

The ME Global Chronicle

www.let-me.be

36 – June 2020



1. Colofon / Personalia



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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



From the Editors,

Welcome to another edition of the ME Global Chronicle

This June 2020-issue (36) includes articles about how COVID-19 pandemic has impacted ME patients as well as concerns about the downstream effect of lumping post-COVID19 in with ME patients. We've seen over the decades how mixing patient groups has led to doctors misdiagnosing patients and giving wrong treatments. What happens if doctors are told ME is the same as post-COVID and then see post-COVID patients recover using rest, diet changes and exercise? Will our cause be set back by decades as doctors return to blaming ME patients for not recovering using those same methods?

We've fought long and hard for ME to be recognized as a distinct disease that can NOT be treated by patients changing their behavior. Let's make sure doctors truly understand the reality of myalgic encephalomyelitis. ME patients need specialist care with the testing and treatments recommended in the IC Primer.

This issue also includes recent science discoveries, stories about advocating for May 12 awareness day despite restrictions to gather, and news from around the globe. Amongst which the joyful news of the motion on ME having been approved by the European Parliament last Thursday. 676 members voted in favor, 4 against and 8 abstained. The driving force behind this motion was a most successful European Citizens initiative started by Dutch ME-patient **Evelien van den Brink**.

Furthermore there's news or updates from 19 countries, personal stories and much, much more. Tips for navigating within the chronicle: click on the desired article in the Table of Contents to be sent to that page. You can return to the Table of Contents at any time by clicking 'Back' at the bottom of the page.

Each quarterly issue of the ME Global Chronicle contains only snapshots from here and there. To describe what is happening all over the world in the field of ME would cover the pages of an entire book each quarter. Contributions to September's release are to be submitted via contribute@let-me.be before the end of August. Preferred format and font: Word, Verdana (size 12).

Have a mild summer all of you in the northern and a mild winter all of you in the southern hemisphere.

The editors, June 2020

Colleen Steckel Eddy Keuninckx Rob Wijbenga

Next issue will be published on September 22, 2020. Please do contribute any article or suggestion at any time via contribute@let-me.be

4. NIH/CDC/HHS



ME/CFS Intramural NIH Study Update from Patient Participant

Sanna Stella participated in the study led by **Dr. Avindra Nath** and **Dr. Brian Walitt** on the National Institutes of Health (NIH) campus and has written about her experience for Solve M.E. Below is her most recent patient participant update on the study.

As I had written about this NIH study from a patient participant's experience before, I thought I would share this brief update. Although I completed my abbreviated second study visit nine months ago and am officially done with this protocol, I still feel very connected to the research team, some other participants, and the study. So last week I was pleased to receive a newsletter the team put together to update study participants, "the 3B19 times."

The goal of the study, according to the newsletter, is "to explore the clinical and biological phenotypes of PI [post infectious] ME/CFS, which can then help us generate new hypotheses to understand the mechanistic underpinnings of this condition." The update on the study participants states that there have now been a total of 51 participants, of which 27 were patients and 24 were healthy volunteers.

Nineteen patient participants have been adjudicated for the second study visit. So far, 62 individuals from 14 different institutes have been involved in the study. For both, patient and healthy participants, the gender distribution is about even, the ages range from 18 to 60, and they have travelled to the NIH from many states all the way from the East coast to the West coast of the U.S., as well as Ontario, Canada.

Dr. Rebekah Feng addressed findings on the bioenergetics of ME/CFS. She explained the extracellular flux assay, which is one method her team is using to measure mitochondrial function. The mitochondria in our cells produce most of the body's ATP (adenosine triphosphate). Because ATP is essential for energy production, mitochondrial function is essential as well. **Dr. Feng** states that the extracellular flux assay "allows us to examine how differently our peripheral blood mononuclear cells are producing energy. Specifically, it measures two variables. The first is oxygen consumption and the second is proton concentration."

Those variables can show whether our cells are using an efficient or inefficient process to produce ATP. **Dr. Feng** goes on to explain that analyzing the relationship and ratio of rates of these two processes can help her team better understand mitochondrial efficiency in ME/CFS. "We have had some pretty interesting findings," she said. "Even with the current sample size, the data is still statistically significant."

The findings include changes in mitochondrial function before and after exercise in ME/CFS patient participants. **Dr. Feng** said the data is evidence that something may be going at the cellular level. One of the next steps for **Dr. Feng**'s team is exploring bioenergetics in muscle tissue extracted via muscle biopsies and PBMCs (peripheral blood mononuclear cells).

Even though the team is still in the midst of its research, as a patient participant anxious to see some findings that will move ME/CFS progress forward, I appreciate that the research team is keeping in touch with study participants.

If you would like more information on participating in the NIH study, either as healthy volunteer or a person with ME/CFS, click here: <https://mecfs.ctss.nih.gov>

Submitted by **Emily Taylor**

5. Dutch Citizen Initiative



ZonMw and ME – an Update

ZonMw <https://www.zonmw.nl/en/> is the Netherlands Organization for Health Research and Development which a.o. states that “international collaboration has been an essential part of our work.

For many reasons! Many of the challenges we face are not restricted to the borders of The Netherlands, so if we want to really solve these challenges we need to work together”. Its major client is the Dutch ministry of health.

Composition of Steering Group/Agenda Committee

As you all may know (well at least those who read the previous messages do) ZonMw has, as a result of several talks with 4 patient representatives (i.e. Group ME-The Hague, the ME/CFS Association, the Support group ME and Disability and the ME/CFS Foundation), put together a research agenda committee.

The respective names of its members were published on ZonMw’s website <https://bit.ly/2Ypp1c1> (Dutch)

Committee’s Objective

The research agenda committee’s main objective is to, like it says, compile a research agenda that prioritizes key points, to function as a template for a research program after which research applications can be submitted for government grants.

The composition of the committee guarantees a 100% biomedical approach. **Ynske Jansen, Jan Willem Cohen Tervaert** en **Rob Wijbenga** were also members of the Dutch Health Council ’s ME/CFS Committee. For them, this is a continuation of a long trajectory started in 2011 by **Mirande de Rijke**’s petition

With the exception of mr. **Cohen Tervaert**, who joined us recently, the steering group has already held three exploratory meetings. A third meeting, in which important choices concerning the direction of the research grants have been made, has been held at the end of April, via zoom because of corona. A fourth one is scheduled at the end of June.

Consulting Foreign Expertise

Consulting the international field of (biomedical) research is ongoing but preliminary results seem to be promising. Getting in line with past and current international research was after all something that was highly recommended by the Health Council and an absolute must for Group ME-the Hague, the petitioner at the base of this entire process.

Schedule

The committee's global schedule is as follows:

- ✚ End of April 2020: a draft of the research agenda and an update of the progress made by the committee has been sent to the Ministry of Public Health, Wellbeing and Sports (WVS in Dutch)
- ✚ July 2020: final version of the research agenda
- ✚ Fall 2020: drafting of the research program

As a result of unforeseen circumstances in the shape of COVID-19, the first step has already been delayed. Group ME-the Hague, consisting of mostly severely ill patients, is not the least bit worried though, as the delay will probably only benefit the quality of content concerning the research agenda.

For example, we now have ample time to organize a seminar for which we are planning to invite international speakers as well. It is a well known fact that busy scientists need, at least, an 8 month heads up when it comes to planning an event like this. So the pressure former minister Bruins put on the original trajectory has basically been nullified.

Looking at the current penciled-in agenda, it's noticeably not that different from the proposals Group ME-the Hague presented back in mid 2018 to the Ministry of Health and Parliament.

If you'd like to know more about them, please check our updates in earlier issues of the ME Global Chronicle under the heading 'Dutch Citizens Initiative'.



6. Grassroot



Danger of Post-COVID Being Lumped in With ME

While we are far from knowing what the future holds for post-COVID patients, I have concerns about statements made indicating there will be a large number of post-COVID patients who will be diagnosed with ME. Some post-COVID patients are not recovering as quickly as possible but articles indicate this delayed recovery is likely due to organ damage not seen in ME.

We don't have enough information to know the long-term damage this narrative will have, but 30+ years of history gives us some insight what could happen. Lumping patients who have something other than ME in with ME patients over the decades has led to disastrous results.

What happens when the post COVID patients recover using GET, meditation, diet change or similar behavior modification therapies? If there is a perception that post-COVID is the same as ME, doctors are going to expect that everyone with the ME label will recover using behavior changes.

This falls into the dangerous narrative we have suffered from for decades. ME is a bunch of symptoms caused by some mysterious process - treated by patients changing their behavior.

The narrative ME patients need is the reality: ME is a distinct acquired disease that can NOT be managed simply through patient behavior. Experts need to be trained to diagnose and treat this distinct patient population.

Dr. Ramsay, who wrote the original description for ME, stated that ME is not the same as post-viral fatigue syndrome (PVFS). Unfortunately, the treatment recommendations for PVFS are too often preferred by many doctors trying to treat ME.

This article from 2019 gives a good example of what post-COVID patients can expect from their doctors:

"Some lifestyle tips may help support the body as it works through post-viral syndrome. These include:

- ✚ sleeping 7–9 hours each night
- ✚ taking naps throughout the day as necessary
- ✚ conserving energy and getting plenty of rest
- ✚ drinking plenty of water
- ✚ engaging in mild exercise during the day
- ✚ eating a balanced and healthful diet that contains plenty of fresh fruits and vegetables and anti-inflammatory foods
- ✚ avoiding heavy, greasy foods, such as fried or fast foods"

<https://bit.ly/2AoHcXF>

Those recommendations are appropriate for PVFS but are completely inadequate for ME.

We don't know what is making post-COVID patients to remain ill but many articles like this one point to damage seen that is not common in ME.

"All these Covid-associated complications were a mystery. We see blood clotting, we see kidney damage, we see inflammation of the heart, we see stroke, we see encephalitis [swelling of the brain]," says **William Li**, MD, president of the Angiogenesis Foundation. "A whole myriad of seemingly unconnected phenomena that you do not normally see with SARS or H1N1 or, frankly, most infectious diseases."

(<https://bit.ly/3ftI9wJ>)

What can the ME community offer to those Post Covid?

We can offer them the International Consensus Primer. There are many conditions that can arise post-viral addressed in the primer. The testing protocol looking for deficiencies is a great place to start. Treatments for B12, Folate, Vit D, CoQ10, magnesium, or zinc deficiencies can be addressed easily if doctors know to look. While they are looking at the MEIC Primer they can see that ME is not the same as PVFS and properly diagnose patients.

Let's make sure they know to look. Give them the IC Primer and guide them to these pages:

- 📄 Page 11 - Laboratory/Investigative Protocol
- 📄 Page 13 - Management and treatment

Link to the primer: <https://bit.ly/2Xr7Lmb>

Colleen Steckel

30+ year ME patient and advocate for adoption of the ME-ICC

CFS/ME and Covid-19 - Some Guidelines and Advices

A lot of you have been asking about guidelines for the management of your health during this very difficult and unusual time, as we are all seemingly at risk of this new infection. Because it is so new, the easy answer is that we really do not know how this infection is likely to impact on those with CFS/ME. Below are a few of the questions I am being asked and I will try to answer them. Then I have provided a list of websites from around the world in relation to these issues. They may vary a little in the advice offered. But just use common sense. Remember you know your body better than anyone else!

✚ Am I more likely to be at risk of Covid-19 if I have CFS/ME?

No-one really knows for sure as this is all so new. In general, many with CFS/ME, often with an over-activated immune system, seem protected against everyday bugs, so the risk may be small.

✚ If I do get covid-19 will it be more severe because I have CFS/ME?

Not necessarily so, unless you already have breathing, cardiovascular or kidney problems. If you do succumb, common sense advice would be to seek medical advice early and make sure someone checks up on you regularly. Also go to bed and rest up.

✚ If I do get Covid-19 will this cause a relapse of my CFS/ME?

It is possible, as any infection poses this risk for you. Again, give in, go to bed and seek medical help. Also, when you are recovering do not try to do too much, as this could stir up your CFS/ME symptoms.

✚ Can Covid-19 cause CFS/ME?

CFS/ME can certainly be as a result of any infection (particularly viral). A prolonged post-viral phase may occur after Covid-19, which can lead on finally to a diagnosis of CFS/ME.

✚ Should I have an influenza immunisation?

This is probably wise, unless you have had a bad reaction to one in the past. Influenza can cause you to become very run down, and more likely then to succumb to Covid-19 if you have contact with that illness.

✚ Is there any special treatment I should add to my regular regime?

Keep going with all your regular medication. Eat sensibly and regularly, with plentiful fruit and veg. Take care not to over-exercise, but make sure you get your daily dose of fresh air. Stress and poor sleep can lower your resistance, so keep working on these aspects of your wellbeing.

✚ Is there any vaccine or drug treatment for Covid-19?

Not yet, but work is going on around the world, and we must all be hopeful.

The good news which we must all cling to as a result of this terrible pandemic, is that there will be an upsurge in research into immunology, biochemistry and virology. The outcome of all that may provide a greater in-depth understanding of CFS/ME and its potential treatment.

Useful websites from around the world in relation to CFS/ME and Covid-19

- ✚ Inst Neuro-immune Medicine, Florida, USA - **Dr Nancy Klimas** video: <https://bit.ly/2Y1sG00>
- ✚ MEAssociation (UK): <https://bit.ly/2UHPqRs> - <https://bit.ly/2UHYCp7>
- ✚ Bateman Horne Centre, USA - Information for doctors <https://bit.ly/3ffHWwW>
- ✚ Emerge, Australia <https://bit.ly/2YyuOw7>

Dr. Rosamund Vallings



#MEAction

Since the coronavirus pandemic hit, #MEAction has pitched news stories and worked with major news outlets to sound the alarm that COVID-19 patients are at risk of developing myalgic encephalomyelitis (ME) and other chronic illnesses. In the past month, #MEAction has worked to tell this story in The Washington Post, The Atlantic and Bustle!

As the world grapples with more and more COVID-19 patients who are not recovering, #MEAction is working to bring knowledge about ME to the world so that the flood of new patients developing ME will find timely diagnosis, treatments and care.

Now more than ever is the time for our government to invest heavily in research and medical education to better understand post-viral diseases like ME.



Washington Post Publishes Perspective Piece Co-Written by #MEAction Co-Founder

#

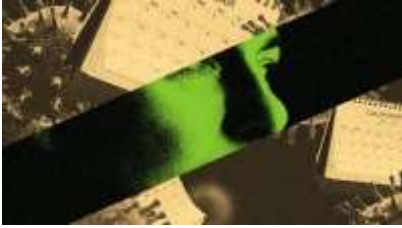
MEAction Co-founder **Beth Mazur** and former reporter **Brian Vastag** recently published a perspective in The Washington Post (<https://bit.ly/3d71Ecx>) about the potential for COVID-19 to lead to ME and other chronic illnesses.

The article was on the Washington Post homepage for more than 24 hours, a sign of high readership, according to the editor that worked on the piece. In addition, it ran on the front page of the weekly print Health and Science section, with some 300,000 copies in circulation. It was also recirculated in newspapers in Seattle, San Francisco, Maine and New Mexico.

In the reported piece, the authors make clear that the symptoms many post-COVID-19 patients are experiencing aren't a new phenomenon, and that governments must invest in ME research.

"Given the historical neglect of ME/CFS — very few medical students even learn about it — many physicians and researchers who follow covid-19 patients may think they're discovering a new phenomenon in the patients who are slow to recover," write **Beth** and **Brian**. "Instead, they'll be rediscovering a common illness that's been known, and neglected and afflicting many people — for decades."

The Atlantic Publishes Article about COVID-19 Patients, Interviews #MEAction Co-Founder, **Jennifer Brea**



A few days ago, The Atlantic published a compassionate and deeply thoughtful piece about COVID-19 patients who are not recovering from the viral infection, called "COVID-19 Can Last for Several Months" (<https://bit.ly/30JSnEW>) by the science writer, **Ed Yong**. #MEAction co-founder, **Jennifer Brea**, was interviewed for the article, and provided background information about the viral onset of ME.

"ME/CFS is typically diagnosed when symptoms persist for six months or more, and the new coronavirus has barely been infecting humans for that long.

Still, many of the long-haulers' symptoms "sound exactly like those that patients in our community experience," says **Jennifer Brea**, the executive director of the advocacy group #MEAction.

In the article, Yong profiles 9 post-COVID patients who are struggling with ongoing symptoms months after first getting infected, including post-exertional malaise (crashing after exertion), fatigue and cognitive issues.

Most of the patients **Young** interviews were never admitted to the ICU or put on a ventilator, and were considered "mild" cases.

Young grapples with the coming wave of ME/CFS and how the pandemic could have broader, longer-lasting impacts than we ever imagined.

The #MEAction Team

How You Doin'?

How are you in these quaran-times, my friends?

My husband and I are doing everything possible to avoid infection because we know how scary COVID-19 can be. I have not left my house for anything except short walks in more than two months. No one has come into our house. We haven't eaten any food that we did not cook ourselves (which admittedly has made for some interesting dinners when we're both crashed out). We lost some of the assistance we had relied on, like our house cleaners, so that has created some challenges. We haven't always been able to get everything we wanted from a store when we wanted it, but many kind people have helped us by shopping for those items on our behalf. I miss my family, and I don't know when I will be able to see them in person.

These are all such small problems compared to what others are enduring. I've watched the federal response to the pandemic with horror and alarm. My grief and anger over the death of **George Floyd** has transformed into a deeper pain as our cities react and burn. There is so much suffering in our country right now, and all I can do is bear witness.

The only way I know how to cope with all of this is to focus on my tiny corner of the world. I've been sewing masks (<https://bit.ly/3cZCjBp>), and writing a bit. Those of us who have socially distanced out of necessity for years have experience that can help those who are struggling with it now. I offered some advice on that in an essay for **Jessica Abel's** blog (<https://bit.ly/3dWG3F4>).

We have found beauty in very small things. We watched two baby bunnies grow large enough to leave our yard. Now there is a chipmunk making himself comfortable here. For some reason, our pink rhododendron put on an incredible show this spring, which made the bees very happy and fat. Someone is leaving painted rocks in the park near our house.

Our county is easing restrictions next week, although most people are acting as if the wait is already over. I don't think our lives will change that much. Until we know more about COVID-19, and the risks for people with health issues like ours, we are not taking any unnecessary chances. I worry a great deal about the people who are required or have chosen to take chances by going back to work, back to stores and public places. I don't think the worst is over.

During my telemedicine appointment last week, my pain management doctor asked me how I was. I said I was doing better than I had in awhile. He said that they're hearing that from many patients in the practice, which really surprised me. Why would people with chronic pain or chronic illness be doing better now?

I have theories. For me, I think that it has helped to have much more control over my sensory inputs and energy outputs. I don't leave the house. The only occasional visitor I've had stays for about an hour, and we talk through the glass storm door. No doctor appointments out of the house, which means no long car rides to and from, and no noisy waiting rooms.

I haven't had to deal with the sensory input of everyday life out in the world. Maybe this has conserved my energy and capacity, and I have been able to channel that into more meaningful activities like making masks. The satisfaction I get from that has definitely improved my mood. I also think it helps that so many people are temporarily living the housebound lifestyle. More people are moving at my speed, now.

Where do we go from here? That's a lot easier to answer for myself than for our nation. I want to keep the things that have made my life better, like telemedicine and more peace and quiet. I am fortunate that I can wait and see what happens with the virus, watch for the next wave(s) and stay safe at home.

I think there are many lessons to be learned from our current crises, especially about our communities and supporting one another. Perhaps people will stop saying to us, "You're so lucky to be able to stay home all the time!" now that they know how hard it can be. Perhaps we will make choices to be truly inclusive of people regardless of race, age, or disability. Perhaps we will try to heal the wounds we are inflicting upon each other.

I hope that you are in a good place, and also that you will see something in your life get better soon. We are nowhere near done with this pandemic or with hard times. Let's remember to take care of each other.

Jennie Spotila, June 1, 2020

<https://bit.ly/2YuwFC6>

Source: Occupy ME <https://bit.ly/37v43Nc>

In Due Time - Nynde

<https://youtu.be/n3uj-qUDuFE>

This beautiful song was sent to us on ME Awareness Day by the mother of **Nynde**, who wrote the following story:

"**Nynde** suffers from ME and turned 26 on May 5th, liberation day in The Netherlands, but not for her and all her fellow sufferers.

