufferers want treatment and cures and that means clinical research. The simple answer is lack of money and resources. Clinical trials involving treatments cost millions and are well beyond the fund raising efforts of most ME groups.

There is a solution, it's called the "Orphan Drugs Act". The same Act has been introduced in a number of different countries, e.g. the USA, EU, Australia, Japan and others and these have been a phenomenal success. The legislation was first introduced in the USA in 1983 and by 2012, Orphan Drug research in the USA was worth $637 million and growing at the compound rate of 25% per annum. By 2015 there had been 1,798 applications for Orphan Disease status, 1,234 of these were successful. It is estimated that by 2020 it will be worth more than two billion dollars.

This is where I need the help of you and your readers. If we can prove that the number of people with ME, (not CFS/ME) is less than O.5% of the population then we can register it as a rare disease with all the different Orphan Drug Acts and so obtain millions of dollars to carry out the clinical trials and research needed.

I have every reason to believe that ME can be registered as a rare disease, since I have evidence that it has a prevalence of around 0.3%, as you will see from the insert in this email entitled, “Things have never looked brighter for M.E.”.

I will be quite happy for you to publish this paper since the information it contains will be of vital interest to ME sufferers, their families and supporters.

Since most ME patients are unlikely to have heard of the Orphan Drugs Act I have also written a short article explaining how it works. I have sent you a copy of this as an insert. If you would also like to publish this, I will be happy for you to do so.

My interest and background.
My youngest son has had ME for the last seven years and has been mainly house and bed bound 24/7 for the whole of that period. I am a research scientist with a PhD in Psychology, and qualifications in Physics and also in Psychology, Social Science and Economics. I am an ex-Senior University lecturer in Management and Psychology.

Yours sincerely
Dr Lionel Wardle

The Orphan Drugs Act. Clinical Research in Myalgic Encephalomyelitis (M.E.)

Kindly comment on this article and let us know if you want us to publish future contributions of ***Dr. Wardle***
The editors

Part 1
M.E. is an umbrella term that covers ten or more biomedical phenotypes or sub-diseases. In "Beyond M.E.", a 300-page book published by the American National Academy of Sciences in 2015, 2,750 biomedical research papers published over the last ten years were listed. Amongst them was one solitary study involving clinical treatment of M.E., the study using rituximab published by **Drs Fluge** and **Mella**.

Why are there so few clinical trials? The simple answer is lack of money and resources Clinical trials involving treatments are expensive and well beyond the fund raising efforts of most ME groups. Is there a solution? It will come as a surprise to ME fund raisers if I say that there is ample money available, if you know where to look for it.

For example, the Orphan Drugs Act, is a source of many millions to invest in clinical treatment and research for rare diseases. M.E. with a prevalence of 0.3% is a rare disease. Sad to say, I have yet to meet anyone in the M.E. community who has ever heard of the Orphan Drugs Act. I found out about it from one of the best economics book available, "The Entrepreneurial State" by **Mariana Mazzucato**.

To get the treatment M.E. patient's need, a basic understanding of medicine is required. That's a necessary but not a sufficient condition. You also need to understand management, economics and finance.

Prior to 1983 pharmaceutical companies would not invest in research into rare diseases, defined in the US as diseases with a prevalence of fewer than 200,000 or elsewhere as a prevalence of 0.5% or less, Drug companies are in business to make a profit and they didn't believe they would get their money back, let alone make a profit from such small populations.

Then in 1983, as a matter of public policy, the US government decided that people with rare diseases did deserve help and shouldn't simply be left to suffer, so they introduced the Orphan Drugs Act.

Under this Act pharmaceutical companies were given a number of valuable incentives for investing in rare diseases including; tax incentives, reduced registration fees, subsidies for clinical research, market exclusivity, enhanced and extended patent rights, and more.

Unanimously the pharmaceutical companies predicted that the Orphan Drugs Act designed to meet the needs of rare disease would be a loss making failure. They were very wrong.

Orphan Drugs are a phenomenal success and starting in 2001 the European Union, Australia, Japan South Korea, Taiwan and other countries around the globe all enacted their own Orphan Drug regulations. (I believe China is working on it!)
By 2012 the US market for orphan drugs was worth $637 million and for the first time exceeded the market sales for non-orphan drugs and it is growing by 25.8% per annum compound.

By 2015 the US Orphan Drugs Act had received 1,798 applications for orphan drug status, 1,234 of these were successful, a success rate of 68%. It's predicted that by 2020 sales in the USA of orphan drugs will be worth around $176 billion.

Drug companies cannot apply directly to be registered for Orphan Drug status. They must be proposed by patient groups to be registered. Since M.E. is a rare disease with an estimated prevalence of 0.3% it can be registered as a rare disease.

It will be noted that Chronic Fatigue Syndrome (CFS) is not a disease. The name says it all. It's a syndrome; a collection of symptoms with no known cause, hence, it cannot be registered as a rare disease. Also it is not rare. According to the American Centre of Disease Control, CFS has a prevalence of 2.53%.

An attempt was made to nominate CFS as a rare disease with the EU's Orphan Drugs Agency by a Belgium CFS group. This was reviewed and rejected in 2009. The group claimed that CFS had a prevalence of 1 in a 1.000 and also claimed that ME was a synonym for CFS.

This latter claim would have made most ME patients spit. The nomination was reviewed and rejected in 2009 on the grounds that it was not a rare disease. But as stated earlier, it is not even a disease let alone rare, so it's surprising that the nomination was even entertained. I hope this action will not jeopardise genuine attempts at nomination by bona fide ME groups. I recommend that ME patient and patient groups and supporters should disassociate themselves as far as possible from labels such as: CFS. CFS/ME, ME/CFS CFIMS, etc.

In their book "Beyond ME" the 15 strong medical committee appointed by the American National Academy of Science" concluded that:
"the term "chronic fatigue syndrome" can result in stigmatization and trivialization and should no longer be used as the name of this illness."

The term CFS has cost ME patients and their supporters dearly, both financially and in terms of suffering. For a comprehensive discussion of how CFS came to be attached to ME, who was responsible and how insurance companies, government welfare departments, psychiatrists and others came to benefit from this attachment see the paper by Jodi Bassett et al on "Who benefits from CFS and ME/CFS on the website of the Humming Bird Foundation for ME (HFME).

The Orphan Drugs Act is a complex topic that requires a good working knowledge of management, economics and finance. I have written to the Chairman of the European M.E. Association and other ME groups in different European countries suggesting that we should register M.E. as an Orphan disease.

This will enable them to join an action group with the aim of promoting clinical research on M.E. by Pharmaceutical Companies in different jurisdictions. I will shortly be writing to American ME groups seeking their support to promote ME as an orphan disease. It will be hard work like most fund raising but the reward in terms of cutting six years the time spent suffering by ME patients will make it more than worth the effort.

In part two, I will not be discussing the Orphan Drugs Act further, instead, I will focus on the need to decide on the priorities that should be set in working on the sub-diseases of M.E.

Dr. Lionel Wardle

His longer article "Things have never looked brighter for M.E." you will find here http://let-me.be/request.php?32
Please mail any reaction to info@let-me.be

#MillionsMissing Protest in 12 Locations all Over the World

On Wednesday, May 25, ME/CFS patients, caregivers and advocates in nine cities around the world gathered for a global day of action to demand equal treatment and an end to the stigma of the diagnosis of ME/CFS.

Protesters demonstrated in front of Department of Health and Human Services offices in Washington D.C., Atlanta, Boston, Dallas, San Francisco, and Seattle to demand Secretary of Health **Sylvia Burwell** take leadership to end thirty years of scientific and medical neglect. A #MillionsMissing protest was held in Raleigh, North Carolina, as well.

A #MillionsMissing protest was held in London at the Department in Health. Over a hundred protested, approximately 350 pairs of shoes were on display, and several officials stopped to speak to those in the crowd.
In Melbourne, the display of shoes outside of the State Library of Victoria was impressive.

The Canadian virtual protest sent over 500 emails to MPs and PM **Justin Trudeau**. The virtual protest has generated over 10,000 tweets with the hashtag #MillionsMissing, which trended on Facebook and Twitter.

There were even some unannounced #MillionsMissing displays in Ottawa and in the Netherlands.

"It was so amazing to see the outpouring of support from patients, caregivers, family and friends," said **Stacy Hodges**, a patient from North Carolina and organizer of the Washington, DC protest. "We are fed up and we demand equal treatment. Now is our time."

"It didn't take me very long to figure out that we are repeating history with ME," said **Terri Wilder**, an ME/CFS patient and member of AIDS advocacy organization, ACT UP New York. "I'm having déjà vu. AIDS patients were made invisible and their real-world knowledge about the changes that needed to be made to end the crisis was ignored."

The US protesters plan to deliver a list of demands to Secretary of Health **Sylvia Burwell** and regional offices including equal research funding and medical education.

“There is no funding for research and the disease is taught in only 5% of medical schools,” said **Jennifer Brea**, co-founder of the #MEAction advocacy group, which is organizing the protests. “The Secretary’s office needs to take leadership.”

Millions Missing demonstration in Washington, DC. (Photo by Mary F. Calvert)

“Today is only the beginning,” **Brea**, said. “We are going to keep fighting until we get what we need and deserve.”

http://bit.ly/28OL3O7

Who am I?

Guest blog by **Anna Wood**, a severe ME veteran of 8 years and physics education researcher. **Anna** writes about how work defines our identity and how not being able to work due to M.E. affects this.

How many times do conversations with strangers end up being about what job you do? My hairdresser asked me recently if today was my day off and even the decorator, recognizing that I don't have a Scottish accent, wondered if I had moved to Glasgow for work.

I am housebound with severe-ish ME. What should I say to these questions? What would you say?

One of the side-effects of chronic illness, and of ME in particular is the effect it can have on your identity. If you thought about it pre-illness (and let's face it, most of don't/didn't think about it when we were well), we would have been clear who we were. Most people define themselves by what they spend the majority of their day doing. If you work, then you think of yourself as, say, a solicitor, or a digger driver. If you look after your children you think of yourself as a mother or father, if you are at school or university you think of yourself as a student.

But when we get ill that changes – often we can no longer do the things that we thought defined us.

Yet we are constantly being asked about our identity – even twitter requires you to write a short biography about yourself. So if I can no longer work – who am I now? Some people say that we shouldn't be defined by what we do, that we are also someone's daughter, or son, sister or brother, someone's friend or lover. I am some of these – I'm a sister, a daughter, a friend and a wife. But I don't want to be defined simply in relation to others (in part because I'm only rarely able to actively engage in these relationships). But for me, it is also important for identity to be about defining who I am simply for myself. I think that what we do does define us, but that doesn't need to be a negative thing, even for someone with a chronic illness.

