The ME Global Chronicle

www.let-me.be

 # 33 –September 2019

1. Colofon / Personalia

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

Picture front page: ***Eddy Keuninckx***

2. Table of Contents

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

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

3. Editorial

Dear friends.
Here is the September 2019 issue of the ME Global Chronicle (#33), with as much important news from and of the worldwide ME community as possible. After all, developments in South Africa or Switzerland have just as much to do with the global community as petitions from the Netherlands or investigations in America.

We have deliberately made one exception. We were asked to pay attention to the new ME/CFS Diagnosis and treatment recommendations of the U.S.ME/CFS Clinician Coalition - http://bit.ly/2lvaYT9 The editors of the ME Global Chronicle try to publish as varied ME news from all over the world as possible. In addition, the editors sometimes have to step beyond their own concerns about what those articles are about.

As is known, the starting point of the ME Global Chronicle is the definition of ME in accordance with the International Consensus Criteria from 2011, and the subsequent primer for clinicians (2012). Precisely because, so far, these are the only criteria/primer in which ME is characterized as a distinct entity outside of CFS - something that is essential to not weaken the seriousness of ME.

From the International Consensus Primer: "Not only is it common sense to extricate ME patients from the assortment of conditions assembled under the CFS umbrella, it is compliant with the WHO classification rule that a disease cannot be classified under more than one rubric. The panel is not dismissing the broad components of fatiguing illnesses, but rather the ICC are a refinement of patient stratification." http://bit.ly/2Y1tIaS In the publication of the U.S. ME/CFS Clinician Coalition the authors have not even consulted or named the ICC. That must have been intentional, and we find that incomprehensible. That's why we think that mentioning the link is sufficient attention.

Once again, we thank all who have actively contributed in the form of copy, links, images and tips to this issue. Without you it would not be possible to release it.

Due to the absence of one of the editors during the month of December, the deadline for articles for the December 2019 issue (#34) has been brought forward to November 15. Contributions to the December issue should be sent to contribute@let-me.be before that date. You can begin sending submissions from now onward. Finally, we want to draw attention once again to the increasingly active fb page of the ME Global Chronicle, where current posts often appear https://www.facebook.com/groups/TheMEGlobalChronicle/

We wish everyone a quiet and beautiful fall or spring.

The editors

4. Cartoon Djanko

5. Grassroot

Here's The Thing

The only one who can really understand how much chronic illness has changed your life, is someone else with chronic illness.

The grief you feel is not validated, accepted or understood by those around you, even in the medical community, because it is often just as invisible as the illness you live with.

Unless you have experienced chronic illness, it's almost impossible to understand or relate to because after all, you generally "look ok."

You can get so caught up in needing people to understand how it feels, especially those closest to you and when they can't, it can feel like such a blow to the spirit and even, like a betrayal.

So let go of the need for them to understand.

They can't. Not truly.

Focus instead on what is most important: that they respect the new boundaries that you now need to put in place, to protect your health and your energy.

Be as factual as you can, without needing to justify your choices.

Do not apologise for the illness because it is not your fault.

Instead, explain clearly what you can and cannot do.

If you get caught up in needing them to understand, it will end up damaging your relationships because you feel hurt, unloved and judged.

Which will make you put more emotional distance between you and make you feel even more alone.

You know how you feel.

You do not need to convince anyone else.

People who love you will be willing to respect the boundaries you set and any limitations you have when you can communicate them clearly and consistently.

You are worth it and you absolutely deserve it.

https://bit.ly/2JWx494

Organizations For ME Face Dilemma

Advocate for distinct disease ME or use broad vague criteria to grow donor base. I wrote this in response to an article about **Carol Head** of Solve ME/CFS resigning as CEO. Instead of posting it on the article, I've decided to make it a note.

Narrative Matters

For decades we have watched as the words used to describe ME were twisted or misinterpreted. Why this has happened is up for debate. No matter who is to blame, the situation we are in calls for a unified narrative about what "ME" is. Two quotes from the article point to the importance of an accurate narrative:
"Similarly, the fate of NINDS's task force recommendations for ME/CFS will be decided by another review panel."

That other review panel will certainly have people on it who have been educated under the misconception ME/CFS is a vaguely defined, fatigue based disease that patients can manage if they just "take care of themselves". The natural response is: "Why waste money on them?" "The Board members go to their friends with high expectations – they pour their hearts out – and they expect a response which just doesn't come – not yet." In my experience, the expected response is lacking because the public narrative is that "chronic fatigue" is either imagined or patients just need to "take better care of themselves".

In almost all cases the narrative has led to patient blaming. If we pace and change our diet and gradually increase activity we will "manage" or recover. Too many patients have little understanding of the depth and breadth of the seriousness of ME… until they've been sick for about 7 years and start realizing the reality of what chronic ME means. In my observation of almost 30 years that's when the suicide risk sky rockets. Promotional materials often focuses on "recovery stories" and not on the reality that many or most of us will spend the rest of our lives quite ill. When the language we use inside our own community shows the severity of this illness, the outside world will better understand the need for research. Sugar coating ME to protect new patients is harming the narrative that will get us to proper research and patient support.

Ignoring the outbreaks or downplaying the contagion aspect of this disease should never have happened. It played into the narrative that patients caused their illness… "worked too hard" "pushed themselves" "should have taken it easier" "led high stress lives".

We need to stop using the watered-down criteria created by the IOM currently labeled ME/CFS usurping the original ME/CFS Canadian Consensus Criteria (CCC). The International Consensus Criteria (ICC) is an updated version of the CCC and is widely accepted in the ME community as describing the disease ME.

The petition for US Health and Human Services to adopt the ICC is approaching 7,000 signatures and has been submitted to HHS for consideration. This is a grassroots attempt to get ME recognized. By downplaying the neurological damage, the immune system dysfunction and cardiac abnormalities we are left with doctors slapping on the ME/CFS label after a cursory look at symptoms and sending patients home with some vague "take care of yourself and you'll get better" directive. Patients may get symptomatic treatments for orthostatic intolerance, or sleeping meds, but ME reality is ignored in the current narrative.

I hope the incoming CEO truly understands the following:

- ME is a distinct disease
- ME should not be lumped in with other diseases or conditions including SEID or CFS as defined by Fukuda.
- Broad vague criteria is dangerous
- Language that misinforms or alienates doctors is prevalent in the current narrative (fatigue, PEM, depression)
- Insurance companies have a vested interest in our NOT being recognized
- Government health agencies have a vested interest in our NOT being recognized.
- Extensive research for decades has not budged either of those entities to recognize ME.
- Offers to sit at the table have led too many advocates to lose their ability to fight for ME as a distinct disease. (Personal threats are known to have happened to advocates who spoke out against the status quo.)
- ME/CFS as described in the IOM is the wrong narrative to properly recognize ME.
- Advocates in this arena are often unwilling or unable to believe that there are institutional biases against us that has led to the current situation or that those same institutional biases are still in play.

My personal advocacy is focused on educating patients about using the IC Primer so they can fight for proper testing and treatment. Whether a patient "fits" the ICC or not, anyone who has been labeled with ME/CFS, CFS, POTS, EDS, Fibromyalgia etc. can use the IC Primer to better understand what testing can be done to rule out other diseases. Missed diagnosis is rampant in our community.

Advocacy orgs should be working hard to kick people out of the ME patient population by helping them know what other diseases should be considered. No advocacy organization should be aiding in this misdiagnosis of patients!

Unfortunately, the reality is no CEO is going to come to work with the goal of removing donors from their organization's donor base.

Link to petition: https://bit.ly/2lTw5OO

Colleen Steckel

“Advances in ME/CFS Research and Clinical Care”

Help “Advances in ME/CFS Research and Clinical Care” win the Frontiers Spotlight Award!

Advances in ME/CFS Research and Clinical Care, a series of 24 papers on ME/CFS published in 2018-2019 in the online (open access, peer-reviewed) journals Frontiers in Neurology and Frontiers in Pediatrics, is in the running to win a $100,000 prize!

The prize money must be used to fund a scientific conference on the topic. If it wins, Ken Friedman, the topic editor, has indicated he will donate the money to the IACFS/ME to help fund their 2020 International conference!

The editors of Frontiers determine the winner of the prize; there is no nomination process. The most active, collaborative and impactful Research Topics from the last year are shortlisted and then the Jury, drawn from members of the Frontiers Editorial Board, is tasked with choosing the final winner.

Finalists are selected and judged on scientific and editorial excellence, international reach, subject novelty, and interdisciplinarity of their Research Topic.

An important factor is the interest the topic generates around the world, based on article views and downloads, citations, and international reach.

We can help by viewing/downloading articles, and encouraging others to do so, especially viewers outside the U.S.

It also helps to post article links on Facebook or Twitter, retweet, and discuss in blogs and on Reddit and Google+. All these metrics are tracked and count toward the impact score.

For a complete list of papers with links, visit https://bit.ly/2yUChcm. This special issue was edited by **Drs. Kenneth Friedman**, **Cindy Bateman**, **Alison Bested** and **Zaher Nahle**.

The papers will be collected and published as a monograph, and cover a wide variety of topics in ME/CFS research. Find several that you are interested in and click away!

- A brief history of the struggle for recognition of ME/CFS as a disease, and the struggles to establish ME/CFS research and clinical care
- Identifying the cause or trigger(s) of ME/CFS
- Case definition: What symptoms best characterize the disease? What symptoms are mandatory to diagnose ME/CFS? How can we make diagnosis as easy as possible for the clinician?
- Methodologies for validating a ME/CFS diagnosis
- A new method to determine the number of individuals within a given population who suffer from the disease
- A sampling of current, ongoing ME/CFS laboratory research: microbiome, the role of neuroinflammation and cytokines, using a bio-bank to study tissue abnormalities
- Clinical research
- Challenges of providing healthcare to the ME/CFS population
- Special needs of pediatric and adolescent patients

Last year's winner received more than 80 citations, 70,000 views and 9,000 downloads, and one of the papers was featured in The Washington Post. The 2017 winner brought together 630 authors, publishing 149 papers and receiving more than 1.2 million views and downloads. So far, the ME/CFS topic has nearly 140,000 views.

We know that **Dr. Anthony Komaroff**'s recent paper on ME/CFS in the Journal of the American Medical Association was one of the top five in JAMA in July, so there is great interest right now in ME/CFS. Let's help publicize these papers and generate even more interest!

Submitted by **Charmian Proskauer**

#MEAction

Great news!

Remember the petition that asks the EU to fund biomedical research on ME? It will be discussed at the meeting of the Committee on Petitions on October 3rd 2019 in Brussels! It is scheduled for discussion at around 11:05 CEST.

Francis and **Evelien** have been working on this project for over a year and they will both try to attend the meeting.

Once the petition has been introduced by the Chair, **Evelien** will be allowed to give a short speech. Then the European Commission will take the floor. After that the MEPs will discuss the petition. The decision is made by the Members of the Committee, live in public, right after the debate.

This will be an important day! The outcome is still uncertain, but our goal is to move forward!

Sign the Petition
If you are an EU citizen you can still support the petition if you haven't done so already! Please click the following link for instructions: https://bit.ly/2kpbrWd

Watch the Discussion!
You can follow the Committee discussion by webstream at the following link: http://www.europarl.europa.eu/committees/en/peti/home.html

If you are unable to watch the meeting live, a recording will be available the following day.

The meeting is public, so anyone can attend! Please note, that if you wish to attend the meeting you must have a security clearance. If you want to visit, please send an email to the PETI Secretariat (peti-secretariat@europarl.europa.eu) and include the following information:

- your name
- date of birth
- the number of your passport or ID card
- the petition number: 0204/2019
- the date of meeting: 03/10/2019

Thank you for your support!

Francis and **Evelien**
Contact us at eu.me.petition@gmail.com

In order to increase our organization's transparency and make it easier and clearer than ever how to engage, participate in and support the work, we'll be rolling out the following tools and initiatives in the coming year:

- A new mission and vision statement
- A formal membership program
- An #MEAction International Community Advisory Board
- A new website
- A clear onboarding and training process for new members and volunteers

We want to formalize membership in #MEAction and engage members in new ways, including meeting quarterly to keep members up-to-date on our wins, setbacks, and plans for the future, as well as to discuss and participate in guiding the direction of the organization, not just through this Values & Policy Initiative, but beyond. (Anyone can participate in this Values & Policy Initiative, whether or not they are a member of #MEAction.)

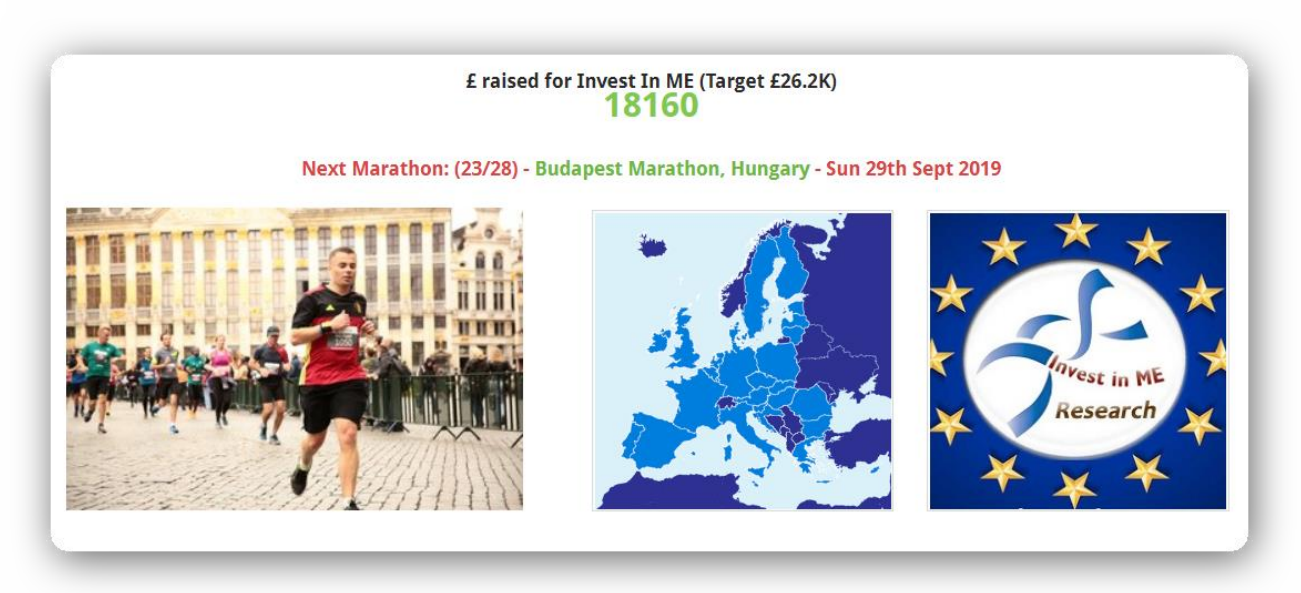
#MEAction International's Community Advisory Board, which we aim to launch next year, will comprise leaders from across #MEAction's network: US state leaders, #MillionsMissing organizers, Facebook moderators and members who reflect the diversity of our movement. This group will help us realize our shared values at every level of the organization and engage with staff in thinking about how best to scale and grow the impact of our work.

Finally, our new website design, a volunteer onboarding process, training, and our new mission and vision statement will make clearer our theory of change, our vision for the movement and future we are building, and how you can participate in helping us realize that vision.

Read more:
https://www.meaction.net/2019/09/24/join-our-values-and-policy-initiative

Marathon Mike

Next run, #23/28 - Budapest (Hungary) - Sunday 29th September
We wish Mike good luck!



(read more http://www.mikeseumarathons.eu)

Thanks for your support!

Mike

The ME Patient Foundation Statement

It is with deep regret that we are issuing this statement regarding the closure of The ME Patient Foundation shortly after its launch on 1st July 2019.

Despite our position as trustees for the MEPF we were as surprised as the rest of the ME community by the charity's closure as we received no indication this was in the pipeline. At our last trustee meeting in early August a positive discussion had taken place concerning the direction the charity was heading and there had been no hint that the closure of the charity was being considered.

We were gobsmacked to be informed via email late on 2nd September 2019 that the other trustees, **Emma** (the charity's founder) and **Adam Joy**, were resigning immediately, stating the workload had become unacceptable due to its impact on **Emma**'s health and family life.

They suggested we take over the running of the charity alone but unfortunately this was not possible as,

- We are both ill ourselves and would not be able to manage the significant workload
- A minimum of three trustees is required to run a charity

We feel we owe the ME community an explanation as we are keenly aware people feel let down by this turn of events, so here we outline some points to help clarify matters:

1. We believe the charity was launched prematurely on 1st July. During trustee meetings we advised that sufficiently qualified volunteers should be in place before the official launch, our concern being the workload would be too much otherwise. We successfully delayed an earlier launch date in May but, at a subsequent trustee meeting, were informed the charity was being launched on 1st July as a fait accompli, without further consultation.

2. In July we were informed during a work meeting that the other trustees would be away on holiday in the USA for the whole of August, and that they would be unavailable for much of this period. Given the charity had only recently been launched, we were surprised by this decision though given how hard **Emma** had been working we were understanding and did not raise any objections. No discussion took place regarding how to structure the month of August and how to proceed with volunteer recruitment.