She had won a scholarship at Boston's prestigious Berklee College of Music and later studied at the Codarts conservatory in Rotterdam but had to give up all her dreams.

In 2016 she needed to undergo a hip surgery which she never fully recovered from. **Nynde** and her partner **Sam**, who stood by her through thick and thin, wrote this song in 2017 about her situation back then.

Meanwhile, her health has severely deteriorated and the pain, grief and isolation are enormous. **Nynde** is a real fighter, is incredibly strong, resilient and funny, and she will never give up hope. She told me several times that she wishes to help others and be a meaningful part of the ME community.

That's why, as a mom, I wanted to share this so that she and all the other invisible ME sufferers won't be forgotten."



In Due Time – **Nynde**

I got the feeling this is all wrong
Been overthinking all day long
Wish I got the answers to clear up my mind
But I guess it's not my time

I can't remember feeling alive
Been losing my senses
Losing my sight
If I only knew how to leave this behind
But I guess things come in time

Sometimes life will make you shiver
You never know what it will deliver
Don't let it bring you down
All the struggles that you're facing
Soon you'll be embracing them the way they are
In due time

I never thought I was able to find
A silver lining, my peace of mind
I don't have the answers but I'm feeling okay
So I guess I'm on my way

Sometimes life will make you shiver
You never know what it will deliver
Don't let it bring you down
All the struggles that you're facing
Soon you'll be embracing them the way they are
In due time



Italy and ME – Part 2

Whilst preparing for the (cancelled) marathon in Rome, '**Marathon**' **Mike Harley** interviewed three Italian ME-patients. We will publish the interview in three parts, of which the second part in this issue.

Mike:

It's estimated that around 500,000 people have ME/CFS in Italy. I've been finding out more about how the illness affects people there. Do you know of any support groups or associations in Italy for those suffering from ME/CFS? If so, what are their aims?

Fabio - In Italy we don't have public hospital with a research / trial centre, we don't even have one Italian centre specialized in ME/CFS, although the situation for Fibromyalgia is better. Associations can do little without doctors, specialized hospitals and no clinical trials available. Among Portugal and Greece, we are an EU state without any clinical trial in ME/CFS. For now, the unique aim is to spread the word about this illness, to share scientific information about progressions with research and to make ill people feel less alone.

Giada - Yes, there are a few, I am president of one, the CFS/ME Italian Association. It was the first funded, in the early 90s. There are others. Their aim is to raise awareness and connect patients, for the most part.

Rosa - I do not know any association or group that helps and supports people suffering from ME and CFS

Chiara - Two active associations, the CFS ME OdV based in Zugliano (VI), my husband and I are members of the board, and the CFS ME Associazione Italiana OdV, based in Aviano (PN). The objectives: to help research and help with the recognition of the pathology in Italy.

Are there doctors who would be interested in the research into ME/CFS and the recent scientific advances?

Fabio - See previous answer.

Giada - I suppose so, potentially. The real challenge is how to interest them.

Rosa - I don't know if there are doctors interested in research, to make progress with these disabling diseases; I have the hope that there are, in a future as close as possible, we need research, I want to be confident that doctors will take our cause to heart and help us.

Chiara - A researcher at present very busy in the study of the syndrome is certainly **Professor Aldo Baritussio**, retired internist physician at the University of Padua, assisted by other doctors and researchers. **Dr. Caterina Zilli**, a pediatrician, and **Dr. Paolo Brambilla**, a general practitioner and a psychotherapist, are part of the Scientific Committee of CFS ME OdV and are very active in listening, supporting and representing the sick and their families.

How do doctors and government officials perceive ME/CFS in Italy?

Fabio - My GP, even after diagnosing me as having 46% disability for ME/CFS and idiopathic hypersomnia tells me that "I'm just stressed." In the best case, doctors say "We know you have a real illness, but we can't do anything for you". However, ME/CFS has never been included in Italian disability tables for assigning a minimum/maximum range disability level, which means that depending on the commission judging you, you can also never be recognized as disabled patient. And keep in mind that in Italy, 100% disability certification gives you only 300 euro for month, which is like being condemned to die.

Giada - Doctors perceive CFS/ME with skepticism at best, most of the time. Most of them are not aware of it at all. Some enlightened few try to follow research and help patients at the best of their ability. As for government officials, they are sensitive to the cause on principle, but do not see a big margin to do much because of the paucity of scientific research and evidence.

Rosa - Many doctors still have the wrong approach to our diseases, they believe they are psychosomatic diseases related to stress or anxiety.

Chiara - Italian government officials perceive it only and only if they have a case in the family otherwise only empty words without turning to facts. Unfortunately most doctors do not know and therefore do not hypothesize the syndrome in people who ask for their opinion by sending them, still too often, to psychological/psychiatric treatment

Do patients receive adequate support? Can they receive disability benefits when they are unable to work?

Fabio - See previous answer.

Giada - Patients do not receive adequate support at all. Technically they should be able to receive disability benefits if they reach the necessary disability threshold: no matter the condition you have, your actual state should count. Truth is they rarely do, because it's hard to prove your condition and your state. Also, even if the name of your condition should not count, some patients have been ridiculed and not taken seriously because of it.

Rosa - Patients are not adequately supported and most of them do not receive disability benefits and many of them are unable to work and cannot access protected categories.

Chiara - Patients do NOT receive adequate support. I was never recognized as disabled either, apart from the fact that I had not been diagnosed with CFS ME, but I had a very serious illness anyway and therefore had to give up teaching. Our son, on the other hand, being bound from the bed to the sofa and from the sofa to the bed, was granted a degree of disability and also the absolute inability to work."

Mike Harley

Source: <https://bit.ly/2Y0qLcT>

Part 1 has been published in the March 2020-issue of the ME Global Chronicle #35, part 3 to feature in the September 2020-issue.



Two Excellent Modules on ME/cfs

As you may have read 2 free educational modules about ME/CFS are now available for GPs and all healthcare professionals.

- 🇦🇺 Australia: 'Busting the myths and redefining Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)'
<https://bit.ly/2LJ9xdi>
- 🇬🇧 England: Myalgic Encephalomyelitis / Chronic Fatigue Syndrome CPD
<https://bit.ly/3bMvpPo>

Both modules are of excellent quality and give 1 hour CPD each. The modules are freely accessible for healthcare professionals from all over the world. CPD points are a great way to stimulate the use of the modules. However, CPD requirements vary from country to country, so this would be worth investigating.

The Australian module is especially designed for GPs. All aspects of ME/CFS, from diagnosis to management, are included in this module and can be used in a GP's practice right away.

Completing the English module after that would be a great addition. This module could fit best for all medical personnel who would like to test their knowledge, understand the main diagnostic features and identify comorbidities related to ME/CFS. In addition the module offers lots of links to the latest scientific studies. Both modules will be found very useful and increase your knowledge about ME.

I would like to thank the developers in Australia and England for their excellent work. I am looking forward to even more e-learning modules about ME in the future.

Thank you so much!

Sylvia Iversen

<https://bit.ly/3fsyjet>

'Leave No One Behind'

I wrote this reflection to decipher the unease I felt during the forced lockdown as a result of the pandemic. Life as we knew it has changed forever. A virus which nobody can see, but is very much lurking in every corner of the world, made us stay at home. Many people experienced what it is like to be housebound. But although the duration of this lockdown is not set in stone, we all know at some point it will end.

For the many, many people with chronic illness and disability, this time has been of mixed emotions. For me personally I spend many of the last 22 years housebound due to becoming ill with Myalgic Encephalomyelitis (M.E.). The start of this long journey was a viral infection in my brain during the summer of 1998.

The first few years I was mostly bed and house bound. I had a few years of gradual improvement in which I partook at life outside my wall at times. I believed eventually I would recover and return to my pre-illness life. It never happened. Before my illness I was a full time Doll Artist. I made sculpted figures and puppets for shops, exhibition and corporate commissions. I taught students from Ireland and abroad in my studio. The months before the sudden onset of illness I was teaching a wonderful group of teenagers in a group-home.

[So, lockdown...](#)

Why did that bring a sense of unease in my heart and mind? Possibly because after a two year long battle with the HSE (health care in Ireland) I had finally managed to be awarded full PA hours (Personal Assistance) to have control over my life and to also be allowed to leave my home with my PA. The irony is that a week after I finally secured full control over my care the general lockdown started. So my newly found freedom, my re-emergence into the world, was halted before I had the opportunity to fully experience it.

In terms of Covid-19, I had great concerns that my PA Support might be curtailed or even canceled. What if my one of my carers get ill? What if I get ill? The worry of ending up in a care home again, was very real. The memory of suddenly being taken into care last year still tightens my heart, and brings me close to tears. However, with my two wonderful PA/carers we found ways to talk about the possible scenarios. We managed to all stay well.

[The other unease is deeper, is older](#)

During this lockdown time the world became accessible via video links. A lot of the requests I made especially during the past two years are now suddenly possible. Being 'Disabled' became a mainstream concern. Disabled by being unable to leave the home. Disabled by having to wear mask. Disabled by not being able to be among friends and family, or to attend work or college.

For a long time I requested if my neurologist appointment could be done via skype. I was too unwell to travel the long distance. The two to three hours waiting time at the hospital for a ten minute consultation were just outside of my reach.

This wasn't possible. I asked again 6 months later (February), and it was kind of agreed but it never happened. Now people have consultations over the phone...

During the two year senseless, frustrating fight with the HSE to obtain PA hours to support me to live independently at home, I requested access to online counselling support. This was not possible. It could not be done. The fact that I could not travel, that I had no accessible transport, that I could not sit up in a chair for an hour all fell on deaf ears. Online counselling was simply not available. Enter Covid-19 and the HSE is spending over a million euro to roll out online support for mental health. Suddenly there is an understanding that being stuck at home is actually very challenging to one's mental health.

I am pretty good in my own company and take great pleasure from nature around me and having access to my creative mind. But yes, I too climb the walls at times and long to be part of a more normal world.

I feel that many people with chronic illness or disability have been screaming at the government and the HSE that directives and supports need to be put in place for this neglected part of society. Nobody listened.

In 2013 I took the brave step to go to college one night a week. Disability Studies. It required more travel than my body was capable of doing. After a few weeks my body gave up, I got extremely ill. But as I had truly enjoyed the course so far, I made the request if I could partake in the course via video link. Oh no! This could not be done under any circumstances. Privacy was an issue. Now, of course all courses are possible via video link.

"Being ill and housebound is still very different from being healthy and housebound"

So, yes. My thoughts on this current lockdown are in a state of confusion.

On the one hand I hope that people might understand our lives often lived in isolation a little better. And yet I can't see this truly happening. Being ill and housebound is still very different from being healthy and housebound.

I do hope that the online access changes made in our global society remain in place so many people with disabilities and illness can be part of the greater world and have access to healthcare from their homes.

Link to Community Radio Castlebar talking about this article
<https://bit.ly/3fqDGKS>

Corina Duyn

Living With An Invisible Octopus

An Interview with **Corina Duyn** (Full podcast <https://bit.ly/3hrjSsS>)



In this Puppet Place podcast, artist **Corina Duyn** talks with **Emma Windsor** about her 'Invisible Octopus' project. **Corina** worked with **Dr. Emma Fisher** through a mentoring bursary from the Arts & Disability Ireland Connect Scheme, to explore alternative forms of puppetry to accommodate the physical challenges due to her chronic illness/disability M.E.

More about octopus on my blog <https://bit.ly/2YD10hO> (series of Seven articles which led to the podcast)

Further information about the project and **Corina's** other work can be found on her website at: <http://corinaduyn.com>. With thanks to Arts & Disability Ireland (<http://adiarts.ie>)

Submitted by **Corina Duyn**

ME/CFS: A Brief History - The Lost Decades

<https://bit.ly/2Ys2lb6>

The WHO classified ME as neurological in 1969 but 80% of doctors still believe its psychosomatic [1]. Many doctors still don't know that over the last 35 years there have been over 9000 scientific publications that compared people with the illness to healthy people and they find a whole variety of abnormalities, like energy metabolism.

Medicine has a history of providing psychological explanations for poorly understood conditions with "little or no evidence" [2]. The psychosocial view of ME started in the 1970s. Two psychiatrists wrote an influential article that described an outbreak of ME as "mass hysteria" despite not seeing any patients [3].

In the 1980s ME was renamed and redefined as Chronic Fatigue Syndrome (CFS), which broadened the criteria, "trivialised" the severity and "stigmatised" people with the disease [4,5]. Psychiatrists argued that there was no underlying disease and the process was "reversible" by adjusting thoughts and behaviour. The theory claims that patients become deconditioned due to a prolonged period of rest following an illness, such as a viral infection. They become sensitive to activity, develop a fear of exercise and get trapped in a vicious circle of disability [6,7].

Psychiatrists developed Cognitive Behavioural Therapy (CBT) and Graded Exercise Therapy (GET) as treatments to change "unhelpful beliefs" and reverse "deconditioning" [6,8]. Exercise as a treatment is counterintuitive in patients with ME as even minimal mental or physical exertion leads to Post Exertional Malaise (PEM), a worsening of symptoms and reduced function [9].

"From my experience of ME/CFS there was no psychological component whatsoever, besides which exercise, if anything, was making me worse not better. I was not deconditioned or frightened to exercise". "The NICE guidelines do not fit" with the patient experience and "perpetuated my misunderstanding" of ME by recommending Cognitive Behavioural Therapy and Graded Exercise - **Dr Nina Muirhead** ME Patient and Specialist Surgeon in Dermatology [10].

Patient surveys consistently report that Graded Exercise makes over 50% of patients worse [12]. "Graded exercise has untold physical damage to thousands Of people [with ME] if it were a drug, it would have lost its licence. The psychological view of ME led to the controversial and now debunked PACE trial. As the trial progressed and the results did not meet the authors' expectations, they simply lowered the threshold to define improvement" - **Carol Monaghan** MP [12].

The Centers for Disease Control and Prevention (CDC) in the US dropped Graded Exercise and Cognitive Behavioural Therapy as treatments for ME in 2017 [13]. NICE is currently updating its guidance, which is expected in December 2020 [14].

"These therapies have been promoted by a group of psychiatrists, neurorehabilitationists and therapists, but with other physicians largely unaware of what was going on until recently few have read the trial reports [15].

ME receives 20 x less research funding than MS despite having 2.5 x as many patients in the UK and ME patients being equally (or similarly) disabled [16,17,18]. The vast majority of money was spent on behavioural studies. These failed to provide evidence for the psychological model as treatments showed no improvements on objective measures [19,20].

In the last 30 years biomedical research into ME has been massively underfunded, no drugs are available and there is nothing on the horizon. In a similar period MS has seen a dramatic shift from no treatments to 14 disease modifying drugs available in the UK and over 25 in development [21,22].

- [1] <https://bit.ly/2yFAtY8>
- [2] <https://bit.ly/2xRPZjw>
- [3] <https://bit.ly/2Lg5fK8>
- [4] <https://bit.ly/3bjR5IM>
- [5] <https://bit.ly/2Wz2Y1C> (8 mins 48)
- [6] <https://bit.ly/2YQ3NWX>
- [7] <https://bit.ly/2YMZICH>
- [8] <https://bit.ly/2yHSjd5>
- [9] <https://bit.ly/2yz1iNY>
- [10] <https://bit.ly/2YNf4XW>
- [11] <https://bit.ly/2WftyOA>
- [12] <https://bit.ly/3fz7UfP>
- [13] <https://bit.ly/3cgObzy>
- [14] <https://bit.ly/3bi6q6b>
- [15] <https://bit.ly/3durYxX>
- [16] <https://bit.ly/2SLIfXq>
- [17] <https://bit.ly/3biVfdJ>
- [18] <https://bit.ly/3cjzVpI>
- [19] <https://bit.ly/2SPc61f>
- [20] <https://bit.ly/2YOMXro>
- [21] <https://bit.ly/2WKcajS>

Broken Battery

<https://www.facebook.com/brokenbattery/>

News From Emerge Australia

Virtual ME/CFS Awareness Day & #MillionsMissing

In response to COVID-19 Emerge Australia ran an ambitious national social media campaign for ME/CFS Awareness Day and #MillionsMissing to overwhelmingly positive feedback, particularly from the many people in the Australian community unable to participate in the usual in-person events.

There were three elements to the campaign, promoted through newsletters and online via social media channels including a dedicated Facebook event page, and through the Emerge Australia website:

- ✚ Supplying locally sourced, high quality and highly visible #MillionsMissing and Emerge Australia T-shirts
- ✚ Producing personalised #MMSelfies to be shared online, replicating the powerful impact of hundreds of empty shoes and story tags that usually feature in #MillionsMissing rallies around the country to represent the millions of people missing from their lives.
- ✚ The #MECFSSchallenge, a humorous and engaging centrepiece of the campaign, which asked members of the community and its many supporters to record themselves on video saying the 'myalgic encephalomyelitis' in a single take with the punchy catchline: 'Hard to say, harder to live with'.

The campaign engaged a number of Australian politicians, international researchers and thousands of supporters, particularly the #MECFSSchallenge videos.

Patients, allies and organisations embraced and amplified the challenge in Australia, New Zealand, throughout the US and the UK, and as far afield as Germany, France, Italy, Portugal, Sweden, Belgium, the Czech Republic, the Netherlands and Japan.

"Even we were surprised at how strongly the challenge and it's catchy tagline, 'Hard to say, harder to live with,' resonated here and overseas," Emerge Australia CEO **Dr Heidi Nicholl** said. "The videos were viewed well over 100,000 times across Facebook and Twitter, in more than 12 countries."

See ME

<https://youtu.be/-PkrqSNjdYg>

The rather new but most active and creative Flemish group of ME-patients vzw 12ME published an online three-day program on May 10, 11 & 12, 2020.

On its second day, they proudly presented an incredible impressive cover (See ME) of the song Chasing Cars of Snow Patrol (If I just lay here...), produced and performed by Flemish ME-patient **Robin De Man** and his son **Seppe**.

'See ME' is a cover of the song Chasing Cars by Snow Patrol.

<https://youtu.be/-PkrqSNjdYg>

The lyrics have been adjusted to reflect the lives of people suffering from Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS). ME/CFS is a chronic and debilitating illness that afflicts millions of people worldwide.

Robin and Seppe wrote the text adjusted to the suffering of severe ME-patients, whose pictures are being shown in the video, some of them already deceased. The pictures of Flemish and Dutch ME-patients were collected by 12ME after an appeal on patients to send them in.

Their appeal on you is to share the video worldwide to arise more awareness of the severity of ME, but to not copy or reproduce the pictures of the persons shown, also out of respect for those who sent them, amongst whom bereaved of the patients who died due to the consequences of ME.

On the 10th May 12ME also published an impressive short film of their own making, "Leven met ME" ('a life with ME') of 7 Flemish patients telling about their experience and perception of their (severe) ME, in Dutch. In this film many aspects of the invalidating effects of ME are being highlighted:

<https://youtu.be/B3ISFZ3HgOM>

Please visit AND like the fb-page of 12ME

<https://www.facebook.com/groups/12MEI/>, also to be found on Instagram
<https://bit.ly/2WGYFlf>

The song has been simultaneously published by 12ME itself, the Belgian ME Vereniging België <https://www.facebook.com/mevereniging.belgie/> and ME Centraal <https://www.facebook.com/MECentraal/>

Fennine

Dutch **Fennine de Weerd** (38) has been suffering from ME for over 20 years.

After many hurdles - as she describes below - she ultimately decided on becoming an artist and painter. Since recently she has been drawing ME-related comic strips with Paco among others - the mascot of the Belgian action group 12ME - as the lead character. We will regularly include these comics in the magazine.

In this article, **Fennine** introduces herself.

The Beginning

"Right before my secondary school exams took place, I fell ill. So terribly ill, that I still wasn't able to attend school after three weeks. During these weeks, I was prescribed strong antibiotics and ibuprofen treatments, and only after three weeks did my family doctor urge me to get tested for glandular fever. And so my blood test results later came in... positive." But fortunately, that was already on its way out after some time.

I couldn't bother to show up for exams that year because everything went as if I were severely aged. Everything made me ill and I was forced onto my bed for days on end. But considering as I didn't see 'being sedentary' as part of my nature, I decided to pick up on drawing and painting.