One thing I have learned is that identity is fluid. It changes with the time of day, with the week, with the season. Of course this happens for healthy people too. An engineer comes home to her family and is now a wife, or a mother. But with chronic illness these shifts are even more pronounced.

For example, in a relapse I focus on myself, I try to see myself compassionately as someone who is sick and needs looking after. This changes my identity. Rather than seeing myself as a 'sick person' with a chronic illness, I become a carer – of myself. In fact, is has been shown that it is helpful for people with ME to view their illness as their job. I agree with this. Focusing on what you need and who you are is not a failing, or a sign of weakness. It is acknowledging how things are in this moment.

When I'm in a better phase I'm able to do research in collaboration with Edinburgh University. Then I see myself as an academic, though in reality, even on good days I spend much more time not doing research as doing it. But still, it gives me a different identity, and I value that.

None of this really helps with answering those 'so what do you do then?' type questions. I still dread them. Sometimes I bend the truth, saying 'I now work from home doing research'. Other times I dodge the question simply saying 'oh yes I was working at the university', then change the subject.

But this week, for ME awareness I will make sure that I give the unvarnished truth. I shall say it as it is – 'I was working and then I became ill with ME, and now I'm pretty much housebound.' I will take the opportunity to mention it because these opportunities are so rare and because many people do not know what effect ME can have, or how severe it can be. I hope that this will help, in some small way to raise awareness of this devastating illness, and I hope that if you get the opportunity, you will do too.

Over to you: How do you define yourself? How did you decide what to put on your twitter profile? You can leave a comment in the comments section.

Anna Wood is a severe ME veteran of 8 years and physics education researcher. She blogs (mostly about science education) at http://learningfrome-learning.blogspot.com and can be found on twitter @annakwood

Source: http://bit.ly/28N4BS1

Taken from **Emily Beardall**'s blog A prescription for ME https://aprescriptionforme.wordpress.com/

7. Karina Hansen, Save4Children

Help Karina – donate to Save4Children

Fund for children with ME who are outplaced against their will, as ME in most countries is considered as a non-physical disease, at times children are forcibly removed from their parental home and outplaced under foster care or in wards of (psychiatric) hospitals. Save4Children is meant to cover the expenses for second opinions by ME-experts on paediatrics, and in some cases to financially help families with outplaced children which cannot afford legal assistance themselves. Thus hoping to influence legal procedures granting the parent(s) their parental rights back.

Organisation Save4Children

We are an international group of ME/CFS patients and advocates who are standing up for parents whose children are unrightfully and against their wills outplaced and put under foster care or even in psychiatric wards, which greatly deteriorates their health.

Where does your money go to

Donations made to this fund will presently solely be used to provide financial support for expenses needed to try and set free **Karina Hansen**, a young ME-patient who was taken from her home against her will in February 2013 and placed under psychiatric care.

The present situation: Karina Hansen

After a long search Danish ME-activist **Bente Stenfalk** together with the Danish Civil Right movement succeeded in finding a highly qualified lawyer, **Christina Poblador** willing to study the case.

Just a few days ago **Bente** received word from her that she expected to discuss the case this very week with **Karina**'s parents and that If they agree she will gladly inform them about the status and next step in the case.

So all the reason to continue to donate to the fund:
http://let-me.be/page.php?11

We published a very detailed and extensive article by Valerie Eliott Smith in last MEGC (http://let-me.be/request.php?31, p. 48-52)

Information about **Karina** and the case can be found in this and future issues of the ME Global Chronicle and at these sites:

Justice for Karina Hansen - find info under notes.
https://www.facebook.com/JusticeForKarinaHansen

Two videos about Karina from 2013:
http://www.youtube.com/watch?v=Dk3e8IWj7M0
http://www.youtube.com/watch?v=JTkkcvlvYf8

The ME Global Chronicle Special Karina Hansen 20151025:
http://let-me.be/download.php?view.24

The Citizen's Rights Group of Denmark-documents in the case in Danish:
http://xn--borgerretsbevgelsen-xxb.dk/

8. Science

Rich' Reviews: New Form Of Magnesium.

A new form of magnesium improves cognitive powers in old folks will it also help the brain fog of FM and ME-CFS? Might it also improve Fibromyalgia pain?

By Richard Podell, M.D, MPH

Cognitive function tends to declines as we age. For most people the decline is modest. This "semi-normal" decline is thought to be due in part to a decrease in the ability of cells to form communication contacts called synapses between one cell and another. A similar defect is seen with Alzheimer's disease.

Animal studies show that one way to increase the number and function of synapses is to raise the brain's level of the mineral magnesium. When scientists increase brain magnesium in lab rats, the rats become smarter—thinking more rapidly and accurately than they did before.

BUT, most forms of oral magnesium don't pass easily from the blood into the brain. An exception is a new form of magnesium developed by a research team from MIT specifically for this purpose. This form is magnesium threonate, which is being developed Neurocentria, Inc., a pharmaceutical company, under the brand name of MMFS-01.

Neurocentria's team with collaborating researchers from both the U.S. and China recently published a very important study. Their results strongly suggest that MMFS-01 can substantially improve cognitive function in aging humans. LINK to the original research report: http://bit.ly/28SxZGm

Link also to a press release from Neurocentria, Inc.: http://bit.ly/28SpF7d

MMFS-01 is not yet commercially available. However, a "generic" magnesium threonate is available from the Life Extension Foundation under the brand name of Neuro-mag. Likely other "generics" are or will soon be available.
Link: http://bit.ly/28YvaEJ

What is truly remarkable about the MMFS-01 study is that improvement in over-all cognitive function was seen within just six weeks. Improvement continued through 12 weeks, the full length of the study. Subjects treated with placebo did not improve much over-all.

More details for the study: The volunteers were age 50 to 70. All had test score evidence of mild cognitive impairment. Twenty five subjects took MMFS-01 and 26 took placebo. The treatment dose was between 1.5 and 2.0 grams per day in divided doses.

Four different cognitive tests were taken before treatment and again at six and twelve weeks. These tests measured executive function, working memory, attention and a concept called episodic memory.

With magnesium threonate executive function significantly improved compared to placebo at 6 and 12 weeks.

Working memory improved significantly at six weeks but at 12 weeks the placebo group had improved also. So, the difference between the groups at 12 weeks was no longer statistically significant.

Attention improved in the MMFS-01 group compared to baseline, but this improvement was not statistically better than for those taking placebo.

Episodic memory improved with MMFS-01 by week 12, but was not significantly better than that seen with placebo.

When over-all cognitive ability was calculated by combining results from the four tests, subjects taking MMFS-01 scored significantly better than subjects taking placebo. This was true at week 6 (P=.017) and at week 12 (p=.003).

As important--subjects taking MMFS-01 who had the largest increase in red blood cell magnesium levels, were also the subjects most likely to show major cognitive improvement. There were no major side effects.

Separate research suggests that magnesium might also help treat fibromyalgia pain. This might be because magnesium tends to inhibit the activity of NMDA receptors. Activation of NMDA receptors is believed to be one mechanism that creates fibromyalgia pain. A recent open label clinical study from Mayo Clinic found that transdermal magnesium chloride spray taken twice daily for 3 weeks was followed by a reduction in fibromyalgia pain. Link: http://bit.ly/28SpF7d

Key Questions: Should physicians treating FM or ME-CFS "brain fog" be offer magnesium threonate as a potential treatment?

The arguments against:

- We don't know whether brain fog in fibromyalgia or ME-CFS has any relationship to the cognitive decline that is common with aging.
- We have only one clinical study to support the beneficial effects of magnesium threonate.

The argument for:

- Brain fog is a major problem for our patients
- We have no proven treatments
- For most (but not all patients), side effects from magnesium are minimal—mainly diarrhea if we get the dose up too high.

Should patients with FM or ME-CFS try magnesium threonate on their own? I strongly recommend that all patients work with their doctor. Certain patients should not take extra magnesium, especially those with any degree of kidney dysfunction. Also, it would be useful to obtain a baseline red blood cell magnesium level and to monitor that level as treatment proceeds.

Since MMFS-01 is not available, using Life Extension's or other generic equivalents would be appropriate.

Of course, ideally, some angel would fund a good controlled study. But, as usual, that's not likely to happen anytime soon.

Richard N. Podell, **M.D.**, **MPH**
Clinical Professor
Department of Family Medicine
Rutgers-Robert Wood Johnson Medical School
Podell2@gmail.com

$3.3 Million Federal Grant To Fund JAX Chronic Fatigue Syndrome Research

Professor Derya Unutmaz, M.D., (http://bit.ly/1tAjtL9) of The Jackson Laboratory for Genomic Medicine, will receive five years of funding — totaling $3,281,515 from the National Institute of Allergy and Infectious Diseases — to find better ways to diagnose and treat Myalgic Encephalomyelitis (ME), the debilitating and mysterious condition more generally known as chronic fatigue syndrome (CFS).

According to the U.S. Centers for Disease Control and Prevention, between 836,000 and 2.5 million Americans suffer from ME/CFS. Symptoms include profound fatigue, cognitive dysfunction, sleep abnormalities and pain.

Researchers have identified several potential environmental triggers and faulty immune system components associated with ME/CFS, but the immunological basis for the disease remains murky. Moreover, the symptoms and severity of ME/CFS vary widely among patients.

Joyce Peterson
Source : http://bit.ly/261g895

Identification And Symptom Management Of Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS)

New Clinical Practice Guidelines for ME/CFS

TOP's new Clinical Practice Guideline (CPG) responds to the need for greater awareness that Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS) is a complex, chronic, debilitating physical condition that can be identified and successfully managed in the primary care setting.

The CPG aims to equip clinicians with the necessary knowledge and tools to identify and provide symptom management while empowering the patient by acknowledging the legitimacy of the condition and respecting the patient's lived experience.

Toward Optimized Practice (TOP) is one of several key programs within the Alberta Medical Association supporting Alberta physicians. TOP works with Alberta physicians and the teams implement evidence-based practices to enhance the care of their patients http://www.topalbertadoctors.org/home/

To view both the CPG and summary document go to: http://bit.ly/1Py7Et3

Clinical Practice Guidelines (CPG) are documents which take into account all of the published, peer reviewed medical literature and make recommendations based on that evidence.

Evidence based guidelines exist in fields like treatment of heart disease where multiple large studies of the same treatment can be compared statistically. In cases where the evidence isn't conclusive many guidelines end up recommending nothing. While statistically accurate, this approach is unhelpful for clinicians who desperately need guidance while waiting for stronger evidence to accumulate.

An evidence informed guideline fills this gap by including expert opinion/consensus where needed. As long as this process is transparent (doesn't imply things are "proven" when they are not) evidence informed guidelines provide a valuable source of information to clinicians.