3. The absence of the other trustees and lack of volunteers meant we took on a significant workload during August, sometimes communicating at cross purposes with prospective volunteers due to the difficulty in contacting the other trustees.

4. On 2nd September, we submitted an extensive report of the work carried out in August, detailing how we thought the charity needed to be structured and run in the future to honour its duties and responsibilities to ME patients. We had informed the other trustees on their return from their holiday that we were preparing the report and no indication was given that they were intending to relinquish their roles in the MEPF.

We wish to make clear that our work and trustee meetings were conducted in a friendly and constructive manner and there was never any argument or bad feeling amongst the trustees. We were concerned that certain decisions, e.g. the launch date, appointment of advisors, were being made unilaterally and that controversial issues regarding certain individuals on the Foundation's website were ignored but thought this was resolvable and were looking forward to achieving great things with the charity.

In the official MEPF statement announcing its closure (a statement released without our being consulted), 'a lack of resources' is given as the prime reason for the charity's closure; if indeed this is the case, it is due to rushing to launch the charity before such resources were put in place. Unfortunately, there had been no discussion that this was an issue before we were informed the other trustees were leaving. Had this issue been raised we would have done all we could to resolve the situation and keep the charity running, in fact, we did so by submitting a detailed work report complete with suggestions along Charity Commission guidelines.

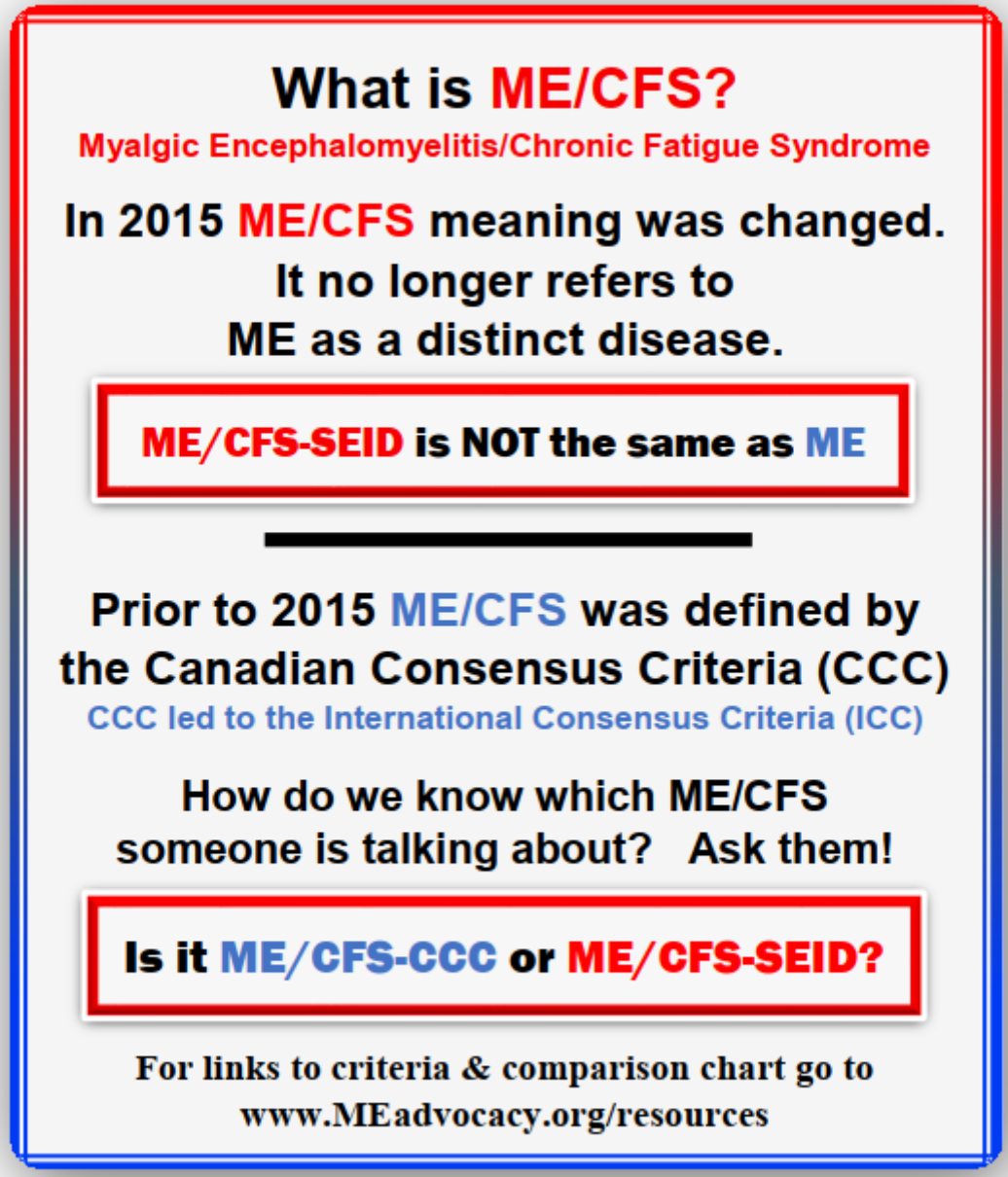
We do not condone the charity's closure and wish to offer our sincere apologies to the ME patients who placed their trust in the MEPF to provide them with much needed support. We were inspired to become trustees due to the founder's passion, compassion, positive spirit and vision. We have asked **Emma** and **Adam** to ensure that donations made to the Foundation be given to Invest in ME or other suitable charities pursuant to legal requirement.

We hope this has provided some clarity for those who were as shocked as we were by the charity's unexpected closure and apologise for our role in what has turned out to be another unfortunate event in the ME world.

Dr Claudia Gillberg - **Geoffrey Jones**

Source: **Utting Wolf spouts** https://bit.ly/2lV85e0

What is ME/CFS?



The Late Dr Don Lewis

The late Dr Don Lewis, a beloved local physician

The greater part of an interview by phone **David Tuller** had with him shortly before **Dr. Lewis**'s demise. Emerge Australia, a group based in Melbourne, issued the following statement (https://bit.ly/2kSTfVf) on July 29th:
It is with deep sadness that we announce the passing of Melbourne ME/CFS doctor, **Dr Don Lewis**, who died this morning following a long illness.

Dr Lewis cared for ME/CFS patients for more than 30 years. He has touched the lives of many, through his clinical and research work, but also through his dedication and compassion.

We know that he will be deeply missed, and we offer our condolences to his loved ones and to his patients.

Although I didn't meet **Dr Lewis** in person, I interviewed him from my hotel room in Perth a few weeks after I had been in Melbourne. I am very sorry I didn't get around to editing and posting it while he was alive. But I wanted to share some of what he told me now.

How did you first become interested in this illness or start working with this patient population?

My wife became suddenly very unwell and collapsed, and I had her admitted to hospital. She was in hospital for about a week and there was nothing that was found, despite all the tests that were done. Despite being a doctor and presumably knowing something, I knew nothing–this was in 1985. I had experienced the disbelief from medical professionals, and being recommended various avenues of psychotherapy that were just really quite out of place and inappropriate. We didn't pursue those because we knew that wasn't the case, but that's what started my quest.

How did patients start coming?

They started to appear—through word of mouth they just started to turn up. I knew what they were going through, because I had personally experienced it. I had experienced the illness by close observation. I didn't prescribe exercise because I knew what it would do. And patients would tell me—they just knew they couldn't do it. They knew if they tried to do more than they should, they would become unwell.

The patients could have symptoms of depression, but everyone wanted to get better. They weren't happy because of the way they were, but they were not primarily depressed. I started to observe that I was getting responses when I used medications that improved neurotransmitter function. By enhancing levels of serotonin, nortriptyline, dopamine you could lessen the severity of quite a number of symptoms. This led me to consider that we're dealing with a neurological problem. That was my baseline understanding. Then I just sort of worked my way along using those things but keeping my ear open to what might impact it.

What did you hear from them about previous interactions with the health care system?

It's embarrassing as far as medicine is concerned. Doctors are just about their worst enemies. They've been told that it doesn't exist, they've been told, 'You've got a mental illness, a psychiatric illness, you must go and have that attended to.' And they really can actually get abused by the doctors.

How did your understanding of the illness develop?

By the time they present, they've often been unwell for years, or the whole illness may be developing before they actually become unwell. There's a certain absorptive capacity that people have to sort of adjust and keep going, until eventually something more major or just one too many things happen, and they just fold up and become unwell. You've got changes that have been happening for a long time, and the body's systems are like interlinked wheels. So if one starts to turn one way the other wheels do as well.

So we've actually got evidence that these people have some background medical issues before becoming completely unwell. They have increased immune activity or some neurological dysfunction or gastrointestinal dysfunction, for example. They might have a number of medical problems and organ systems that are not working properly. It led me to consider, for example, that the infections might be just be the trigger on top of what was already happening in that person.

The average length of illness before they came to see me was 5 years. Some have 20 years of illness, but on average people have been trying to find an answer for five years. Only one out of five were able to fully care for themselves. That is the degree of limitation we find at initial presentation. Some of those limitations may well have appeared prior to presenting themselves for treatment. There may have been some manifestation of this illness to a lesser degree—there may have been times when these sorts of symptoms appeared until ultimately there was an event or events at a period of time that undid everything, and then you ended up with a multi-system illness.

How would you actually diagnose people with the illness?

I came across the so called case definition, the CDC criteria. I could see whether they fulfilled the criteria and of course they would, and then after that the Canadian criteria [Canadian Consensus Criteria, or CCC] came out. Before, when I would follow the CDC criteria, I would say, 'We've done that, and what else is the matter?'

They would go off on their other symptoms as well, and my list of symptoms grew and grew and grew—there would be quite a list of complaints that they had. Then to my delight, the actual Canadian criteria said a lot of what CDC criteria didn't say and basically took account of the different things I had begun to notice when talking to the patients. So that's what got me into using CCC rather than the CDC criteria.

How would you develop treatment plans?

They're not going to get better unless you start to deal with these baseline things. First you need to spend some time uncovering these foundational issues. I've created the concept of a tree with trunk and roots and many branches. So often the attention is what's going on in the branches but not what's in the trunk and even the roots. This analogy helped my patients understand why we do what we do.

When we went over their medical history, people would remember that when they had an infection, maybe it took them two months to get over it. You could often find these experiences, which were the whole deal to a lesser degree, and they'd get over it. This really became the basis of what I do—I've developed a protocol that takes into account all the things that I would have to know to justify what I'm doing. Before patients come, they're sent a history, and it's about maybe 10 or so pages—questions about the sorts of things we need to know about their history and family background.

So is it managing or treating the illness?

It's managing, it is explaining the whole thing, supporting them and suggesting this or that and the other thing. I'm not saying that I'm treating their CFS, which implies that you know what is wrong with them and are going to get them better. But there are some things we might find that are wrong with them, and managing their illness means treating that and addressing the mechanisms if we can.

Source: Virology Blog, **David Tuller** https://bit.ly/33PZbjw

Every Day Should Be Severe ME Day

Earlier this month, the myalgic encephalomyelitis (ME) community recognized Severe ME Day of Understanding and Awareness. Every day should be Severe ME Day - and at MEadvocacyOrg, that is exactly what we strive to do.

August 8th - as a dedicated day to raise awareness of the plight of the severely affected ME patients - was conceived in 2013 by **Diane**, the mother of a severely affected ME patient, and was subsequently taken on by The 25% M.E. Group. In 2013, when writing a blog for Severe ME day, advocate **Gabby Klein** interviewed **Diane** asking her to explain why she thought this special day was important and to describe what it is like being the carer of a severely affected daughter. Carers are truly the unsung heroes of this tragedy.

From **Diane**'s own words:

"The question that's been dancing in my mind for a long time is, how can the general public be made aware of the seriousness of Myalgic Encephalomyelitis? How can their minds be re-programmed to the truth because up until now Myalgic Encephalomyelitis has been globally misunderstood and gravely trivialized. Myalgic Encephalomyelitis is not a new disease, yet if you were to type 'M.E. symptoms' into a search engine, the chances are words like fatigue, malaise, brainfog, sore throat, insomnia, and depression would jump off the page. But where are the words that truly describe severe Myalgic Encephalomyelitis – the seizures, paralysis, intractable pain, blackouts, coma-like experiences, incontinence, tremors, cardiac dysfunction, dyscalculia, dysphasia?

A hundred symptoms could be listed here with not one mention of fatigue or any of its common misconceptions. And where are the explanations that a group of seriously ill adults and children, are so severely ill that everyday activities and sensory stimuli, like being washed or the noise of a passing airplane, can be life-threatening?

My daughter has very severe Myalgic Encephalomyelitis and she is the reason why 8th August Severe Myalgic Encephalomyelitis Understanding & Remembrance Day has come into being. Well, her and over 25% of the M.E. population. When you take that percentage into consideration, it means there's hundreds of thousands of people around the world with severe/very severe Myalgic Encephalomyelitis. We're not talking about a rare disease here, so why is M.E. cloaked in so much ignorance?" **Diane** asks an important question. Why is ME cloaked in so much ignorance?

The current situation

In effect, all people with ME (pwME) suffer from a severely debilitating disease which is greatly amplified for those who are bedbound/tubefed. MEadvocacyOrg's mission is to fight for proper diagnosis, research and education which will bring proper recognition and proper treatments for this neglected and marginalized debilitating chronic disease. The best way to ensure ME patients receive proper care is by properly defining the disease. MEadvocacyOrg has been advocating for and urging the Department of Health and Human Services (HHS) to adopt and use ME experts' 2011 International Consensus Criteria (ICC), the International Consensus Primer for Medical practitioners (IC Primer), as well as pressing for ending the use of the newly government supported overly broad criteria, Systemic Exertion Intolerance Disease (SEID) which has taken over the ME/CFS label. Problems with using overly broad criteria

- Leads to misdiagnosing many who are suffering from other conditions or idiopathic fatigue
- Lacks adequate information to support patients with the distinct disease ME - especially those most severely affected
- Leads to treatments that may work for people suffering from fatiguing conditions but are harmful to pwME
- Does not ensure patient selection for research will exclude those who suffer from other fatigue-inducing illnesses (as shown by **Leonard Jason** and **Frank Twisk** published works)

For detailed information about the harms of overly broad criteria and the reality of Severe ME, including the importance of recognizing paralysis as a symptom ignored in current information, we recommend this article from Stonebird" Severe/Very Severe ME: The need for proper symptom identification." (https://bit.ly/2kW5ssj) Read more about how advocacy organizations have failed the Severe ME patients, how treatment information leaves ME patients, especially the most severely affected, out of the conversation, the benefits of advocating for severe ME using ICC and IC Primer, and advocacy steps everyone can do at https://www.meadvocacy.org/every_day_should_be_severe_me_day

MEadvocacy.org, August 2019

Unrest

So thrilled that UNREST was nominated for a News & Doc Emmy!

Awards ceremony was this week.

Altough we didn't win, congratulations to our editors, **Kim Roberts** & **Emiliano Battista**, to our team, and to our entire #MECFS community for sharing their stories, lifting up this film, and turning it into a movement.

Our gratitude to our broadcaster, Independent Lens | PBS, for believing in all of us!

https://emmyonline.tv/news-and-documentary-40th-nominees/
https://emmyonline.tv/wp-content/uploads/2019/09/news-40th-winners.pdf

Llewellyn King interviews.....

Vicky Whittemore, **PhD**
Episode 108 – funding ME/CFS Research
https://youtu.be/CY71-qeT5p8

Vicky Holets Whittemore, **PhD**., is a program director of the Channels, Synapses and Circuits Cluster in the National Institute of Neurological Disorders and Stroke (NINDS) at the National Institutes of Health (NIH) in Bethesda, Maryland, United States.

She leads the Trans-NIH Working Group on myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS).

Dr. Ron Davis
Episode 109 – "Finding an ME/CFS Biomarker"

https://youtu.be/BW4LIITEhIA

Ronald W. Davis is a Professor of Biochemistry and Genetics at Stanford University and Director of the Stanford Genome Technology Center.

He also has a personal connection to ME/CFS: his son was diagnosed almost 10 years ago.

In this interview, Ron discusses his research at Stanford.
Read: https://med.stanford.edu/news/all-new.

Treatment Database AMMES

What treatments have worked, or not worked, for you?
AMMES wants to know!
Please share your experiences on the AMMES Treatment Database https://ammes.org/treatment-database

The more people who share their experiences, the better! (It's easy to share. It takes about 2 minutes.)

Although it is routine for doctors to prescribe drugs to help alleviate the symptoms of ME/CFS, patients may respond in unpredictable ways. Specialists report that it is common for ME/CFS patients to have paradoxical responses. For example, an anti-anxiety drug may produce anxiety. Patients may also be unable to tolerate the normal dosages recommended for the general population.

For these reasons, many patients turn to alternative treatments and modalities, such as herbal formulations, yoga, acupuncture, and others. Unfortunately, very few studies have been performed on the efficacy of these treatments for ME/CFS patients, despite their popularity.