At that point, at 17 years of age, I lived through my years of school on and off. One year I was able to take my exams; the next year I was too ill to attend my dream college, the HKU University of the Arts in Utrecht. Another year forward, I finally made it to the HKU, but halfway I packed my bags and left for home, sick and disappointed.

Vortex

My life ended up in a confusing whirlpool. The UWV <https://www.uwv.nl/overuwv/english/index.aspx> determined that, because I was a student, I was able to work. It was evident that I followed my education under many adjustments and had taken two years to complete a single year of my studies - I either had to work or keep advancing towards my diploma. I was 21 at the time and just stood and watched how the UWV stripped me of my dreams for the future and cut my unemployment benefits. I had no choice left but to work, with no diploma.

I lasted two years as a graphic designer before suffering a complete breakdown. I'm not able to remember a lot from that period of time, except that I followed an intensive, internal program at a rehabilitation center. This inspired me with brief thoughts of me being there, of me being able to take my workload. The following year saw me attending an art academy; after all, I was determined to get a degree. This wasn't a smooth ride entirely, and many hurdles were run into. After being able to cut as many school years in half, I managed to receive my diploma in the end.

Art Teacher

Since a couple of years, I've been given the opportunity to be an intern art teacher from time to time. Seeing as these encompass periods consisting of a couple of months, for a couple of hours a week, it's feasible for me. I need the same amount of months I've spent working to restore myself back to a 'livable' level. It may not be the future I had envisioned for myself, but it's something at the very least. And that something fills me with joy, even if it means I have to greatly exceed my own limits.

I'm thirty-eight now, and enjoying painting and drawing anything I happen to make. In 2019 I started creating a cartoon series about my life with ME, in which in a relaxed way (and with a lightly sarcastic undertone) I describe how something you might not see, can definitely be there.

Fennine



The Dialogues for a Neglected Illness Project: An Update

Two new videos addressing Severe and Very Severe ME/CFS have been released, following the "Introduction to ME/CFS" and two videos on "Post Exertional Malaise" released just before lockdown. <https://bit.ly/2YDmJWP> and <https://bit.ly/2YAqWuz>

The writing on the images on the home page, showing the different topics take you to pages with the different video for that topic. The videos can be shared by using the buttons below the home page images for each topic.

The Severe/Very Severe ME/CFS videos have been made using input and feedback from medical professionals who are specialists in Severe/Very Severe ME/CFS, patients and carers. There is a third on Hospital Admissions to follow shortly, before we move on to the next area looking at the symptoms described by patients who are mainly from the UK ME/CFS Biobank. These may help doctors with making a diagnosis.

We've received an amazing testimonial for the project from ME Research UK, which is now on the Dialogues website, along with the earlier appreciation given by **Mary Dimmock**, a highly respected and effective advocate currently working on education for clinicians in the USA.

MERUK: "This series of videos is of superlative quality and has become a unique resource for many – from those affected by the illness, healthcare professionals and those with family members coping with ME/CFS. It demystifies the illness, makes it real to those with no connection to ME/CFS and is a testament to the work of the creators. The quality of the information given and the high quality of the videos is a model that others should follow."

Mary Dimmock: *"By shining a light on both the widespread misinformation and the biological reality of ME/CFS, the powerful videos being delivered by Dialogues for a Neglected Illness will help to change the fundamental narrative about the disease that has derailed research and harmed patients for decades."*

The other good news is that the "Severe and Very Severe ME/CFS" video is linked to as a Summary Video in Healthcare's proposed "Special Issue: ME/CFS Severely and Very Severely Affected Patients" edited by Prof Ken Friedberg with **Dr Lucinda Bateman** and **Dr Kenny DeMeirleir**.

<https://bit.ly/2MZs1ql>

Project videos are also being included and linked to in other educational material for clinicians - details later..

Natalie Boulton

The Lost Years

I'm 55 this year. I suppose you could call that half a milestone; it certainly seems a lifetime ago that at the age of 17 I walked out of my GP practice with a diagnosis of Glandular Fever.

I have to admit my main concern was that it would mess up my A Levels. I certainly didn't anticipate the affect it would have on my life.

I was ill for a few weeks, maybe months, and then something happened... I never really got better.

After two or three years I became more and more unwell, painful limbs, extreme exhaustion, sometimes the inability to walk more than a few steps, dizziness, repeated infections, passing out, just feeling very, very ill.

I remember vividly even after all these years sitting opposite a GP in those early days who looked at me sternly over the rim of his glasses and said, "If you think you feel better then you will feel better," and then he ushered me towards the door.

Medical ignorance

A few weeks later I went back and this time I was told that I needed to exercise more. "What you need," he said, "is a job harvesting cabbages." And he was serious!

It seems laughable now, but it was definitely the most damaging thing a healthcare professional has ever said to me and believe me there have been a few. For about the next year or so I thought I must just be imagining an illness, that it was my fault, it wasn't real, and therefore I must hate myself for creating a set of self-destructive symptoms.

Then I saw a GP who having listened to my symptoms diagnosed M.E. But let's not forget that this was the 1980s and M.E., I was informed, was a form of depression and so there was still very much a responsibility on me to snap out of it (not my words) and feel better.

I remember one-night laying on a makeshift bed on my parents' bedroom floor, too ill to sleep alone in my room. Mum held my hand and told me she would look after me whatever it took.

The next day I remember laying on the sofa thinking to myself that there had to be some way out of feeling so terribly unwell, so almost completely drained of life and spirit... not even having the energy to move.

What I find so unbelievable is that there was no help whatsoever from any healthcare professional and instead I lay there feeling guilty for having an illness that most people dismissed as being all in my mind, or that did not really exist at all.

After a year or so my symptoms began to improve. I was able to go to work as long as I came home and went straight to bed. I had to make a decision – do I hold down a job or have some sort of life for myself?

Working in mental health

Financially it was more important to have a job... but it exhausted me at times, and I was in pain every day, and my stress tolerance levels were very low indeed.

Fortunately, my job was in mental health services, so at least my colleagues were understanding. I had long spells of time away from work when my symptoms got worse and I needed to rest all of the time.

For about ten years this illness went on and on. From the age of 18 to 28, these were the lost years indeed. They were the years when my friends went off to university, got jobs, got married, bought houses, had kids – in other words, all those around me were establishing their lives.

I spent a lot of those ten years lying in bed, feeling guilty, trying to cover up how I felt so as not to worry those who cared for me. I tried to do things, then I suffered extreme pain and exhaustion as a result.

I think the worst thing was the psychological damage that was done. I gave thanks every day that I did not have a progressive illness.

I still give thanks, but having an illness that had such an impact but that hardly anyone believed in just made me feel blame and guilt. Big powerful words aren't they?

Oh, and then there was shame too, shame and embarrassment at saying "I have M.E." and the insults that came back from people in return. So those ten years or so taught me that this illness was something I had to manage on my own, to cover up, to make excuses about, and to feel so useless and guilty about.

Learning to live with ME

Fast forward to 2018. I'd worked out how to live with ME... Rest, rest, and more rest. Listening to my body very closely, not pushing too hard, it certainly seemed to work. Outwardly life carried on, inwardly it was different.

Increasingly I felt weak, my walking changed, I felt my coordination deteriorating, and that worried me.

I also saw a significant change in my cognitive function, short-term memory, word recall, and sensory overload. I was also experiencing panic attacks.

I went to see a GP, I felt I needed to check that there was nothing else going on. Now don't forget we're in 2018 now.

The GP sat there in front of me and she said, "The best thing you can do is snap out of it and get on with life," and do you know what I did? For the first time in my life, I sat in front of a healthcare professional and burst into tears.

A couple of weeks later I saw another GP, he said he'd refer me to a consultant, "You might have mitochondrial disease, Google it." I got home, Googled it, it gave me the news that this could be fatal... I sat staring at the screen... I cried.

I waited 10 months to see the consultant, 10 months when Google and I became good friends.

Good old Google found me article after article about mitochondrial disease so that I could rule that out, and article after article about M.E. that made me determined to stop feeling so bad and guilty and useless and to blame.

When I saw the consultant and he actually said, "You have M.E.," it was a moment that rather perversely made me smile.

I could have hugged him... Someone actually just took me seriously, someone understood... I had waited a long, long time to feel like everything was justified.

The next day one of my friends, who happens to be a senior healthcare professional, asked me how I got on at my hospital appointment. I told him, he laughed, "Ah, well, as we expected, it's all in your head."

One day, and I hope it will be in our lifetimes, people will look back with outrage at how those of us with M.E. have had to cope with our illness. We have two battles to face, both our illness and others ignorance and perception of it...and sometimes I'm not sure which is the hardest to bear.

Ruth Rookledge

Source: ME Association <https://bit.ly/2MXJ5NF>

To All Ye Heroes



ME patients are not lesser

They need to be treated with respect and kindness

They still have SO much to give

They are more courageous than we could know

More than most

Resilient

Tenacious

Strong

Innovative

Just because someone looks weak and tired and stuck doesn't mean they are that as a person.

It's an illness

Miranda Hart

<https://bit.ly/2UIIDbt>

I pushed Too Far

Bonjour,

As many of you know throughout May 2020 (<https://bit.ly/2YayxRL>) I shared one of my poems every day to raise M.E. awareness and better understanding. This year I didn't share as widely as last year (<https://bit.ly/3fuzCJP>) as it took a serious toll on my level of health. It's a really hard and challenging task to complete. Both last year and this year I nearly gave up but with some wonderful support I carried out my promise (<https://bit.ly/2YAzz8q>). Anyway the top five poems for this year were as follows:

- ✚ I pushed too far
- ✚ M.E. Groundhog Day
- ✚ Pretend
- ✚ Turn the clocks back
- ✚ Sadness

You can see and share my poems from my Facebook Page (<https://bit.ly/3d5CMCd>), Twitter (<https://bit.ly/2UOzpJy>), Instagram (<https://bit.ly/3hv2T8V>) and Pinterest (<https://bit.ly/3e6pabf>). Feel free to share any of my poems at any time. Although there is a lot more M.E. awareness raising and sharing in May it can and must continue throughout the year.

**I pushed too far
I pushed too long
I didn't know
that it was wrong
I pushed myself
I pushed in pain
I didn't know
it was in vain
I pushed too much
though I was ill
I had to pay
every bill
I pushed myself
past my limit
not knowing I'd
suffer for it
I pushed myself
What price I paid?
Now it's too late
the damage is made**

© The French Femme

So this is the winning poem and it seemed to resonate with so many people

This is a common scenario for many of us who become ill with M.E. especially at the debut of the illness. At that stage we most likely have no idea what is wrong with us and diagnosis can be difficult and long. I had to wait a year before I was given a diagnosis and I've heard of cases of where people have to wait much longer than that. Even when I had a diagnosis I had little help or advice apart to do graded exercise. So I pushed myself despite how I felt and despite the pain. I knew next to nothing about M.E.

In my ignorance I probably pushed myself too much and for too long, hoping that one day I would recover. I also had a mortgage and bills to pay. I was a single mother. I couldn't afford to stop working. So I did everything to stay in work. Now I wonder at what cost. How many of you have made the same mistake and pushed yourself too far at the beginning of your illness? How many of you have been forced to continue working? How many feel that you have caused permanent and lasting damage? In the early stages of the illness we are most likely clueless and with little or next to no help. Maybe now with the internet and social media people are better informed. I had an unsympathetic doctor and only one book for guidance. I now know in hindsight and from what I have learnt in later years that lots of rest in the early stages of the illness is likely to lead to a better prognosis. If only I had known that before! In the early stages we are unlikely to know

- ✚ That PEM will occur after physical or cognitive exertion
- ✚ • That prolonged physical and/or cognitive exertion will cause a relapse
- ✚ That relapse can last weeks, months or years
- ✚ A relapse may become severe and permanent
- ✚ How to pace
- ✚ That we need to rest, rest and rest
- ✚ The amount of rest we need

<https://bit.ly/2YDYGHW>

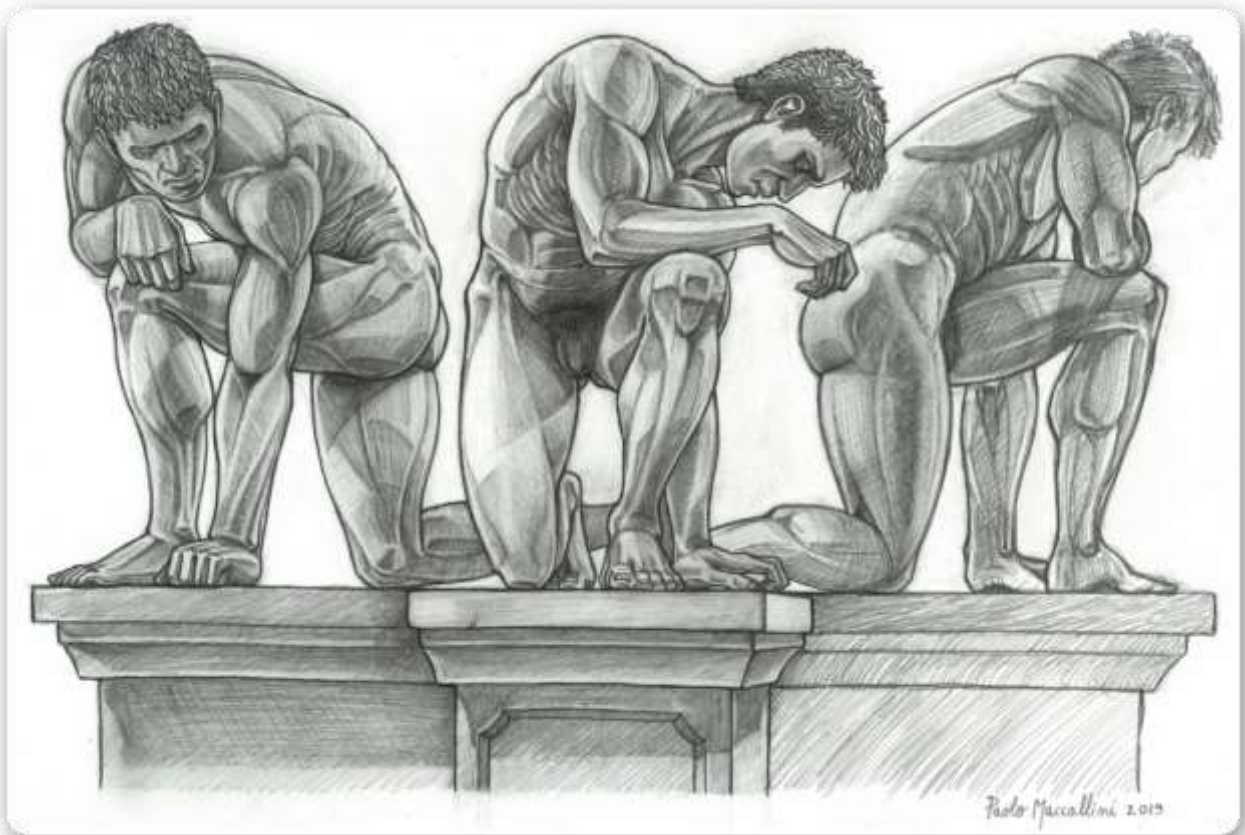
I've taken a few quotes from the superb book 'Shattered, life with M.E.' by Lynn Michell who echoes what I have experienced and write about in my poems.

<https://bit.ly/30MgGIF> "Anecdotal evidence suggests that those who get an early diagnosis and who rest thoroughly in the first months stand a better chance of an early and full recovery. But people with M.E. do not know that the harder they push, the more likely they are to propel themselves into a more profound version of the illness. Only with the wisdom of hindsight and armed with more information can they say, 'If only I had known, I would have rested more and I might not be so ill now'. Others struggle on because they are the breadwinners and fight off the alternative of exchanging financial security for the subsistence living of disability benefits – assuming they are granted them. Others struggle because they have young children or are single parents. Their determination to carry on was finally thwarted when their symptoms overwhelmed and defeated them. " It just remains to say a big **Thank You** for all those who have shared my poems and please continue to do so.

À bientôt
from the **French Femme**
xxx

Resilience-2

In 1999, just before my mind faded away for 18 months, I started studying the anatomy of a man who carries a heavy weight on his back. That was my first attempt of communicating what was happening to me, of describing my disease.



Only recently I considered to not represent the weight, which is a more appropriate solution since this is a mysterious disease with no known cause, and I made a draft that I then used as a starting point for this drawing.

I finished this new drawing at the beginning of September, in a motel room of San José, in California, just in time for donating it to **Ronald Davis** when I moved to the US to attend the third Community Symposium at Stanford.

Paolo Maccallini

Source: <https://bit.ly/3dgse3b>

7. 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

8. Science



Australia's ME/CFS Research and Clinical Centre: The National Centre for Neuroimmunology and Emerging Diseases Research Up-date



NCNED is committed to publishing novel high quality and rigorous research papers in the field of ME/CFS in order to provide new insights in the pathomechanism of the illness. Their research aims to help develop an accurate clinical diagnosis and to improve treatment and prognosis for ME/CFS patients. NCNED also endeavours to robustly evaluate the research literature (also known as systematic reviews) in ME/CFS to assist and inform researchers and patients.

The NCNED team has recently published a systematic review of neurological impairments in ME/CFS. This systematic review is the first to collect and appraise the literature related to the structural and functional neurological changes in ME/CFS patients as measured by neuroimaging techniques and to investigate how these changes may influence onset, symptom presentation and severity of the illness. Specifically, this systematic review assessed the data from research reporting using neuroimaging techniques, for example magnetic resonance imaging (MRI), positron emission tomography (PET) and electroencephalography (EEG). The results suggest widespread disruption of the autonomic nervous system network including morphological changes, white matter abnormalities and aberrations in functional connectivity. However, these findings are not consistent across studies and the origins of these anomalies remain unknown. Future studies using standardised protocols are required to confirm the potential neurological contribution to the pathology of ME/CFS.

Importantly, in another new systematic review NCNED reviewed all research reporting metabolomic changes in ME/CFS patients compared to healthy controls. The findings of this systematic review reports that a lack of consistency with scientific research design provides little evidence for metabolomics to be clearly defined as a contributing factor to the pathogenesis of ME/CFS. Further research using the same ME/CFS diagnostic criteria, metabolite analysis method and control of the confounding factors that influence metabolite levels are required.

The NCNED is currently doing in vitro drug investigations that they hope to take to clinical trials later in the year.

NCNED's priority are ME/CFS patients. They continued their support of ME/CFS patients by supporting and raising awareness for International ME/CFS Awareness Day by illuminating in blue their research and clinical centre as well as the Bridge of Knowledge at Griffith University. The symbolism of the Griffith University bridge being illuminated demonstrates the bridging of knowledge by NCNED researchers to where NCNED ME/CFS research takes place.

Clinical and Medical ME/CFS Research Centre where NCNED undertake their worldleading research





Bridge of Knowledge at Griffith University illuminated blue to symbolise the bridging of knowledge by NCNED researchers to identify the pathology of ME/CFS.

NCNED also created a "Blue Brigade Movement" where NCNED were encouraging everyone to post pictures of themselves wearing blue t-shirts to the Griffith NCNED

CFS/ME Facebook page to show solidarity. Examples of some of the supporters are shown below.



Submitted by **Prof. Sonya Marshall-Gradisnik**

Myalgic Encephalomyelitis, Post viral fatigue syndrome & their relationship

Researchers need to be careful expressing in clear terms what they are referring to in their research. This is all the more vital now that ME-research is being connected more and more to research into postviral COVID-19 effects.

Too often people don't seem to have a precise grasp of what characterizes M.E. and differentiates it from other diseases, particularly post-viral states.

The following statement by **Dr. Ramsay** explains that ME is not the same as Post Viral Fatigue Syndrome: The Myalgic Encephalomyelitis Syndrome - **A. Melvin Ramsay M.A. M.D.**

(It is fortunate that a second edition of my monograph affords me the opportunity to demonstrate that the clinical features of Myalgic Encephalomyelitis provide a sharp contrast to all other forms of postviral fatigue syndrome.)

The clinical identity of the Myalgic Encephalomyelitis syndrome rests on three distinct features, namely:

- ✚ A unique form of muscle fatiguability whereby, even after a minor degree of physical effort, 3, 4, 5 days or longer elapse before full muscle power is restored.
- ✚ Variability and fluctuation of both symptoms and physical findings in the course of a day. And,
- ✚ An alarming tendency to become chronic.