This new guideline is evidence informed combining a thorough review of the literature with expert opinion derived in large part from the IACFS/ME 2014 Primer for Clinicians http://bit.ly/1UA9cbI

The Guidelines use the Canadian Consensus diagnostic criteria developed in 2003 http://bit.ly/1Yxdemn

This CPG was drafted by an expert committee of Towards Optimal Practice (TOP). I served as the content expert on the committee. We also had one scientist/researcher, one patient advocate, one psychologist and 3 family physicians on the committee.

All the committee members have considerable knowledge of and experience with individuals with ME/CFS. We had access to a professional librarian to access all of the literature needed and a professional guidelines facilitator to draft the guidelines. It was a positive experience with everyone agreeing on the importance of the task and having an understanding of the unmet needs of individuals with ME/CFS. I am very proud of the guidelines.

My hope is that these guidelines will be promoted and used across jurisdictions in Canada and abroad. All family physicians and relevant specialists in Alberta were sent an email about these guidelines. Please read these guidelines and consider lobbying for adoption in your area. If you are a patient, please discuss these guidelines with your doctor. Maybe they can help him/her help you.

For more information, please contact me.

Ellie Stein MD FRCP(C)

4523 – 16 A Street SW
Calgary, Alberta T2T 4L8
Phone: 403 287-9941 Fax: 403 287-9958
e-mail: espc@eleanorsteinmd.ca
web: http://www.eleanorsteinmd.ca

ME & mitochondrial functioning

Three studies **of Prof. Garth Nicolson**

We have been involved in research on the role of mitochondrial function in ME/CFS for some time and have found that restoring inner mitochondrial membrane (IMM) trans-membrane potential is essential. When mitochondrial membrane lipids are damaged, the IMM becomes leaky and the membrane potential cannot be sustained, which results in loss of ATP production and increases in fatigue.

Since 2003 we have published several scientific papers that show that ME/CFS and other chronic illness conditions, including chronic infections like Lyme disease, chronic Mycoplasma and other complex infections, cause IMM dysfunction that can be repaired by Membrane Lipid Replacement (MLR) with NTFactor Lipids, resulting in improvements in fatigue, cognition, short-term memory and mood (**Nicolson**, **G.L.** Membrane Lipid Replacement: clinical studies using a natural medicine approach to restoring membrane function and improving health.
International Journal of Clinical Medicine, 2016; 7: 133-143.
http://bit.ly/1YwwLnd

NTFactor Lipids is an all-natural membrane glycerolphospholipid product (for example, Patented Energy, http://www.NTFactor.com). This has been reviewed recently in our article in Discoveries 2016 (**Nicolson**, **G.L.**, **Rosenblatt**, **S.**, **Ferreira de Mattos**, **G.**, **Settineri**, **R.**, **Breeding**, **P.C.**, **Ellithorpe**, **R.R.** and **Ash**, M.E. Clinical uses of Membrane Lipid Replacement supplements in restoring membrane function and reducing fatigue in chronic diseases and cancer. Discoveries 2016; 4(1): e54.) http://bit.ly/21quIjN

There are other potential useful benefits of MLR that we rarely discuss, such as the removal of excess, potentially toxic, cholesterol from cellular stores. (Presumedly similar mechanisms exist for removal of the damaged membrane glycerolphospholipids and their secretion and eventual excretion).

As quoted in an article just published in Lipid Insights by **Thomas A. Lagace** of the University of Ottawa Heart Institute, "Phosphatidylcholine plays a critical role in cellular cholesterol sinks that buffer against cholesterol-induced ER stress and assist in the maintenance of cellular cholesterol gradients that drive interorganelle cholesterol transport." (Lagace, T.A. Phosphatidylcholine: greasing the cholesterol transport machinery.
Lipid Insights 2015; 8(S1): 65-73. doi:10.4137/LPI.S31746).

Phosphatidylcholine is the most prevalent lipid in NTFactor Lipids, and it plays an essential role in cholesterol transport and its removal at the cellular level and at the organ and systems levels. This may be due to a rather simple concentration gradient mechanism that sequesters cholesterol and oxidized glycerolphospholipids into Lipid Droplets for their eventual removal.

This could explain why our ME/CFS patients have better cholesterol, homocysteine and other blood tests after 6 months on MLR. (**Ellithorpe**, **R.R**, **Settineri R.**, **Ellithorpe**, **T.** and **Nicolson**, **G.L.** Blood homocysteine and fasting insulin levels are reduced and erythrocyte sedimentation rates are increased with a glycophospholipid-vitamin formulation: a retrospective study in older subjects. Functional Foods in Health and Disease 2015; 5(4): 126-135.)
http://functionalfoodscenter.net/files/102987419.pdf

Eventually the use of MLR may enhance and hopefully replace costly cholesterol-reducing drugs (with side effects) that Big Pharma has been pushing for some time. For years ME/CFS patients have benefited from NTFactor lipid products without adverse reactions or events.

Submitted by
Prof. Emeritus Garth Nicolson, PhD, MD (H)
Department of Molecular Pathology, The Institute for Molecular Medicine
http://www.immed.org

Progressive Brain Changes In Patients With Chronic Fatigue Syndrome: A Longitudinal MRI Study

Zack Y. Shan, PhD, **Richard Kwiatek**, MBBS, **Richard Burnett**, MBBS, **Peter Del Fante**, MBBS, **Donald R.Staines**, MBBS, **Sonya M.Marshall-Gradisnik**, PhD, and **Leighton R.Barnden**, PhD

Abstract

Purpose
To examine progressive brain changes associated with chronic fatigue syndrome (CFS).

Materials and Methods
We investigated progressive brain changes with longitudinal MRI in 15 CFS and 10 normal controls (NCs) scanned twice 6 years apart on the same 1.5 Tesla (T) scanner. MR images yielded gray matter (GM) volumes, white matter (WM) volumes, and T1- and T2-weighted signal intensities (T1w and T2w). Each participant was characterized with Bell disability scores, and somatic and neurological symptom scores. We tested for differences in longitudinal changes between CFS and NC groups, inter group differences between pooled CFS and pooled NC populations, and correlations between MRI and symptom scores using voxel based morphometry. The analysis methodologies were first optimized using simulated atrophy.

Results
We found a significant decrease in WM volumes in the left inferior fronto-occipital fasciculus (IFOF) in CFS while in NCs it was unchanged (family wise error adjusted cluster level P value, $P_{FWE} < 0.05$). This longitudinal finding was consolidated by the group comparisons which detected significantly decreased regional WM volumes in adjacent regions ($P_{FWE} < 0.05$) and decreased GM and blood volumes in contralateral regions ($P_{FWE} < 0.05$). Moreover, the regional GM and WM volumes and T2w in those areas showed significant correlations with CFS symptom scores ($P_{FWE} < 0.05$).

Conclusion
The results suggested that CFS is associated with IFOF WM deficits which continue to deteriorate at an abnormal rate.

Source & complete research:
http://onlinelibrary.wiley.com/doi/10.1002/jmri.25283/epdf

The Biological Challenge Of Myalgic Encephalomyelitis / Chronic Fatigue Syndrome: A Solvable Problem.

Professor **Jonathan Edwards**, along with several ME/CFS patients and a carer with scientific backgrounds have co-authored a peer-reviewed editorial (http://bit.ly/1OwHnQX) on the disease that appears in the latest issue of the journal Fatigue: Biomedicine, Health & Behavior (http://bit.ly/1OwH5JM).

The article is titled, The biological challenge of myalgic encephalomyelitis/chronic fatigue syndrome: a solvable problem (http://bit.ly/1OwHnQX). The paper has gained over 1600 views in the three days since publication, making it already Fatigue's second most-read paper since the journal began in 2013.

The paper is an overview of the most promising developments in biomedical research into ME/CFS. The authors "call on the wider biomedical research community to actively target this condition" and make a "concerted effort."

Simon McGrath, an ME/CFS patient well-known for his blogs (http://bit.ly/1WVGHqP) on the science of the illness, was one of the editorial's authors. He said, "We felt it was time to make the case for biomedical research, aiming to summarise the most promising research, while acknowledging its limitations".

He added, "The aim of the paper is to provide a 'way in' to biological ME/CFS research for researchers who might be interested but were overwhelmed by the vast literature of mainly unconfirmed findings, or those who doubted there was anything of merit in biological research."

The paper includes what he described as "the most interesting studies, including the two-day exercise challenge, changes in gene expression after moderate exercise, and brain scans indicating microglia activation". The editorial also highlights the promising rituximab treatment pilot studies and ongoing trial (http://bit.ly/1V75emz).

He added that the article "sets out some possible general models, and proposes some important practicalities including better infrastructure/cohorts, stress-testing, replication, and exploring immunological, autonomic and CNS factors."

The team used a private subforum on the online ME/CFS forum Phoenix Rising (http://bit.ly/1YyYFPk) to collaborate on the work. **McGrath** thanked Phoenix Rising and its organisers, and said, "We live in three different countries and have still never met, but it shows what can be accomplished when patients are given the tools… for discussion".

He added that the project had been possible because a researcher had been "willing to judge patients by what they can contribute, not who they are… a lot of researchers would not dream of doing so".

Emeritus Professor Edwards of University College London is well known in the ME/CFS community for his work supporting B-cell research and the effort to have a rituximab trial in the UK. He proposed (http://1.usa.gov/28ObR7z) in 1999 that self-perpetuating B lymphocytes drive human autoimmune disease and his 2004 studies (http://bit.ly/1YyXCyN) of rituximab for rheumatoid arthritis, published in the New England Journal of Medicine, confirmed the concept.

Source: **MEAction** http://bit.ly/1UVr1QU

Science to Patients

Since last ME Global Chronicle: http://let-me.be/request.php?31 four webinars of **Dr. Neil Harrison** have been broadcast by the Dutch ME/cvs Vereniging (http://www.me-cvsvereniging.nl):

#78, April 19, 2016: ME & the brain, part II: parts of the brain associated with ME, connection brain-immunesystem, connection brain- gastrointestinal track, cognitions & priming and strongest arguments that ME is not a psychic condition: https://youtu.be/q4SsixfuYKE

#79, May 3, 2016: ME & inflammation, part I: general effects of inflammation on the body, general effects of inflammation on the brain & relation to feelings of fatigue, different responses to an inflammation in ME, different effects of inflammation, and interferon: https://youtu.be/K4br0X7CJE0

#80, May 17, 2016: ME & inflammation, part II: ME-patients & inflammation: the differences, evidence of inflammation in the blood after the infection is gone, evidence of effect of inflammation in the brain after an infection, evidence of brain-inflammation in ME, and microglia and their function: https://youtu.be/BdkKWf13huM

#81, May 31, 2016: ME & diagnosis: present and future possibilities and technologies, what is an MRI and what is an fMRI, SPECT- & PET-scans, other hopeful possibilities, and if he expects a breakthrough in research on ME: https://youtu.be/hlR0J3rJdfs

Presently seven webinars of **Dr. Byron Hyde** from Canada are in preparation, which will be broadcast during this fall/winter.