The Treatment Database offers a means for patients to share their experiences with others in the ME/CFS community – patients, caretakers, and clinicians – about pharmaceuticals, natural remedies and other alternative treatments.

How it Works

Patients enter their treatment experiences on a brief form. How patients rate the treatment – including side effects and overall satisfaction – can be viewed on an easy-to-read table. A search bar is included on every page that will allow you to search for a specific treatment either by typing in a few letters or by browsing through an A – Z. There is no cost, and you don't have to be a member to view information on the database, or to fill out the form to rate your experience. Parents of ill children may enter treatment information for their children.

Information about treatments is invaluable for ME/CFS patients, so please share your experience!

If there is any treatment that does not appear in the Treatment Database, please contact us through our contact form
https://ammes.org/contact-us/

Important: Please go to the AMMES website to post your review: https://ammes.org/treatment-database/ You will have to register to post a review. But the registration is free.

Erica Verrillo

Please Stop Trying to 'Fix' My ME/CFS

When you become ill, all you want is for others to be compassionate and understanding. Yet when you come down with something like ME (myalgic encephalomyelitis), that not even your doctor comprehends, it's a different story. Others are quick to pass judgment, believing you are somehow causing your misfortune or not trying hard enough to turn it around. In brutal terms, they see you as failing at life. (I know this, as I was healthy once and conditioned to think this way, too.) Worse still, people think they know better than us because they are well – so they must be doing things right and we must be doing something wrong – but I believe we were dealt a bad hand and they were lucky.

They patronize us by offering bits of trivia they've read in women's magazines: "You should eat more turmeric… Have you tried juicing carrots?… What about acupuncture?" Seeing me use a wheelchair intermittently, onlookers assume I am simply deconditioned, and suggest physiotherapy, as if I don't have the sense to come up with that myself. The fundamental flaw in that plan is that exercise can exacerbate symptoms of ME! (https://bit.ly/2ksa6Oo) Or more commonly, friends guess I am "just depressed," and pressure me with positive psychology and sermons on the mind-body connection (yes, I've heard of it, thanks!). Well, I am tired of everyone's incessant questioning and spouting their uninformed opinions. What they don't know is that, while I strive to remain hopeful, I've discovered there is no quick fix for any of my ailments. I've read every book on health and wellness I could get my hands on, searching in vain for answers, and still haven't found the key to my healing. I am aware of most of the options out there, even though I haven't gotten around to trying them all out yet. And while I haven't found The Answer, I have found some answers. I can keep my symptoms under control. In fact, I excel in that area.

Like most people with ME, I've been forced to become my own doctor, nursing the red-faced, raging baby that is ME all day long. I self-inject medicine seven times a week to keep my condition stable and choke down supplements by the handful. While confined to my bed, I helped grow #MEAction's grassroots movement for health equality, taught myself to speak Spanish and play the ukulele, and am proud to say I have almost finished writing my first novel. I'm not moping around at my parents' home, shirking employment, as some like to imagine. The state of scientific research in this field may be failing me, and the lack of medical knowledge and viable treatment options is certainly failing me, but I am fighting this thing every day with all my wit and might, while trying to maintain my mind. Some days I laugh, some days I cry, and it's a continuous painful struggle. But this is my life now – the only one I've got. So people, even if you mean well, please leave me be and stop trying to fix me (https://bit.ly/2Luuk6X). And do us all a favor and stop talking down to ME patients. You don't know who you're dealing with! We're strong, passionate warriors and we would do anything to have our health back.

Simone DM in The Mighty https://bit.ly/2m6mVP6

Rotary Resolution to Support (ME/CFS)

Rotary Resolution to Support Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)

What is Rotary?

For more than 110 years, Rotary members have been addressing challenges around the world.Rotary links 1.2 million members to form an organization of international scope.Rotary members believe that they have a shared responsibility to take action on the world's most persistent issues. Their 35,000+ clubs work together to: promote peace, fight disease, provide clean water, sanitation, and hygiene, save mothers and children, support education, and grow local economies. Rotary provides service to others, promotes integrity, and advances world understanding, goodwill, and peace through the fellowship of business, professional, and community leaders. The Rotary Foundation helps fund humanitarian activities, from local service projects to global initiatives. Over 35,000 Rotary clubs unite dedicated people to exchange ideas, build relationships, and take action.

Background on the Proposed Rotary Resolution

Jim Lutey is a Rotarian and when he was with the Greeley After Hours Rotary Club in Greeley, Colorado, he proposed a resolution for ME/CFS in September 2018 that the board of directors and club members supported. **Jim**'s wife, **Pam Lutey**, is mostly home bound due to a 3-year struggle with ME/CFS. **Jim** then worked with the Council on Legislation designate for the Rotary District 5440 (Wyoming, part of Idaho, part of Nebraska, and north central Colorado). They worked on a resolution in March and April 2019 that was presented at a District 5440 Conference in May 2019. Rotary club delegates at the conference unanimously voted to approve the resolution.

Then, the resolution was submitted from the District Governor to Rotary International in early June 2019. Resolutions submitted by Rotary clubs and districts will be voted on by each Council on Resolution delegates from 535 districts worldwide between October 15 and November 15, 2019. If the Rotary resolution is approved by these delegates, then it goes to the Rotary International (RI) board of directors for consideration.

The Proposed Rotary Resolution

This is the Resolution that will be considered by Council on Resolution delegates from 535 districts worldwide between October 15 and November 15, 2019.

Resolution 19R-23

To request the RI Board to consider collaborating with those working on myalgic encephalomyelitis/chronic fatigue syndrome research

Proposer(s): Rotary Club of Greeley-After Hours, District 5440, USA

Endorsed by: District 5440 through an annual district conference, Gering, Nebraska, USA, 18 May 2019

Whereas, the virus that often triggers myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is closely related to the virus that causes polio, and

Whereas, an estimated 15 to 30 million people worldwide, predominantly women, have ME/CFS, and

Whereas, government and organizational funding for research and education to recognize and treat ME/CFS is woefully inadequate

It is resolved by Rotary International that the Board of Directors of Rotary International consider using the vast knowledge and resources Rotary has already developed and implemented to eradicate polio for the support of, encouragement of, and collaboration with those working to fund myalgic encephalomyelitis/chronic fatigue syndrome research and education.

Purpose and effect

This resolution would leverage Rotary's worldwide reputation and expertise on polio eradication to raise awareness of the need to educate the public and medical practitioners on the importance of treating and ultimately finding a cure for those suffering from ME/CFS.

Financial impact

If implemented, this resolution would have a financial impact on RI which cannot be determined at this time. Cost would be dependent on the scope and extent of support provided by the RI Board for collaborating with those working on ME/CFS research.

Article Submitted by **Jim** and **Pam Lutey**,
Johnstown, Colorado

In Memoriam: Professor Peter Behan

Tribute paid to **Professor Peter Behan** – M.E. expert and ME Association patron

Dr. Peter Oliver Behan died peacefully at home in Edinburgh on the 31st August 2019, aged 84.

Dr. Charles Shepherd:

I knew **Peter Behan** as a friend and colleague for almost 40 years.

Professor Peter Behan sadly passed away on 31st August 2019

I first met him when the late **Dr Melvin Ramsay**, who originally diagnosed my own M.E. following an episode of chickenpox encephalitis, suggested that I should go and see **Peter** at the Institute of Neurological Sciences at the University of Glasgow to help with the research that he was doing into the condition.

It was immediately obvious that **Peter** was a very kind and caring physician who knew all about ME.

Peter was also an outstanding neurologist who, along with his wife **Professor Mina Behan** and virologist **Professor John Gow**, was carrying out important research into brain, muscle and immune system function, along with the role of infection, in people with M.E.

Unlike most of his neurology colleagues he had no doubt that M.E. was a serious neurological illness and that the patients were being badly let down by both clinicians and the research community.

The papers that were published from his research group at the time played a significant role in helping to change medical opinion about M.E. and the whole situation regarding research.

The fact that M.E. was firmly on the medical curriculum at the Southern General Hospital also meant that a succession of neurologists working in **Peter**'s team gained a solid knowledge of the condition – **Dr Abhijit Chaudhuri** in particular, who now advises the ME Association on neurology.

Peter continued with his research interest well into retirement and helped to develop the research strategy for the MEA Ramsay Research Fund and made personal donations to the fund.

In recognition of his contribution to both clinical and research work he was invited to become a Patron of the ME Association – a position he held until his death at the end of August.

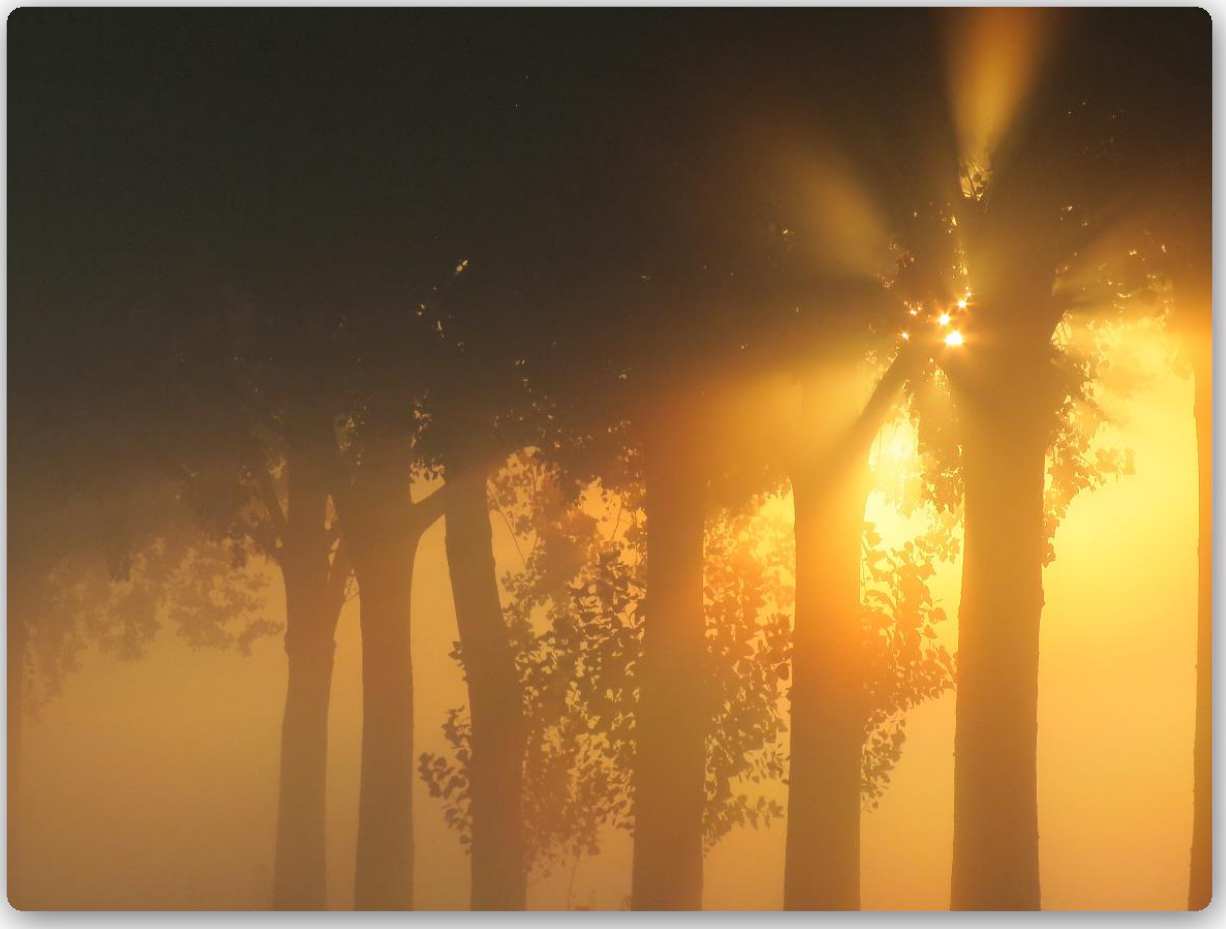
Peter was excellent and amusing company – either in Glasgow, or up in Denkeld where he was an accomplished fisherman with an encyclopaedic knowledge of salmon fishing. Each year at Christmas we would receive one of **Peter**'s whole smoked salmon from the Tay!

I kept in touch with **Peter** following his move to Edinburgh where, despite failing health in the past few years, he was always keen to know what was happening to research into M.E.

We all owe an enormous debt of gratitude to Peter. He will be sadly missed.

Dr Charles Shepherd, Hon. Medical Adviser, ME Association, 09 September 2019

Source: ME Association https://bit.ly/2kl0lS2



6. Save4Children – An Update

The charity Save4Children has been created by the editors of the ME Global Chronicle (https://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.

In recent years, the Save4Children fund has directed its attention and help at the Danish ME patient **Karina Hansen**.

As we know, **Karina** had been forcibly accepted into the Neurocenter in Hammel, Jutland. On Monday November 17th, 2017, she returned back home, never to return to the clinic at which she had been staying - a clinic for patients with brain conditions.

The primary obstacle on the road to fully getting her personal freedom back was her state-appointed guardian, who had been sort-of cooperating during the duration of her forced stay at the Hammel Neurocenter.

On October 10th 2018, a judge deemed **Karina** to have legal capacity to make decisions about her own life, and revoked guardianship over her, with her guardian's permission.

The Save4Children fund has been able to contribute a small amount towards undoing the high costs this event has brought with it.

Now is the time to spend this fund's donations on one or multiple new cases. We're still at a stage of deliberation, but in case you're familiar with any cases where young ME patients are being forced to stay at psychiatric institutions or are about to, make sure to tell us via info@let-me.be.

As we know, the fund is intended for parents who can't afford to dispute such a process, who can prove their lack of sufficient funds.

New way of donating

Because the Dutch ME/CFS Association refused to collect any more donations to Save4Children since 2 years ago, these are no longer tax-deductible. Hence why we found a way to reduce the incurred costs when collecting and sending donations (see next page), making sure they will, after all, still entirely be used for the good of their goal.

EUR bank details:
TW Account Holder: Save4Children
IBAN: DE51 7001 1110 6053 5236 40
Bank code (SWIFT / BIC): DEKTDE7GXXX
Address:
Handelsbank
Elsenheimer Str. 41
München
80687
Germany

GBP bank details:
Account Holder:Save4Children
Account number: 70983145
UK Sort Code: 23-14-70
Address:
TransferWise
56 Shoreditch High Street
London
E1 6JJ
United Kingdom

AUD bank details:
Account Holder: Save4Children
Account number: 494016722
BSB Code: 082-182
Address:
TransferWise
800 Bourke Street
Melbourne VIC 3008
Australia

USD bank details:
Account Holder: TransferWise FBO Save4Children
Account number: 8310172655
Wire Routing Number: 026073008
ACH Routing Number: 026073150
Address:
TransferWise
19 W 24th Street
New York
10010
United States

7. Science

Diagnosing M.E. using qEEG

From the paper:
Significance

It appears highly likely that the vascular cuffing phenomenon arising from enteroviral infection in poliomyelitis and it's associate ME in the early part of the last century remains alive and well in the world today with the latter enjoying the benefits of being overlooked or conflated with the nonsensical CFS definitions and their offspring by the general medical profession. Despite this, essential data describing the basic nature of ME have been increasingly well developed by the dedicated and insightful work of a small handful of experienced physicians and researchers. Contrary to erroneous assumptions that ME cannot be measured, or is defined solely by subjective fatigue, the evidence herein shows that reliable empirical measurement is possible right now with the use of appropriate functional brain imaging technology. This includes SPECT and now qEEG in combination with sLORETA software. Both modalities strongly support the historical record of symptomology going back to 1934 as told by the neurons and blood cells themselves."

Letter to participants of the study:
"Hello Volunteers,
By now an update on the progress of our study is long overdue. Included below is a description of where we are and where things are going from here.

To start with, the data we obtained last summer has been used to generate a single brain representative of the brain activity unique to our group of 45 volunteers. This means that we took all of the eyes closed data from each individual and put everything together into an "aggregate brain" that represents the entire group of individuals with a medical diagnosis of ME/CFS.

Next we statistically compared this aggregate brain to a healthy brain of the same average age as the group of volunteers. As you can see in the results section of my thesis (which is attached below), the areas of statistically different brain electrical activity shown on qEEG reproduce essentially the same regions of the brain shown to be abnormal as the SPECT studies done of ME brains by **Dr. Byron Hyde**. In summary, our study was successful in establishing that the patterns of brain anomalies discovered by Dr. Hyde can be confirmed i.e. reproduced using qEEG with SLORETA software."

Andrew Pellegrini

Source: https://bit.ly/2m16F1r

$2.9 NIH Grant For a Threefold MRSI-Study

$2.9 NIH grant for a threefold MRSI-study by **Jarred Younger**

Jarred Younger (**PhD**), Director of the Neuroinflammation, Pain and Fatigue Lab at University of Birmingham at Alabama, received $2.9 million in funding from the National Institutes of Health to complete a brain imaging study over the next five years.