If we take the well known condition of post influenzal debility as an example of a postviral fatigue state we see that in all these particulars it constitutes a complete contrast. The fatigue of post influenzal debility is part of a general debility with no distinguishing characteristic of its own, it shows no variation in intensity in the course of a day and although it may last weeks or even many months it has no tendency to become chronic.

The clinical course of the Myalgic Encephalomyelitis syndrome is consistent with a virus type of infection. It most commonly commences with an upper respiratory tract infection with sore throat, coryza, enlarged posterior cervical glands and a characteristic low-grade fever with temperatures seldom exceeding 101°F.

Alternatively there may be a gastro-intestinal upset with diarrhoea and vomiting. In 10% of the 53 cases we reported between 1955 and 1958 the onset took the form of acute vertigo often accompanied by orthostatic tachycardia.

The prodromal phase is characterised by intense persistent headache, paraesthesiae, blurring of vision and sometimes actual diplopia. Intermittent episodes of vertigo may occur at intervals both in the prodromal and later phases of the disease. Loss of muscle power is accompanied by an all-pervading sense of physical and mental wretchedness. Some patients lack the mental initiative to cope with the situation; on the other hand the more extrovert types show a determination not to give in to the disease but their efforts to compel their muscles to work only serves to make the condition worse.

Once the syndrome is fully established the patient presents a multiplicity of symptoms but these can conveniently be discussed under three headings, namely:

Muscle Phenomena

The unique form of muscle fatiguability described above is virtually a sheet-anchor in the diagnosis of Myalgic Encephalomyelitis and without it a diagnosis should not be made. I am informed of two families who are said to have all the conditions conforming to the clinical picture but lacking the muscle fatiguability. These cases should be very carefully reviewed. It is quite common to find that muscle power is normal during a remission and in such cases tests for muscle power should be repeated after exercise.

In severe cases of M.E. muscle spasm and twitchings are a prominent feature and these give rise to acute muscle tenderness. In less severe cases muscle tenderness may not be so readily elicited but careful palpation of the trapezii and gastrocnemii (the muscle groups most commonly involved in M.E.) with the tip of the forefinger should enable the examiner to detect minute foci of exquisite tenderness. It is interesting to note that **Dr. Garnet Simpson** in Sydney, Australia (1986) without any prior knowledge of my writings devised the identical technique and found that detection of these foci 'will make the patient yelp'. In the aftermath of the disease patients frequently complain of a tendency to 'fumble' with relatively simple manoeuvres such as turning a key in the lock or taking a cork out of a bottle.

Circulatory Impairment

Most cases of M.E. have cold extremities and hypersensitivity to climatic change but the most striking illustration of this conditions the observation by relatives or friends of an ashen-grey facial pallor some 20 or 30 minutes before the patient complains of feeling ill.

Cerebral Dysfunction

Impairment of memory, impairment of powers of concentration and emotional lability are the cardinal features. Inability to recall recent events, difficulty in completing a line of thought thus becoming 'tongue-tied' in the middle of a sentence and a strong inclination to use wrong words, saying 'door' when they mean 'table' or 'hot' when they mean to say 'cold' are all common deviations from normal cerebral function. Complete inability to comprehend a paragraph even after a second reading is very noticeable.

These may be accompanied by bouts of uncontrollable weeping which proves acutely embarrassing to those of a stoical temperament who regard such an event as demeaning to their philosophy of life. Alterations of sleep rhythm and/or vivid dreams are common and these occur in patients with no previous experience of such phenomena. In a very tragic case in a young University student complete reversal of sleep rhythm led to suicide.

Frequency of micturition and hyperacusis are an almost invariable accompaniment of these cerebral features and together with episodic sweating and orthostatic tachycardia can only be attributed to involvement of the autonomic nervous system. Though less frequently encountered episodic sweating is a very striking event. The wife of one such case is a trained nurse and reports that her husband may wake around 4 a.m. lying in a pool of water and with a temperature of 94 to 95°F. I diagnosed this patient as a case of M.E. fifteen years ago; the sweating episodes still persist.

Variability and fluctuation of both symptoms and physical findings in the course of a day is a constant feature in the clinical picture of M.E.

The Chronicity of Myalgic Encephalomyelitis

The alarming tendency of M.E. sufferers to become chronic is the final distinguishing feature from all other forms of postviral fatigue syndrome. In a group of 150 members of the Association in the North of England 36 have had the disease for 10 years or more. Of 55 members in a small group in Surrey 29 have had the disease for 10 years or more; of these 4 have had the disease for over 20 years, 4 have had it for over 30 years and one for over 40 years. One member in the north country group has also had it for over 40 years. I am fully satisfied that at a conservative estimate 25% of victims of M.E. have had the disease for 10 years or more.

Only Myalgic Encephalomyelitis has such a legacy."

Source: <https://www.hfme.org/wramsay.htm>

News From the Open Medicine Foundation

Mestinon Clinical Trial for ME / CFS.

This trial is being conducted at the Brigham & Women's Hospital by **Dr. David System** in association with the Harvard ME / CFS Collaboration at the Harvard Affiliated Hospitals. **Dr. System** has found that some people with ME / CFS and suffering from fatigue, have what is known as Preload Failure.

In this instance, Preload Failure is thought to come from an imbalance in the autonomic nervous system and results in reduced filling of the heart during exertion. The clinical trial will test the exercise response to Mestinon in people with ME / CFS, with Preload Failure.

Prior studies have shown improvement in patients in the general population with Preload Failure after treatment with Mestinon. **Dr. System** intends to evaluate the short-term effects of Mestinon on the autonomic nervous system and neurovascular control in people with ME / CFS, who also have Preload Failure.

Studying these features will deepen our understanding of ME / CFS, and this trial may lead to new and specific therapeutic options for people with ME / CFS."

This is just the first phase of this research. Much work remains to deliver treatments for ME / CFS and other chronic complex diseases. OMF strives to overcome the disparity in funding in our field of research, harnessing the passion of our community and the talent and commitment of researchers across the globe to bridge the funding gap and keep up research momentum towards a cure.

Source: <https://bit.ly/3cOMOr7>



Kynurenine Clinical Trial for ME / CFS

Kynurenine is naturally produced in the body, is a key metabolite in the tryptophan metabolism, and serves several roles in the immune system and inflammation.

OMF has provided support to initiate the study in a randomized, double-blind, placebo-controlled, crossover study. The purpose of the study is to evaluate whether kynurenine is directly connected to ME / CFS patient symptom severity.

Project Description

Participants will be randomized to either receive Kynurenine or a placebo for a period of three months and then after a “washout” period, patients will switch to an additional three-months of Kynurenine or placebo in a crossover design.

This design does not require healthy controls and instead focuses on whether Kynurenine supplementation has any benefit above placebo in people with ME / CFS.

The main study endpoints will be the effects of supplemental Kynurenine to improve cognitive impairment (“brain fog”), memory and headache. Patients will also be asked to register their activity by using wearable sensors and have biological samples taken for further testing.

New methods have been developed under **Dr. Bergquist** to measure the metabolic pathways relevant to Kynurenine. These new methods are used to identify people with ME / CFS that have low Kynurenine in the plasma. This method will also be used to monitor the metabolic effects of Kynurenine supplementation during the trial.

Source: <https://bit.ly/2YqO1zI>



Conversion of COVID-19 patients to people with ME/CFS

“We are proud to announce the initiation of a study of patients with COVID-19 to monitor the course of their disease and its sequelae (the medical term for chronic conditions after an illness) to ascertain whether they convert to ME / CFS and if it occurs, to study the molecular transformation.

This will involve the collection of body fluid samples at frequent intervals, continuous health monitoring via wearables, and symptom data recorded at many separate time points over two years. The expected outcome is that some will develop ME / CFS, as many other viruses serve as triggers for the disease.

The COVID-19 pandemic is an unprecedented opportunity to study the biological factors that may determine or predict the development of ME / CFS.

In a significant percentage of patients, severe viral infection preceded their development of ME / CFS. In this current COVID-19 pandemic, it seems likely that COVID-19 may also be a trigger, and that many people will develop ME / CFS.

It is thought that up to 11% of patients who had severe infections from Epstein-Barr virus (EBV), Q fever (*Coxiella burnetii*), or Ross River virus (RRV), and others, develop ME / CFS. Other studies following SARS and MERS suggest an even higher proportion (50%) develop ME / CFS or Fibromyalgia.

After COVID-19 patients recover from the acute phase of their disease, they may be at significant risk for a prolonged period of post-viral fatigue, which may last six months or more before returning to their previous normal state. However, for some patients, their fatigue may fail to resolve or become even more profound over these initial six months and continue indefinitely, converting to ME / CFS.

A detailed genomic, metabolic, and proteomic analysis over time will likely provide tremendous insights to understand how to identify those pathways that can be useful to predict, diagnose, or treat ME / CFS.

The world is intensely focused on COVID-19 at the moment. The likely conversion of thousands of patients to a disease that causes life-long suffering provides a unique opportunity for the world to finally pay appropriate attention to ME / CFS.”

Source: <https://bit.ly/3e4bhKk>

Submitted by Kathleen Morgan & Sara Piccer, OMF



Exciting New Research Initiative In ME/CFS

In collaboration with researchers in Poland, Spain and Oxford we are launching a £1.6 million campaign to support clinical research infrastructure in the three countries and to explore the exciting new research area linking the presence of L-form bacteria and fungi as a key disease driver in ME/CFS. The project will focus on the Diagnosis and management of ME/CFS: understanding the biology and identifying therapeutic targets.

Our industrial collaborator SoftCell Biologicals have already committed \$750,000 to the project to support whole genome sequencing bacteria in the blood of patients and controls.

The project will run over 5 years and allow us to build towards competitive funding applications to larger UK funders.

Our priority project is an Oxford based L-form project in ME/CFS, Stroke and Lymphoma this will run over 2 years recruiting 400 patients and controls. To reach our running budget we need to raise £203,000 by December 2020. Details on the project are shown in the PDF link below.

Click here to see the Full Project Plan PDF (Research and Budget):
<https://bit.ly/3fjwVKW>

Click here to see Project Summary PDF: <https://bit.ly/2YyitrT>

To donate please visit our donations page here: <https://bit.ly/2B5kPGy>

Your donation will contribute to important research on the causes of ME/CFS, helping us work towards better diagnosis and management.

With between 20-30 million people affected worldwide and associated family and friends we are very hopeful we can reach our target.

Talk from the 2020 Bristol CMRC meeting including L-form data:
<https://bit.ly/2Y2Lwos>

Karl Morten

<https://bit.ly/3fsOb0C>

Historia Magistra vitae?

What is happening with the CCI-hypothesis in the ME/CFS community closely resembles what happened in Italy (mainly, but not only) with the CCVI-hypothesis of Multiple Sclerosis (MS). There was this new avenue, completely unexpected and very fascinating (to me, at least), that linked MS to a defect in the venous system of the neck, named Chronic cerebrospinal venous insufficiency (CCVI) by the Italian researcher **Paolo Zambon** (<https://bit.ly/2B5m8Fs>) [1 <https://bit.ly/2B5Dq5t>].

Several MS patients underwent surgery to correct one or more veins of the neck and described themselves as cured of MS thanks to this surgery. Among them also a prominent patient advocate, **Pavarotti's** wife, who gave enormous publicity to this kind of technique [2 <https://bit.ly/2XZfQeG>].

The diagnosis of CCVI was somehow subjective, and only CCVI-literate doctors could do it properly. The same applied for the surgery. Several surgeons in private practice started doing the surgery on MS patients, earning a lot of money in a very short period of time.

Does this seem familiar?

After a decade and several well-designed studies, no correlation between CCVI and MS has been demonstrated [3 <https://bit.ly/3hweqVq>], [4 <https://bit.ly/2N2lPha>].

I am not saying that there is no correlation between CCI and ME/CFS. We don't know yet. I personally find interesting these new hypotheses about the effect of abnormal mechanical strains on the functioning of the brainstem and the possible link to ME/CFS-like symptoms and I am trying to study this new field (see this blog-post <https://bit.ly/3d1nT3J>), among all the other hypotheses about the aetiology of ME/CFS.

What I would like to point out with this post is that it is perfectly possible that several patients improve with this kind of surgery even in the absence of any link between CCI and ME/CFS. This is a weird (and fascinating) phenomenon that we have already seen in other diseases. It always has the same pattern: a somehow subjective diagnosis that only a few physicians can do, a surgery or a drug that many physicians are warning against, a huge amount of patients who say that they have recovered after the intervention.

Source: **Paolo Maccallini**

<https://bit.ly/3hxBhAi>

Mitochondria and ME

In April 2020, the ME International website posted a guest blog by John Duncan entitled "Mitochondria and ME" that discusses recent research into mitochondria and myalgic encephalomyelitis.

From the blog: "Perhaps one of the most characteristic signs of Myalgic Encephalomyelitis (ME) is the intolerance to any type of exertion whether it is of a passive type brought on by surroundings (hearing a voice, seeing lights), or an effortful type (lifting a cup, holding a conversation). Given this bizarre sign, it is only natural that for many of us and many doctors, the mitochondrion has been a perennial suspect."

The blog highlights the need for good selection criteria in practice. "The problem of selecting a single disease picture and not many, can be solved by using a rigorous criteria of selection such as the International Consensus Criteria (ICC)."

The blog cites several studies that directly implicate the mitochondria abnormalities in ME. From the blog: "One of the exciting aspects of mitochondrial research is, given the pervasive impact of mitochondrial health on the cell, a deeper understanding of many earlier abnormal discoveries and observations may be gained through understanding the abnormalities of mitochondria in ME."

To read the entire blog go to <https://bit.ly/30HmFIo>



David Steckel,
VP ME International

The Effect of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) Severity on Cellular Bioenergetic Function

Cara Tomas, Joanna L. Elson, Victoria Strassheim, Julia L. Newton, Mark Walker

Abstract

Myalgic encephalomyelitis/ Chronic fatigue syndrome (ME/CFS) has been associated with abnormalities in mitochondrial function.

In this study we have analysed previous bioenergetics data in peripheral blood mononuclear cells (PBMCs) using new techniques in order to further elucidate differences between ME/CFS and healthy control cohorts.

We stratified our ME/CFS cohort into two individual cohorts representing moderately and severely affected patients in order to determine if disease severity is associated with bioenergetic function in PBMCs. Both ME/CFS cohorts showed reduced mitochondrial function when compared to a healthy control cohort.

This shows that **disease severity does not correlate with mitochondrial function** and even those with a moderate form of the disease show evidence of mitochondrial dysfunction.

Equations devised by another research group have enabled us to calculate ATP-linked respiration rates and glycolytic parameters. Parameters of glycolytic function were calculated by taking into account respiratory acidification.

This revealed **severely affected ME/CFS patients to have higher rates of respiratory acidification** and showed the importance of accounting for respiratory acidification when calculating parameters of glycolytic function. Analysis of previously published glycolysis data, after taking into account respiratory acidification, showed severely affected patients have reduced glycolysis compared to moderately affected patients and healthy controls.

Rates of ATP-linked respiration were also calculated and shown to be lower in both ME/CFS cohorts.

This study shows that **severely affected patients have mitochondrial and glycolytic impairments**, which sets them apart from moderately affected patients who only have mitochondrial impairment. This may explain why these patients present with a more severe phenotype.

Full text (open access): Plos One <https://bit.ly/3e7Yx5C>

Solving the ME/CFS Criteria and Name Conundrum: The Aftermath of IOM

Leonard A. Jason and **Madeline Johnson**

In 2015, the Institute of Medicine (IOM) recommended the adoption of the term systemic exertion intolerance disease (SEID) and clinical criteria that required specific symptoms such as post-exertional malaise and unrefreshing sleep.

On the name of the disease

Historically, the term ME was coined following a 1955 outbreak of cases in the Royal Free hospital, London, whereas CFS was established following a 1984 outbreak in Incline Village, Nevada. Patients have been dissatisfied with the term CFS because focusing on just one symptom of the illness tends to downplay its overall debilitating nature. On the other hand, some scientists are uncomfortable with labeling the illness ME, as they feel, for example, there is a lack of evidence indicating inflammation of the brain area.

The IOM committee members recommended the new term SEID because they felt “exertion intolerance” succinctly describes how mental, physical or emotional exertion significantly decreases functioning in many areas of life for patients with ME/CFS. SEID was recommended to replace ME/CFS, and for these authors, ME/CFS included ME, CFS and ME/CFS.

Several patient polls that were completed after the IOM name change recommendations found overall negative attitudes toward SEID. A number of patient and advocacy organizations have asserted that ME and ME/CFS are not the same, and therefore reject the adoption of SEID that combines them. For example, the patient organization MEadvocacy indicated that ME is a highly distinct neuroimmune disease not included in the vague SEID criteria.

On the Clinical Case Definition

In a sample of 796 patients, **Jason, Sunnquist, Brown**, and others found that the SEID criteria identified a group larger in size to those identified by the CCC and ME-ICC criteria. This is primarily due to the IOM criteria, in contrast to the Fukuda et al. criteria, the CCC, and ME-ICC, establishing few exclusionary conditions. The IOM’s SEID Report Guide for Clinicians states: “The presence of other illnesses should not preclude patients from receiving a diagnosis of ME/CFS (SEID) except in the unlikely event that all symptoms can be accounted for by these other illnesses”.

Due to the inclusion of formerly excluded illnesses, the IOM criteria increased prevalence rates by 2.8 times, as 47% of those with Melancholic Depression met the IOM criteria, and 48% with a clear medical illness (e.g., multiple sclerosis) that caused their fatigue also met the IOM criteria. Amongst 22 clinicians and researchers who worked with patients with ME the two highest endorsed case definitions that were considered appropriate for clinical use were CCC (82%) and the IOM criteria (64%), and the two highest rated case definitions for research use were also the CCC (73%) and the IOM criteria (59%).

Advantages and disadvantages

The new IOM clinical criteria has its merits, particularly focusing on core symptoms and with easy to use cut off ratings. Research criteria and clinical criteria do not need to be the same. But there are significant problems when using expanded clinical criteria for research purposes. Rates of ME/CFS have been found to differ dramatically, from .34% to 2.52%, and much of this was due to differences in case definitions. Changes in case definitions are also a major reason why the CDC estimates of ME/CFS prevalence rates increased 10-fold in their studies published between 2003 and 2007.

Using the IOM clinical criteria, many individuals with a range of other fatiguing disorders will be included in their case definition. But other CFS and ME/CFS criteria were correct in excluding those with a psychiatric condition like a major depressive disorder, and it is clear they are not similar illnesses as self-reproach occurs with major depressive disorder but not with ME/CFS. But here is the consequence of not excluding psychiatric disorders, if some patients in a treatment trial with those selected by the IOM criteria really have another illness, particularly one that responds well to exercise, this can lead to the inappropriate conclusions that exercise is an effective intervention for those diagnosed with the IOM case definition.

Roadmap for Change

In this publication Jason & Johnson lay down a most needed roadmap for change, consisting of 6 conditions/steps.

- ✚ a prominent role for all stakeholders (i.e., patients, scientists, clinicians, and government officials).
- ✚ an administrative body could initially appoint committee members
- ✚ committee members to commission working papers on issues that need resolution, particularly regarding core symptoms of ME/CFS and their measurement
- ✚ working groups to develop recommendations regarding how to define systematic exclusions due to a variety of other conditions including depression and anxiety; over-exertion; medications; poor sleep hygiene, weight, and diet; deconditioning; and inactivity.
- ✚ once working papers are finalized, a conference could bring the different working groups together for adoption of a research case definition and name.
- ✚ other activities of this group could include exploring and validating this new diagnostic system with existing data sets, and comparing the findings with other case definitions

The authors give an example of what might occur:

- ✚ the name ME to be reserved for those patients who meet the research criteria, and it would identify a smaller more homogenous group of patients with more functional impairment (using either the CCC, the ME-ICC, the IOM with more exclusions, or a new set of empiric criteria).
- ✚ the name ME/CFS (or a different name) to apply to those who meet the IOM clinical criteria.
- ✚ the name CF (chronic fatigue) to define those with six or more months of fatigue that do not meet the criteria for the above groups.

Conclusion

In the aftermath of IOM, the criteria and name conundrum can be solved, but it will take a concerted commitment to a process and collaboration from government officials, patient organizations, and the scientific community.