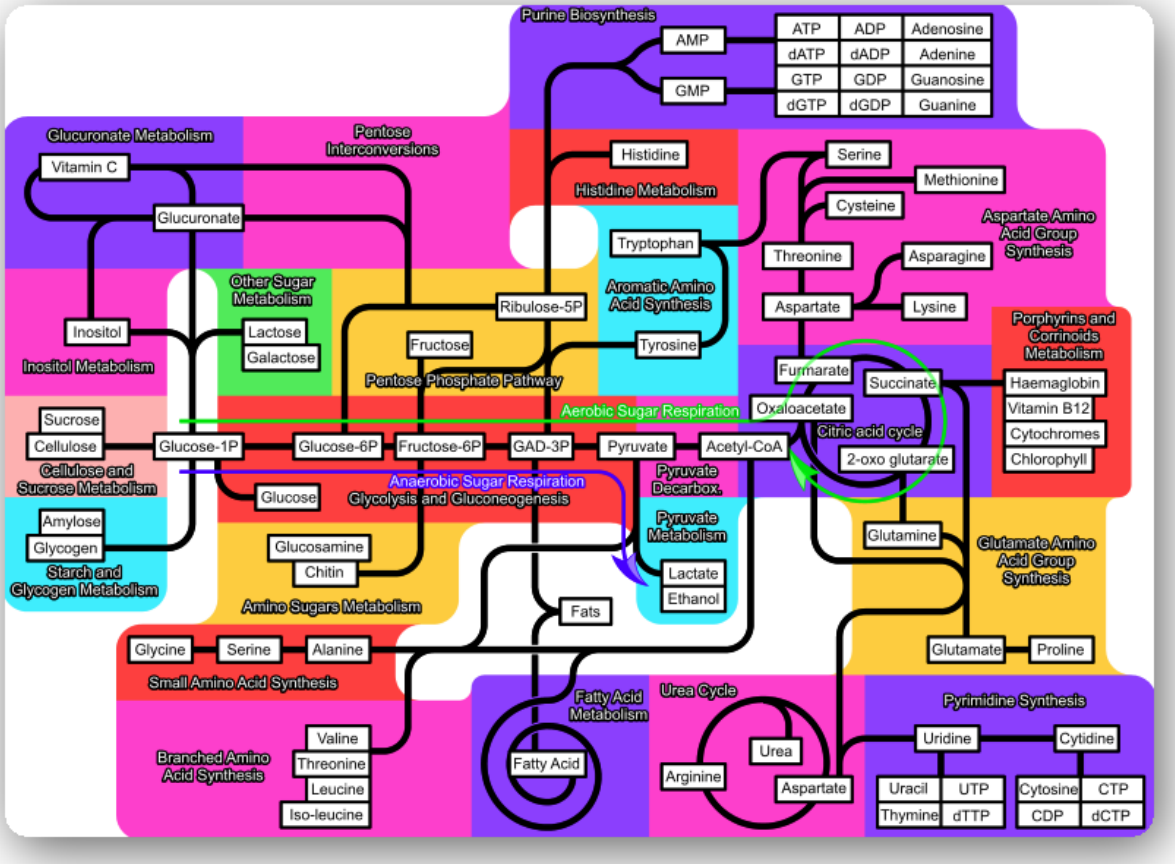
For all video's up till now see http://www.wetenschapvoorpatienten.nl/

It is striking that even the first webinars of 2012 still contain a treasure of still actual and enlightening information.

Metabolomics & ME

Professor **Ron Davis** presented new findings from his Big Data study at the Invest in ME 2016 conference on June 3, 2016. **Davis**'s preliminary data show serious problems with the biochemical processes needed to convert sugars and fats from food into energy the body can use. If these findings are replicated, this could prove a major step forward in understanding ME/CFS.

Davis's study is unusual: it's small with just twenty patients and ten controls, yet generated two billion data points; in fact, the researchers' biggest problem is dealing with so much data.



Cellular metabolism is incredibly complex, requiring and producing a wide variety of chemicals to function, day to day.

The strategy for the study was to focus on severely ill patients because their biology would show the greatest differences compared with healthy controls. In the past, bedbound, severely ill ME/CFS patients have often been viewed as simply too difficult to study, rather than as key to making progress.

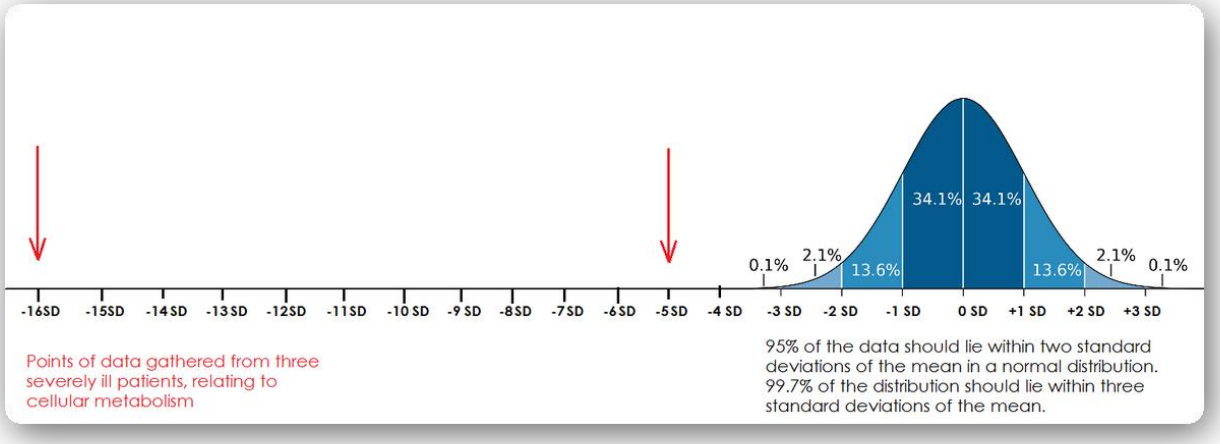
The purpose of the study was to collect a prodigious amount of data and use it to identify biomarkers. The study examined a huge number of aspects of patient biology including immunology, proteomics (the production and interplay of proteins), and gene expression. But the main finding revealed at the conference related to metabolomics, the "systematic study of the unique chemical fingerprints that specific cellular processes leave behind" (http://bit.ly/1UHI1HZ). Metabolomics can help to reveal what's going on, and what's going wrong in cells.

Metabolomics is very expensive because it needs some very high-tech equipment, and that limits sample size. The study was only possible because the work was done at cost by new company Metabolon (Metabolon). In fact, **Ron**'s son **Whitney Dafoe** was the first person ever studied using Metabolon's new process. So far, just three sick patients were studied, and were compared with 43 controls.

Tiny sample, huge differences

To find a meaningful difference in such a small sample would usually be impossible – only an enormous difference between patient and controls could be statistically significant because so much variation could be down to the "random noise" of chance. In this case, the differences were vast enough to be considered significant; and, as **Professor Davis** told the audience, studying three people is not a big study but in personalized medicine, you can learn from just one patient.

Professor Davis illustrated just how big the difference is by using standard deviations, the most common measure of differences in science. The standard deviation is a measure of how much the data within a sample varies on a particular variable (http://bit.ly/1tCOBJY), such as people's height or blood sugar. At least one data point from **Whitney Dafoe**'s energy metabolism molecules was 16 standard deviations away from the average of the control group. To put that into perspective, 99.7% of all data should fall within three standard deviations away from the average in either direction, and only 0.3% beyond that boundary. The more standard deviations the data is from the average, the less likely that the difference is due to chance. Findings from ill patients that are sixteen standard deviations away from the average in healthy patients is extraordinary.



Patients had big problems generating energy.

The metabolomic data in the three patients who were examined highlighted that the main metabolic engine of energy molecule generation – the citric acid cycle (http://bit.ly/24YKOSw) in mitochondria – isn't working properly. Glycolysis also does not look like it's working very well in patients.

Researchers were able to determine these errors by looking at the molecular byproducts of the cell and noting abnormalities in the compounds usually consumed and generated by these reactions. The basic biochemical process to turn sugars from food into energy molecules just wasn't delivering for patients.

This might not surprise many patients, but it's big news in the world of ME/CFS research. There have been findings along these lines before, notably on the second of a two-day maximal exercise test (the day one test results look normal), and in a study on the products of glycolysis (http://bit.ly/1Ui24Cl) in the blood and urine of ME patients by **Christopher Armstrong** and colleagues.

More research is needed to replicate these findings, and such a study is already in the works; but this could be the start of a dramatic shift in the field.
Ron Davis, who has previously studied patients with physical trauma also noted that mitochondria "shut down" in these patients and said that a key question is why they don't start up again in ME/CFS patients.

Davis said that his son **Whitney** showed errors in B-vitamin metabolism, resulting in a very rare deficiency of biotin; this is important, because enzymes in the citric acid cycle are dependent on biotin. In another patient, tryptophan metabolism was a problem.

Professor Davis's talk generated excitement both at the conference and among those following the Twitter coverage. His wife, **Janet Dafoe**, commenting on his talk, said that his team hoped to work quickly towards tests for personal biomarkers for all patients. She said of the research, "*We know it's frustrating and that people are rightfully chomping at the bit! So am I! Every morning… when I wake up, he brings me coffee and I quiz him about what has happened that day so far. I wish you could all be flies on the wall. It's so exciting. If everyone knew all of what he's doing, I can't believe he wouldn't get big funding.*"

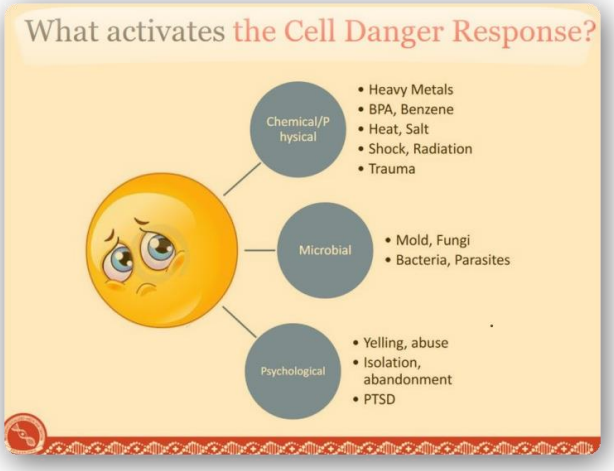
Donations can be made to **Professor Davis**'s work via the Open Medicine Foundation. **Janet Dafoe** has noted some confusion in regards to the OMF, the OMI, and the CFS Research Center; donating to the Open Medicine Foundation is the best way to make contributions. Please note that this article is based solely on tweets from Phoenix Rising's team (http://bit.ly/1Ui3WLv) and **Maija Haavisto** (http://bit.ly/1QdSbEd), who were at the conference. Huge thanks to them: tweeting on the fly about a technical presentation is not easy. The article has not been checked with **Professor Davis**, and any errors are ours. **Jaime S** and **Alex** made significant contributions to this article.