In a pilot project funded by Solve M.E.'s Ramsay Grant Program, **Dr. Younger**'s Ramsay study brought novel use of a neuroimaging technique called magnetic resonance spectroscopy imaging (MRSI) to measure whole-brain differences in an ME/CFS cohort. The researchers found metabolite and temperature differences in the brains of people with ME/CFS compared to healthy controls; supporting a neuroinflammatory driver of the disease.

The Ramsay seed funding was leveraged by **Dr. Younger** into a powerful R01 study that will replicate the use of MRSI in a much larger cohort of ME/CFS and healthy control subjects. The study will also incorporate a longitudinal design in a smaller group of participants to correlate neuroimaging results with fluctuations in symptoms over time. Additionally, PET scan will be used to validate the MRSI findings. Check out the study on NIH RePORT:

Project Summary/Abstract

In this R01 project, we will test a magnetic resonance spectroscopic imaging (MRSI) technique to assess several markers of neuroinflammation across the entire brain. We will use the technique to investigate the pathophysiology of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), a condition of unknown etiology that is characterized by profound fatigue not alleviated by rest.

The lack of information on ME/CFS pathophysiology has posed a substantial obstacle to the development of treatments that are specific and effective for the disorder. We hypothesize that ME/CFS is the result of low-level inflammation in the brain. Chronic activation of microglia and astrocytes provokes the release of proinflammatory agents that interact with neurons to cause symptoms of fatigue, pain sensitivity, and cognitive and mood disruption.

MRSI may be able to detect that neuroinflammation by showing elevated myo-inositol, choline, lactate, brain temperature, and lower N-acetylaspartate that have been associated with abnormal microglia activation.

In this five-year R01 study, we will conduct three separate studies.

Study #1 examines 90 women with ME/CFS and 30 age- and body mass index-matched healthy controls. Neuroinflammatory markers will be assessed on a voxel-by- voxel basis throughout the entire brain, yielding approximately 4,000 assessments in gray matter, white matter, and cerebrospinal fluid. We hypothesize that the neuroinflammatory markers will be elevated in several brain regions in the ME/CFS group.

Study #2 uses a "good-day, bad-day" longitudinal design to examine correlation between neuroinflammatory markers and symptom severity fluctuations in 20 women with ME/CFS. We hypothesize that the higher fatigue severity days will be associated with higher levels of neuroinflammatory markers.

In Study #3, we will validate the MRSI scan with positron emission tomography (PET) analysis of 18F-DPA-714, a marker of activated microglia. We expect to see spatial overlap in MRSI and PET indicators of neuroinflammation.

Support for these three hypotheses would show that ME/CFS is associated with brain inflammation. This test would allow for safe and inexpensive longitudinal assessment of neuroinflammation that is not possible with positron emission tomography (PET) or lumbar puncture measures of cerebrospinal fluid.

Because we collect the entire available spectrum in each voxel, we will also have the first whole-brain metabolic data in ME/CFS. The MRS data can be used to quantify other markers of interest to ME/CFS researchers, such as glutamate and glutamine. We will therefore make the entire dataset available to other researchers for secondary analyses. Ultimately, we hope this non-invasive scanning technique will aid in ME/CFS diagnosis, treatment decisions, and the development of new treatments.

Solve ME https://bit.ly/2KiUBkF

Study Identifies Potential Biomarker For a Debilitating Fainting Condition

New research from the University of Toledo College of Medicine and Life Sciences strongly suggests postural orthostatic tachycardia syndrome, or POTS, is an autoimmune disorder, and may help pave the way for a simple blood test that could help physicians diagnose the condition.

POTS is characterized by large increases in heart rate and sometimes decreases in blood pressure when standing up. That can cause lightheadedness, heart palpitations and even loss of consciousness. In addition to fainting, POTS patients also regularly suffer from a litany of additional symptoms, including fatigue, pain, gastrointestinal issues, bleeding disorders, anxiety and brain fog.

About 3 million Americans are believed to be affected, but because of its wide-ranging and seemingly unrelated symptoms, POTS is notoriously difficult to identify.

"The trouble with diagnosing POTS is that it's currently principally a clinical diagnosis. It's based on history, the absence of other illness as well as the finding of increase in heart rate when standing. There is no blood test right now to aid in the diagnosis. It can be an incredibly frustrating process for patients," said **Dr. Blair Grubb**, Distinguished University Professor of Medicine and Pediatrics in the UToledo College of Medicine and Life Sciences and director of electrophysiology services at the University of Toledo Medical Center.

In the largest study of POTS patients to date, published Sept. 9 in the Journal of the American Heart Association, Grubb and UToledo research collaborators found 89 percent of patients they examined had elevated levels of autoantibodies against the adrenergic alpha 1 receptor.

"People have suspected an autoimmune connection for years, and other small-scale studies have suggested it," said Grubb, one of the world's foremost experts in syncope and disorders of the autonomic nervous system. "We did a much larger cross-section of patients than has ever been done before, and found that almost all of them tested positive for autoimmune antibodies. That's a significant finding."

None of the 55 patients who participated in the study had another recognized autoimmune disorder. Fifty-two were female, with an average age of 30.

Researchers screened the patients' blood for autoantibodies against nine receptors. A handful of patients showed elevated levels against all nine. But it was the prevalence of adrenergic A1 subtype receptor autoantibodies that make their findings so intriguing.

"I think that we have identified a biomarker. We now might have the ability to diagnosis this, or at least have an inkling. Like other autoimmune disease, we can take a blood sample and detect if there are increased levels of autoantibodies present. According to our results, autoantibodies against this particular receptor should be present in about 90 percent of patients with POTS," said **Dr. William Gunning**, a professor of pathology in the UToledo College of Medicine and Life Sciences, and the paper's lead author.

Gunning and **Grubb** say much more research is needed. However, this study adds significantly to the evidence that POTS is an autoimmune disorder—and it shows it may be possible to give physicians unfamiliar with the condition an easy way to test for it.

"What this does is prove the concept," **Grubb** said. "Other studies had used very expensive research tests. What we used are the same kind of testing methods that would be used by regular hospitals. We wanted to do something that would potentially be a test applicable to the general population, not just a research test."

While **Gunning** and **Grubb** caution they're still investigating the precise methods by which POTS is established, their study does raise the possibility that existing immune modulating medications could be a viable therapeutic method for some patients.

Source: https://bit.ly/2miP3hO

Hope, Disappointment and Perseverance

Hope, disappointment and perseverance: Reflections of people with Myalgic encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and Multiple Sclerosis participating in biomedical research.

A qualitative focus group study.

Eliana Lacerda PhD, **Clare McDermott PhD**, **Caroline C. Kingdon MSc**, **Jack Butterworth BA**, **Jacqueline M. Cliff PhD**, **Luis Nacul PhD**

The Clinical Understanding and Research Excellence in ME/CFS group (CureME) at the London School of Hygiene & Tropical Medicine has supported and undertaken studies in immunology, genetics, virology, clinical medicine, epidemiology and disability. It established the UK ME/CFS Biobank (UKMEB), which stores data and samples from three groups: participants with ME/CFS, Multiple Sclerosis (MS) and healthy controls. Patient and public involvement have played a central role from its inception.

Aim

To explore the views of participants with ME/CFS and MS on CureME research findings, dissemination and future biomedical research priorities.

Method

Five ME/CFS and MS focus groups were conducted at two UK sites. Discussions were transcribed and analysed thematically.

Results

A total of 28 UKMEB participants took part: 16 with ME/CFS and 12 with MS. Five themes emerged: (a) Seeking coherence: participants' reactions to initial research findings; (b) Seeking acceptance: participants explore issues of stigma and validation; (c) Seeking a diagnosis: participants explore issues around diagnosis in their lives; (d) Seeking a better future: participants' ideas on future research; and (e) Seeking to share understanding: participants' views on dissemination. Focus groups perceived progress in ME/CFS and MS research in terms of "putting together a jigsaw" of evidence through perseverance and collaboration.

Conclusion

This study provides insight into the emotional, social and practical importance of research to people with MS and ME/CFS, suggesting a range of research topics for the future. Findings should inform biomedical research directions in ME/CFS and MS, adding patients' voices to a call for a more collaborative research culture.

Source: https://onlinelibrary.wiley.com/doi/full/10.1111/hex.12857

Latent Class Analysis of a Heterogeneous International Sample of Patients With Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

Kayla A. Huber, **Madison Sunnquist**, **Leonard A. Jason**

Abstract

Background:

Individuals with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) routinely display differences in symptomatology, as well as illness course, onset, duration, and functional disability. Given such diversity, previous work has attempted to identify symptom-based ME/CFS subtypes.

However, results have been inconsistent.

Purpose:

This study sought to elucidate potential subtypes of ME/CFS as well as explore the impact of subtype membership on health functioning.

Methods:

Twelve non-core (i.e., less frequently endorsed) symptoms were included in a latent class analysis of 1,210 adults with ME/CFS. Demographic and illness-related predictors of class membership were evaluated with a multinomial logistic regression. ANOVAs were then performed to determine if there were significant differences across class on the eight subscales of the ShortForm Health Survey (SF-36).

Results:

A six-class solution was selected, which consisted of one class that was likely to endorse all non-core symptoms, one class that was unlikely to endorse any non-core symptoms, and four classes that were likely to endorse either one or two non-core symptom domains (i.e., circulatory/neuroendocrine impairment, orthostatic intolerance, and gastro-intestinal distress).

Significant functioning differences by class were present for all SF-36 subscales.

Conclusions:

These results are suggestive of subtypes of ME/CFS and, if replicated, may assist physicians in providing tailored treatment to patients and allow researchers to form more homogeneous samples.

Source: **HHS Public Access** https://bit.ly/2kiHA1A

The IDO Metabolic Trap Hypothesis For The Etiology of ME/CFS

Alex A. Kashi , **Ronald W. Davis** and **Robert D. Phair**

Abstract

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a debilitating noncommunicable disease brandishing an enormous worldwide disease burden with some evidence of inherited genetic risk.

Absence of measurable changes in patients' standard blood work has necessitated ad hoc symptom-driven therapies and a dearth of mechanistic hypotheses regarding its etiology and possible cure.

A new hypothesis, the indolamine-2,3-dioxygenase (IDO) metabolic trap, was developed and formulated as a mathematical model.

The historical occurrence of ME/CFS outbreaks is a singular feature of the disease and implies that any predisposing genetic mutation must be common. A database search for common damaging mutations in human enzymes produces 208 hits, including IDO2 with four such mutations.

Non-functional IDO2, combined with well-established substrate inhibition of IDO1 and kinetic asymmetry of the large neutral amino acid transporter, LAT1, yielded a mathematical model of tryptophan metabolism that displays both physiological and pathological steady-states. Escape from the pathological one requires an exogenous perturbation.

This model also identifies a critical point in cytosolic tryptophan abundance beyond which descent into the pathological steady-state is inevitable. If, however, means can be discovered to return cytosolic tryptophan below the critical point, return to the normal physiological steady-state is assured.

Testing this hypothesis for any cell type requires only labelled tryptophan, a means to measure cytosolic tryptophan and kynurenine, and the standard tools of tracer kinetics.

Source: Diagnostics, https://www.mdpi.com/2075-4418/9/3/82
Open access. Full text: https://www.mdpi.com/2075-4418/9/3/82/htm

Update on "Dialogues For a Neglected Illness"

First video draft screened for health professionals in NI.

We are now nearly a year into this three-year project, made possible by an award from the Wellcome public engagement fund. **Josh** and I have been making visits to film patients (biobank participants and advocates), doctors and researchers. I have many more visits and interviews to arrange, but several videos are now well underway, as we gather more material. The first video to have been screened is a two-part video on Graded Exercise Therapy. This was shown at the Hope 4 ME & Fibro conference in Belfast recently, on September 4th. Theconference was for medical professionals in Northern Ireland and was held at the University.

Part one of the GET video uses interviews with members of the Workwell team, who explain how inappropriate and even dangerous GET can be for ME/CFS patients. In part two, **Prof Brian Hughes** from NUI Galway, author of 'Psychology in Crisis', and **Prof Jonathan Edwards**, comment on the behavioural/psychological research often cited as evidence to support the use of GET. There are still a few changes to make to the video and then it will be freely available online - initially on the 'Voices from the Shadows' film website. There are still a few changes to make to the video and then it will be freely available online - initially on the 'Voices from the Shadows' under a new 'Dialogues Project' tab https://bit.ly/2ksjq52 I am currently working on the Severe ME videos, as well as an Introductory video, a PEM video, video's exploring patients' accounts of symptoms and a video in support of patient advocates. At a later date, when several videos are completed, they will be available on a separate project website alongside links to further resources and then later the project will be copied to the CURE ME website and the ME Research website, so they can be found more easily by patients, doctors, researchers and anyone else interested.

In about a year's time there will be a free 'Opening' event at the LSHTM. However, since they are needed now, videos will be made available to view as soon as possible, with the project remaining a 'work in progress'. We have interviewed patients ranging from those who have only been ill for a few years to those with decades of experience, as well as doctors and researchers in various fields. This week in Belfast we were able to interview **Dr David Systrom** about his experiences and his discovery of what he finds to be an objectively measurable, hallmark physiological abnormality in ME/CFS - pre-load failure. This is a very interesting project to work on, although somewhat all consuming! I am most grateful for all the help I am receiving: the patients and professionals who have welcomed Josh and me into their homes, the doctors and researchers who have given up their time for our interviews, the invaluable advice and feedback from many patients, patient advocates, doctors and researchers. Many, many thanks to all of you who are making this project possible.

Natalie Boulton

Diagnostic Sensitivity of 2-Day Cardiopulmonary Exercise Testing in ME/CFS

Diagnostic sensitivity of 2-day cardiopulmonary exercise testing in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

Maximillian J. Nelson, **Jonathan D. Buckley**, **Rebecca L. Thomson**, **Daniel Clark**, **Richard Kwiatek** & **Kade Davison**

Abstract

Background

There are no known objective biomarkers to assist with the diagnosis of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS). A small number of studies have shown that ME/CFS patients exhibit an earlier onset of ventilatory threshold (VT) on the second of two cardiopulmonary exercise tests (CPET) performed on consecutive days. However, cut-off values which could be used to differentiate between ME/CFS patients have not been established.

Methods

16 ME/CFS patients and 10 healthy controls underwent CPET on a cycle-ergometer on 2-consecutive days. Heart rate (HR), ventilation, ratings of perceived exertion (RPE) and work rate (WR) were assessed on both days.

Results

WR at VT decreased from day 1 to day 2 and by a greater magnitude in ME/CFS patients ($p < 0.01$ group × time interaction). No interaction effects were found for any other parameters. ROC curve analysis of the percentage change in WR at VT revealed decreases of − 6.3% to − 9.8% provided optimal sensitivity and specificity respectively for distinguishing between patients with ME/CFS and controls.

Conclusion

The decrease in WR at VT of 6.3–9.8% on the 2nd day of consecutive-day CPET may represent an objective biomarker that can be used to assist with the diagnosis of ME/CFS.

Source: BMC https://bit.ly/2YrHEya (open access)

From Pathophysiological Insights to Novel Therapeutic Opportunities

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: From Pathophysiological Insights to Novel Therapeutic Opportunities

Gerwyn Morris, **Basant K. Puri**, **Adam J. Walker**. **Michael Maes**, **Andre F.Carvalho**, **Ken Walder**, **Catherine Mazza**. **Michael Berk**

Abstract

Myalgic encephalomyelitis (ME) or chronic fatigue syndrome (CFS) is a common and disabling condition with a paucity of effective and evidence-based therapies reflecting a major unmet need.

Cognitive behavioural therapy and graded exercise are of modest benefit for only some ME/CFS patients, and many sufferers report aggravation of symptoms of fatigue with exercise.

The presence of a multiplicity of pathophysiological abnormalities, in at least the subgroup of people with ME/CFS diagnosed with the current international consensus "Fukuda" criteria, points to numerous potential therapeutic targets.

Such abnormalities include extensive data showing that at least a subgroup has a pro-inflammatory state, increased oxidative and nitrosative stress, disruption of gut mucosal barriers and mitochondrial dysfunction together with dysregulated bioenergetics.

In this paper, these pathways are summarised, and data regarding promising therapeutic options that target these pathways are highlighted; they include coenzyme Q10, melatonin, curcumin, molecular hydrogen and N-acetylcysteine.

These data are promising yet preliminary, suggesting hopeful avenues to address this major unmet burden of illness.

Source: Elsevier https://bit.ly/2lY9VuG, Paywall

The Development of The DePaul Symptom Questionnaire

The Development of the DePaul Symptom Questionnaire: Original, Expanded, Brief, and Pediatric Versions

Leonard A. Jason* and Madison Sunnquist Center for Community Research, DePaul University, Chicago, IL, United States

One of the key requirements of a reliable case definition is the use of standardized procedures for assessing symptoms. This article chronicles the development of the DePaul Symptom Questionnaire (DSQ) to assess symptoms of the major chronic fatigue syndrome (CFS) and myalgic encephalomyelitis (ME) case definitions.