Source:

<https://www.tandfonline.com/doi/full/10.1080/21641846.2020.1757809>

Extracted from the full text, generously provided by **Prof. Leonard Jason**



Rebekah Maksoud , Stanley du Preez, Natalie Eaton-Fitch, Kiran Thapaliya, Leighton Barnden, H  l  ne Cabanas, Donald Staines, Sonya Marshall-Gradisnik

This systematic review is the first to collect and appraise the literature related to the structural and functional neurological changes in ME/CFS patients as measured by neuroimaging techniques and to investigate how these changes may influence onset, symptom presentation and severity of the illness.

A total of 55 studies were included in this review. All papers assessed neurological or cognitive differences in adult ME/CFS patients compared with healthy controls using neuroimaging techniques. The outcomes from the articles include changes in gray and white matter volumes, cerebral blood flow, brain structure, sleep, EEG activity, functional connectivity and cognitive function. Secondary measures including symptom severity were also reported in most studies.

The results suggest widespread disruption of the autonomic nervous system network including morphological changes, white matter abnormalities and aberrations in functional connectivity. However, these findings are not consistent across studies and the origins of these anomalies remain unknown. Future studies are required confirm the potential neurological contribution to the pathology of ME/CFS.

Full text: Plos One, Open access <https://bit.ly/37CY6hm> and like that FB-page!

Advancing in Inflammatory Research With ME

<https://bit.ly/36p0InL>

Recorded especially for ME Research UK (MERUK) and its supporters around ME Awareness Day, **Prof Jarred Younger** of the University of Alabama at Birmingham, USA discusses this project funded by ME Research UK.

The Name of the Disease

Of the name ME or myalgic encephalomyelitis, the last word basically means brain inflammation. The problem is we never had a good way to show it. One of the things my lab does is to try to create techniques to do that.

Body & Brain

Our immune systems are different in the brain and in the body. In our body we have T-cells and B-cells and T-helper cells – lots of different cells doing very specific jobs. In our brain it's a different story. We have cells called microglia that do most of that work. And they're not supposed to cross. They're separated by the bloodbrainbarrier. I think in ME/CFS those peripheral immune cells have broken through the bloodbrainbarrier. They are now in the brain and they don't know what to do in that environment. They don't know what's friend or what's foe. They may become inflamed and produce inflammatory factors because they don't know e.g. what a neuron is.

Making it Visible

How do we show if that's the case. In this project we draw blood from people and we're isolating those peripheral immune cells – T-cells and B-cells and things like that. And then we're tagging them with a radioactive tracer that will last for multiple days. Then we inject those cells back into the person and we give it a few days to let those cells go wherever they're gonna go and then we scan them with the PET-scan. What I'm hypothesizing is that in ME/CFS those cells are going to pop up in the brain. If we see that, that will give us very concrete evidence that there is a serious problem with how the peripheral and central immune systems are working. And that could easily explain the symptoms people with ME have.

Realistic Hope

We've jumped through several hurdles – e.g. how to keep those cells alive, how to effectuate this without risk for the participants. Of course we have a delay right now, but when we get back to normal we'll finish that and start to run participants.

I'm sure we're going to have information on them in 2020 and we'll give updates through MERUK and also through our lab. So I hope this is something that will give us information that will really forward a diagnosis of ME/CFS and will generate new treatment ideas.

Source: <https://bit.ly/36p0InL>

Entire transcript: <https://bit.ly/2MYc57J>

Fighting the COVID-19 Pandemic and Major Diseases at the Same Time

A balancing act for biomedical scientists

Researchers, politicians and funding bodies find themselves in front of a unique situation and enormous challenge: The mounting pressure to accelerate and intensify efforts to tackle the COVID-19 pandemic while handling the growing threat from all other diseases endangering our society.

This balancing act and how well the scientific community will respond to it will define health across the globe for years to come, argue scientists at Helmholtz Zentrum München and Deutsches Krebsforschungszentrum (DKFZ) in the latest issue of the leading journal *Cell*. In their commentary, the researchers discuss how to strike a good balance between maintaining and redefining research priorities.

The COVID-19 crisis has already changed the research community. Some of these changes and adaptations can be used to improve how we deal with other health challenges. International research teams are working together rather than in competition -- across organization, disciplines and borders. Regulatory bodies have accelerated their processing and the sharing of critical data has been faster than ever.

Read the entire article: <https://bit.ly/2MYcHdx>

Source: Science Daily, May 14, 2020 <https://bit.ly/3cALeKI>



Mitochondrial Functions in Infection and Immunity

Highlights

- ✚ Bacteria and viruses have evolved specific ways of targeting mitochondria to perturb mitochondrial function that can prove to be beneficial for these microbes.
- ✚ Many bacteria and viruses use specific virulence mechanisms to modulate mitochondrial dynamics, leading to either mitochondrial fusion or fission.
- ✚ Mitochondrial metabolism can also be impacted by bacterial and viral infections.
- ✚ While in some cases bacteria and viruses induce the mitochondrial cell death pathway, in others cell death is inhibited promoting intracellular bacterial and viral proliferation.
- ✚ Mitochondria regulate different innate immune signaling pathways induced upon bacterial or viral infections.

Mitochondria have a central role in regulating a range of cellular activities and host responses upon bacterial infection.

Multiple pathogens affect mitochondria dynamics and functions to influence their intracellular survival or evade host immunity. On the other side, major host responses elicited against infections are directly dependent on mitochondrial functions, thus placing mitochondria centrally in maintaining homeostasis upon infection.

In this review, we summarize how different bacteria and viruses impact morphological and functional changes in host mitochondria and how this manipulation can influence microbial pathogenesis as well as the host cell metabolism and immune responses.

Full text: <https://bit.ly/2B4bOxr>

Coming Soon: You + ME Registry

Following several months of development, user testing and partnership with the community, Solve M.E. is fast approaching the launch of the You + M.E. Registry! You + M.E. is driven by a big vision - building a community of thousands contributing health information and biological samples (e.g. blood) to create the largest possible global data set from people living with ME/CFS and controls. We believe it will be transformative in advancing our understanding of ME/CFS. After signing up, participants complete a series of surveys on their computer, including medical history, co-occurring conditions, symptoms, medications, and quality of life. Once this information has been entered, ME/CFS participants will receive a link to download a mobile app to record symptoms, factors, and activity on an ongoing basis. Biological samples will be collected from people with a confirmed case of ME/CFS and healthy controls. The combination of patient-reported data and biological samples can be used by researchers from around the world to help uncover causes and subtypes of ME/CFS, and identify possible treatments. It was important to us to co-create the Registry with people who will be using it. This end, we conducted surveys to identify participant needs among hundreds of people, held 1:1 in-depth interview, and integrated people with ME/CFS, caregivers, clinicians, and researchers into our app development and beta testing. We've received several inquiries and thoughts regarding approaches to track both the impact of COVID-19 on people with ME/CFS and the development of ME/CFS-like symptoms following COVID-19 exposure. We believe the You + M.E. Registry is well-suited to be leveraged in this effort. Here's what we're planning:

- ✚ We've integrated a COVID-19 questionnaire in the You + M.E. survey dashboard so that we can track the impact of COVID-19 on the health of people with pre-existing ME/CFS
- ✚ We've initiated partnerships with established COVID-19 registries and apps to include questions that ask participants whether they have developed post-viral ME/CFS-like symptoms. If they answer yes, they will be referred to You + M.E. so they can provide more comprehensive information.

You + M.E. will initially be open to participants 18 + years living in the United States. Expansion to international and pediatric groups is a priority; Solve M.E. is working with our partners at the UK ME Biobank and Emerge Australia to open global enrollment in the coming months. If you live in Australia, sign up for the Australian ME/CFS Biobank & Registry mailing list from our partners at Emerge Australia: <http://eepurl.com/gzzB4n>

If you live in the United Kingdom, visit this page on the UK ME Biobank website to get updates from our partners at Cure ME: <https://bit.ly/2Y0hYru> For residents of the United States who are age 13-17, or residents of other countries, use this form to sign-up for updates: <https://solvecfs.org/you-m-e-registry/>

We hope the end result of You + M.E. will bring impactful change for the ME/CFS community!

Submitted by **Emily Taylor**

Robert Phair's Metabolic Trap

Out of the blue **Dr. Robert Phair** offered all his services and skills and knowledge to the Open Medicine Foundation. We get to know him and his theory of the metabolic trap somewhat better in this video:

<https://youtu.be/d9oVHDh8rjk>

At the start **Dr. Ron Davis** introduces him with the words that he is far ahead of his time. When **Ron** comes with an idea, **Robert** says: "I'll make a model of it". In other words: I'll let you know if it's right or wrong.

Robert himself came with the idea of the metabolic trap. Now **Ron Davis** and his team have to prove that that theory is wrong. That's science. Of course **Ron** hopes he won't succeed.

Robert Phair's entire family consists of engineers but he wanted to combine it with his other great field of interest: biology.

In this presentation he touches upon three subjects:

- ✚ What is the IDO-metabolic trap
- ✚ New results of IDO2 genmutations in the SGTC-ME patients
- ✚ How can patients get out of the metabolic trap.

Here you'll find his explanation in more detail

<https://mecentraal.wordpress.com/2020/04/26/robert-phairs-metabolic-trap>

Enterovirus Season – a Warning

The month of June marks the beginning of the Enterovirus season in the Northern Hemisphere, continuing until October/November, with the usual peak in August. In the Southern Hemisphere, the season is roughly the opposite.

Enteroviruses (EVs) are part of the Picornavirus order, and include ECHO, Coxsackie, and Polioviruses. They can cause illnesses from the mild (Hand, Foot and Mouth Disease) to the very severe (Polio, Encephalitis, Acute Flaccid Paralysis, and, according to many experts, M.E..).

Numbers appear to be comparatively low for the severe and paralytic illnesses, but the public should nonetheless be aware of them. Also, accurate recording of these numbers is limited by several variables. Here are just a few issues affecting reporting of Acute Flaccid Paralysis (AFP). We may recognize a few patterns familiar to the M.E. community.

- ✚ Differing disease names : WHO names it AFP, but U.S. and others use Acute Flaccid Myelitis (AFM).
- ✚ Use of a less-frightening term (Myelitis vs Paralysis) means less public and medical awareness.
- ✚ Low press coverage, low urgency, low public outcry. (More attention was paid to AFP/AFM once the phrase "polio-like" started appearing in headlines.)
- ✚ Thorough testing is not readily available at onset in most countries.
- ✚ WHO only requires reporting in the under-14 age group, leaving teenage and adult cases unreported (and quite probably undiagnosed because Doctors expect to only see it in children).

All of the above leads to confusion in epidemiology, research, and patient care.

We should take particular notice of the possibility of AFP cases in 2020, because spikes in numbers have occurred in 2012, 14, 16, and 18. In any case, we should be aware that this is the season for EVs in general.

Whether or not every reader agrees upon EVs being the cause of M.E., we should all keep an eye on these things for friends and family. We know only too well the experience of not having proper testing or diagnosis at the beginning of our illnesses.

EVs are transmitted mainly through secretions (saliva, sputum, mucous) and travel the oral-fecal route ("entero" means "intestine"). The best prevention is washing hands thoroughly. Let us hope that, with the current awareness of hand-washing, there will be fewer cases in 2020.

Allison Haynes May

9. Severe ME



'Just' a Picture

Today is #MECFSAwarenessDay and I have honestly been struggling with what to write or say.



I have decided to share this photo I took of my brother, **Whitney**, a few months ago.

He was unaware I had whipped out my phone to snap a photo, but this moment was so moving I knew I would want to share it some day.

This is **Whitney** experiencing rain on his skin for the first time in almost a decade. He looked up into the sky with a small smile on his face, closed his eyes, and held out his hands to feel the rain coming down onto his skin.

It was hard to hold back my tears knowing this was the first time my brother had felt rain drops in almost 10 years. While walking him to the ambulance it all came down on me; the weight of this disease, the profound loss that patients and families experience, the anger that they are being discarded like trash from society, and the arrogant doctors telling us time and time again that he is perfectly healthy.

Look At Him.

This man is not healthy, he is fighting for his life and I will continue to fight beside him for as long as it takes. I will fight for all patients so that they know they are not alone and they will never be forgotten in the darkness. I am here, my family is here, and we are ready for the fight. [#MillionsMissing](#)

Ashley Haugen, May 12, 2020

How Are You Going to Help ME?



I am in tremendous pain

I cannot think

I cannot call out to get help

Light hurts me

Everything is out of reach

I cannot move any part of me

Communicating my needs is beyond me

I cannot tolerate touch

I cannot prepare, make or fetch food Or drink

I cannot get to the toilet

Every noise and movement is painful and assaulting

I have severe headpain and body pain

How are you going to help me?

Stonebird
THE EXPERIENCE OF SEVERE ME
- Since 2006 -

Answer:

- ✚sensitively, slowly, carefully, tenderly.
- ✚ With great awareness of your hypersensitivities, by not worsening light exposure.
- ✚ By being extremely quiet, calm, peaceful, gentle; by patiently working together with you in partnership.
- ✚ By avoiding any sudden movement or gesture;
- ✚ By waiting for the right moment to try to meet your need safely.

Greg Crowhurst

For much more information on caring in complex illness, please see:

<https://stonebird.co.uk/Notes>

Dialogues For a Neglected Illness



<https://25megroup.org/about-us>

I was particularly excited to learn about this new video series about ME which includes videos about Severe ME being made by the producers and directors of the brilliant 2011 documentary *Voices from the Shadows* which looked at five people with Severe ME to illustrate the neglect and disbelief faced by people with Severe ME. I found that film so powerful that, despite having very little money, I bought several DVD copies to give to my new GP, my Social Worker, and to show to my new carer. It had a powerful effect on them. You can find out more about *Voices from the Shadows* here <https://voicesfromtheshadowsfilm.co.uk> (Please note that this film is not suitable for children and young people who may find it too disturbing to watch)

These videos are not just useful for those who suffer from Severe and Very Severe ME, but for everyone who has ME, their families, their friends, their health and care professionals. Those with ME know that over-exertion leads to temporary (and sometimes permanent) deterioration. Some people become severely affected by ME very quickly, others (like myself) deteriorate over time. Maybe the people you share these videos with will be more understanding about how vital it is that you don't overdo things, that you need to prevent worsening your symptoms. By watching these videos you can perhaps arm yourself with more knowledge, understanding, and advocate for better treatment for people with Severe ME. With such a wide range of symptoms and experience of people with ME, these short videos can't cover every single issue that people with Severe ME suffer and they don't discuss those, like me, who didn't have sudden onset Severe ME, but I think they've done a really good job of producing videos which give powerful insights into the lives of sufferers and how doctors and carers can help.

You might recognise some of the names of those featured in this video:

- ✚ The first video includes contributions from **Dr William Weir, Caroline Kingdon, Dr Nigel Speight, Dr Charles Shepherd**
- ✚ The second video includes contributions from **Dr Nigel Speight, Dr Nina Muirhead, Dr William Weir, Caroline Kingdon** - Research Fellow and Nurse, **Prof Todd Davenport**
- ✚ **Tom Kindlon** and his mother **Vera Kindlon, Rob, Naomi Whittingham, Robert (Bob) Courtney, Anne Oertegren, Sophia Mirza. John Peters, Graham McPhee** also discuss the patient's perspective.

Detailed Description of the Video's – particularly useful for those who find it difficult to watch informative videos.

Severe & Very Severe ME/CFS shows how sudden onset ME devastates lives and how approximately 25% of those affected by ME are housebound and need extensive support - how even minimal exertion such as reading a book can lead to worsening of symptoms.

We learn that some of the most severely affected patients can be in total body pain, paralysed or almost paralysed, tube fed, catheterised - how those caring for people severely affected have feared that their loved ones might die from the illness. As many people reading this review may already know, the prognosis for younger patients is better than for adults, some make full recovery. Sadly, the prognosis for adults with Severe ME is not great. At the very severe end of spectrum some have sadly died, and there is an upsetting number of suicides, due in part to lack of medical and care support. Because many who suffer from Severe ME are totally bedbound or housebound, they are excluded from medical care because they can't get to clinics so they need doctors to keep in touch - by phone or video consultations, home visits and doctors need to make sure that patients receive the benefits they need and appropriate nursing care. Sadly, doctors often face difficulties when trying to get help from specialists in local hospitals who are unwilling to help or to make home visits. [My own GP (in the UK we register with a local medical doctor known as a General Practitioner) is supportive of me having phone consultations, email requests and, when needed, home visits.]

I am one of the lucky few regarding phone consultations and home visits by my GP who even made a special home visit to me the day before his practice went into its Covid-19 practice changes. He told me that all patients would initially have phone consultations (they were also investigating the use of video calls) and if the doctors decided they needed to see the patient in person, the doctor would visit the patient at the patient's own home. I wonder if his supportive attitude is because of the powerful influence he felt from viewing the Voices from the Shadows DVD I gave him. Many of us are hoping that the phone, Skype and other initiatives implemented by medical professionals during the Covid-19 pandemic will lead to a more flexible and supportive attitude to our needs in the future.

I hope that many people who suffer from Severe ME will be able to show this relatively short video to their health and care professionals and also to their own family and friends to let them see what Severe ME can be like. I, personally, did not become severely affected straight away. I was constantly advised to "push through", to "try harder". That was before we all had internet and smart phones or tablets. Perhaps if we'd had easy access to videos like this back then, people like me could have learned what happens when you push someone who has ME. Perhaps I would never have become Severe. So I think this is a powerful video for everyone with ME. When people trivialise your condition and say you're just a bit tired, you can show them this video and explain that you are staying within your energy capability in order to avoid making yourself more ill, possibly permanently more ill.

Symptoms and Management of Very Severe ME/CFS discusses more about symptoms and possible treatment/management to help easy patient suffering. Symptoms such as total body pain, severe continuous headache, cognition and concentration problems, sensitivity to touch, being turned in bed, toileting, sensitivity to sound are all problems which are discussed. Patients and their family tell in their own words about the symptoms. The benefits of pacing are discussed, as doing too much brings back the symptoms and pain to those who have fortunately improved a little.

Anything sensory: light sensitivity, smell sensitivity, touch sensitivity, reading, thinking, can all exacerbate symptoms and pain. Patients exposed to light, smells or touch can take some weeks to recover from the extra pain caused by these events. Those who enter a patient's bedroom need to be very quiet, maintain a quiet voice level and keep the lighting low. Reading, thinking, breathing and bed mobility can all exacerbate symptoms. A safe, low sensory environment is essential for some of the most severely affected.

Although there may be no curative treatment, doctors can help. Pain is often resistant to conventional painkillers, but Amitriptyline, Carbamazepine, anticonvulsants like Gabapentin and Pregabalin may be useful. Sometimes opiates are the only effective painkillers. Sleep dysfunction is discussed. **Dr Speight** advises that patients in general should not try to fight the sleep experience, that sleep hygiene measures can actually be harmful. Those who feel the need to sleep, say 12 hours a day, should be allowed to, and those who can't sleep can sometimes be helped with drugs like Melatonin or anti-histamines.

Abdominal pain, sometimes due to secondary food intolerances and nausea need to be managed. We hear about how one man was badly treated when he sought help - how he was not given the help he desperately needed, but was instead sectioned (being admitted to hospital and being detained, whether or not you agree to it, under the UK Mental Health Act 1983) and told if he lost weight again he would be sectioned again and we learn how he ultimately took his own life.

More recently, doctors and patients are becoming aware of a quite frightening condition - Mast Cell Activation Syndrome - which is a severe intolerance due to histamine release. This condition is not a cardinal part of ME, but it may be an added complication for some people with Severe ME, and it has been linked to recent fatalities. It is useful for those who do suffer from this to know that it is responsive to oral Sodium Cromoglycate, anti-histamines - H1 and H2 blockers (not proton pump inhibitors).

Inability to move due to extreme weakness. Darkened rooms. How some can't move their own head, need to be toileted, can't speak, can't open their eyes. Some lose the power of speech and breathing can be painful. We are told that these severely affected patients, with a more severe phenotype, have a glycolic impairment in addition to the mitochondrial impairment. The effort of eating and drinking and toileting can be too exhausting for some of the most severely affected and **Dr Speight** advises that gastro nasal tube feeding and a urinary catheter (to avoid using energy to use the commode) at an early stage to reduce the amount of energy expended. Those who can't move in bed need help from those who care for them by turning them in bed to avoid bedsores.