Simon McGrath

Expanded ME/CFS Metabolomics Study

In May 2016, we launched an Expanded ME/CFS Metabolomics Study led by and in collaboration with **Dr. Robert Naviaux** (http://bit.ly/28OBC11) (at UC San Diego), **Dr. Eric Gordon** (http://bit.ly/28QqP6d), **Dr. Paul Cheney** (http://bit.ly/28N8dSU), and the Stanford Genome Technology Center (http://stan.md/28NebSA) under the direction of our ME/CFS Scientific Advisory Board director, **Ronald W. Davis**, **PhD** (http://bit.ly/28OBC11). The purpose of this study is to validate earlier findings of a possible diagnostic signature for ME/CFS by measuring metabolites.

Dr. Naviaux completed an initial study of 90 participants (both healthy controls and patients) that showed abnormal metabolites in patients.



The abnormalities indicate the mitochondria is in hypometabolism due to a chronic cell danger response (http://bit.ly/28MZaE1) state in ME/CFS patients (http://bit.ly/28Mn2mA).

This second study is an expansion of the first one, testing a new set of patients from different parts of the country to see if they also have the same abnormal metabolites as did the patients in the first study. Verifying these findings could lead to a diagnostic tool for the disease and pilot studies for possible treatments.
The total participants in this validation study are 110 and include patients from across North America, plus geographic, gender and age-matching healthy controls. The patients meet the IoM, Canadian, and Fukuda criteria.

The metabolite tests that were done in **Dr. Naviaux**'s first ME/CFS metabolomics study have also been conducted in the patients participating in our ME/CFS Severely Ill-BIG DATA Study. So this Expanded ME/CFS Metabolomics Study cohort is a third group that could validate the initial abnormal metabolites findings. We expect the Expanded ME/CFS Metabolomics Study to take one year from launch date to study publication.

Read **Dr. Naviaux**'s explanation of this study (http://bit.ly/28SZQVo).

Source: Open Medicine Foundation
http://www.openmedicinefoundation.org/expanded-mecfs-metabolomics-study/

9. 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

IMEC 11th Invest in ME conference, London, June 3, 2016

11th Invest in ME conference, London, June 3, 2016

The Invest in ME Conference Events have become an increasingly bright focal point on the global calendar for anyone with an interest in progress in biomedical research on this disease over the past 10 years. The 2016 events were held at an impressive new venue, One Great George Street, close to the former venue in the heart of Westminster, London, UK.

The charity's 6th Biomedical Research into ME Colloquim #BRMEC6 took place over the two days 1st & 2nd June. This is a closed workshop in which the world's leading and emerging biomedical researchers in the field may freely discuss and share their ideas and current work, which may be as yet unpublished, and plan collaborations to benefit patients worldwide by establishing biomarkers for differential diagnoses and potential treatments.

Over 200 delegates at the charity's 11th public conference #IIMEC11 on 3rd June included patients, carers and a range of professionals in the fields of science, healthcare, politics and media. There was a photo opportunity to get #UnderTheUmbrella of the European Federation of Neurological Associations on behalf of member organisation since 2015, the European ME Alliance.

The full conference presentations will be on the IIMEC11 DVD, as well as a very moving and powerful presentation by **Kjersti Krisner** from Norway, mother of three children with ME, and the performance by professional violinists, **Emanuela Buta** and her husband **Carmine Lauri**, kindly given at the pre-conference evening dinner before going on tour.

To mark the 10th anniversary of Invest in ME, Chairman **Kathleen McCall** presented Victory Awards to key supporters since the work of the charity began; **Declan Carroll** and **Michael O'Reilly** of the Irish M.E. Trust, **Dr. Daniel Peterson** of Simmaron Research, **Dr. Ian Gibson**, and **Professor Malcom Hooper**. The awards were in the form of pens made of wood from HMS Victory. **Admiral Lord Horation Nelson** was from Norfolk, the hub of the charity's Centre of Excellence.

Other events during the week included the AGM of the European ME Alliance and a meeting of their European ME Research Group, formed in 2015 and which **Professor Simon Carding** spoke about in his conference presentation.

Reports from numerous sources suggest a buzz of excitement among the researchers themselves and unanimous agreement that these were the best yet IIMEC Events, something that's been said every year since their first international conference in 2006, and is echoed in the words of Henry Ford, which were chosen by the charity as the theme for BRMEC6;

"Coming together is a beginning, keeping together is progress; working together is success."

IIMEC11 Conference Report -
http://investinme.eu/IIMEC11.shtml#report

IIMEC11 Conference Report in pdf -
http://bit.ly/28RVFqX

IIMER Journal, Conference Edition -
http://bit.ly/28SmTCX

Order IIMEC11 DVD -
http://investinme.eu/IIMEC11.shtml#dvd

IIME BRMEC6 -
http://investinme.eu/BRMEC%20Colloquiums.shtml#BRMEC6

IIMEC11 & BMREC6 News (including pre-conference presentations & awards) -
http://investinme.eu/IIMEC11-news.shtml

IIME Conference Events Sponsors -
http://investinme.eu/IIMEC11.shtml#sponsors

Submitted by **Jo Best**

The 4DVD conference-video of all presentations of the 10th international conference on May 29, 2015 can be ordered here:
http://www.investinme.eu/IIMEC10-DVD-Order.shtml

10. ME And Children

A Parent's Perspective: Lost Voices As The Years Pass

A presentation given by **Natalie Boulton** at the Hope 4 ME & Fibro conference in Belfast - June 6th 2016.

Some extracts

Full text and video clips at: http://bit.ly/23fYglv

"One of my friends has a daughter who is ill with severe ME. In her medical notes it was recorded, less than three years ago, that the hospital was advised by the influential regional CFS paediatrician that; "N.G. [naso-gastric] tube feeding is not part of the spectrum of even severe CFS". Alternative diagnoses of an eating disorder, or a mental health problem were therefore suggested, even though the child had not even been seen by that paediatrician, at that point. The child had originally been admitted to hospital with a mistaken diagnosis of idiopathic chronic pain syndrome - for which the treatment was intensive physiotherapy.

This had caused her to deteriorate disastrously, to the point of needing tube feeding and experiencing intermittent paralysis in her legs and arms. Further problems arose later when the same paediatrician, (having by then seen the child briefly), informed the hospital that paralysis is not part of the clinical presentation of CFS/ME, and gave a new diagnosis of disassociation/conversion disorder. It was also advised that children do better if the anxiety, expected to develop in a long term condition, is treated. I think many people would question treatment on the basis of such an assumption.

A few months later while very, very severely ill, the child was subjected to a lengthy interview by social services who were concerned whether, if such severe symptoms exclude a diagnosis of ME, could her parents be making her ill? Within days of making a superhuman effort to answer all their questions and allay their concerns, the child lost her ability to use her voice.

…. So I am concerned that this research could well have the potential to influence paediatricians and doctors around the UK, to accept a similarly restricted definition of severe CFS and ME. My experience is that such severe ME in young people is often preceded by serious mismanagement of their ME having taken place: the consequence of a wrong diagnosis or ignorance. This happened to my daughter's friends **Lynn Gilderdale** and **Naomi**, as well as the child 'B' in 'Voices from the Shadows', **Sophia Mirza** and other young people we know.

I am concerned that a stealthy realignment is taking place, and that what is called CFS, ME or CFS/ME interchangeably and depending on the audience, is being redefined to focus on the large number of generally fatigued children who are much more convenient subjects for research and much more amenable to behavioural management programmes.

Young people who deteriorate severely with such management could then be dismissed as having other diagnoses, not ME/CFS! Individually these families of children with ME are now very, very vulnerable. Other local paediatric research projects have the potential to have a detrimental impact on children with ME…..

So when I consider the future for **Anna** and her friends and for the younger generation of children with ME, I am horrified.

Horrified at the inexorable expansion of a self-perpetuating CFS/ME research and delivery mechanism, involving a Russell Group University, a very large paediatric CFS centre with outposts around the country and a children's charity - with support from the Science Media Centre, and even the CFS/ME Research Collaborative!

The influence of this powerful alliance is sweeping all who stand in its way into oblivion - not only severely ill ME children and their families, but also the only UK consultant specialist in severe paediatric ME who had the courage to be effective in supporting and protecting them.

He has now been silenced via the GMC: is not permitted to see patients, speak at conferences or continue his role with international teams of paediatric ME/CFS specialists. "

Submitted by **Natalie Boulton**

Help Karina – Donate To Save4Children

The charity **Save4Children** has been created by the editors of the ME Global Chronicle (http://www.let-me.be) and helps parents whose children have been forced into psychiatric wards by authorities, to try and set them free by legal procedures, if the parents have proven to be incapable of affording needed legal assistance.

They helped in **Joanne**'s case – the German teenager who has been held under psychiatric care for 18 months, and **Joanne** has been allowed to go home last July. Now they would like to help **Karina Hansen**.

Karina is a severely-ill ME patient who has been held in a hospital against her will for 2 ½ years. Her parents are still not allowed to see her. Her condition is worse now than when she was forcibly removed in 2013.

She can no longer speak in full sentences. She sits in a wheelchair and mumbles to herself. She is allowed to wear her earplugs as she becomes very distressed when they have tried to take them from her.

When she was first taken, she actively resisted treatment and was therefore given the diagnosis of Pervasive Refusal Syndrome.

This is the same diagnosis as **Joanne** was given. Now **Karina** no longer resists treatment and the psychiatrists claim that this is improvement. **Karina** has never resisted eating, which is a core symptom of PRS, so of course this diagnosis is completely ridiculous.

Also, **Karina** is a young adult and PRS is exclusively a pediatric diagnosis.

Although it does not look good for **Karina** at the moment, the fact that "**Joanne**" has been released gives us hope.

If you would like to help, please donate to **Save4Children** at:
http://www.geef.nl/doel/save4children

The money that will be donated will be transferred in mutual deliberation to a volunteer non-profit civil rights group called The Citizens Right's Group (Borgeretsbevægelse) that has taken up **Karina**'s case.