The original questionnaire has been modified and expanded over time to more fully capture symptoms from various adult case definitions, and a brief as well as pediatric version have also been developed.

The DSQ has demonstrated very good psychometric properties in terms of test-retest reliability and sensitivity/specificity, as well as construct, predictive, and discriminant validity. The DSQ allows for a clear characterization of a patient's illness and allows scientists and clinicians to improve diagnostic reliability and validity when employing case definitions of ME and CFS.

Since 1994, many researchers have used the Fukuda et al. chronic fatigue syndrome (CFS) case definition to select cases, but problems emerged in part due to this case definition not requiring core symptoms of CFS . In contrast, myalgic encephalomyelitis (ME) and CFS specialists have developed several adult case definitions that require essential symptoms of ME and CFS: the Canadian Consensus Criteria ME (CCC), the ME-International Consensus Criteria (ICC), and Systemic Exertion Intolerance Disease (SEID).

These case definitions are a set of rules that allows investigators and clinicians to determine who has and who does not have an illness. In other words, the goals involve sensitivity (selecting those with the illness) and specificity (not selecting those without the illness).

Criterion variance represents the largest source of diagnostic unreliability for case definitions, and it involves specifying symptoms to classify patients' symptoms into diagnostic categories . Criterion variance can occur when there are multiple case definitions without a consensus on which symptoms need to be manifested to arrive at a diagnosis. In addition, case definition unreliability occurs when there is no consensus on scoring rules that specify how to determine whether a particular symptom is severe enough to qualify as satisfying criteria for the case definition, or when symptoms are not assessed by standardized instruments.

These issues can result in investigators selecting samples of patients who are different on fundamental aspects of this illness. The consequences of these types of unreliability include difficulties replicating findings at different laboratories, estimating prevalence rates, identifying biomarkers, and determining effective treatments.

ME and CFS case definitions have some overlapping and some different diagnostic criteria. In spite of the fact that there are currently alternative case definitions, it is still important to develop standardized ways to measure the symptoms just as this has occurred with other illnesses.

The National Institutes of Health/Centers for Disease Control and Prevention (NIH/CDC) Common Data Elements (CDE) working group has recently recommended a set of instruments to be used by researchers, and for baseline symptoms the working group recommended using either the DePaul Symptom Questionnaire (DSQ) or a combined instrument using both the CDC's Symptom Inventory (SI) as well as items from the DSQ (even though the SI and DSQ differ on a number of dimensions, including the time period in which symptoms are measured and anchor points for the assessment of symptoms).

Because of the recommendation for the use of the DSQ, this article reviews the genesis and psychometric properties of the different versions of the DSQ.

Source: https://bit.ly/2m0Yi6c Open access

Work Rehabilitation And Medical Retirement For Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Patients

A Review and Appraisal of Diagnostic Strategies
by **Mark Vink** and **Friso Vink-Niese**

Received: 7 June 2019 / Revised: 11 September 2019 / Accepted: 13 September 2019 / Published: 20 September 2019
(This article belongs to the Special Issue Biomedical Insights that Inform the Diagnosis of ME/CFS) https://bit.ly/2svVX3i

Abstract
Myalgic Encephalomyelitis/Chronic Fatigue Syndrome leads to severe functional impairment and work disability in a considerable number of patients.

The majority of patients who manage to continue or return to work, work part-time instead of full time in a physically less demanding job.

The prognosis in terms of returning to work is poor if patients have been on long-term sick leave for more than two to three years.

Being older and more ill when falling ill are associated with a worse employment outcome. Cognitive behavioral therapy and graded exercise therapy do not restore the ability to work. Consequently, many patients will eventually be medically retired depending on the requirements of the retirement policy, the progress that has been made since they have fallen ill in combination with the severity of their impairments compared to the sort of work they do or are offered to do.

However, there is one thing that occupational health physicians and other doctors can do to try and prevent chronic and severe incapacity in the absence of effective treatments. Patients who are given a period of enforced rest from the onset, have the best prognosis.

Moreover, those who work or go back to work should not be forced to do more than they can to try and prevent relapses, long-term sick leave and medical retirement.

Read the whole paper (open access) here: https://bit.ly/2mtq4sj

Thanks to **Lydia Neilson**

8. Severe ME

Left To Exist

People with severe ME cannot participate in social activities, cannot work, cannot volunteer for anything, cannot travel, cannot go to school, cannot do anything in this life. We are left to exist, that is it.

There is no life from it.

We lose everything, friends, relatives. The relationships fall apart because we aren't well enough for keeping them up.

We lose our ability to work and go to school. We cannot volunteer for anything. We lose are reliability, we are too sick to guarantee we can be anywhere at any given time.

Severe ME is a horrible form of living death.

We exist in an unended state of being fully aware that the world is going on without us. That is Severe ME.

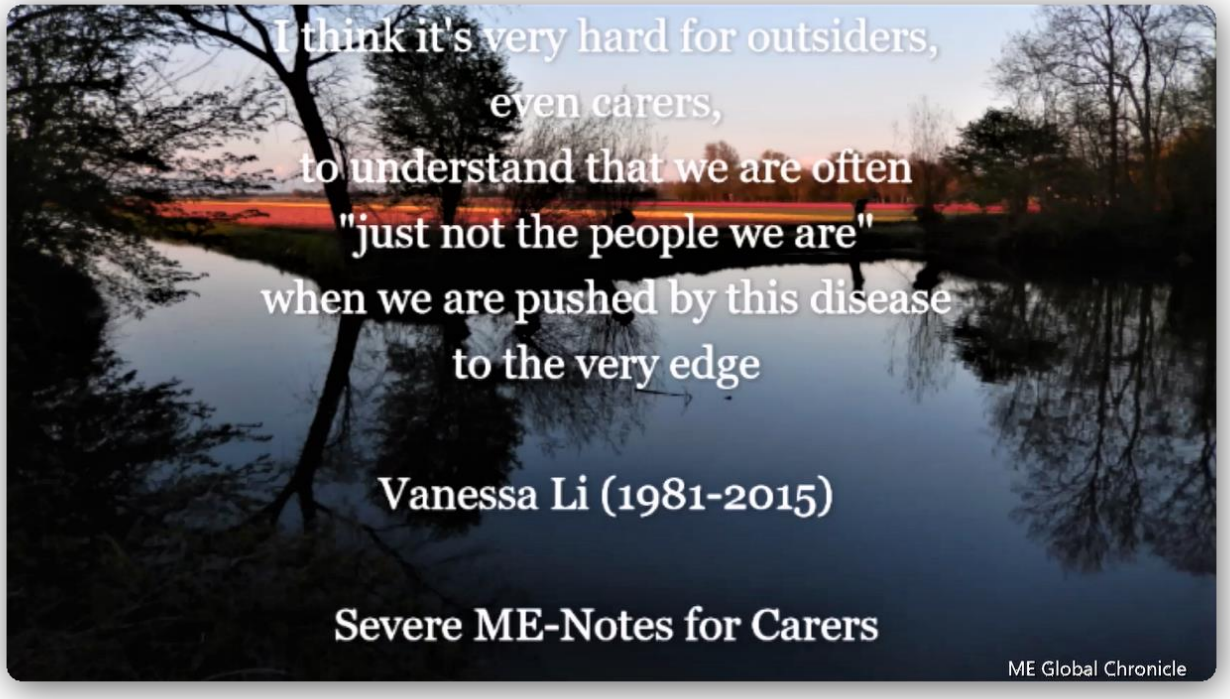
No cure, no treatment, no one is giving us even a glimmer of hope or light at the end of the tunnel.

We are ignored and if we dare speak of it, we are ridiculed.

Julie Carrigon

As in Severe ME-Notes for Carers
https://stonebird.co.uk/Notes/index.html

Outsiders


I think it's very hard for outsiders,
even carers,
to understand that we are often
"just not the people we are"
when we are pushed by this disease
to the very edge
Vanessa Li (1981-2015)
Severe ME-Notes for Carers
ME Global Chronicle

What I Need From a Carer

For me the most important issues are
respect,
sensitivity,
willingness to engage with me
in a world they cannot possibly really comprehend,
but will accept as true for me,
being able to be present with me
and understanding when I am distressed and having to say go away,
not judging or reacting to me,
but lovingly responding appropriately
and not taking it personally,
but willing to try again later –
fundamentally respecting my horrific reality
due to noise sensitivity,
light,
food,
touch,
movement sensitivity
and chemical sensitivity
and really trying to help me in the most quiet way.
Helping me to see we are in this together,
no matter how broken or tortured I am by normality.
Being endlessly patient
when I struggle with paralysis.
Working out what is best in any one moment
because it is so unpredictable
yet relentless
and not obvious always
what is the best thing.
What is hard
is the invisibility of symptom experience inside of me.
understanding and reaching out to me sensitively,
just as I am,
not judging me,
is such a powerful thing.
And smiling at me
Genuinely brings a comfort
and hope for the moment.

Linda Crowhurst
Severe ME – Notes for carers
https://stonebird.co.uk/Notes/index.html

Severe/Very Severe ME : The Need For Proper Symptom Identification

Greg and **Linda Crowhurst**, August 2019

Living tortured, isolated, invisible lives of silent agony, on the furthest edges of existence, people with a Severe/Very Severe ME diagnosis are some of the most tormented and isolated, neglected people in the UK.

Their illness is a trauma and a tragedy. Deterioration can be instant, unpredictable and severe, following even the slightest interaction or intervention. The disease goes on for decades and decades, without resolution or proper recognition.

Unfortunately an incredibly powerful psychiatric lobby has dominated social, health and welfare policy in the UK, for decades on end, perpetuating the untruth that Myalgic Encephalomyelitis (ME), a WHO G93.10.3 classified neurological disease, is a mental health disorder.

Things have only got worse in recent years with the promotion, incorrectly, of ME as MUS, a mental health condition treatable through IAPT psychological therapies.(NHS 2019) If someone has any other physical disease, most likely their symptoms will be correctly identified and recognised, the physiological cause will investigated and there will be an understanding of what to do, to treat the person, once diagnosed.

Unlike people with ME, patients with other common diseases like Diabetes or Cancer, do not have to contend with:

- interchangeable names with totally different interpretations
- unsafe treatment protocols
- invisibility of suffering
- no appropriate tests or thorough investigation
- neglect of symptoms
- specialists choosing whether or not to believe the patient is physically ill
- no recognition of the specific cause of the disease, leaving it open to misinterpretation
- no long term specialist support

Cancer and Diabetes, however, both have a clinical pathway, monitoring, support and respect.
What a different world to ME!

Complete text https://bit.ly/2m59Vt2

Severe ME - Poster

9. ME And Children

ME in Children and Young People – Part 2

By **Dr. Nigel Speight**

I am a British paediatrician who has a special interest in paediatric ME which I have developed over the last 30 years. During this time I have seen over 700 cases, and been involved is a number of contentious and controversial cases. I have been asked to write this chapter based on my experiences. Not knowing my audience or the current situation in German medicine I do this with all due diffidence.

Spectrum of severity

It is important to understand that there is a very wide spectrum of severity in ME, and that there is marked fluctuation of severity over the course of an individual patient's illness. The severity ranges from

- 70-90% of Normal
  Mild – these patients may look perfectly normal and lead virtually normal lives but they cannot undergo serious exertion and if they do can suffer a relapse
- 40-70%
  Moderate – these patients can do part-time work or school but are always on the brink of mini-relapses. They are at risk of indulging in "Boom and Bust" whereby they overexert themselves when well and then suffer the consequences
- 10-40%
  Severe – these patients are unable to work or attend school. They lead very limited lives being virtually housebound
- 2-10%
  Very severe/life threatening – these patients are bedbound and suffering severe symptoms especially pain

One of the problems conversing with people with ME is the confusion between a simple greeting "How are you?" and a medical question "How are you". The patient may politely reply "OK thanks" and the doctor may mistakenly take this as a sign of improvement.

For this reason I ask patients what their percentage has been over the last few weeks. I also find it useful to chart a rough graph of each patient's severity scores since the onset of the illness.

The Mild Case

Mild cases deserve being officially diagnosed for a variety of reasons. Firstly, they need to understand their condition which otherwise can be maddening. Secondly even mild cases can get worse if triggered by over-exertion or a severe virus infection, and early correct advice can prevent the former.

Case A

A 14 yr old girl had virtually recovered from her ME of several years duration. She was symptom free and attending fulltime school (ie 90%). Her paediatrician had cautiously advised her not to recommence sporting activities yet. Despite this her teachers coaxed her into doing a crosscountry run, as she used to be very athletic. As a result she suffered a relapse which kept her off school for 18 months

Case B

A 15 yr old boy had been reasonably well for the previous 3 years, apart from the fact that every time he caught a virus/common cold he would be off school for a month (Undue susceptibility to virus infections is an under-recognised feature of ME) He was probably suffering from Mild ME all this time. Not knowing this he went on a strenuous back-packing and camping holiday with his father, which unmasked his ME. He was in the Moderate level of severity for several years and missed a lot of schooling. Had he been diagnosed with ME he might have been counselled against the trip and avoided the relapse.

Case C

A 13 yr old girl presented with moderate ME for several months. She then deteriorated markedly for no obvious reason. She became bed-ridden and eventually needed tube-feeding for over 2 years. Thereafter she made a slow but good recovery over the next 5 years

The Moderately Severe case

Here diagnosis is less of a problem as long as they see the right doctor. The main problem for the patient is coping with the illness which severely affects normal life. It has been said that for the patient it is easier to have ME severely than moderately. This is because the severe case has no choice over most issues, whereas the moderate case has choices to make every day.

These are the patients most at risk of "Boom and Bust", and this is quite understandable. The relief of feeling relatively normal one day leads to the patient trying to do too much, either regarding work or leisure. In my experience, until given advice, most patients are trying to do too much when first diagnosed. Many will benefit from reducing their activity levels. A 10% reduction in activity can lead to the patient feeling 90% better.

My motto is "Take two steps backward and then one step forward", which is a variation on the Duke of Wellington's motto "When I am in trouble, I retreat to a safe place from which to plan my next advance"

The Severe and Very Severe Case

Those ME patients who enter the severe end of the spectrum are truly unfortunate. Most suffer from unpleasant symptoms (general body pain, headaches and exhaustion) on a continuous basis for months or even years. Their lives are "put on hold" both in terms of careers and relationships. Adolescent patients are especially unfortunate as this is the stage in life where they develop their sense of identity, and therefore their identity for this period is that of an invalid.

The very severe cases pose a major challenge for both the patient and the doctor. Many cases are too weak to eat or drink and need tube feeding, ideally at home. The management of their severe symptoms is an area where "the art of medicine" is more important than the science, and ideally the doctor should lean over backwards to try anything to help with symptom relief. Pain can be sometimes so severe that opiates are necessary, although the pain does not respond as well to these as normal musculoskeletal pain.

Immunoglobulin

Having previously stated that currently there is no absolutely curative treatment for ME, it should be recognised that there is some research evidence that immunoglobulin can be of significant benefit in some cases. For this reason I offer it to all my severe cases. While still practising in Durham, I had 6 severe cases who were all bedbound for over 6 months, and 5 out of the 6 needed tube feeding. All made near total recoveries over 2-5 years.

Case D

This 14 yr old boy had a severe and sudden onset. He was given Immunoglobulin by another doctor and made a near miraculous recovery. After missing two years of school he returned to full activity, and at one stage climbed the three highest mountains in the UK within 24 hours, and suffered no ill effects. He has a mini-relapse at university following a virus infection but then recovered fully over several months.

Case E

Despite my positive experience with IgG I have trouble persuading UK doctors to at least offer their patients a trial of it. However, when lecturing in Norway I met a family whose 19 yr old daughter had been lying bedridden in a darkened room for 5 years ie c 10%. Her family doctor followed my suggestion to offer IgG and over the next 6 months she improved to c 90%

My most severe case ever

This 14 yr old girl had a very rapid onset of her ME and deteriorated rapidly from the outset. I avoided over-investigating her (from bitter experience from previous cases in whom this had been very distressing).

I admitted her to hospital for a quick MRI scan and second opinion, then managed her at home with frequent visits. I started her on Immunoglobulin, but she remained so severe that I felt I had to try more. I accordingly gave her a trial of Clarithromycin, based on the work of **Garth Nicholson** who found some cases of ME are due to atypical Mycoplasmata.

However she continued to deteriorate and her breathing was so shallow that I genuinely feared for her life. After 9 months I added Doxycycline just in case she was a case of Lyme Disease. Over the next three months she made a rapid recovery and at 2 years from onset she was virtually normal. Follow up at 10 years confirmed total recovery

Mast Cell Activation Disorder (MCAD)

Recently in the UK there have been a number of very severe cases in which severe abdominal pain and vomiting has led to marked wasting and in two cases fatality. It is being increasingly recognised that in some of these cases this is due to MCAD, and treatment with oral Cromoglycate, antihistamines and ranitidine can be very helpful.

Dr. Nigel Speight as written for © Fatigatio 2019
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Part 1 has been published in the June 2019 issue of the ME Global Chronicle.
Part 3 will appear in the December 2019 issue.

Why Can't This Child Get to Class?