Doctors sometimes misdiagnose those with severe ME/CFS and wrongly diagnose them as having a psychiatric illness - "Functional Neurological Syndrome" which can lead to inappropriate/harmful treatments such as CBT, GET, reablement. Myoclonic jerks (shock-like jerks of muscles or groups of muscles) are discussed.

Children with ME are sometimes misdiagnosed with PRS (Pervasive Refusal Syndrome). **Dr Speight** has been involved in 20 cases over the last 5 years where parents of children with ME have been incorrectly accused of FII (Fabricated or Induced Illness). Such misdiagnoses can lead to harmful treatment regimes.

Regular supportive contact with a doctor or consultant is essential. Sufferers of Severe ME still get other illnesses which need treatment and they need their medical practice and consultants to arrange home visits. The importance of listening, rather than enforcing the doctor's opinion on how quickly the patient can do things, was advised, to gain patients' and families' trust.

The video ends with three typed lists:

- ✚ symptoms occurring commonly in Very Severe NR/CFS
- ✚ advice on Practical Management which sums up the information provided in the video and also refers to Orthostatic Intolerance
- ✚ Principles of Care

Review by **Jan Johnson**

for The 25% ME Group

June 2020

<https://25megroup.org/about-us>

10. ME And Children



Myalgic Encephalomyelitis (ME) in the Young. Time to Repent

As a good covering editorial to **Kathy Rowe**'s article on paediatric ME in Acta Paediatrica "Paediatric patients with myalgic encephalomyelitis /chronic fatigue syndrome value understanding and help to move on with their lives" (<https://bit.ly/2C7M5Vp4>)

Dr.Ola Didrik Saugstad wrote a letter of which some crucial parts below:

"Myalgic encephalomyelitis (ME)/ Chronic fatigue syndrome (CFS) is a complex disease with symptoms from multiple organ systems. The severity of these symptoms ranges from mild to severe with the most severely affected confined to a dark room to achieve sensory deprivation. Two incidence peaks have been described between age 10-19 years and 30-39 years, respectively. Typically women are more often affected than men in a 3:1 ratio. In spite of such severe symptoms, ME is poorly understood and for years has been a controversial condition.

Already in the 1990s, it was demonstrated that ME affects the central and autonomic nervous system. In recent years, metabolic and immunological changes have been detected. One of the most exciting findings come from very new studies indicating that low-grade neuroinflammation triggers many of the symptoms of this illness such as pain, cognitive problems and sleeping disorders.

A condition called postexertional malaise (PEM) is a hallmark of ME and should be included in all diagnostic workup of this illness. Patients experiencing PEM will often describe a «crash», relapse» or «collapse» after mental or physical exertion that was previously tolerated. It can take hours, days, a week or even longer to return to the previous baseline after a crash. One reason for the controversy regarding this disease is that investigators are applying different inclusion criteria. Definitions before 2003 when the so-called Canadian criteria were published did not include PEM. It is also important to know that modified diagnostic criteria should be applied to the paediatric ME patient group.

Today, there is agreement that inclusion criteria without PEM are not satisfactory. The wide variation in understanding and in prevalence reported maybe caused by different inclusion criteria. For instance, the so-called Oxford criteria, which do not include PEM, would involve a large percentage of pure psychiatric conditions and should not be applied. Many patients are in fact misdiagnosed by applying inadequate criteria, such as the Oxford criteria. Especially for paediatric patients, this may have severe implications. As pointed out recently by **Geragthy** and **Adeniji**, false positive diagnosis may lead to inappropriate labelling and improper intervention and treatment of this vulnerable patient group.

Cognitive changes as so-called brain fog, concentration and memory problems are typical in children and adolescents with ME, with severe consequences for well-being, development, school performance and future employment. The study in this issue of Acta Paediatrica by **Katherine Rowe** regarding management of ME patients aged 6-18 years is therefore timely and of importance.

The patients from Victoria, Australia were diagnosed with ME/CFS between 1991 and 2009.

The study has some weaknesses. Due to the long observation period, inclusion criteria of ME changed. The first enrolled patients were diagnosed according to the so-called Holmes criteria from 1988—a purely research diagnosis that did not include PEM. Further, the study does not include the most severe ME patients who are housebound.

Based on evidence from **Rowe's** study and the biomedical data summarised above, there is an imminent need to avoid patients being misdiagnosed or further stigmatised by falsely equating the disease with chronic or unexplained fatigue, psychosomatic classifications, functional disorders, medically unexplained symptoms or neurasthenia.

It is, therefore, concerning that the child welfare in several countries, including my own, starts custody cases, threatening to remove young ME patients from their families into emergency placement in youth centres or foster homes. These child protection cases are based on the not updated view that ME is a functional disorder that can be addressed by ignoring physical symptoms and increasing scholarly, physical and social activity. Parents are accused of life-threatening neglect by letting their children rest in isolation.

This attitude, however, ignores the international consensus definition of ME/CFS as a serious somatic disorder in which overexertion may have long-lasting or even permanent detrimental effects. To my knowledge, removing such patients from their parents has never been proven to be effective therapeutically. To the contrary, such non-evidence based practice has been shown to contribute much harm and should not be accepted.

A reorientation of the understanding and attitude to ME patients occurs worldwide. ME patients, especially the worse cases, suffer enormously. Among them, the paediatric patients are most vulnerable, representing a special challenge due to the occurrence in the midst of somatic growth and emotional development. We are waiting for a biomarker of this disease, and some are in the pipeline. And even more, we are hoping for an effective treatment. Still, it is already now time for the medical profession as well as the whole society to repent, as these patients have previously often not been treated with the respect and care they need and deserve.

Dr.Ola Didrik Saugstad

Source: Wiley Online Library <https://bit.ly/3htL1v1>

Link submitted **by Dr. Nigel Speight**

Edited by ME Global Chronicle

“Child Abuse by Professionals”

As a reaction on the letter of **Dr. Didrick Saugstad** to the editors of Acta Paediatrica (see the article just before this one) **Dr. Nigel Speight** wrote a letter in support, which was published in Acta Paediatrica on Jan 22, 2020.

Dear Editor

I strongly support **Professor Saugstad**'s plea in your journal for an apology from the western medical profession over our failings with respect to meeting the needs of the community of ME patient (<https://bit.ly/3e54nVw>). I would further endorse his comments about the way in which some innocent families of young people with ME have been subjected to persecution in the form of threats to remove children. These can truly be called examples of “Child Abuse by Professionals”.

As a paediatrician in the UK, acting as an adviser to several ME charities, I have had the unhappy experience of witnessing many of these failings in the population of paediatric ME sufferers. In many of these cases the problem arises from the failure of the paediatrician to make the diagnosis of ME. This is often compounded by inappropriate referral to psychiatric services. If a young person is deprived of the protection of an official diagnosis of ME, the machinery can often be set in motion as a result of the school's inability to tolerate poor school attendance. Multidisciplinary case conferences are arranged and the meeting decides that the young person is “At risk” and the child is put on a register for either “Emotional Abuse” or “Neglect”. Both these terms are naturally grossly stigmatising and upsetting for the families.

Of even greater concern is when the paediatrician actually drives the proceedings. This is usually because he or she has been influenced by a new growth industry in UK paediatrics, which has resulted in a marked lowering of the threshold for considering a diagnosis of Munchausen Syndrome by Proxy (MSBP). As initially described, all paediatricians knew that MSBP was extremely rare. However, when the name was changed about 20 years ago (2) to Fabricated and Induced Illness (FII), there appears to have been a form of “mission creep”, whereby the diagnosis is considered in any mildly puzzling case, especially when the parents keep (understandably) asking for second opinions.

New terms have exacerbated these tendencies, such as “Medically Unexplained Symptoms” and “Perplexing Presentations”.

Over the last 30 years I have been involved with over 50 families subjected to proceedings, and nationally the figure must be well over 100. Fortunately, despite the distress caused and the massive amount of scarce resources wasted, no families have actually been broken up. However, some have been bullied into allowing their child to be admitted to hospital for damaging regimes of active physiotherapy.

I have the distinct impression that the problem is becoming more common. I have been involved in over 20 ME families accused of FII within the last 5 years.

I have attempted to bring this problem to the attention of our profession in this country, so far without success.

I am accordingly grateful to you for the opportunity to raise these issues in your journal

- ✚ Myalgic Encephalomyelitis in the Young. Time to repent, Acta Paediatrica, Oct 2019 <https://bit.ly/2ArtAuN>
- ✚ Fabricated and Induced Illness by Carers, Report of a Working Party of the Royal college of Paediatricians and Child Health, Feb 2002 <https://bit.ly/30Ivfqu>

Dr Nigel Speight

Paediatrician
Durham
United Kingdom

The author has no conflicts of interest to declare

Submitted by **Dr. Nigel Speight**

11. News from



Australia



Launch Website NAAC Australia

The Australian National Advisory Advocacy Council for ME/CFS Research (NAAC) officially launched its website on the 12th May, International Awareness Day for ME/CFS.



NAAC has been established in response to a recognised need for an independent collaborative platform to give consumers a voice in ME/CFS research and to help researchers to deliver high quality ME/CFS research of value to consumers and the public.

NAAC also supports and promotes best practice in effective consumer and community engagement in research and builds capability and capacity of consumers and researchers to engage in ME/CFS research. NAAC gives impartial advice on research questions on the basis of evidence, both nationally and internationally.

The image of **Merryn Crofts** on NAAC's website is a stark reminder of the seriousness of ME/CFS, used with kind permission of **Clare Norton, Merryn's** mother. **Merryn** died in 2017 shortly after her 21st birthday and was only the second person in the UK to have myalgic encephalomyelitis listed on a death certificate.

Early diagnosis of ME/CFS and access to the best possible therapeutic treatments and management strategies are identified as valued goals for people living with ME/CFS. These consumer priorities are at the centre of NAAC's direction and activities.

Further understanding of the pathophysiology of ME/CFS; timely development of a diagnostic test; and identification of evidence based pharmacological treatments and management strategies; will improve the outcomes for young people living with ME/CFS who, at present, mostly grow into older people living with ME/CFS with years and quality lost to those lives.

Source: **Kathy Dallest**, NAAC Chair.

Senior Health Informatician, Queensland Facility for Advanced Bioinformatics, Queensland Cyber Infrastructure Foundation, The University of Queensland

More details: <http://www.naac-mecfs.org>

Belgium



In Belgium we celebrated the international ME/CFS awareness day with an online campaign. The Belgian patient organization 12ME made a film in which patients explain (in Dutch) what ME/CFS means to them and how it has impacted their lives. This could be a useful tool to educate doctors, politicians, and the general public about ME/CFS.



ME/CFS patient **Robin De Man** and his son **Sepe** made a song and video together that has been viewed over 5000 times on YouTube (available here: <https://bit.ly/3dTFX0S>). The song is a cover of Chasing Cars by Snow Patrol with the lyrics adjusted to reflect living with ME/CFS. It commemorates the millions who have disappeared from public life

and were forced to live an isolated life between four walls because of ME/CFS. The video shows pictures of patients with severe ME/CFS taken from their beds and their homes, including those who have now sadly passed away.

In the city of Diest, 12 May did not go unnoticed as fountains on the main square turned blue to raise awareness of ME/CFS.



Belgian patients have also raised funds for ME/CFS and this year 5000 euro was donated to the Open Medicine Foundation (OMF). Hopefully our country will be able to donate an even larger amount next year.



Meanwhile we're waiting for the report on ME/CFS by the Belgian Superior Health Council, which seems to be delayed due to the COVID-19 outbreak.

Michiel Tack



Emails to Prime Minister re Covid and ME/FM

The National ME/FM Action Network has now sent three emails to the Prime Minister, with copies to the Minister of Health and the Minister for Disability Inclusion, concerning Covid-19.

The first email (May 20, included in Quest 123) points out three immediate issues for the ME/FM community – access to health services, income security and food security.

The second email (June 5) asks the government to spread the message to Covid patients, health care providers and the public that recovery from Covid can be slow and could possibly lead to long-term ME/FM.

The third email (June 10) is based on the government's June 5th announcement that the government is giving financial support to people who have qualified for the disability tax credit. We thank the government for recognizing the financial needs of persons with disabilities, but point out that the DTC provides a seriously incomplete list of people with disabilities.

You can read the government announcement here:

<https://bit.ly/3foPI7E>

We always appreciate your feedback. Let us know if there are other issues we should be looking at.

Stay safe.

National ME/FM Action Network

Margaret Parlor

President

Source: <https://bit.ly/2YEZsE5>



Calling On Our Leaders to #ChangeTheFuture4ME (<https://bit.ly/3hCT3SK>)

Please Read **Jason's** Story for #MEAwareness (<https://bit.ly/2Bij0Gb>)

Through proper medical and social support, **Jason** has made a partial recovery because he had proper medical and social support. However, **Jason** acknowledges he's more fortunate than most Canadians with ME, who usually have access to neither and are often dismissed by their doctors due to their lack of training in ME.

Here is part of **Jason's** story:



"The photo on the left was taken during an Olympic distance triathlon in the summer of 2011. I was about to enter my fourth year of engineering, excited for the path that lay ahead of me. 2 months later, I suffered an injury that changed the course of my life.

Jump ahead five years (right), I had lost over 50 pounds, was almost completely bedridden and was too weak to sit up, talk, or feed myself.

I was diagnosed with fibromyalgia and myalgic encephalomyelitis or chronic fatigue syndrome, two illnesses that we still know very little about.

I am one of the lucky ones that had the proper medical and social support so that I could make a partial recovery. Even with those supports, it has not been an easy path. The majority of patients are not as fortunate as me. Most patients don't have access to doctors knowledgeable about these illnesses.

Even worse, many doctors will downplay or dismiss the symptoms of their patients altogether. Patients are told that they need to lose weight or that they're depressed. These stigmas only add to the heavy burden patients must carry.

These illnesses may be invisible but the symptoms are very real. My illnesses developed following a sports injury; some people catch a virus, develop a bacterial infection, or experience trauma. Sometimes they develop seemingly for no reason at all. They can happen to anyone at any time."

The time for leadership, greater understanding, research and change is now!

Patty Hajdu (<https://bit.ly/2Y4Dyv0>)

Bill Morneau (<https://bit.ly/2AEROS4>)

Justin Trudeau (<https://bit.ly/3hxlwJx>)

Christine Elliott (<https://bit.ly/30PeB8y>)

Canadian Medical Association (<https://bit.ly/3fsAXkj>)

Ontario Medical Association (<https://bit.ly/2UROmue>)

Jason Herterich

Source: <https://bit.ly/3huZJ58>

Czechia

We are currently preparing an open letter to the representatives of the Czech healthcare system, which should be published within one month.



The letter will be supported by foreign experts dealing with ME/CFS.

We have decided to take this step because we have no other choice after many years of efforts without any progress. So please keep your fingers crossed.

Of course, the coronavirus may still change our plans.

me-cfs@seznam.cz





Stig Gerdes

Throughout the years with the indispensable help of Danish ME patient **Bente Stenfalk** and British **Valerie Eliot Smith** in former issues of the ME Global Chronicle we followed **Karina Hansens** case.

Those who read those articles are certainly familiar with the name **Stig Gerdes**, a physician who tried his utmost to help **Karina** all through. His authority as a doctor was temporarily denied him. Recently in an interview with the newspaper *Federica Avisen* he announced to abandon the case and to opt for another pathway:

Former physician **Stig Gerdes** explains why he has now chosen to abandon his lawsuit to get his authorization back.

In doing so, he also waives a replacement. He estimates the case has now cost him 6-7 million DK (about a million USA \$), but in this interview he tells he refuses to give up. Instead, he will write a book explaining the whole matter to the public. The High Court recently ruled that he should not be allowed to try most of the medical questions he has at the Judicial Council, and therefore believes that he will have lost in advance.

The former doctor has since 2017 fought first against the health authorities and later on the court to accept that he did nothing wrong. A decisive factor in the outcome of the trial in the Court of Kolding was that the Judicial Council had made a statement in the case. **Gerdes** did not believe that the Judicial Council had the correct composition, as psychiatrists had assessed the case of the well-known patient, **Karina Hansen**.

That is why **Stig Gerdes** wanted to answer a number of specific questions by the Judicial Council during the appeal to the *Vestre Landsret*, but this was rejected by the national court except one. Against this background, **Gerdes** has now assessed that the legal battle has been lost. He also misses the opportunity for compensation, but is not bitter. Instead, he will now write a book on the whole matter: "I haven't given up. It annoys me that people believe so. But to continue with legal spin-offs and spend even more effort on it, when it doesn't work anyway, I won't. Now people can even assess the matter when I get my book written".

Stig Gerdes has spent almost DK 700,000, - on legal fees, and in addition to this he has lost his practice and source of earnings. Overall, he considers that the case cannot be won because it is based on medical issues, and since his questions are not allowed to be brought before the Judicial Council, he considers it a sign that he will not win in the national court either.

Source: <https://fredericiaavisen.dk/stig-gerdes-jeg-har-ikke-givet-op/>



- ✚ **Duodecim** (<https://www.duodecim.fi/english>) got an assignment from the Finnish Parliament 2018 to form "good practise" specifications for ME/CFS. An advisory board/working group was formed, that consists of professionals and 2 patient representatives. The working group started its work in the autumn of 2019 and has met several times already. The working group members have agreed with strict confidentiality and can't talk about their meetings, so there is little to no info how it is proceeding. The report should be published at the end of 2020 or at the beginning of 2021. Disability forum published an open letter 2.3.2020 (<https://bit.ly/2XXWv2q>) "Functional disorder -terminology displaces ME/CFS and EDS patients in society". The Finnish Social and Health Ministry defines ME/CFS as a "functional disorder" despite the definitions of for example WHO, CDC and other Nordic Countries.
- ✚ Helsinki University Hospital continues to treat ME/CFS as a functional disorder at their functional disorder clinic (<https://bit.ly/3cUEYMM>). YLE published an article (<https://bit.ly/2B3wRAm>) of criticism the clinic has gotten from recommending treatments that haven't been scientifically proven. These treatments include commercial products such as DNRS (<https://bit.ly/3foy9Vc>) and "get rid of the symptoms" ("get rid of the symptoms") -course created by a Finnish blogger and architect **Maria Nordin**.
- ✚ Head of the Helsinki University Hospital Functional Disorder Clinic, **dr Helena Liira** published an article (<https://bit.ly/2XYDoFi>) 26.2.2020 "Managing functional disorders: opportunities and threats", which states for instance:

"The Research Clinic for Functional Disorders and Psychosomatics in Aarhus, Denmark is a GP led clinic that pursues a research agenda in this field. It has applied the terms 'functional disorders', 'health anxiety' and 'bodily distress syndrome', which is also a new ICD-11 code. A lot of criticism from patient organizations has been focused on the term 'functional disorders' and all psychological treatments for them. The criticism stems from some patient representatives still believing these disorders to have a solely biological origin. Chronic fatigue syndrome (CFS) and its causes are particularly debated.
- ✚ However, an increasing amount of research evidence exists to support the term 'functional' instead of medically unexplained. These disorders most likely have a multifactorial origin, including genetic, predisposing and triggering factors. Stress is prevalent, and even toxic stress experienced in childhood is linked to these conditions. The central mechanism in functional disorders appears to be a sensitization of the central nervous system, which can cause a multitude of symptoms from the overactive autonomous nervous system. Recent imaging studies that used functional MRI, support this theory.

- ✚ A worrying phenomenon is that researchers working on functional disorders, especially CFS, face harsh online abuse and harassment. Like many leading scientists, **Michael Sharpe**, an Oxford based psychologist, quit the CFS research last year saying that the field had become 'too toxic'. Guidelines editors and health policy makers have experienced similar campaigning from the CFS community."
- ✚ In June 2019 (<https://bit.ly/3htdzVK>) a ME/CFS-network was formed within the Finnish Parliament
- ✚ Chairman of the ME/CFS Parliament network and PM, **Sari Tanus** published a wonderful piece (<https://bit.ly/30GPXXu>) on international ME-awareness day (May 12,2020) describing the harsh reality Finnish ME-patients are in (in Finnish).

Submitted by **Millions Missing Finland**



Nothern Ireland



News from Hope 4 ME & Fibro Northern Ireland

The charity is replacing monthly meetings in Newry by providing specialist speakers online by Zoom, until Covid - 19 social distancing rules are lifted.