CRG fights for cases that are examples of principle human rights violations and they are finding many violations in **Karina**'s case.
Donations will be collected at the S4C site here:
http://www.geef.nl/doel/save4children

Information about the **Karina** and the case can be found in this and future issues of the ME Global Chronicle and at these sites:
Justice for **Karina Hansen** - find info under notes.
https://www.facebook.com/JusticeForKarinaHansen

Two videos about **Karina** from 2013:
http://www.youtube.com/watch?v=Dk3e8IWj7M0
http://www.youtube.com/watch?v=JTkkcvlvYf8

The Citizen's Rights Group – documents in the case in Danish
http://xn--borgerretsbevgelsen-xxb.dk/

The ME Global Chronicle Special Karina Hansen 20151025:
http://let-me.be/download.php?view.24

New documents will be added as they become available.

11. News from

Australia .

Our SA society hosted the Australian premiere screening of The Forgotten Plague (http://bit.ly/292KgGv) at our April seminar, followed by a screening at Emerge (Melbourne) in May, with special guest **Scott Ludlam** https://www.facebook.com/events/772312959570391/

Senator Scott Ludlam has created quite a stir in the ME/CFS community by raising some important questions for us about the general lack of support, and insufficient research funding for ME/CFS in Australia. We will be watching closely to see how this progresses. If you haven't seen the video, this is a big deal. We suggest you have a look: http://bit.ly/28UNNuL

"Health bureaucrats just sharply revised down estimates of how much research funding goes into trying to understand Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS). They then clarified that there is no other Commonwealth support out there, either for people dealing with this condition, or for GPs. It is time this changed."

Scott Ludlam is currently the Greens member (MP) of the Australian Senate, i.e. the Upper House of the (federal) Australian Parliament. He is one of 12 senators representing the state of Western Australia at a federal level, so this is an office with considerable clout. He has a personal interest in ME/CFS as he knows people suffering from the illness, and has been eloquent and quietly persistent in asking questions on two Senate Standing Committees on Community Affairs about research investment, funding for advocacy groups and other matters relating to ME/CFS and Lyme Disease.

As there is another election looming on July 2nd, the Committees of the 44th Parliament are suspended, pending election of the 45th Parliament.

He again spoke eloquently a few months later in this Committee http://bit.ly/28TaUWZ (around the 13:33 mark)

You can give **Senator Ludlam** some love and encouragement here: https://www.facebook.com/SenatorLudlam/

We have put ME/CFS Australia (SA) Inc. on this world map of disease prevalence (http://bit.ly/28WZ5gu) and would love you to join us in this endeavour to help spread the word and assist the push for more research funding. Every head adds more weight!

Mark Camenzind (http://bit.ly/292LUYJ) (PhD, Research & Development Advocate to Cure ME and father of a son with ME) is leading an international drive to put a million ME/CFS people, organisations, doctors and friends on the map (10 days ago <1000 – now over 1800 people with ME/CFS listed).

He suggests that you get onto map (with pseudonym or just first name), near your home but not exactly, preferably with the option "able to contact".

For many around the world, this will help to organise regionally, so people can meet to share or advocate, coordinated with #MEAction (http://bit.ly/28Sk9D1) for May 12th (http://www.may12th.org/) and May 25th (http://bit.ly/28Rh8DZ), #MillionsMissing global campaign in various cities (Washington DC, San Francisco, Seattle, London, etc.). You can also encourage your doctors, family, friends and other ME organisations to add their names.

It's very simple to do: Just find "Chronic Fatigue Syndrome/M.E." (http://bit.ly/28RKDDl), have a look at the current map, then click on "Join the map" button (http://bit.ly/28R9ECi), top right. The rest is quick and easy.

You can add as much or as little to your profile as you like, choose to have your age shown, whether to allow others to contact you, etc.
If you have Fibromyalgia then add this too http://www.DiseaseMaps.org

Submitted by **Melanie Smith**

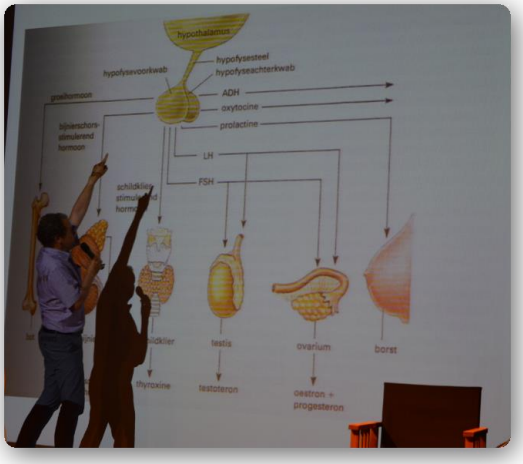
Belgium

On Wednesday, May 18th, a third info-show of the "Stop the CFS Diagnosis" took place, with another one of **Mira**'s live performances. She is a Belgian singer and patron of the campaign, for which she composed and performed a special song: "Race" (https://www.youtube.com/watch?v=buwH7zhvgvM)

As it had been announced, this performance took place in cultural center "De Bogaard" (Sint-Truiden). There was a vast amount of interest and much information was exchanged.

The announced guest speaker had to call off at the very last moment, but **Dr Coucke** has finely accounted for this.

Please note that a fourth show will already take place in October. This time in Antwerp, and the draft build will look slightly different. Further news and details are to come. Also, here are several images of the past show:



You can also still visit the website for more information:
http://stopdediagnosecvs.be/

Next info-show 'Stop the diagnosis CFS' will take place in Antwerp on October 15th. More info on: http://stopdediagnosecvs.be/

Become member of the WUCB now, because numbers count:
http://www.wakeupcallbeweging.be/wucb/word-lid
Membership is for free.

Eddy Keuninckx

Canada

Network meets with Chair, Health Committee

June 20, 2016

Don Davies

In March, Member of Parliament **Rob Oliphant** wrote the Chair of the House of Commons Health Committee recommending that the committee look at issues around ME/CFS and FM. In May, the Network met with MP **Don Davies**, the vice-chair of the Health Committee.

Last week, the Network met with the MP **Bill Casey**, the chair of the Health Committee. We outlined why ME/CFS and FM were important enough to put on the committee's agenda and what kinds of issues the committee might consider.

Bill Casey

Mr Casey agreed to bring this topic to the committee's attention. Before thatcould happen, the House of Commons adjourned for the summer. We expect this issue to be raised with the committee in the fall.

Follow-up letter to MP Bill Casey (http://bit.ly/292YnMf)

Attachments to the letter include:

- the original letter from MP Rob Oliphant recommending ME/CFS and FM be considered by the committee
- suggestions of the types of recommendations the committee could make
- CIHR research funding for 2015-16 and 2016-17 (as of April 8, 2016)

Source : National ME/FM Action Network http://bit.ly/28U1icJ

France

Event #MillionsMissing – a report

May 25 was held #MillionsMissing, an event in order to make visible the situation of people with Myalgic Encephalomyelitis and seek increased funding for medical research.

Implemented in 2 months by #MEAction, #MillionsMissing is the most ambitious outreach project ever launched for ME / CFS. Demonstrations were organized in nine cities around the world, and complemented by a virtual international protest on the internet.

Francophone participation

There is still very little information on ME/CFS available in French, patients are rarely diagnosed and have very little visibility. The community of patients is still poorly organized, especially in France, and many people are isolated. Obtaining ownership rights, whether in France or Quebec, is very difficult.

This is the first time that the francophone community was involved in such action. The results are still modest, but will hopefully mark the beginning of a better organization of patients and the implementation of many projects.

Photos of all participants were retweeted and shared on FB. We have gathered them here http://www.sfc-em.com/millionsmissing-2016/

Quebecers had the opportunity to participate in the protest-email campaign sent to Canadian MPs, with a French version of the letter.

From the Twitter https://twitter.com/sfc_fr?ref_src=twsrc%5etfw and Facebook https://www.facebook.com/syndromedefatiguechronique/ accounts of this site, we posted throughout the day of the figures and claims directed to **Marisol Touraine**, the French minister of health.

Hope

This first edition of #MillionsMissing is overall very positive. Much remains to be done, in particular to mobilize the press, but the feeling of cohesion of the patient community is strengthened. This event helped to strengthen networks, connect people willing to invest, test ideas, help people to feel less alone, make contacts with politicians and people working in health institutions. And above all it gave us visibility, showed that we exist and that we can mobilize.

#MillionsMissing 2016 is perhaps the first of many upcoming events, the basis of an emerging movement. Begin to prepare to organize the #MillionsMissing 2017, to consider events in Paris, Brussels, Geneva or Quebec. To achieve this, we must multiply the means to meet, to organize ourselves, to make this community more visible and to break the isolation that this terrible disease inflicts upon us.

Anne, May 29, 2016

Source: http://www.sfc-em.com/millionsmissing-bilan/

Germany

Petitition to recognize ME in Germany

ME or "CFS" patients ask:

- RECOGNITION OF WHO CODE G93.3
- GRANTS FOR BIOMEDICAL RESEARCH OF ME ("CFS")
- STOPPING DISCRIMINATION BY OUR HEALTH SYSTEM

Myalgic Encephalomyelitis? - Never heard!

Myalgic Encephalomyelitis (ME) is the most common and devastating disease (http://huff.to/28QZ8WK), from which your doctor has never heard. Many doctors believe that this disease exists only in the minds of patients. ME was classified by the WHO in 1969 under the diagnosis code G93.3 as organic disease.

In Germany ME is also being played down and incorrectly termed as "Chronic Fatigue Syndrome". These names are the result of (http://bit.ly/28VlLNz) an unprecedented Bagatellisierungs (http://bit.ly/28RkN65) - and Psychopathologisierungskampagne (http://bit.ly/28UZoJH), which began shortly after the WHO classification. (If you want to learn more about the disease, and from whom they can take, please scroll down.)