Online Program
https://bit.ly/2mookAD
Learn How ME/CFS* Keeps Youth from Attending School
**Myalgic Encephalomyelitis / Chronic Fatigue Syndrome*

The Massachusetts ME/CFS & FM Association is pleased to announce a new online program about pediatric ME/CFS and educational issues of young people with ME/CFS, presented by the foremost clinical expert in pediatric ME/CFS in the U.S.

This program is offered in the U.S. for credit for school nurses, teachers, and school guidance counselors, and contains up-to-date information on pediatric ME/CFS which is also valuable for parents, pediatricians, and very useful for families working with their child's school.

This online presentation is offered by the Northeastern University School Health Academy, and is available to interested persons anywhere in the world for a nominal fee, although credit may not be transferrable outside the U.S.

Overview
Dr. Peter C. Rowe,
Pediatrician, Director, Children's Center Chronic Fatigue Clinic at John Hopkins, and Professor of Pediatrics and **Lisa Hall**, RN. Northampton Integrative Medicine, discuss an illness and disability that keeps afflicted children from attending school for months or even years at a time: ME/CFS (Myalgic Encephalomyelitis / Chronic Fatigue Syndrome), a disease the Centers for Disease Control calls America's hidden health crisis.

Contact Hours 3.25
Cost $25 USD

This program is provided by Northeastern University School Health Academy, which operates within Northeastern University School of Nursing, an ANCC-Accredited Provider, in collaboration with joint provider, Massachusetts ME/CFS & FM Association.

Not Today

I gently walk into the room.
Saying good morning in a soft voice.
The answer from her bed is barely audible.
«I cannot move my hands.»
Carefully, I stroke her hands.
You will have to stay home from school today.
«But I want to go.»
I know she doesn’t want to stay at home.
She prepared yesterday.
Laid out her clothes and some makeup.
To make it easier to prepare for this day.
She can only tolerate small whispering words.
I leave the room quietly.

We can try again tomorrow.

By a Mother of teenager with M.E.

Source: ME Foreldrene https://bit.ly/2kVng6J

Karina Hansen

Karina Hansen's forced hospitalization and treatment at the Hammel Neurocenter
By **Bente Stenfalk** & **Stig Gerdes**, shared with permission of **Karina Hansen**

Regarding forced hospitalization and misdiagnosis, by **Stig Gerdes**

The journal shows the following:

December 12, 2013: The reason for the admission is that the diagnosis is unclear. According to the Functional Disorders Research Clinic, it is similar to functional disorders and the patient is transferred to Hammel Neurocenter for further assessment and treatment.

Upon admission, the inpatient physician's examination of **Karina Hansen** showed that she was relatively unaffected, and moved freely in bed. There is eye contact and she responded to being spoken to. There are signs of anemia. There are no bed sore or anything immediately noticeable.

Blood tests at hospitalization show nothing acute, there's light deficiency due to iron deficiency and slightly reduced albumin.

Comment:
These journal notes describe a relatively unaffected patient, which does not warrant forced entry, forced detention, forced treatment, forced medication, and refusing contact with family and friends for 3 years and 8 months.

Karina's diagnosis was ME (myalgic enchephalomyelitis) determined by 2 hospitals and 3-4 competent doctors and she was receiving correct treatment for an ME patient in her parents' home. Therefore, there was no reason why Holstebro municipality or the Research Clinic interfered in the case. **Karina** was not dirty and unwashed as the Research Clinic claimed, and she also wore clean clothes and was in clean bedding on the day of hospitalization on 12/2 13 according to her parents. Her language was also intact.

Per Fink's statement in "The Psychiatry's Dilemma" at the DR (TV documentary)i, that **Karina Hansen** was in very poor state and that it was reflected in the blood tests, is directly untrue. Had **Karina** been as ill as **Per Fink** stated, she should have been in an intensive care unit and not a neurocenter.

Karina Hansen should never have been hospitalized, and not at all forcibly, there was nothing that justified it !!!

Furthermore, the record confirms that **Karina**'s mother **Ketty** does not have Münchausen by Proxy. By also giving **Ketty** a misdiagnosis, the Research Clinic shows what a substandard and wrong diagnosis system they are using.

Finally, I would like to express my surprise that the Research Clinic, with the blessing of the health authorities, has treated **Karina Hansen** so scandalously. It should get consequences.

There is no doubt that Karina's forced admission was an experiment for the Research Clinic to prove that their diagnosis and treatment are sublime. This failed to the same extent that all previous experiments world wide failed!

I will refer further to **Bente Stenfalk**'s analyzes and comments below.

VH Stig Gerdes

12.2.13 - Quote from the admission journal from Hammel Neurocenter:
"The initial triggering cause may be related to mononucleosis, but this is uncertain. Along the way, patient has been examined for various medical conditions without one being able to give a specific diagnosis. Chronic fatigue syndrome/ME has been considered, but overall the diagnosis code has been uncertain. It's more and more developed into a unified picture where functional disorder is suspected. This is the background for moving the patient to Hammel Neurocenter for further assessment and treatment for this condition. "

In other words, **Karina** was sectioned based on "considerations" and "suspicions" about functional disorders. Her original diagnosis was called into question, even though it was given by leading specialists from home and abroad. As far as mononucleosis is concerned, antibodies can be measured in the blood with certainty, even long after the disease.

Where was the reason for the forced hospitalization?

Karina Hansen's treatment at the Hammel Neurocenter, from journal notes
The daily treatment/exercise was to push **Karina** a little further than she felt she could handle. Coercion was also used. If she didn't do what was demanded, the exercise still got carried out by several people 'helping' her over to the exercise bench, and only if **Karina** broke down completely, the exercise was cut short or skipped for a day, only to be resumed the next day in order not to 'break the good routine'. Many times **Karina Hansen** resigned and did what was demanded while crying.

Daily treatment: bath, tilting while counting up to a certain number, massage, stretching of muscles and tendons, visualization exercises, breathing exercises, standing in a support chair, ball blanket exercises, ball exercises, balloon exercises and pool exercises , all in order to strengthen her body, and everything done for a little longer than **Karina** could hold, which is why **Karina** often broke down crying several times a day.

If **Karina** didn't want to attend the exercise, but rather stay in bed, the duvet was removed and the headboard raised. If **Karina** didn't show up to treatment, she was told that some of the staff would come and physically move her to an exercise or bathing bench.

Karina was supposed to eat sitting and up, and should as a minimum fetch her own food from a table far from the bed. If she didn't pick it up or she didn't want to get up, the food got removed. (However, this was sometimes canceled out of fear of **Karina** losing weight. If **Karina** subsequently became too unhappy and insisted on staying in bed, she was sometimes allowed to eat in bed).

Karina had to sit in a wheelchair and take part in cooking and cleaning in the kitchen, or lie in bed in the kitchen and watch the food being made.**Karina** was to take part in the change of bedding, laundry and hanging up and folding clothes.

If **Karina** was in her living room, she often had to accept staff sitting there reading magazines, writing on PC, arranging laundry, cooking, blending smoothies, knitting, drinking coffee, talking and making noise (deliberately, allegedly in order to get **Karina** used to it).

When **Nils Balle Christensen** became too overbearing, not only did **Karina** turn her back to him (which she always did when he arrived), she also occasionally put her fingers in her ears.

Karina was exposed daily to people (**Nils Balle Christensen** and the staff) who thought she refused to speak intentionally and that she could just start talking, if she wanted to. In this situation, empathy was lacking in the staff, who often seemed annoyed that **Karina** didn't open up to them through speech.

Karina was prevented on a daily basis from going to bed when she wanted. If she was in the garden in bed or wheelchair, they would not go back in until she had finished her juice. When exercising, the exercise would always be kept a little longer, for instance by counting a little slower. When the TV was turned on, the time was dragged a little longer than what she would prefer before it was turned off again. All allegedly in order to train her for ordinary life.

Karina was exposed to many well-meaning caregivers, all of whom did what **Nils Balle Christensen** demanded of them, but fortunately they didn't do it very persistently. If you read the 1000-page journal, it clearly shows that some of the staff were gentle with **Karina**, while others provoked several bad situations and experiences and to them **Karina** spoke up far more often.

Karina Hansen's reaction to the treatment

Karina has a strong personality and she managed to hold onto who she was every day, despite illness and exhausting treatment and massive 'persuasion' attempts by the staff and **Nils Balle Christensen** to make her believe she was suffering from functional disorder and not from myalgic encephalomyelitis, and that they could make her well if she did what they said.When asked, **Karina** did not think her stay had made her stronger.

Graded exercise did more harm than good, pushing **Karina** further on a daily basis, and it became a kind of (well-meaning?) mental and physical torture.

On 7.5.14, it was pointed out at a meeting at Hammel Neurocenter that **Karina**'s stay was voluntary. It is a crime to let a sick citizen stay hospitalized without telling her and the family that she could go home if she wanted, especially when Karina had asked to come home many times.

The next stay and medications at the residence Tagdekkerervej, to where **Karina** was moved in September 2014, could have been avoided if **Karina** had been informed that her stay was voluntary. **Karina** would have been much better today without the psycho-drugs, which is so hard to escape.

With love
Bente

Edited for length. See original post for full details: **Karina Sagen** http://bit.ly/2n5D9Ip

10. News from

Australia

Dissemination of the NHMRC ME/CFS Advisory Committee Report

The final report (https://bit.ly/2lSrEnf) to the CEO of the National Health and Medical Research Council (NHMRC) on ME/CFS was released early in July 2019. Emerge Australia sent copies of this important report to a total of 40 parliamentarians including federal MPs and senators who are known to have shown support to people with ME/CFS in the last 12-18 months. The NHMRC report was also sent to the ministers and shadow ministers whose portfolios are relevant to ME/CFS issues. Accompanying letters included an invitation to join the ME/CFS Parliamentary Friendship Group. The NHMRC reports and letters have been positively received and meetings are being organised with **Dr Heidi Nicholl** in Canberra to discuss the implementation of the report's recommendations.

Telehealth Campaign

In July, we launched a lobbying campaign (https://bit.ly/2kQawOQ) for the inclusion of people with ME/CFS in the telehealth program, established by **Federal Health Minister Greg Hunt**. Many people with ME/CFS are unable to attend doctors' appointments and would benefit from telehealth consultations. For this campaign, we encouraged ME/CFS patients and allies to write to their federal MPs to ask that people with ME/CFS be included in the telehealth program as a priority. We're pleased to announce that more than 33 different federal MPs have received letters, some receiving several letters. This total represents more than 20% of all federal MPs, which is a great result. Treasurer **Josh Frydenberg**, **Ministers Peter Dutton**, **Karen Andrews**, **Ken Wyatt** and Shadow Minister **Bill Shorten** were among the high-profile members who received correspondence. Many of the MPs have forwarded the letters to **Minister Hunt** which was the desired outcome. Numerous emails were also submitted directly to **Minister Hunt**'s contact page. Emerge Australia has sent a letter requesting a meeting with the Minister to follow up on the issue. The Health Minister is more likely to offer a meeting due to the volume of letters landing on his desk. Thank you to everyone who wrote to their Federal MPs or contacted **Minister Hunt** directly. Our campaign ended on 9th, but people are welcome to send letters to their MPs about the issue at any time.

Severe ME-day 2019

Emerge Australia invited its supporters to nominate loved ones severely affected by ME so that they would receive a specially designed greeting card in the mail. This small gesture was done to send an important message; for the 25% of patients who are kept house or bed-bound by the severity of their condition, they are constantly in the hearts and minds of people who love them, and people that are working to improve the quality of their life.

In addition to the greeting cards, ten of those nominated were also randomly selected to receive a pack of the beautiful 'Energy Saving Cards' created by **Ricky Buchanan** – we trust these will be valued. Thank you, to all those who participated by nominating a friend or loved one to receive a card.

Source: September newsletter of Emerge Australia

Belgium

In Belgium there are a number of organizations that are committed to the rights of ME / CFS patients.

For example, we have #MEAction and its project #MillionsMissing. A project that last time on 12th May managed to get an unprecedented crowd in Diest.

But there are other, less well-known organizations that join this. Take the Women's Council of Belgium for example. The Women's Council is the umbrella organization for associations that work on equal opportunities for women and men within a multicultural society.

They stand up for equal rights and opportunities for all women and men, regardless of their age, origin, sexual orientation, belief, disability or other grounds of discrimination.

They have drawn up a Memorandum in which they ask, among other things, that (more) biomedical research should be carried out, that more and better diagnostic centers are to be established, that what advising physicians, company- and insurance doctors diagnose should be monitored more strickly and unambigeously, and more.

You can download the complete memorandum (in Dutch) here:
https://let-me.be/download/52/vrouwenraadmemorandum-gezondheid-2019

Source: http://www.vrouwenraad.be

Eddy Keuninckx

Canada

Dear Friends:

CIHR published the News Release on its website and is followed after the quotes which I am highlighting here first to show you that the ME/FM community is not invisible anymore. Thank you, everyone – advocates, patients and dedicated medical professionals who had the courage to believe. I have taken the liberty of putting more paragraphs in to make the information easier to read.

"CIHR aims to improve the health of Canadians, and this community of Canadians is one that has tremendous need. People living with myalgic encephalomyelitis were at the forefront of this successful high-quality research application. This network will produce important clinical results—treatments for patients with ME—as well as improving health professional education and connecting Canada with international leaders in this field." **Dr. Karim Khan**, Scientific Director of CIHR's Institute of Musculoskeletal Health and Arthritis

"Cutting-edge research at the Centre hospitalier universitaire Sainte-Justine is at the forefront of scientists' efforts to unravel the mystery of debilitating diseases that weigh heavily on patients and their families. I am very proud to see our institution and our scientists at the heart of this initiative that brings hope to so many people." **Ms. Caroline Barbir**, President and CEO, Sainte-Justine University Hospital Centre

"ME is possibly the last medical enigma of the 21st century. The complexity of unresolved questions around its etiology and pathophysiology requires the coordinated efforts of an interdisciplinary collaborative research network to benefit the health of all Canadians living with ME." **Dr. Alain Moreau**, Professor, University of Montreal, Scientific Director, Viscogliosi Laboratory in Molecular Genetics of Musculoskeletal Diseases, CHU Sainte-Justine Research Centre, Scientific Lead and Director of the Interdisciplinary Canadian Collaborative ME Research Network

"Myalgic encephalomyelitis is a long-term disabling disease that greatly affects individuals who live with it. This CIHR grant is a huge opportunity for Canadian researchers and clinicians to work together with patient partners towards finding answers and developing effective treatment options to improve the quality of life for those living with ME." **Dr. Luis Nacul**, Medical Director and Research Director, Complex Chronic Diseases Program, BC Women's Hospital + Health Centre

"ME has devastated my personal and professional life, as it has that of so many individuals living with this disease. Today, we applaud the Government for recognizing the debilitating life-changing effects of ME and for funding urgently needed research. As we embark in a new partnership with researchers, clinicians and government, we hope that this financial support will be a stepping stone to further funding and research required to understand this complex disease and develop diagnostic tools and effective treatments." **Christiane Garcia**, Interdisciplinary Canadian Collaborative ME Research Network Patient Partner, Board Member - Action CIND and AQEM (Association Québécoise de l'Encéphalomyélite Myalgique)

News Release – August 22, 2019

Government of Canada invests **$1.4M** in biomedical research to improve the quality of life of people living with myalgic encephalomyelitis.

It is estimated that more than 580,000 Canadians live with myalgic encephalomyelitis (ME), formerly known as chronic fatigue syndrome, or ME/CFS. This poorly understood, multi-system disease is debilitating and can strike individuals of all backgrounds and at any age. Patients experience symptoms including unrelenting exhaustion following mild physical and cognitive activity that is not relieved by rest; muscle and joint pain; headaches; inability to remain standing due to sudden drops in blood pressure; and poor sleep quality. The cause is not fully understood, there are no diagnostic tests available, and there is currently no cure.

People living with ME, and their families and caregivers, can now look forward to a more promising future as a result of a $1.4M investment in a new national network that will create critically needed scientific knowledge about the causes of, and treatments for, myalgic encephalomyelitis. The Honourable **Ginette Petitpas Taylor**, **Minister of Health**, made the announcement today while visiting the Sainte-Justine University Hospital Research Centre in Montreal, where the network will have its headquarters. This investment comes from the Government of Canada, through the Canadian Institutes of Health Research (CIHR).

Minister Petitpas Taylor made the announcement together with **Dr. Alain Moreau**, a professor at the University of Montreal. Working with a team of patient partners, clinicians, and more than 20 researchers, **Dr. Moreau** will lead the network that will fill gaps in biomedical ME research and build capacity for research into the disease here in Canada.

Submitted by **Lydia Neilson**

Denmark

False accusations

To Editor-in-Chief Bo Hasseriis, http://ugeskriftet.dk (Journal for Doctors)

The Danish ME Association has been wrongly accused of harassing **Per Fink** in an article dated September 20, 2019 written by **Dorte R. Jungersen**, where **Per Fink** is interviewed. http://bit.ly/2n5TUTT

The article states:
"The highly activist ME Association (ME=myalgic encephalomyelitis) has been harassing and discrediting **Per Fink** and the center in Aarhus for years, where the association and its supporters have filmed patients and demonstrated in front of the research clinic at Nørrebrogade with banners, megaphones and the lowest type of heckling."