Our Zoom meeting in July will be dedicated to the needs of children with ME, presented by the charity's Paediatric Medical Adviser **Dr Nigel Speight**, with support from our Paediatric Social Worker **Tony Crouch**.

Date and Time: Tue, 7 July 2020 19:30 – 21:30 CEST

Location: Online Event

Admission: £5.98 Tickets <https://bit.ly/3fnssac>

Refund Policy: Contact the organiser to request a refund. Eventbrite's fee is nonrefundable.

Program

6.30pm - 7.00pm - The zoom meeting room will be opened to allow attendees time to set up

7.00pm - 7.45pm - **Dr Nigel Speight's** and **Tony Crouch's** presentations

7.45pm - 8.00pm - Q&A

There will an opportunity for attendees to ask questions to **Dr Nigel Speight** and **Tony Crouch** directly or via the Zoom chat facility

We would ask attendees to mute their speakers and keep movement to a minimum during the meeting to help avoid too much sensory overload.

8.00pm - 8.30pm - After the main presentation, attendees are welcome to remain for a general group chat, facilitated by HOPE committee members

We welcome all and we look forward to meeting you!



L'intervista

di Mario Luzzatto Fegiz

«**S**apessi com'è strano / Darsi appuntamento a Milano / In un grande magazzino / In piazza o in galleria / Che pazzia che pazzia».
Parole dell'intramontabile canzone «Innamorati a Milano» scritta da Memo Remigi con Alberto Testa e poi proposta anche da Ornella Vanoni. «Versi diventati attualissimi di fronte alla tragedia che siamo vivendo», spiega Memo Remigi, che il 27 maggio compirà 82 anni e che conosce una seconda giovinezza artistica grazie alle sue ospitate a «Propaganda Live» (Laz).
«La Milano che io ho cantato ora non esiste. Stento a riconoscere una delle più belle metropoli d'Europa immersa in un clima di guerra con la gente che fa la fila per far incetta inutile di cibo inutile. All'inizio forse l'abbiamo presa alla leggera. Poi le carovane di carri mortuari... Nascondiamo la nostra paura dietro una mascherina. Il mio pensiero corre a quelli che sono finiti in riammissione senza poter salutare i propri cari. Che poi si sono visti recapitare una fattura da tremila euro per spese di cremazione avvenuta chissà dove e chissà quando».
Come è cambiata la sua vita in questi due mesi?
«Stavo facendo un tour proprio nella casa di riposo per anziani. Ho visto persone ben curate e assistite con tenerezza. Quando vado in questi posti — l'ultima esibizione in una Rsa di Clusone — canto con loro le canzoni che loro conoscono. In genere il concerto diventa un coro. Gente della mia generazione meno fortunata di me. Ho dovuto interrompere questo tour per ovvi motivi. Il programma di venerdì in Propaganda Live mi ha messo a confronto con tanti giovani che prima non mi conoscevano. Mi sono messo in gioco».
Come spiega la sua longevità artistica?
«Ho fatto gli incontri giusti».

Nel Comasco

Esplode villetta
Muore l'enne



Tragedia. La villetta distrutta (Cesati)

Un ragazzo di 21 anni è morto nell'esplosione di una villetta a schiera a Fino Mornasco (Como). Il giovane, Alessandro Fino, aveva un piccolo laboratorio chimico in cantina, dove pare vi fossero anche sostanze potenzialmente esplosive. Dopo i primi scoppi si è sviluppato un incendio, poi l'esplosione



Sorridi Memo Remigi in una delle residenze per anziani dove si esibisce: l'ultima prima dell'emergenza Covid-19 è stata quella di Clusone

Memo Remigi, il ritorno «Vado in tour nelle Rsa, gli anziani fanno il coro»

L'artista alla vigilia degli 82 anni: ora mi diverto in tv

Con Alberto Testa che è stato il mio Mogol e soprattutto con Fedele Giovanni D'Anzi. Ogni mattina prendevo il treno da Como. Poi a piedi da Cadorna. Via Dante fino a Gal-

ria del Corso. Bussavo all'ufficio di D'Anzi e lui mi metteva al pianoforte e mi ordinava in dialetto milanese "Fam senti sa ta suna stà matina". Poi mi fermava e diceva "questo va

bene, questo no. No, quel che ta ha fatto prima».

Che Milano era?

«Si girava in auto in corso Vittorio Emanuele, si faceva crocchion in piazza Pattari e

poi tutti a mangiare alla Grotta Piemontese. Dietro i grandi portoni, grandi cortili su cui si affacciavano case di ringhiera e dappertutto gerani e basilicani».

Le sue giornate oggi?

«Ho un cane bassotto a pelo ruvido chiamato Bacio che bacia tutti e morde solo me. Ma lo fa con tenerezza. Gli ho dedicato una canzone intitolata "Un essere speciale"».

Un ricordo di quegli anni?

«Avevo un cocker towatello e gli dedicai un brano chiamato "Mon ami", il mio amico in francese. Ero in auge grazie all'aiuto di Pippo Baudo che mi ospitava a "Settevoci". Accettai una serata in Veneto. Attaccai "Mon ami" e la gente che ignorava il francese si in-

Chi è

LA CARRIERA



Memo Remigi (vero nome Emidio), è cantante, paroliere e volto televisivo. Nato a Erba (Como) nel 1938, viene scoperto da Giovanni D'Anzi e inizia a esibirsi nei primi Anni 60. Il suo più grande successo è «Innamorati a Milano», scritta da Alberto Testa (sopra, Remigi nel '63)

furiò. Mona a chi? Mona te sarà ti e i tui parenti».

Ha avuto una vita sentimentale molto intensa. Barbara d'Urso parla sempre bene di lei...

«Lei arrivava da Napoli. Abbiamo convissuto bene assieme per quattro anni. Lei voleva fare la modella e io le insegnavo come destreggiarsi nel mondo dello spettacolo e della moda. Lei aveva vent'anni e io 39. Le evitai di perdere tem-

Ricordi

«La Milano che cantavo non esiste più. Io sopravvivo felice con mia moglie Lucia»

po con i mariponi. Però Barbara è molto cambiata da allora».

E adesso?

«Sopravvivo felice con mia moglie Lucia Russo. Ce la spassiamo. Viviamo insieme. Ci amiamo nonostante le mie numerose scioglite d'alto».

Cosa ha imparato dalla vita?

«Mi viene una battuta politicamente scorretta: il cane ti dà tutto e non ti chiede niente, mentre la donna non ti dà niente e prende tutto».

Cinco? Deditissimo?

«Sapessi come è strano scortarsi contaminato a Milano...».

Nel Foggiano

Bomba sotto
l'auto della coop



Ordigno il fumo dopo l'esplosione

Un ordigno è stato fatto esplodere l'altro ieri notte a Carapelle (Foggia) sotto la Ford di una imprenditrice agricola di 48 anni, moglie di Matteo Sgarro, titolare della cooperativa Natura Duonia, che ha già subito un attentato incendiario il 29 aprile scorso. Ignori avevano dato fuoco a 4.000 cassoni in plastica per la

12 MAGGIO
Giornata Mondiale della Sindrome da Fatica Cronica

Si stimano
+500.000
PERSONE IN ITALIA AFFETTE DA
ENCEFALOMIELE MIALGICA

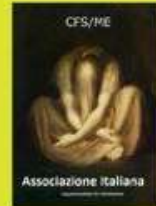
Dona una goccia di energia a chi è cronicamente in riserva!
5xMILLE - codice fiscale: 91046240247

L'Encefalomielite Mialgica o Sindrome da Affaticamento Cronico (ME/CFS) è una sindrome multisistemica complessa che altera la vita dei pazienti. I sintomi più comuni sono malessere post-sforzo, compromissione cognitiva, intolleranza ortostatica e dolore. Il 25% di questi sono costretti a vivere a letto e nei casi più gravi devono essere nutriti tramite sondino. In Italia sono più di 500 mila i casi e oltre 20 milioni nel mondo. Ad oggi la ricerca è sottofinanziata.



12 MAGGIO GIORNATA MONDIALE MALATI DI CFS/ME

Insieme per una maggiore
consapevolezza





International Release of “Hope to Our Hands: The Hidden Story of ME/CFS in Japan”

Mieko Shinohara (President, Japan ME Association)

The nonprofit association Japan ME Association will soon release on VIMEO an English-subtitled version of the Japanese documentary film “Hope to Our Hands: The Hidden Story of ME/CFS in Japan.”

Originally created to raise awareness among medical professionals and policymakers and screened across Japan since its completion in 2018, the new English-subtitled version brings the film to an international audience for the first time.

The trailer (with an English translation) may be viewed here:

<https://bit.ly/2YkKov9>

The situation of Japanese ME/CFS patients has been unknown outside Japan. Most Japanese patients lack the English skills to access online information from abroad. Amidst this isolation, the Japanese government and medical profession have continued to neglect the disease as a “fatigue” illness with psychogenic factors for the last 30 years.

It is also the story of a patient advocacy association created in 2010 by a patient who fell ill while living in the United States and their efforts to raise awareness and bring about much-needed change.

Receiving recommendations from the Japan Medical Association president and the former Japanese Society for Neurology president and the strong support of patients and doctors alike, it is our hope that in sharing the documentary, Japan can begin to join the international ME/CFS community to advocate for patients’ lives.

Further info at: www.mecfsjapan.com

New Zealand



The Covid 19 Lockdown has been a unique and challenging time for everyone. We can say we did well eliminating the virus from NZ at this stage. (though we have just had 2 cases come through our border). We have been making history as school children and others will learn about the great pandemic of 2020. In the International Science Community there are apparently millions of dollars being put into Covid 19 research and the pay back is that ME/CFS research is getting a boost as well. For ME/CFS day we were a bit limited because of the Covid Crisis as to what could be done. ANZMES sent to the support groups, put onto the ANZMES webpage and Facebook and sent in our magazine a lobbying letter so that people could send this to their MP, Minister of health etc. ANZMES also sent out a media release that was picked up by several newspapers and was also talked about on Radio New Zealand.

We usually send resource packs to support groups but because of the Lockdown this is only happening now. **Wendy Matthews** had made several posters for ME day with the Theme of Hidden Disability and we sent these out by Facebook to be shared and put these on our webpage. They went far and wide and we got a lot of positive feedback from them. ANZMES has a writing competition on our topic ME/CFS the Hidden disability. We have had some great stories, essays and poems sent into the office. I congratulate **Suzanne** from Otago for being the winner and **Anne-Marie** and **Kaye** for being runner ups. Our committee has decided if the Covid cases in NZ are still negligible and we are in level one that we will have the AGM in Dunedin in early November. We are hoping to celebrate ANZMES 40th anniversary at this meeting. One of our medical **Drs, Ken Jolly** has been working on the history of ANZMES.

ANZMES is releasing a short survey to help with our lobbying of parliament with up to date information. This information will also help with funding accountabilities. ANZMES has sponsored **Professor Tate's** research Team to help keep this research continuing in New Zealand. Thanks to **Dr Ros Vallings** who has written an information sheet on Covid19 that was sent out to support groups and put on our ANZMES Facebook page and Webpage. It has been decided not to hold the lecture tour next year of an overseas specialist that was planned. With the Pandemic and uncertainties about travel and closed borders it has been decided to now wait. Both **Richie Barnett** (our face of ME/CFS in New Zealand) and **Dr Ros Vallings**, one of our medical advisers have been interviewed by a TVNZ 1 documentary team. They arrived and filmed on the day before Lockdown. This documentary should be shown on TV around September. **Michael Ferrari** who is a Member of the New Zealand Order of Merit and well known for mentoring business's and not for profit organisations has agreed to help ANZMES committee to update the constitution. These will hopefully be finished in the next few months and we will have a special meeting to pass them. Keep safe and warm over winter and remember be kind to yourselves.

Heather Wilson, ANZMES New Zealand

Norway



Norwegian newspaper Dagbladet's biased reporting on CFS/ME Guest blog written by **Jørn Tore Haugen**, M.Sc. in Engineering Through a series of articles in Dagbladet, the newspaper has raised themes associated with CFS/ME. In the articles, it is not difficult to register which side the Journalists have taken. It is poor journalism when one fails to illuminate the matter soberly from both sides.

I won't go any further on this, but it's a central argument when the Journalists repeat several times in their articles, for example in the interview with **Professor Saugstad** it says:

"However, both individual patient stories, incl. the once Dagbladet has written about, and randomized studies, have shown that cognitive behavioral therapy and graded exercise have a good effect on ME."

This is an argument without substance in reality, nor can it be linked to any relevant scientific publications. Nevertheless, Wyller and the other supporters of the biopsychosocial dogma continue to repeat this argument in attempts to maintain their point of view, while at the same time disputing the overwhelming biomedical findings of recent years.

Statement of facts:

The Norwegian Directorate of Health writes the following in the National Guidelines for CFS/ME:

"Prolonged aggravation of fatigue after physical or mental exertion is considered a cardinal symptom. In English the term "Post Exertional Malaise" and the abbreviation PEM are used."

In 2015/16, the US Health Authorities and affiliated Agencies published several reports on CFS/ME. However, it was the report published by the National Academy of Medicine (NAM, formerly the Institute of Medicine) that was the most important one, and in which an expert group determined, after undergoing more than 9,000 scientific studies, that: "ME is a serious, chronic, complex, multi-systemic disease.... "

The report describes PEM as an absolute prerequisite for diagnosis and is thus in line with the Norwegian Directorate of Health in that issue.

As a consequence, the CFS/ME center at Aker Hospital (part of Oslo university hospital) uses the Canada criteria.

With a search in PubMed.gov on different terms for CFS/ME from 2015 (post NAM/IOM report) up to today, one gets a total of 1499 publications. Of these, only 35 contain the keywords "Graded Exercise Therapy" and/or "Cognitive Behavioral Therapy" and/or Lightning Process which claim positive effects associated with CBT/GET/LP and the like.

In reviewing these 35 studies, one sees that most of them are open-label trials (open studies, which means that both patient and therapist know which treatment is being performed), and with the exception of two, they rely solely on subjective self-reporting as the primary endpoint. Open studies with such endpoints have a significant risk of bias, and therefore have very limited value.

But most importantly; in all of these 35 studies, they used diagnostic criteria which didn't require the patient to have PEM, or PEM was not a mandatory symptom.

Based on the Norwegian Directorate of Health and NAM/IOM's premise of PEM as the cardinal symptom of CFS/ME and e.g. the routines at the CFS/ME center at Aker Hospital, does not leave any relevant studies supporting CBT, GET, LP or similar biopsychosocial interventions to be effective in monitoring and treating CFS/ME patients.

One question survey?

Dagbladet is hereby suggested to do a small survey, and ask all the interview subjects who support the biopsychosocial dogma in the article series, the following question:

✚ Which studies show a positive effect of GET, CBT, LP or the like where the patients recruited for the study are all diagnosed according to the Canadian criteria (or ICC or SEID) and thus suffer from PEM, such as the Norwegian Directorate of Health and NAM/IOM requires?

By raising this simple question, the proponents of the biopsychosocial dogma will at best be quiet. Most likely the answer will be that diagnostic criteria don't matter and a reference to a study by Brurberg et al from 2014 will be made. The problem with this reference is that it doesn't say that criteria don't matter. In the conclusion the authors states:

"Classification of patients according to severity and symptom patterns, aiming to predict prognosis or effectiveness of therapy, seems useful. ... Consistency in research can be achieved by applying diagnostic criteria that have been subjected to systematic evaluation".

The result of this small test will demonstrate the lack of substance of the biopsychosocial dogma, given CFS/ME patients with PEM, diagnosed according to the Canada criteria. The above question also demonstrates that the only way to be able to have scientific references to support the biopsychosocial dogma is to claim that diagnostic criteria doesn't matter. However, only the supporters of this dogma support this point of view.

Not all research is good research!

Although it's claimed in the Dagbladet-articles that the studies are both randomized and follow the gold standard, they don't. The claim that the studies are on CFS/ME patients is also wrong. The broad inclusion criteria used in recruiting the study participants cause a heterogeneous group of people, which makes it impossible to know what they in fact are suffering from.

Among the other 1499 studies published since 2015, there are a number of promising findings related to neurology, immunology and energy metabolism.

Dagbladet's entire article series is based on the technique which in science is called cherry picking. This means to only pick the arguments that support a preferred hypothesis and fail to check the other science to test whether one's own opinion make sense. For that reason, Dagbladet has a great potential for improvement and should consider their methods.

The claims in this text are based on my own separate analyses of what is available at PubMed, in addition to reading through the 35 studies mentioned. Similar analyses should be very easy to do for Dagbladet as well.

Finally, I have no illusion that Dagbladet will respond to this letter, write other more balanced articles, or examine what significant biomedical findings have been made in recent years. Still, they should pay some attention e.g. to comparable findings made by four research groups, independent of each others.

Both the groups of **Ron Davis** (Stanford), **Fluge & Mella** (Haukland/UiB), **Karl Morten** (Oxford) and **Bhupesh Prusty** (Würzburg) have demonstrated the following:

- ✚ cells from CFS/ME-patients and also from healthy controls, behave sick in serum from the patients (reduced energy metabolism)
- ✚ cells from CFS/ME-patients and also from healthy controls behave normally in healthy serum (normal energy metabolism)

Please note that these studies and analyses are performed on patients diagnosed according to the Canada criteria. **Ron Davis** has even published a study (<https://stan.md/2C8pXdy>) that suggests a potential biomarker and test.

Likewise, there are a number of studies that demonstrate measurable nonconformities (lactate, oxygen uptake) in CFS/ME patients (Canadian criteria) compared to all others (other diseases or healthy) by two day- ergospirometry tests. Please find an overview here (<https://bit.ly/2Bd3X0o>).

It is very difficult to see how mental processes cf. Lightning Process's thesis that you "do ME" can have an impact on this.

Simplifying, one can say that **Wyller, Flottorp**, etc. build their line of arguments, and for which Dagbladet makes speeches, on 2.3% (35/1499) of the total research, and neglects everything else.

It all becomes even more absurd when none of these 2.3% studies are done on CFS/ME-patients defined as recommended by the Norwegian Directorate of Health, NAM/IOM, the CFS/ME Center at Aker Hospital, the Norwegian ME-Association and most others who have worked on the disease for a long time.

Other criticism

Please be aware that during the 20 years Wyller has been working on ME/CFS (note: he most often uses self-developed criteria, thus his studies are not comparable with findings of others) since he barely got his doctoral thesis passed (read **Jørgen Jelstads** book: The secluded ones) have not yet succeeded in documenting his favourite hypothesis. Rather, he has disproved the hypothesis through both his Clonidine study and most recently by his music study (please find a review of the music study here <https://bit.ly/30FDIA4>).

What is referred to as ME-activism by the proponents of the biopsychosocial dogma, as an attempt to downplay their opponents, is in fact factual and justified criticism of junk science. Nor are patients the only ones raising this criticism. Among the critics are also high profile and reputable researchers:

- ✚ Criticism of the PACE study by scientists (<https://bit.ly/2UFYg24>).
- ✚ The PACE study is used as an example by **Professor Bruce Levin** (<https://bit.ly/2zwFJOk>) of Columbia on "how not to conduct a randomized clinical trial.
- ✚ Criticism of **Crawley's** LP study on children by 72 world-leading researchers (<https://bit.ly/2N4uQ9v>) with special expertise in CFS/ME and 68 patient organizations.

You may very well continue to argue for the biopsychosocial dogma, but by doing so you won't leave the impression of having an educated point of view or knowledge up to date on the latest scientific findings made in CFS/ME.



The letter was sent to Dagbladet on 30 May 2020 by **Jørn Tore Haugen**. Highlights and headlines are made by the blogowner, **Sissel Sunde**. Source: <https://bit.ly/30HMnwr>



More about this by **David Tuller**

<https://bit.ly/2UJG9bD> and <https://bit.ly/3fnLey1>

The Editors



ME-Patients in Portugal – Part 3

Before running the marathon of Porto on November 3, 2019, Mike Harley interviewed Elle, André and Ana, three Portuguese ME-patients. This is part 3 and the last one.

Do patients receive adequate support? Can they receive disability benefits when they are unable to work?