What we call for is as follows:

- An official confession of BMG, the G-BA, the Federal Medical Council, the SHI, the MDS, the AWMF and the DRV to a WHO-compliant classification of ME (and "CFS") under the key G93.3
- An official confession of BMG, the G-BA, the Federal Medical Council, the SHI, the MDS, the AWMF, the BMBF and the DRV, their future actions in relation to the disease ME or "CFS" under Article 2 (2) and Article 3 (2 u. 3) of the basic law align [Article 2 (2) "Everyone has the right to life and physical integrity. ... ". Article 3 (2) "Men and women have equal rights. The state shall promote the actual implementation of equal rights between women and men and works towards the elimination of existing disadvantages. "Article 3 (3)" ... No one shall be discriminated because of his disability. "
- The complete elimination of all references to "CFS" and ME in the AWMF guideline S 3 (http://bit.ly/28Vm2jy)
- The new version of a guideline on AWMF Myalgic encephalomyelitis based on the International Consensus Criteria (http://1.usa.gov/28RkQis) of 2011, and the International Consensus primer of 2012
- The complete elimination of the chapter "Chronic Fatigue Syndrome (CFS)" and all references to other chapters on "CFS" and ME including deletion of patient letters from DEGAM guideline no. 2 "fatigue" (http://bit.ly/28XdYiQ)
- The recast of a medical guideline on Myalgischen encephalomyelitis based on the International Consensus Criteria of 2011 (http://1.usa.gov/28RkQis), and the International Consensus primers 2012 (http://bit.ly/28RtNH2)

- The development of patient letters based on the International Consensus Criteria of 2011 (http://1.usa.gov/28RkQis), and the International Consensus primers 2012 (http://bit.ly/28RtNH2)
- The transmission of information (new guidelines and patient information, so) to general medicine, internal medicine, neurological, infectious disease, immunological, allergological, rheumatology, cardiology, hematology, endocrinology, environmental medicine, sports medicine, physiotherapy, osteopathy, psychiatric and ENT practices
- Information and education campaigns to disease for doctors, hospitals, emergency rooms, rehabilitation clinics, health departments, school boards, youth services, social services, health insurance, pension insurance, disability insurance, appraiser, job centers, VdK
- Medical Training on Myalgic Encephalomyelitis based on international biomedical research
- The establishment of the theme in the curricula of medical schools
- The complete elimination of all references to "CFS" and ME and G.93.3 from the DRV "Guidelines for the sociomedical assessment of people with mental disorders" (http://bit.ly/28PPR3z)
- A nationwide awareness campaign to ME based on the International Consensus Criteria of 2011 (http://1.usa.gov/28RkQis), and the International Consensus primers 2012 (print and digital media) (http://bit.ly/28RtNH2)
- The withdrawal of deficient (http://bit.ly/28R079D) researched RKI reports (http://bit.ly/28U7UYG) "knowledge at the" Chronic Fatigue Syndrome "(CFS)"
- The establishment of a research budget for biomedical research into ME. The size of the budget should comply with diseases of comparable prevalence and comparable level of disability (eg MS)

We ask for your signature! (http://chn.ge/28RuvRw)

Regina

Ireland

Noreen and **Anthony Murphy** took part in Walk for ME 2016, organising a successful event at the beautiful Belvedere House Gardens & Park in Mullingar, Ireland, raising awareness and €3115 for the Invest in ME Gut Microbiome in ME Research Fund

https://www.justgiving.com/fundraising/gutmicrobiom

Northern Ireland

Northern Ireland: "Chasing Competent Care" conference and #MillionsMissing Demonstration.

Hope 4 ME & Fibro Northern Ireland ran an ambitious and exciting conference on Monday 6th June in The Stormont Hotel, Belfast.

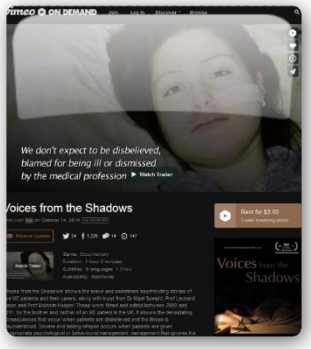
Trustees, **Martina Marks**, **Joan Mc Parland** and **Sally Burch** each spoke briefly at the beginning of the event, welcoming attendees, describing the current poor care situation and explaining why things need to change.

Lined up, to the side of the speakers' podium, was a haunting display of over 200 pairs of empty shoes. These were part of the global #MillionsMissing campaign. Each pair of shoes carried a tag with the name of a patient unable to participate in their active lives due to ME and/or fibromyalgia. During the conference many attendees took time to read the comments on the tags and to consider the magnitude of the devastation caused by these largely forgotten and ignored conditions.

Six guest speakers delivered a strong overall message. They included:
Dr Joe McVeigh, who outlined the problems with exercise and fibromyalgia. He explained exercise must be conducted at a level manageable for each individual patient. He called this the "Goldilocks approach", and explained that at no time should attempted exercise cause a patient to relapse.

Professor Malcolm Hooper, who gave a strong talk berating the inadequacies and misleading conclusions of the PACE Trial. At one point, he suggested that the PACE Trial was potentially fraudulent and told us that he had once even said as much in The House of Lords. This elicited a spontaneous round of applause from the audience.

Professor Hooper recommended that patients reference **Mark Vink**'s paper, "The PACE Trial Invalidates the Use of Cognitive Behaviour and Graded Exercise Therapy in Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome: A Review" *, any time they were asked to undertake these therapies.



Natalie Boulton, who opened her talk by showing a clip from the video "Voices from the Shadows". **Natalie** told us she had recently followed up with some of the patients from the video and found many of them had worsened, and that both **Emily Collingridge** and **Lyn Gilderdale** had since died. She spoke of the horror of the treatments doled out by psychiatrists who believed patients to be faking their illness. Hers was a genuinely moving and sobering talk.

Professor Mady Hornig from Columbia University, USA, who gave a detailed and highly informative account of her work towards developing blood biomarkers. Although much of what she described cannot be simply summarised, the audience was left with a strong feeling that **Professor Hornig** is now working determinedly to solve the biochemical riddles produced by ME.

Dr Pamela Bell who spoke about the problem with pain. She emphasised the widespread nature of chronic pain and its disabling effects, noting that once pain becomes chronic it no longer serves a useful purpose in the body.

The final speaker of the evening was **Louise Skelly** from the Patient and Client Council of Northern Ireland, who spoke of her frustration at trying to bring about change to the current impasse with Health and Social Care Board in Northern Ireland regarding the care on offer for ME and fibromyalgia patients. She spoke of her determination to follow through with the campaign to improve the situation, and of the great need of these neglected patient cohorts.

As the hall emptied, the lines of lonely shoes from the #MillionsMissing campaign were gathered up, their labels still attached, and some-one was heard to say: "These are the folk we do all this for, they will not be left forgotten any longer." http://bit.ly/28X4xQi

Submitted by **Sally K. Burch**

Norway

737 inputs for ME-Froskning- the Norwegian research council

ME-Froskning has received 737 suggestions for research on CFS/ME patients and their families. The input proposes research on everything from diagnostic criteria and causes of treatment and follow-up care.

From April 10 to May 3, the Research Council invited patients with CFS/ME and their families to provide input into research topics and research questions.

They have received 737 contributions which show a very large need for knowledge about everything from diagnostics through causes of treatment and follow-up care. There are also many that give to know that they think that the knowledge about the disease among health workers is inadequate.

Managing Director of the Research Council **Arvid Hallén**, is impressed with both the breadth and quality of many of the ideas, saying they form a good basis for further work.

"We are very pleased with the massive involvement and desire to help identify knowledge needs of ME", says **Hallén**. "Now we look forward to continue working with all input and user panel to facilitate good research that can help improve the lives of patients and their relatives".

The way forward

Research is working on putting together a wide user panel that will discuss the feedback and prepare funding announcements. Because we have received far more input than expected, it may be necessary to push the original schedule for the announcement, which was in the middle of June. The panel will seat patients, families, clinicians, researchers and health officials.

The composition of the panel has been published on 26th May. Also a short report with general information about the feedback they have received has been published (http://bit.ly/28Rdw1N)

Geir Aas

Norwegian source: http://bit.ly/28Si7D0

The Netherlands

#MillionsMissing is dedicated to the millions of patients with Myalgic Encephalomyelitis (ME) (often wrongly diagnosed as Chronic Fatigue Syndrome) who have to miss out on their jobs, families, schooling and social lives due to the invalidating symptoms of their illness. Simultaneously, ME is missing out on the millions of euros in research and clinical education subsidy it should receive. And millions of doctors around the world lack the training to correctly diagnose and help ME patients.

On May 25th 2016, #MEAction organized a worldwide day of action and equality for ME. ME patients, advocates, caregivers and allied parties joined together in a protest against the lack of government subsidy for research, clinical studies and education of medical staff and the general public, which has resulted in ME patients not receiving the proper support.

In the Netherlands, many people took part in this action of protest by sending their shoes over to other locations across the globe where the same protest was being held, by uploading pictures of themselves and their shoes to Facebook and Twitter and by writing comments on these social media platforms.

Millions Missing Holland seeks to join this action of protest by partaking in the worldwide actions on September 2016. Help us and register on the Facebook page below, where you can follow what is being organized, but where you can also take a look at how you can contribute yourself!

http://www.facebook.com/MillionsMissingHolland/
Currently Millions Missing Holland is collecting shoes of patients and deceased patients to represent them on September 27, 2016. Permission is being requested to display the shoes collected in Amsterdam and The Hague. More cities are being contemplated and tried to set up. Tags will be attached with what you as a patient miss most of all. Thus we're going to demonstrate that ME doesn't mean one's 'just' always tired. Show everybody you're there. Just because physically you won't be able to.

The Groep ME Den Haag and all patients' organizations in the Netherlands are strongly opposing the composition of the ME/CFS (wrong name already...) panel of the Health Council of the Netherlands which is to implement the demands of the Dutch parliament to investigate the state of art of ME and formulate advices to proceed. Read more in the section Dutch citizen initiative, and pleas sign the petition ME is not MUPS http://bit.ly/22r5cKN

Chronically extremely limited by ME and

bottling up all day long?

invisible to the world,
while you would like to make clear to everybody
how disastrous this desease is?

Documentary photographer Kees Muizelaar
would like to help you telling **your story**
by photographing a moment in the daily life
of the group 'hidden' ME-patiënts, whom
outsiders never gets to see.

Are you/do you know anyone who likes to participate in this project
to create awareness of **serious forms of ME**,
please contact:

keesmuizelaar@gmail.com
or tel.+31- 06 227 36 565

Kees will take account of your constraints
(such as light/noise-intolerance).
He will **disturb you as little as possible**
and you don't need to 'pose'.
If prefered, it is possible to be photographed **unrecognizable**.

For the **accompanying text** you may
tell a little about your day to day life
and anything about ME you would like
to tell the world outside;
any moment it suits you.
Or by your caregiver if prefered.

See *www.keesmuizelaar.com*
for photographs of Kees.

Thank you for your attention,
Kees Muizelaar

United Kingdom

Bristol Fibromyalgia ME/CFS (FM.E) United Support Group
Local Support Line 0844 887 2475
Email bristolfmeunited@gmail.com

Free self-management Toolkit workshop for people with fibromyalgia and ME/CFS
Wednesday 10th August 2016
Places are limited
Wescott Community Room
1 -9 Wescott Grove, De Clifford Road, Lawrence Weston, Bristol, BS110WG

Time 11.30 – 14.00
Liquid Refreshments will be provided
Feel free to bring snack/lunch
For More Information, Contact
Shass 0844 887 2475 0796 393 7383
bristolfmeunited@gmail.com

New children's and young people's services for Cornwall and the Isles of Scilly | 11 June 2016

New services for children and young people under 16 with ME/CFS have been commissioned by Kernow Clincal Commissioning Group for patients registered with a GP in the county. Services now exist for those under 16 as well as for adults over this age.