Unfortunately, this is a series of false statements.

When a journalist and a trade journal write such extreme statements from a single source, it is good journalism to allow the accused party to speak as well. This one-sidedness is journalistically deeply critical and does not comply with ethical press guidelines under which a trade magazine is expected to work.

The ME Association did not stand behind/arrange the named demonstration, which took place 6 years ago. We do not believe that threats and harassment contribute to understanding. The ME Association advocates informing and communicating in a business-like way and with respect for the other party.

The ME Association cannot take responsibility for the individual communication of patients or citizens. We encourage our members to maintain a good tone to ensure dialogue.

These kinds of misinforming and discrediting statements, which are presented unchallenged, are destructive to a patient association.

The association would like to be informed whether or not the Journal for Doctors has now registered their website with the Press Committee, which we understand they previously expressed regret for not doing so.

Sincerely,
Rebecca Hansen, Chairman, ME Association

Prize for Civil Courage to psychiatrist **Per Fink**

Jydsk Medical Society has awarded a Prize for Civil Courage to psychiatrist Per Fink in Aarhus on September 19, 2019.

Rationale: "Jydsk Medical Society awards Per Fink the company's 'Prize for Civil Courage' because with a business-like and continued effort and with great empathy, he has made an important difference for a group of vulnerable patients. Often against strong resistance, he did stick to the truth.

With the prize comes 25,000 Dkr.

Certain diseases, conditions and areas of illness are surrounded by more emotions than others, and attitudes can play a greater role than facts. Some fear that the re-classification of conditions and diseases will make them disappear.

Per Fink, under great and often fierce opposition, maintained the truthfulness and desired to help his patients, although this was difficult.

The Jydsk Medical Society's award to **Per Fink** may well be an encouragement to doctors and medical organizations to take public action in delicate cases with great emotions involved. "

Source: Millions Missing Denmark
https://www.facebook.com/millionsmissingdenmark

Finland

Extremely troubling news from Finland: HUS, Helsinki University Hospital has opened a "functional disorder" clinic to treat ME-patients.

We, Finnish ME patients, need help from the international ME community to put pressure on Finnish healthcare! Please share this post.

The neglect of ME-patients in healthcare has been recognised in some level in Finland as well as the huge need for a center of expertise of ME/CFS with multi-professional team. Two years ago HUS, Helsinki University Hospital formed a working group to plan treatment for ME/CFS patients. The working group was lead by **Dr. Harri Hämäläinen** and **Dr. Risto Vataja**.

For some reason the working group decided to bypass all the biomedical research of ME/CFS and focus on the psychosomatic theories. So called "Danish model" was chosen to be implemented in Finland. The working group even made an excursion to **Per Fink**`s clinic in Århus, Denmark.
https://bit.ly/2mpopnB

As the international ME-community is well aware, the situation in Denmark for ME-patients have been the worst as **Dr. Per Fink** was pretty much in charge of educating, researching and treating ME-patients with his theories and methods, that were in huge contradiction to the WHO definitions of the disease as well the biomedical research. Below there is an excellent interview from spring 2018, where **Rebecca Hansen** from the Danish ME Association explains what the "Danish model" of treating ME patients meant before March 2019.

The great news in March 2019 was that the Danish Congress decided to abandon **Dr. Fink**`s "functional disorder" definitions of ME and start obeying WHO`s definition and decided that Denmark will renew all the official educational material, treatment plans etc. and look for new information from abroad
http://www.investinme.org/IIMER-Newslet-190301Danmark.shtml

The amazement of Finnish ME patients was huge when 11/09/2019 Lääkärilehti ("Doctor's magazine") published a podcast interview of **Dr. Helena Liira**, the head of the newly opened "functional disorder" clinic in Helsinki. **Dr. Liira** discusses in the interview of the plans and the facilities they offer to the patients
https://bit.ly/2kqviV6

The "multi-professional team" in charge of examining and treating ME patients consists of a family doctor, a nurse, a psychologist and a social worker. **Dr. Helena Liira** speaks in the podcast systematically about "functional symptoms" and emphasizes how "functional disorders" used to be called psychosomatic disorders. She doesn't mention the somatic foundings of ME in biomedical research. Instead she pretty much repeats **Per Fink**'s theories.

"Everybody is experiencing symptoms as part of everyday life – symptoms that are not signs of any physical disease. When you are suffering from a functional disorder you have severe symptoms that lead to worries or affect your daily life. The symptoms have become the disease.", says **Per Fink**s manual "When the body says stop" https://bit.ly/2mlVzV2

Even more peculiar is that **Dr. Liira** herself wrote recently in Lääkärilehti ("Doctor's magazine") about **Professor Anthony L. Komaroff**s article on JAMA, where **Prof. Komaroff** states: "Over the last 35 years, there have been over 9,000 scientific publications that compare people with the illness to healthy people of the same age and sex, and they find a whole variety of abnormalities."

We called to the clinic and asked what kind of material the clinic offers to the patients and we were told that **Per Fink**s "When the body says stop" -manual, that has been funded by Trygfonden (The Danish Insurance Fund), is one and they also recommend **Dr. Helena** Miranda's book "Ota kipu haltuun" ("Manage your pain"), a book about managing pain without medication https://www.otakipuhaltuun.fi

We, Finnish ME-patients are astonished that the methods that in other countries have been already debunked and found harmful and not effective are now introduced in Finland. We, Finnish ME-patients, demand the State of Finland to establish a proper Center of Expertise of ME/CFS with proper multi-professional team. It is evident that the new "functional disorder" clinic does not serve as one.

We, Finnish ME-patients, demand that as Finland has decided to follow Denmark in treating ME-patients, they do continue their chosen path, and learn from the mistakes done in Denmark and keep updating "the Danish model" and start obeying WHO`s diagnostic code and definition of ME/CFS (ICD10: G93.3 and ICD11: 8E49).

Source: Millions Missing Finland https://bit.ly/2kVoHlD

New Zealand

ANZMES in the near future is meeting with minister **David Clark** and the Ministry of Health to continue our lobbying for education of General Practitioners and Medical Professionals plus home help etc. This is a follow up of our last meeting.

We also have had earlier meetings with the Royal New Zealand College of General Practitioners in the last few years and are able to put any visiting specialists in ME/CFS into the Continuing Medical Points that GPs must get for training. This Points system encourages Medical Professionals to come to lectures.

Next year ANZMES Committee are looking at bringing an overseas specialist on ME/CFS into NZ to talk to Medical Professionals and GPs for education training and give information on the latest research. We will once again be giving resources to the GPs around New Zealand.

Last Lecture Tour ANZMES Committee brought **Kathy Rowe** from Australia, a paediatrician, and her lectures were well received. We have had **Prof Nancy Klimas** and **Prof. Charles Lapp** over to NZ as well as other specialists and it gives a unique chance for Drs. to upskill in ME/CFS.

ANZMES is sponsoring **Prof. Warren Tate** and his research at the Biochemistry Department, University of Otago. The results the team are getting are encouraging.

Our Medical Adviser **Dr Ros Vallings** has recently run workshops for over 200 GPs in Palmerston North on Managing and Diagnosing ME/CFS. **Ros** has also spoken to various support groups around the country on the latest medical releases.

Next year we have pencilled in for August a National meeting for Support group managers and field workers. This will give a training opportunity and a chance to talk to other people running support groups around New Zealand and will give peer support for any problem solving needed.

Our ANZMES President is on the IAMFE committee and working on responses to WHO and other lobbying. ANZMES has over 40 information sheets and we are updating them as we go. We also have several booklets available on various subjects such as pregnancy, pacing, and Dr. Vallings's booklet on ME/CFS (the Turtle booklet).

The ANZMES new strategic plan is being worked on and progressing well. ANZMES administrator for the last six and a half years has moved onto a new position and we wish her well for the future. There may be a slight delay in getting back to queries until our new coordinator starts in a few weeks.

Heather Wilson

Scotland

Meeting with the Scottish Government

Earlier this week #MEAction Scotland volunteers attended a meeting, organised by the Scottish Government, to discuss the Scottish Health Council's forthcoming gathering views exercise, entitled: 'What does good care look like for people living with ME?' This meeting was part of the Scottish Government's response to the ongoing parliamentary petitions process regarding #MEAction Scotland's petition
http://www.parliament.scot/GettingInvolved/Petitions/PE01690

Rebecca Duff of the Neurological Alliance for Scotland chaired the meeting, with the ME Association, ME Highlands and Islands, Action for ME, Tymes Trust in attendance as well as MEAction Scotland. The 25% Group were not able to send a representative on the day, but had had an opportunity to contribute beforehand, as did nurse specialist, **Keith Anderson**. ME Research UK was present for the latter part of the meeting involving the Chief Scientist Office. Also in attendance were the Scottish Government Clinical Priorities division, representatives from the Scottish Health Council and CSO and **Dr Gregor Purdie**.

It was evident from the meeting that the Neurological Action Plan is going to be a crucial document forming the basis for all future neurological policy. At the Petitions Committee meeting on 24th January 2019, MEAction Scotland suggested to the Cabinet Secretary, **Jeane Freeman**, ways in which the NAP could be updated to better reflect the needs of people with ME. ME stakeholders in Scotland have sent in amendments to the Neurological Action Plan, which are under consideration, and it will be published in October.

The Scottish Government Clinical Priorities division repeated their intention to update the Scottish Good Practice Statement after the NICE guideline review. All ME stakeholders present were insistent that the statement should be updated immediately, due to the current inclusion of CBT/GET, and that any educational materials or module should be based on an updated SGPS. However, the government would not commit to an immediate update, which remains something we will continue to push for.

The representative from the Chief Scientist Office essentially said that they were open to research applications for ME, they just weren't receiving any. He was also adamant that it was not their role to solicit research funding, and that attracting researchers and encouraging research was very much our job. Despite the disappointing response from the CSO, the meeting was positive overall. It was agreed that MEAction Scotland would draft a proposal for the Gathering Views exercise, consulting other stakeholders in the process. Those organisations which were present are keen to continue working together and we are optimistic that we can agree a framework for the consultations.

Source: Millions Missing Scotland, 31st August http://bit.ly/2n3PvRm

Hannah Sweeney Kyle

#MEAction Scotland is delighted to share some exciting news about one our #MillionsMissing speakers, Hannah Sweeney Kyle!

Those of you who attended the Millions Missing event in Glasgow earlier in the year will have heard Hannah speak, very movingly, about how ME had robbed her of the chance to continue with her education after her diagnosis.

A lack of understanding on the part of her school meant Hannah was denied a lift pass and had to use the stairs instead, even though she sometimes passed out from exhaustion. Unsupported in school and regarded as being 'unwilling to learn', Hannah had no option but to withdraw from education.

However, far from being a reluctant student, Hannah was determined to find a way to continue studying. Shortly after speaking at Millions Missing, she had a positive meeting with the head of the Education and Improvement Team for Falkirk Council. Earlier this week she announced that she would soon begin studying for her National 5 Maths and English!

Hannah will use an online system with direct links to her school, enabling her to receive regular feedback and have her work marked.

Congratulations, **Hannah**! #MEAction Scotland wishes you every success.

Source: Millions Missing Scotland http://bit.ly/2m72gdP

South Africa

The ME CFS Foundation South Africa has been helping some patients over the last few weeks. We started with a campaign asking people for donations in the form of clothes, linen, food, toiletries, etc. We have received a quite a few items and distributed this to a few families. We are providing a few patients with data and airtime for their cellphones so they can stay connected and remain part of our online support group.

Our laptop packed up and we were extremely grateful that someone donated a refurbished laptop to the Foundation. We are over the moon as we found a healthy volunteer who is going to assist us with some important aspects such as looking for potential donors, distributing pamphlets containing information on ME and our Foundation.

Stanford has invited us to be part of a genetics study, we are waiting for the study to begin. We have connected with a few fundraiser experts and will be following their advice in terms of raising funds. We are in the process of appointing two new members to our board, so the Foundation is definitely growing.

In South Africa we have no disability benefits from the government and private insurers seem to be doing everything they can not to grant disability claims. Another patient's application for disability benefits was declined and we are trying to assist to see if it can be appealed successfully.

Our highlight, however, is that we have been able to make a real difference in the lives of a family of 5. The mother has severe ME and was the main bread winner. As a result of her illness, the family had to move into a Wendy house at the back of a house, there are 5 other Wendy houses on the premises. The house has not toilet or running water and had a zinc roof, making it unbearable hot in summer and extremely cold in winter. Thanks to donations we were able to assist them in putting in a ceiling, the temperature inside the Wendy house has improved significantly.

Kind regards

Retha Viviers
Founder and Director: The ME CFS Foundation South Africa
Website: http://www.mecfssa.org

Switserland

In Switzerland a brandnew association, founded by **Maya Leutwiler** and **Jonas Sagellsdorf**, is working hard on a stronger foundation.

Besides a website, recently a fb-page has been created (https://www.facebook.com/sgmecfs/ by all means like it to support them!) and recently they published their first newsletter (in German) which is to be published on a regular base.

The introduction reads:

Association Founded

Last year, we (**Jonas Sagelsdorff** and **Maya Leutwiler**) together organized the Unrest demonstrations with podium discussions in Kosmos in Zurich and in Kino Rex in Bern.

In order to continue this work in the long term and to connect people with ME & CFS, we have now founded the Schweizerische Gesellschaft für ME & CFS (Swiss Society for ME & CFS). We want to represent the concerns of people with the neuro-immunological disease Myalgic Encephalomyelitis (ME) and people with Chronic Fatigue Syndrome (CFS) and their relatives.

We are committed to ensuring that ME is recognized as a physical disease in Switzerland and that adequate medical, nursing and social care can be guaranteed for those affected.

We would like to educate both the general public and healthcare professionals about ME and CFS, inform about international scientific and health news regarding ME and CFS, and raise awareness of the currently very difficult situation of those affected.

If you want to know more, you can look on our website https://sgme.ch/ We are also present on Facebook https://www.facebook.com/sgmecfs/.
Memberships can be completed here: https://sgme.ch/mitglied-werden

An Appeal

On their fb-page there's also a recent appeal which may be applicable to you if you happen to live in Switzerland and not too far from Zürich.
A journalist from Tsüri.ch is looking for an article for a person affected by ME. A chance for more visibility - if you are interested, you can contact her directly.

Here's her call:

"Dear community.
For an article about ME/CFS in the online magazine Tsüri.ch I am looking for an affected person who would like to talk about his/her history. Of course, it may also be someone who is in the recovery phase.

Planned would be a personal conversation, which could take place either at the person's home or in a neutral setting (if possible). If desired, the conversation can also be divided into 2 or 3 visits, if the planned location is not too far from Zürich itself.

The interview will probably be published in text form and supplemented with information on the disease. Of course, the person may appear anonymous in the text, if so desired.

For more information or questions you may like to write me! isabel.brun@tsri.ch

Kind regards **Isabel** from the Tsüri team "
https://bit.ly/2m0incP

The Netherlands

Patient survey in a large (Dutch) cohort of respondents

A new patient survey was published three weeks ago by the Dutch ME/CFS Association (ME/CVS Vereniging - http://bit.ly/2lr9sRT). It was conducted online in 2017 and had valid results for 418 respondents. I would like to highlight some of its results regarding the efficacy of cognitive behavioral therapy (CBT) and graded exercise therapy (GET). The survey asked about patients' experiences with these treatments and, as in other surveys, these were mostly negative.

Of the 129 respondents who said they had followed CBT without GET, 47% said it had a negative effect on their health. Of the 142 respondents who said they had followed CBT with GET, 66% said it had a negative effect on their health. These figures can be compared to those of the 214 respondents who said they had received 'biomedical treatment' for ME/CFS. In this group only 11% said the treatment had a negative effect on their health. The survey also asked patients to give a score from 1 (bad) to 10 (good) to each of the three treatments. CBT with GET got an average score of 2,5, CBT without GET got a score of 3,7 and 'biomedical treatment' received a score of 6,3.

Also interesting: the survey asked whether respondents were members of a ME/CFS patient organization or not. Almost half was not a member, and they were equally negative about the effects of GET and CBT than the group that was a member of a patient organization.

The survey also asked about the reasons for deterioration following CBT or CBT plus GET. The most supported statements were that the treatment was too taxing and that the therapist instructed them to push their limits. Patients said they increased their activity level as the treatment goal prescribed but that it was too much for them. More than 80% of patients who deteriorated in the CBT groups said it affected their ability to do daily chores such as the household and (self-) care. A disturbingly high figure of 40% in the CBT plus GET group said that this treatment was mandatory, for example, because they thought they might get into trouble with work, school or receiving disability benefits if they didn't follow the treatment.