Elle - I am an expat here, and I'm unfamiliar with how Portuguese citizens are treated, but I would imagine it is difficult. They probably try to get benefits with a fibromyalgia diagnosis, even if ME/CFS is what they have. But the public healthcare system is good and free, if you can be persistent. The hematologist that I saw was in a public hospital, and ran extensive tests on me. It was all covered for free under the public health system, even specialized diagnostics like autoimmune tests sent to Oxford, and MCAS tests sent to a lab in Spain. I should note that as an expat, it's possible I know more about what to ask for, and it's possible that doctors treat me differently. I don't even speak Portuguese, as am unable to learn it with my cognitive difficulties.

André - No. The best you can expect is to find a doctor that believes in CFS or is very comprehensive. Regarding disability benefits, you won't receive any based on CFS. Since CFS has no legal recognition, the only thing you will receive are the Social Security payments and according to the general stipulations for sick leaves.

Ana - Not at all. However, this issue isn't specific to ME/CFS. Ever since the last global financial crisis, it has been very hard for someone who isn't at death's door to obtain disability benefits. And there's often stories on the news of people who are actually dying and being forced to work regardless because they were denied. Another issue is the evaluation itself. The reference table we have for disability evaluation was created for occupational injuries. It is wholly inappropriate to evaluate systemic and/or invisible illnesses. Many patient associations have protested this for years, but nothing was accomplished so far. I'm currently awaiting evaluation, but I'm not feeling very optimistic. Even so, I believe I only have a chance because I am also hard of hearing and progressively losing vision due to another unrelated condition.

What changes would you like to see to the treatments currently proposed in Portugal?

Elle - It would be great if doctors recognized this disease and were trained in understanding the constellation of symptoms, how to treat them, and to differentiate from fibromyalgia.

André - The major change I'd like to see would be for CFS to be recognized as an illness, especially since it is recognised by World Health Organization.

As for treatments, what I'd really like it was that we patients were allowed some level of management of our illness in workplaces, that is, to be allowed to take a break when the body "feels" it needs to stop. That could be the difference between doing relatively ok and triggering a crisis.

Ana - The few doctors I managed to find who were aware of ME/CFS, including the one who diagnosed me, recommended CBT and GET. So whatever little information there is, it's poor. It's clear it is more UK sourced, and logical as this is Europe, but we would all benefit if doctors also got their information from other sources like the CDC, which excludes GET.

What does the future look like for ME/CFS patients in Portugal? Is there reason to be positive?

Elle - At first glance, it might seem a bit hopeless here. But, Portugal actually has both a private and public health care system that is ahead of most countries. They have moved some records and prescriptions online. There are LOTS of doctors in this country, and many universities. The older Portuguese can seem more entrenched in traditional ways of thinking, including some misogynistic attitudes. But the young people of Portugal are well educated and curious. There are many young female doctors, even neurosurgeons. This is huge in making a leap out of paternalistic health care attitudes. There is a strong sense of community and taking care of each other built into the culture. Most young people here speak English well, which means they can learn easily from global research. They travel and feel part of Europe, but have a real sense of pride about their country, and strong belief in their own potential. So, despite the current lack of awareness, this attitude puts them in a good position to learn more as science progresses, and as ideas spread online with patient awareness growing globally.

André - I'd like to end in a positive tone, but I cannot. The future looks bleak: from the lack of treatments and not being recognized as having a disability to simply being misunderstood or outrightly perceived as "lazy", I see no reasons to be optimistic. We don't have the law, the medical community and the Social Security siding with us. Unless you're wealthy or have a supporting family and friends, it's basically living off of scraps.

Ana - It doesn't look like anything, because it isn't possible to imagine a future when there is no present. The illness isn't known or talked about, besides the times when it is confused with chronic fatigue. I can only have hope for the future. I hope the international interest in the disease will eventually awake the interest of some Portuguese health professionals. It would be great if we had even just one specialist focused on correctly diagnosing and managing ME/CFS, who could give the face and expertise for the disease, dispelling the CFS/chronic fatigue confusion

Mike Harley

Part 2 has been published in the March 2020 issue of the ME Global Chronicle <https://bit.ly/2znIn9d>, p.105;

Part 1 in the December 2019 issue <https://bit.ly/2BVQ6MC>, p. 91

Scotland



We're trying something a little different with some of our social media posts.

The intention is to post a regular round-up of activities that are going on 'behind the scenes', in an attempt to keep you better informed about what we're up to in terms of advocacy and campaigning.

The 'email your MSP' campaign which we ran prior to #MillionsMissing (<https://bit.ly/3cXsMe8>) was a great success resulting in two thirds of MSPs (a total of 84 MSPs) being emailed by their constituents.

This was even better than we had hoped for and we were especially pleased to receive a number of offers from individual MSPs to ask parliamentary questions. So far, we have approached MSPs from the Conservatives, Lib Dems, Labour and SNP to take up their offers of support and we're contacting Green MSPs as well.

If you received a response from your MSP(s) but haven't had a chance to submit it yet, please let us know here <https://bit.ly/2N4wRCB>

#MEAction (<https://bit.ly/2Y4W9XT>) Scotland suggested a number of questions, some of which have already been lodged. Asking questions of the government, especially on a cross-party basis like this, will help to maintain pressure on politicians and remind them that #pwME (<https://bit.ly/2Yw9ur4>) aren't going away.

We've been overwhelmed by the positive feedback on the short film <https://youtu.be/e3Pd0o-rwrU> we made for this year's Millions Missing event and we would like to make sure that it continues to have an impact.

A couple of volunteers have been looking at film festivals (there are A LOT of them out there!) as a possible route to reach a wider audience but if you have any other ideas how we might achieve the goals of letting more people see the film and gaining some recognition for its directors, please let us know.

If you would like to help with our parliamentary campaign or to find out more about what we are doing, please email us on Scotland@meaction.net

Source: ME Action Scotland <https://bit.ly/30Mamun>

South Africa



✚ News on **Retha Viviers** - founder of The ME CFS Foundation South Africa - cancer's journey

Retha Viviers was diagnosed with Stage 4 cancer on 5 January 2020. Her prognosis was very poor, however, on 2 June 2020, she, her family and her friends experienced great joy when she was able to ring a bell at the end of a course of chemotherapy treatments. It is tradition when you are treated for cancer to mark progress with ringing a bell.

Retha's cancer markers have come down so low that her prognosis has changed from a devastating chance of early mortality to a happy possibility of recovery... The ME community has pulled together and has carried **Retha** with good wishes, prayers, sharing of posts and monetary contributions to pay for **Retha's** expensive cancer treatment.

If this did not happen the outcome could have been very different. There is a very special, very generous anonymous donor, who suffers from severe ME and who has donated substantial amounts of money offline. There are no adequate words to thank her for her contribution. **Sally Callow, Willa Truter, Bettie Hough, Chantelle Spies** and a few others played a substantial role in raising funds for **Retha**.

✚ Covid-19, lockdown and having ME/CFS in South Africa during this time

The ME CFS Foundation South Africa is running a fundraiser as COVID-19 intensifies poverty amongst poor disabled South Africans. There are no disability benefits for ME patients in South Africa.

The main objectives of the Foundation are:

- ✚ The provision of healthcare services to poor and needy persons with ME/CFS across all races, sexes and socioeconomic classes; and
- ✚ The care or counseling of terminally ill persons or persons with severe physical disability due to ME/CFS

Covid-19 and the lockdown impacted extremely negatively on the already poor disabled South African, especially those who do not receive any disability benefits from the government. PEOPLE ARE IN DANGER OF HAVING NO ACCESS TO FOOD, BASIC NECESSITIES OR EVEN LANDING ON THE STREET.

Being the ONLY organization in South Africa representing the ME/CFS community, the foundation has started a fundraiser to assist those in extreme need during these uncertain times.

✚ May month in South Africa and Africa On 12 May the South African Government posted on their Coronavirus Instagram page that:
It was International Awareness day for Neurological and Immunological Diseases such as ME, CFS, FM, MCS, Gulf War Syndrome, etc

The positives of the post were

- ✚ It was the first time they posted something on 12 May
- ✚ These illnesses are classified under Neurological and Immunological Diseases.

However, unfortunately exercise was on top of the list of lifestyle behaviour. This once again emphasized the importance of advocating for ME/CFS in South Africa/Africa.

✚ The ME CFS Foundation South Africa activities during May 2020

The ME CFS Foundation South Africa participated in #MillionsMissing again this year. It was obviously virtual (due to Covid-19) and alongside with #MEAction. Members participated by telling their stories via a template Char Schoeman made in a previous year.

We were extremely grateful that our dear friend and fellow ME patient, Bettie Hough, was in South Africa during May this year. Bettie shared and is still sharing her own and other resources, her valuable time and wonderful ideas with us. Willa Truter, Chantelle Spies also raised substantial awareness of ME/CFS and other illnesses during May month.

✚ Covid-19 and the risk of developing ME/CFS

As many other organization, we are trying to raise much awareness of Covid19 patients potentially developing ME/CFS.

Submitted by **Retha Viviers**



'Nobody listens to us'

A newspaper report on a manifestation for extremely severe ME-patient **Holger**

Outside Skillingehus in Vaggeryd, Sweden, in the first week of June there were some 45 relatives and friends of **Holger** and others, gathered to make **Holger's** cry for help heard. More were represented, but due to the disease ME only the shoes of the affected were present, exhibited with name tag on.

The preceding appeal read:
For **Holger** and all other ME patients.

We have decided you should pre-register that you will come and demonstrate. We intend to demonstrate one and a half hours here outside Skillingehus and at the same time outside Folkets Hus in Vaggeryd.

Holger has been ill with ME for eight years, but he has become much worse in recent years. The Social Insurance Office and the medical services blame each other. We don't get care of the municipality, there is no help to get. Nobody listens to us. We want help with personal assistance, but "because there are no guarantees that it is permanent" the help has been denied, says **Holgers** dad **Carl-Gustaf Karlsson**.

The manifestation

When the clock is beaten and the demonstration starts, the municipal director **Annika Hedvall** and the municipal council chair **Gert Jonsson** came to meet the cry of the relatives for help.

We have been crying for a long time now without getting help, **Bholgers** brother **Anton** tells the Deputy Director.

As recently as Friday, we got a no from the social service and the assistance manager. Nobody listens to us. There is no medicine or care that can help **Holger**. He needs care and security, said **Holgers** mother.

"You have a responsibility, but you do not listen to us," his sister said.

"We have been offended", **Holger's** father-in-law cries.

Annika Hedvall and **Gert Jonsson** listened and explained that they do not have the knowledge and the assessment to come from the aid managers.

"We need urgent help for **Holger** to continue to live. We need help now. The officials blame the politicians and vice versa". Someone else with a placard shouts "There are more people who have ME who need help, like our daughter".

“We wonder what value the municipality has?”

“It is a place to make a difference”, responds the deputy director.

“Then it's time for you to show it. The municipality should be ashamed of its empty words. We have been crying for a long time and no one is listening. **Holger** needs help. NOW”, answers **Holger's** sister.



Source: <https://bit.ly/3d668jN> (with pictures of the shoes exposed)

With thanks to Millions Missing Sweden



ME Research UK is delighted to announce that we have approved funding to **Prof. Julia Newton** and colleagues at Newcastle University for a new research project which aims to provide a better understanding of how to involve people with severe and very severe ME/CFS in research.

Despite the considerable impact of their illness on these individuals' health and wellbeing, their poor quality of life, and the restrictions on their day-to-day activities, very little research has been done on severe and very severe ME/CFS. This is largely because the health burdens on these people make it very difficult for them to engage with research.

This area has been the subject of a series of studies carried out by **Victoria Strassheim** and **Prof. Julia Newton** over the last few years. The last phase included home visits to five individuals with severe ME/CFS, who underwent a number of assessments and took part in a recorded, semi-structured interview.

The researchers now plan to analyse these recordings in more detail, to identify patterns in the participants' responses. Their hope is that this will provide a better understanding of this population, to enable the research and practice community to engage with them more effectively.

For more information about this study, please visit our website: <https://bit.ly/2UQm4jN>

Submitted by **Dr. David Newton**

The Netherlands



Not much of interest is happening in the Netherlands currently, with the exception of the important course of implementing a bio-medical research agenda and program, of course! More about this can be read in the article on the Dutch Citizens' Initiative of this issue.



What's noteworthy about the ZonMw committee (the so-called Steering Committee), is that its board of members consists half of representatives of patients' interest groups, and half of researchers, of which only two have experience in dealing with ME patients. This is how little bio-medical research has been done so far in the Netherlands... total ignorance surrounding ME reigns supreme among all layers of our health system. Where doesn't it, one could ask oneself...

Nevertheless, these four patients' representatives represent several groups of patients, from ME/ICC patients to those affected by chronic fatigue (syndrome). Hence it might be a good idea to give a brief description of these differences in this article. Important to note is that the input counts equally as hard for all four.

The ME/CFS Foundation (ME/ CVS Stichting) employs the loosest criteria to categorize ME, considering the fact that they estimated the amount of current ME patients in the Netherlands to be around 100,000 in a recent press release. For comparison: the ME/CFS report by the Health Council, published in March 2018, concludes this prevalence to be between 30,000 and 40,000. Apart from the text from the Citizens Initiative that resulted in this course of action, this report is essential to establish a research agenda and program.

As made clear by its name, the ME/CFS Foundation is supported solely by donors who have no way of influencing its policy, which instead is being determined by its board and CEO.

The ME/CFS Association (ME/cvs Vereniging) was founded in 2005 by several patients who found themselves alienated by the narrative and actions of the ME/CFS Foundation. Through meetings and nominations, its members determine internal policy, drafted by the appointed directors.

Upon the International Consensus Criteria for ME being published in 2011, the ME/CFS Association helped with translation and funding towards its publication within the Dutch sphere. Currently, the Association is running a crowdfunding campaign to send as many printed publications of the ICC to GPs as possible as part of raising awareness.

In 2011, the ME/CFS Association got the opportunity to take part in the VWS (Dutch HHS)-funded "Science for Patients" project, in cooperation with the MS Association and the Osteogenesis Imperfecta Association, where 88 short lectures on ME were recorded and published between 2011 and 2014, based on questions from patients <https://www.youtube.com/user/WetenschapvMEcvsVer/videos>

The ME and Unemployment Support Group (Steungroep ME en Arbeidsongeschiktheid) operated dependently under the ME/CFS Foundation before becoming a separate entity in 1994, and later an independent foundation in 1995. They now occupy a crucial position within the Dutch ME landscape as a beacon of information, like for patients who end up facing inspections when applying for unemployment benefits. The decisions of this foundation are also made and carried out by its board and CEO; the donors have no say in this matter either.

The Group ME-The Hague (Groep ME-Den Haag), last but not least has no members or donors. It has been founded in 2011 by ME-patient Mirande de Rijke. She formed a group of mostly severely affected ME sufferers and started a successful petition. 56,000 signatures were handed in to the Parliament on October 29th, 2013. This caused the parliament to ask the Health Council to compile a report documenting the current state of affairs on ME in the Netherlands, and formulate plans to improve the patients' position.

The Group ME-the Hague was also a member of the ad hoc ME/CFS Committee of the Health Council to write the report, and is currently part of ZonMw's Steering/research agenda committee, like the other three organizations mentioned before.

In July 2018, Group ME-The Hague submitted a declaration compiled by 75 international ME researchers and clinicians to the Dutch parliament, as well as the minister of health <https://bit.ly/2Bfq1I7>

The guiding principle of the Dutch citizens' initiative is ME in accordance with the WHO-ICD 10 classification G93.3 and the International Consensus Criteria for ME (2011). The Group also contributed to its translation and publication. Group ME-The Hague especially fights for those who are most debilitated by the condition, who haven't received any care nor acknowledgement, already for decades. For some of them, perhaps even many, this progress may be too late.

That's why the Health Council stated the urgency of researchers and clinicians in the Netherlands to catch-up, which most probably also will be reflected in the decisions the current ZonMw-committee will take.

12. Petitions



#PwME4ICC Demanding US Health Agencies to Recognize Myalgic Encephalomyelitis as Defined by the ICC

Sign this petition: <http://bit.ly/2xjbuF>

More than 7500 fellow sufferers already preceded you and it is of utmost importance for a better (research) future for all pwME!

This is what is being demanded:

We are international medical practitioners and researchers in the field of myalgic encephalomyelitis (ME), ME advocates, patients and their supporters.

We are located in the US and in other countries that are affected by US health policy.

We call on the US government health agencies to accurately name, define, fund and represent the distinct biomedical disease ME which has been recognized by the World Health Organization (WHO) since 1969 as a neurological disease with the ICD code G93.3 and has been well-defined by the 2011 International Consensus Criteria (ICC).

Since October 2015, the US ICD-10-CM classifies ME with the same neurological code, G93.3, as the WHO ICD.

We demand the US Department of Health and Human Services (HHS) and all its agencies:

- ✚ Adopt ICC for diagnostic purposes
- ✚ Adopt ICC for research purposes
- ✚ Use ICC on all HHS and all HHS agency websites and all educational materials created by or for HHS and its agencies
- ✚ Educate medical practitioners to use the IC Primer for diagnosis
- ✚ Disseminate the IC primer to educate medical practitioners on testing and treatment
- ✚ Insist that ME researchers use ICC for their research funded by HHS or HHS agencies

Why?

In an attempt to mystify and marginalize this severely debilitating disease, government health agencies have misrepresented ME as part of an ill-defined chronic fatigue syndrome (CFS) (Reeves', Fukuda, Oxford)

The latest attempt at obfuscation by the US Department of Health and Human Services (HHS) has been sponsoring and adopting the recommendations by the Institute of Medicine (IOM) (now called the National Academy of Medicine) to use the name Systemic Exertion Intolerance Disease (SEID) and the ME/CFS-SEID (IOM) criteria.

The ME/CFS-SEID (IOM) definition does not require any neurological or immune dysfunction symptoms and because of its lack of specificity will include many who do not suffer from ME.



So, once more the link to sign:

<http://bit.ly/2xjbuF>

The European Petition to Recognize and Subsidize ME as a Biomedical Disease

An update

On June 18, 2020 The ME-motion has been approved by the European Parliament with 676 votes in favor, 4 against and 8 abstentions

On Thursday, April 30th 2020 the Committee on Petitions of the European Parliament (PETI) voted on the Motion for a Resolution on additional funding for biomedical research on Myalgic Encephalomyelitis (ME). The motion was unanimously adopted; all 30 votes were in favour of the resolution, there were no abstentions. A very impressive result.

The motion can be found here: <https://bit.ly/2YeqOSG>

A press release about the vote was published on the website of the European Parliament. It reads: "Underfunding of biomedical research into Myalgic Encephalomyelitis is unjustified, say MEPs." (<https://bit.ly/3hDPk7h>)

We are incredibly grateful for the hard work and support of the Committee on Petitions and would like to extend our thanks to all Members! This is major progress for all ME patients.

The next step has been a vote in Plenary. This means that all Members of the European Parliament were able to vote on the Motion for a Resolution.

On June 18, 2020 the motion has been approved by the European Parliament with 676 votes in favor, 4 against and 8 abstentions.

It is thanks to the support of the ME community that the petition that led to the creation of the motion was this successful. A big thank you to everyone who signed and helped to collect signatures!

There is a magnificent total of 15,039 signatures online and on paper!

You can still sign the petition if you haven't done so already. Detailed instructions are provided in the link below. There's more good news: our advocacy group now has an official name: European ME Coalition (EMEC) <https://bit.ly/2YOzKwO> and a brand new website: <https://europeanmecolition.com>

We have also published an open letter to ask the European Parliament's attention for a possible link between the COVID-19 pandemic and a potential future increase in ME-cases. The document can be found here: <https://bit.ly/3ee0RrU>

Submitted by **Evelien van den Brink**

13. Poem – Doctors of Delusion

Doctors of Delusion

With your antiquated theories,
And your disbelieving queries.
The only voice I'm hearing
Is YOUR condescending tone!
So here lies my confusion,
With you doctors of delusion.
The old Masters you aspired to,
Had delusions of their own.

With your psychiatric labels,
You contrive to turn the tables.
Dismissing the real illness,
As a delusion of the mind.
It's a forgone conclusion,
With you doctors of delusion.
Your gross misdiagnosis,
Both unfounded and unkind.

With your blindness to the truth,
When faced with blatant proof.
The science is presented,
Yet you STILL refuse to see.
Ensnared in this collusion,
With you doctors of delusion.
I must live with this injustice,
And the care denied to me.

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14. Connecting You To M.E.



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

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

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

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