Increasing numbers of children and young people with this condition have now been funded as an addition to the adult service at Royal Cornwall Hospital Trust. Referral is by paediatrician only to the Cornwall and Isles of Scilly CFS/ME Service based at Lighthouse, Royal Cornwall Hospital Trust. Truro. TR13LJ
Carol Wilson, MSc, PGCE, BSc (Hons)
Specialty Lead & Clinical Specialist
Cornwall & Isles of Scilly CFS/ME Service
The Lighthouse
Royal Cornwall Hospital, Truro. TR1 3LJ
(The service can be contacted on 01872 252 935).

A Role for the Intestinal Microbiota and Virome in Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS)?

Navena Navaneetharaja, **Verity Griffiths**, **Tom Wileman** and **Simon R. Carding** http://www.mdpi.com/2077-0383/5/6/55

Published: 6 June 2016

This article provides a comprehensive review of the current evidence supporting an infectious aetiology for ME/CFS leading us to propose the novel concept that the intestinal microbiota and in particular members of the virome are a source of the "infectious" trigger of the disease.

Such an approach has the potential to identify disease biomarkers and influence therapeutics, providing much-needed approaches in preventing and managing a disease desperately in need of confronting.

Center of Excellence for ME (http://ldifme.org/a-uk-centre/)
Invest in ME Research wish to establish a Centre of Excellence for ME – a centre which would exist to bring discovery, knowledge, and effective treatments to patients with ME and possibly, in future, other illnesses that are caused by acquired dysregulation of both the immune system and the nervous system.

The proposed centre would become a Centre of Excellence in the treatment of ME in Europe and would attract researchers, physicians and healthcare staff from around the UK and Europe and USA. It will be based at Europe's largest grouping of scientific institutes – Norwich Research Park.

International collaboration is facilitated by the annual Invest in ME International Conference and Biomedical Resarchers into ME Colloquium (http://bit.ly/1Wpsxg8), and now also by the European ME Research Group (http://bit.ly/28RuFIY) formed by the European ME Alliance (http://bit.ly/28X1QOU), which is a member of the European Federation of Neurological Associations (http://bit.ly/1WKm2mE). Source : http://bit.ly/28V7XTj

The June 2016 issue of Vintage Life Magazine features a superb account by **Laura Chamberlain** of **Joanna** and her Vintage Violet's Charity Catwalk, held in April at The New Caterham Arms, raising over £1200 for Invest in ME. Earlier this year, **Joanna Chamberlain** explained why she was organising this spectacular event for the charity in her story on JustGiving (http://bit.ly/28X2POI).

Amy Stone has produced a hand-painted 'ME Mythbusters' cartoon. She wrote, "Took about a year with my dysfunctional brain but I got there! I would be really grateful if you guys would read and share it wherever you like. I want it to be used to help raise awareness and money for Invest in ME. Any donation would be greatly appreciated." You can contact **Amy** for other formats and view it here http://bit.ly/28TXQyJ

12. Worth Seeing, Hearing, Reading & Noticing

Three new episodes of ME/CFS Alert by Llewellyn King & Deborah Waroff

#78: interview with Mary Dimmock,
published April 17, 2016
https://youtu.be/q2c1kstA8pY

#79: interview with **Dr. Linda Tannenbaum**,
Published May 8, 2016
https://youtu.be/L_7XmWcI3fE

#80: **Llewellyn King**'s observation of Millions Missing-action day,
Published May 25, 2016
https://youtu.be/ieTsBOVpY0I

Miranda's Experience

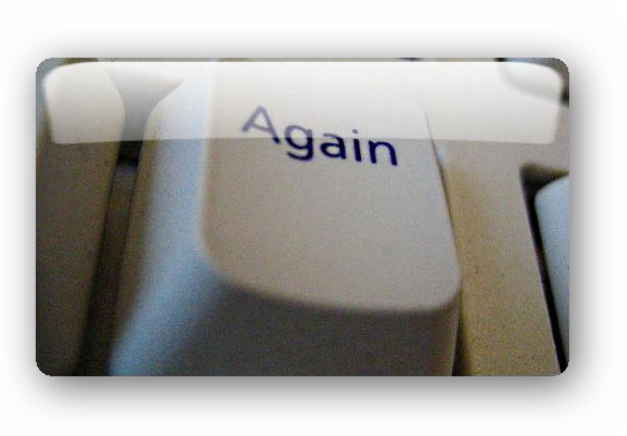
https://youtu.be/0f18MBIbKCQ
Miranda (who has severe ME) describes her experience of being in hospital for 4 days in 2014. It was not an easy experience.

Hidden Voices of ME

created by **Sophie Tennent**
https://youtu.be/mK48D72s-NU
published on 30 May 2016

Myalgic Encephalomyelitis effects millions of people worldwide and this video is to help raise awareness for M.E by using the voices of real M.E sufferers. We are the hidden voices of M.E wanting to try and make a difference!

13. Poem – Explain



Explain

How do I explain
My illness and its name?

How can I explain
My suffering and pain?

How can I explain
This feeling in my brain?

How can I explain
That nothing is the same?

How can I explain
Again, again and again?

Rosalynde Lemarchand

From a blog dedicated to the demise of **Jody Bassett**
http://roslemarchand.blogspot.nl/2016/06/jodi-bassett.html

14. Column – The Small Russet Darling

Joy is finding, at the end of a difficult day, that the diamonds you've found in the dark are bright enough to comfort you.

It is knowing there are lovely moments left for you to gather, to make the world seem possible again.

The one who reminds you of this is the fox; a small russet darling, only two feet away, while you spoon out his food. He is unafraid to be alone with you, beneath the starless sky. He lets you talk to him, and his gentle eyes observe you quizzically, as if to suggest you are the most curious and impractical thing he has ever seen.

You talk about your friends, who are the colours on a wide canvas. You tell him they make days more beautiful, even when you are afraid. Which you often are. You say the thought of would-be lovers keeps making you smile, and your eyebrows remember it.

You add how much you wish sorrow, and all of his associates, would forget your name and the names of those you cherish. You speak of the people you witness being incredible everyday, and you wonder if they know quite who they are. Then you marvel, at how it is the other humans who unfailingly make your heart glad to be keeping its own time.

You leave the little fox. You go back indoors, where you stand at the window to watch him eat, and for a second you think you know that the whole universe is always beaming itself through us, like a light through a prism. It explains why we can reach each other so completely, even from so many miles away; We are just fixed points between the travelling light of everything.

Sarah-Louise Jordan
http://bit.ly/24VJP5x

15. Column - Illness Versus Chronic Illness

A virus has a firm chokehold on you. Not just like a three-day cold, but a flu virus that knocks you into your bed for two weeks and still leaves pains for several weeks after. You can't go to work, care for your family, or perform household tasks. You're shivering in bed, sweating bullets. All over, you experience fierce muscle cramps, a sore throat, ear pains, migraines, sleeping problems, intestinal symptoms, the thought of fainting any second, you can hardly think and with every step you take, you profusely wheeze like a horse.

Your condition is simply lost, day in-day out. Even when you manage a successful sleep, you still feel just as sick as when you went to bed yesterday. You confine yourself from the outside world, as that's currently the only way to mend at all. Your body fortunately lets you know all of this, since you're ill - terribly ill, and your body is clamoring its way back to good health.

You're happy when somebody comes over to visit to check up on your well-being, but you're even happier once they leave. Because you're currently too sick for any kind of company. It does feels gratifying when someone cooks or goes grocery shopping for you, because that simply can't be done on your own. The only nice place for you to be is your bed. It's the place with the least amount of inhibitions and the best place for you to recover. It's a kind of love-hate relationship.

You may be very thirsty, have to visit the bathroom, or you're in desperate need for something to get rid of that agonizingly sore throat. It seems impossible, but nonetheless you trudge your way to the sanitary area, being as sick as a rat. You lean against walls and doors to keep yourself from toppling to the ground, and despite your brave efforts, you still manage to bash into everything. You regularly opt to ignore things like thirst or a painful throat. Any amount is too much, because you're ill. Thankfully, everyone understands. Just keep calm, and get well soon.

Imagine you're as sick as described above, except it lasts forever. There's no hope of getting better, and if this is ever going to happen at all. Day after day, you lose your capability to do anything. People no longer seriously believe you're ill, because this should have been over a two weeks ago. You enter the hospital and because the papers say you're as healthy as a fiddle, it has to be a psychic disorder. The staff speculate about motion sickness or a personality disorder, though they don't say this out loud.

In order to be eligible for welfare, you do have to make any effort to recuperate, and this is something you want yourself, too. So despite actually being unable to accomplish such a thing, you loyally enter into a psychic revalidation program, in which, despite being horribly ill, you try to begin to move around again.

Despite all energy having to be reserved for your own purposes, you're allowed to prove to your family, friends, employer, company doctor and the employee insurance provider that you are indeed ill, that it's not a psychic disorder and that you'd like to work, sport, cook and even do housekeeping again. That you do want to work again but can't, that you do want to invite your friends but can't, that if you tell someone you're unable to go somewhere with them, it doesn't mean you're preoccupied or don't like them as a person. But that it means you are literally unable to go.

You don't just miss working hours. You're ill 24/7, seven days a week, 365 days a year without free days or holidays. The fact that you're going to suffer from psychological problems suddenly isn't so strange anymore. After pressure from outside to regain your functionality, everything is lost. Your entire future is obliterated in a flash. You're sick and deprived of any real medical help.

Welcome to the world of ME!

The doorbell rings. Struggling to get up, I open the door. As a result of fatigue, I haven't dressed up yet. Whoever it may be, I secretly hope they quickly leave because my energy is nowhere to be found. She looks at me and asks "are you sick?" I know that "do you have the flu" is what she actually means, so I say no - I'm just my regular old self. Ill for almost 5 years and locked away from real life. It's become a part of it for the outside world.

This is my life with ME and that of seventeen million others in the world.
#MillionsMissing

ME is not MUS. Mental treatment doesn't help in the least and trying to move around only exacerbates the symptoms due to concentration intolerance. I started with physical therapy in which I did a six-minute cycling exercise twice. It backfired for every extra minute I had to go through.

I had to spend two whole months recovering to return to the physical state I was in before the exercise. Not only at the gym but also at home. This has repeated itself about six times over the course of 2.5 years. I've never been able to go beyond 2x6 minutes on a recumbent bicycle. Even the physical therapist could tell it wasn't a psychic disorder - no motion sickness or lack of physical condition was a factor. After all, you don't lose your stamina in an instant just like that.

Despite 2.5 years of psychological treatment, I'm still sick with these symptoms after five years. Due to my long-lasting revalidation program, any modicum of recovery has sadly been blown completely out of the picture. Help those with ME, sign the petition below and give ME patients a fair chance of recovery.

http://bit.ly/22r5cKN

X Windy

16. Connecting You To M.E.

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

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

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

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