Finally, the survey presented several assumptions of the cognitive-behavioral model such as the idea that they perpetuate their illness with unhelpful thoughts, fear-avoidance, deconditioning etc. On all these statements, ca. 90% of respondents said they disagreed. The full report can be read in the link below. I've been told that there will be English summary soon. Many thanks to all those involved! http://bit.ly/2nAuI8l

Michiel Tack
Note from the editors: the cohort was selected as per the IOM-criteria

Parliamentary debate

In response to questions asked by MP's about minister **Bruno Bruins**' implementation of the Health Council's recommendations, a parliamentary debate took place on September 11th.

Of the 6 proposed parliamentary motions, 4 have been put "on hold", and the remaining two have been subjected to a vote on September 23rd, and did pass. They are as follows:

- For the minister to issue a formal request to the NFU (Netherlands Federation of University Medical Centers) to start with a study into the potential usefulness of an ME-center of expertise.

- For the National Health Care Institute to be requested to put a revision of the current guidelines for CBT and GET, which have been worrying patients, on their official agenda.

The minister's response: it is not his duty to revise the guidelines, but that of the medical professionals. He is, however, willing to apply pressure on those working in the medical field to consider acting as such in the near future.

On one motion, the minister is seeking to first deliberate with a colleague of the Ministry of Social Affairs and Employment, only to touch back on it at a later point in time:

- To actively inform the ME/CFS patients whose applications for disability benefits have been refused of the possibility of re-evaluation by the UWV https://www.uwv.nl/overuwv/english/index.aspx.

The following 3 motions have been regarded by the minister either as concluded, or as irrelevant but have been put on hold nonetheless by the respective MPs:

- For the minister to acknowledge ME/CFS as a chronic illness.
- For the minister to order the UWV to check if any practicing physicians are not acting in accordance with the UWV's guidelines, as reports have been suggesting.
- To allow for funding towards a center of expertise. The submitting party demands direct payment and has observed that such a center might not be able to be readily equipped.

The minister is expected to receive a research agenda by ZonMW https://www.zonmw.nl/en/ during the first 3 months of 2020, which will be compiled in collaboration with patients' advocate groups, and will then be looking into how the budget(s) can be spent most efficiently. Until then, this motion will be on hold.

This debate can be rewatched by following this link: http://bit.ly/2lqodnR

The OMF

Conversation **Ronald G. Tompkins**, MD, ScD, with patient and advocate, **Dr. Alan Gurwitt**

Recently, **Dr. Tompkins** had the opportunity to sit with **Dr. Alan Gurwitt**, Massachusetts ME/CFS & FM Association patient advocate, and talk about what living with ME/CFS is like. Alan shared his experiences with ME/CFS and the medical community over the past several decades: https://youtu.be/AAKKHRBL71k

The IDO metabolic trap

Dr. Robert Phair has recently published a paper detailing his "metabolic trap" hypothesis underlying ME/CFS, a theory that combines engineering and physiology put together by a man adept in both fields (see section Science in this issue of the MEGC)

Dr. Chris Armstrong wrote a quite comprehensible explanation of this paper which you can find here: https://bit.ly/2kleC16

Karin Alvtegen OMF Ambassador

Karin Alvtegen, one of Scandinavia's most widely read and appreciated authors, has become the third OMF Ambassador. **Karin** is recognized for her psychological thrillers, which include Guilt, Missing, Betrayal, Shame, Sacrifice, and Shadow, and has established herself as a celebrated bestseller worldwide.

Her books have been translated into more than 35 languages. Missing has been made into a praised British television mini-series, and international producers are adapting some of her other books. She has also won many literary awards including The Glass Key for Best Nordic Crime Novel and many more.

In 2013, **Karin** came down with ME/CFS and was seriously ill. She has since become an active supporter of OMF on Facebook, and on her most recent birthday, she hosted a successful fundraiser for OMF. She has been the subject of a book on ME/CFS (in Swedish) titled "Invisible ill – while life passes," which included a chapter by Scientific Advisory Board member **Jonas Bergquist**, **MD**, **PhD**. Although she can no longer write, she has the active support of her family and the ME/CFS community.

Karin Alvtegen ME/CFS's Announcement: https://youtu.be/ghY13XgECpw

Submitted by **Marilyn Simon-Gersuk**

The NCNED

The National Centre for Neuroimmunology and Emerging Diseases (NCNED) Griffith University Australia continues to achieve significant discoveries in ME/CFS as recently they re-confirmed significant dysfunction in transient receptor potential (TRP) melastatin 3 (TRPM3) receptor in ME/CFS patients compared to healthy controls. In this latest study NCNED researchers aged and sex matched ME/CFS patients and healthy participants to report TRPM3 ion channel dysfunction in ME/CFS patients. By examining natural killer (NK) cells using the gold standard technique of patch clamp electrophysiology, NCNED researchers have identified changes in ion channel function of these TRPs which reflect similar changes in all body tissues containing cells expressing these ion channels. The importance of these ion channels is they have a primary role in transporting calcium ions (Ca2+) into cells.

NCNED also examined the possible beneficial effects of therapeutic drugs such as Nifedipine as it is a TRPM3 activator in providing restoration of ion channel function. However, NCNED researchers determined TRPM3 ion channel function was not significantly improved and this drug was not beneficial as a therapeutic intervention. Importantly, NCNED is actively pursuing further important investigations to expand the range of drugs which may have a therapeutic benefit in ME/CFS.

The National Centre for ME/CFS Research in Australia (NCNED) has now commenced further ME/CFS research initiatives in Victoria, in collaboration with the Australian Rickettsial Laboratory, World Health Organisation Reference Laboratory, and Western Australia to further examine TRP ion channel function in ME/CFS patients.

Advances in neuroimaging to describe changes in brain pathways and connectivity between brain areas is currently being conducted and it is anticipated these data will be published in the coming months.

Best wishes
Sonya, **Don** and the **NCNED Team**, Australia

Solve ME/CFS

$1 Million Grant Awarded for Australian Biobank and Registry

Emerge Australia and La Trobe University received a $1 million grant from philanthropic trust the Mason Foundation to establish the first Australian ME/CFS Biobank and patient registry. The biobank will enable a collaborative research project spanning multiple institutions and create a rich repository for future research.

Solve M.E. is a co-investigator on this grant, alongside collaborators at UK ME Biobank (UKMEB), led by the CureME team, and other dedicated partners. The collective is committed to developing a unified, global approach to ME/CFS research.

Solve M.E. has been developing a symptom tracking app that will enable patients to register and track their symptoms on an ongoing basis. This will allow researchers to access standardized, anonymous information about patients' symptoms, which can be analyzed for a more detailed understanding of the condition and how symptoms change over time. The app, along with other web-based tools and established infrastructure from the UKMEB, will be a key component of the Australian biobank and registry.

Read more about Emerge, La Trobe and the $1 million grant from the Mason Foundation in the Sydney Morning Herald (https://bit.ly/2m5Vp3W).

Merits of the late **Jonas Blomberg**

A research group published findings in Frontiers in Immunology with support from Solve M.E.'s Ramsay Grant Program. A study of three ME/CFS cohorts had the same risk of being infected with a human Herpes virus as healthy controls, but subtle differences suggest complex interactions with the immune system. Solve M.E. would like to express our gratitude to the late **Jonas Blomberg** for his dedicated work in ME/CFS. He initiated a pilot study (https://bit.ly/2lZm6rg) through the Ramsay Grant Program with a group of collaborators in 2017, which has resulted in two publications in Frontiers in Immunology to-date.

More than just a report: the NANDS Working Group's strategic, coordinated approach to ME/CFS

One year ago, the National Institute of Neurological Disorders and Stroke (NINDS) formed a Working Group of the National Advisory Neurological Disorders and Stroke (NANDS) Council focused on how best to advance research on ME/CFS and defining the pillars that would become a strategic plan for advancing those needs. Solve M.E. was invited to join the Working Group and was represented initially by former Solve M.E. President and CEO **Carol Head**, then later by Chief Scientific Officer **Dr. Sadie Whittaker**.

Also present in the distinguished group were Solve M.E. Research Advisory Council (RAC) members **Dr. Rochelle Joslyn** and **Dr. Anthony Komaroff**, and recently appointed Solve M.E. board member **Amrit Shahzad**.

The Working Group has now published its report on how the NIH can address identified gaps in ME/CFS research, and it was unanimously accepted by the NANDS Council. You can read the full report here, and read an overview of the report by **Dr. Sadie Whittaker** here.

Solve ME/CFS "Advances in ME/CFS Research and Clinical Care" Webinar Series:
October 2019 Webinar
(Date and Presenter TBA)
Genetic Predisposition for Immune System, Hormone, and Metabolic Dysfunction in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: A Pilot Study (https://bit.ly/2mtm2QI)

November 2019 Webinar
(Date and Presenter TBA)
ME/CFS in the Era of the Human Microbiome: Persistent Pathogens Drive Chronic Symptoms by Interfering with Host Metabolism, Gene Expression, and Immunity (https://bit.ly/2m76sd6)

December 2019 Webinar
(Date and presenter TBA)
Estimating Prevalence, Demographics, and Costs of ME/CFS Using Large Scale Medical Claims Data and Machine Learning (https://bit.ly/2mqqzmR)

More webinars in the "Advances in ME/CFS Research and Clinical Care" webinar series will be added for October and December.
Check our webinar schedule for updates (https://bit.ly/2koHBRE).

Submitted by **Karman Kregloe**, Solve ME/CFS

11. Events


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

12th Conference on ME/CFS

ME/CFS – A Multiple Challenge For Researchers And Caregivers. The 12th Conference on ME/CFS,
Two days of ME-conferences in Sweden, organised by RME Sweden,
Wednesday October 16th 2019 1 p.m. – 5 p.m.
in Stockholm,
Venue: Landstingssalen,
Landstingshuset (the County Council Hall), Hantverkargatan 45, Stockholm

13:00	Conference opening Henrik Fransson, RME Stockholm & **Ella Bohlin**, Stockholm County Council member
13:10	Att möta ME/CFS-patienter i klinisk verksamhet (To meet ME-patients in clinical work) **MD Jesper Mehlsen**, Clinic Mehlsen, Copenhagen
13:45	INMEST-behandling, immunologi och hjärnavbildning vid ME (INMEST-treatment, immunology and brain imageing in ME) **MD, PhD Petter Brodin**, KI; MD, **PhD Per Julin**, KI & The Stora Sköndal ME/CFSclinic
14:20	Att leva med ME/CFS – patientenkät till RME:s medlemmar (To live with ME – a patient survey to members of RME) **Assoc Prof Sture Eriksson**, Umeå University, vice chair RME
14:45	Break, refreshments
15:15	The Brain on Fire (Presentation via video link, in English) **Assoc Prof Jarred Younger**, PhD, University of Alabama, Birmingham, USA
15:50	State-of-the-art. Vad vet vi om ME/CFS? Vad tror vi att vi vet? Vad är osäkert? (What do we know about ME/CFS? What do we think we know? What's uncertain?) **Professor Jonas Bergquist**, Uppsala University
16:25	Panel debate
17:00	Closing

And on Thursday October 17th, 2019 1 p.m. – 5 p.m. in Umeå
Venue: Kommunfullmäktigesalen (the City Council Hall), Rådhusesplanaden 6II, Umeå

13:00	Conference opening Björn Hedman, chair RME Norr Birgitta Nordvall, KD, municipality politician
13:10	Att möta ME/CFS-patienter i klinisk verksamhet (To meet ME-patients in clinical work) MD Jesper Mehlsen, Clinic Mehlsen, Copenhagen
13:45	INMEST-behandling, immunologi och hjärnavbildning vid ME (INMEST-treatment, immunology and brain imaging in ME) MD, PhD Petter Brodin, KI; MD, PhD Per Julin, KI & The Stora Sköndal ME/CFSclinic
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16:25	Panel debat

All presentations will be in Swedish
Signing in via https://bit.ly/2ksohTO

Submitted by **Kerstin Heiling**

Harvard Symposium 'Finding Clarity'

June 7th & 8th , 2019

All presentations have been filmed and are available here:
https://bit.ly/2knljzL

Opening remarks, **Linda Tannenbaum**
https://youtu.be/x5VkQx-jrwU

Open Data Sharing for ME/CFS Research, **Wenzhong Xiao**
https://youtu.be/FWDxSlpDTuw

ME/CFS Research Activities, **Dr. Ron Davis**
https://youtu.be/02TUcGqTFAI

Neuroinflammation imaging, **Michael VanElzakker**
https://youtu.be/bJ3UxSZ6MII

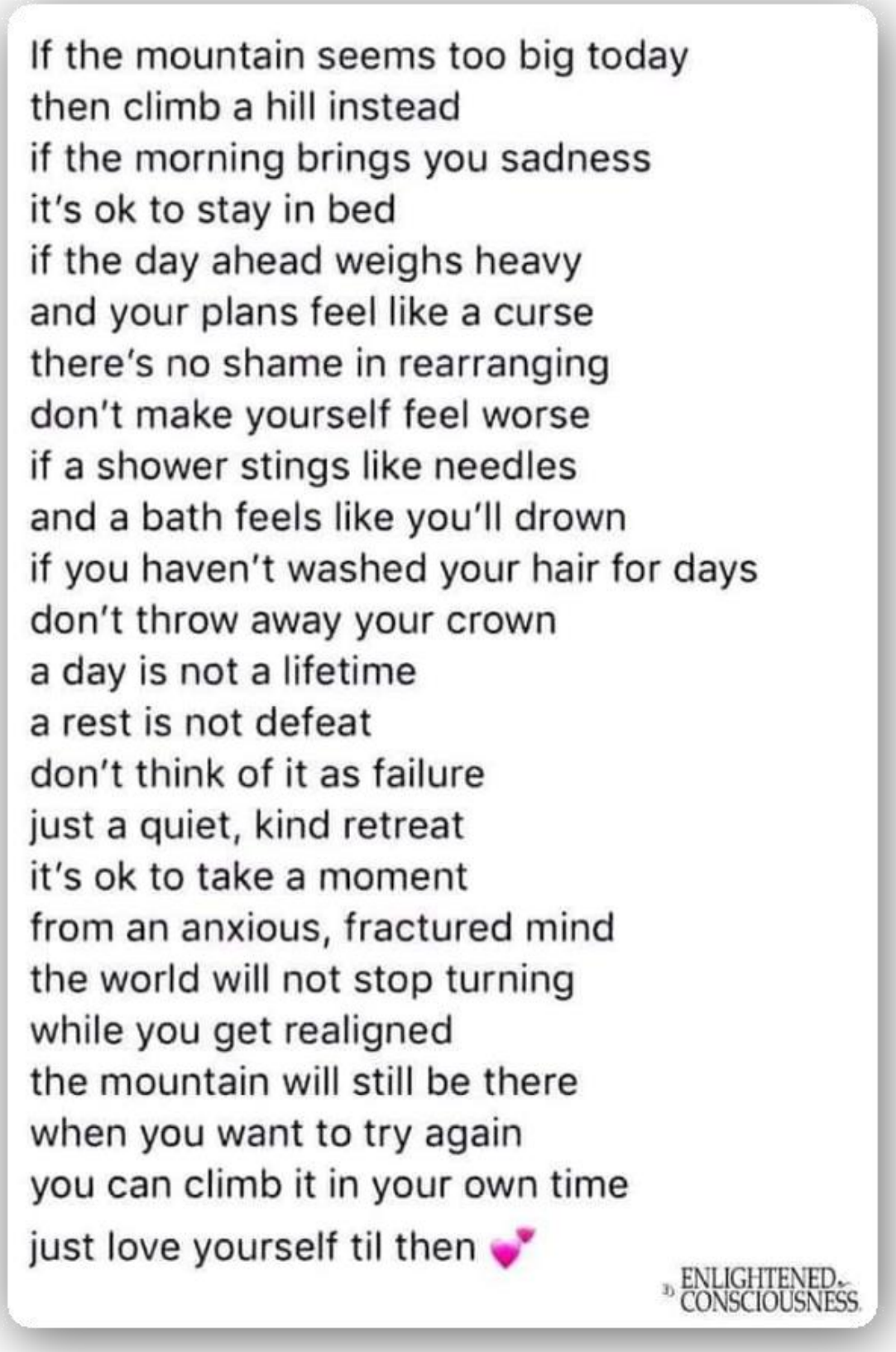
Immune System Function of ME/CFS, **Dr. Maureen Hanson**
https://youtu.be/QAdZNU6D7Gs

Panel Dicussion
https://youtu.be/IGwV-kwzA50

Closing remarks, **Dr. Ron Tompkins**
https://youtu.be/Qd48hzyLxmU

Submitted by **Marilyn Simon-Gersuk**

12. Poem


If the mountain seems too big today
then climb a hill instead
if the morning brings you sadness
it's ok to stay in bed
if the day ahead weighs heavy
and your plans feel like a curse
there's no shame in rearranging
don't make yourself feel worse
if a shower stings like needles
and a bath feels like you'll drown
if you haven't washed your hair for days
don't throw away your crown
a day is not a lifetime
a rest is not defeat
don't think of it as failure
just a quiet, kind retreat
it's ok to take a moment
from an anxious, fractured mind
the world will not stop turning
while you get realigned
the mountain will still be there
when you want to try again
you can climb it in your own time
just love yourself til then
ENLIGHTENED CONSCIOUSNESS

13. 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."