

The ME Global Chronicle

www.let-me.be

37 –September 2020



1. Colofon / Personalia



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Subscribe to this newsletter.

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

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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



Dear reader,

This edition of the ME Global Chronicle will once again touch upon the most important bits of news in the sphere of ME that have happened over the last three months, subdivided by topics of interest.



Over the course of several years, this magazine has served the purpose of bridging the gap between the potentially isolated ME communities across many countries on Earth.

Especially considering ME in practice has been designated a bio-medical condition almost nowhere in the world and well-informed doctors are few and far between, the sharing of information and experiences from patients itself remains the driving force that keeps knowledge about ME afloat.

The patients themselves are also the experts when it comes to the differences and nuances between the numerous different definitions and designations of ME, ranging from chronic fatigue to severe cases of potentially fatal myalgic encephalomyelitis.

Despite many attempts being made at describing the illness on the basis of systemic symptoms, government funding for bio-medical research remains sporadic. As such, research is still dependent on gift funds and research-`islands`.

It's hopeful that such a small country as the Netherlands has developed a bio-medical research agenda to be subsidized by the Ministry of Public Health, the basis for which was formed by a largely successful civil initiative. Otherwise, this development wouldn't have happened in the Netherlands either. This magazine has kept track of this long road ever since, as has British ME patient and blogger Simon McGrath. A link to his useful blog can be found in the article under the header "Dutch Citizens' Initiative".

And, as always, this Chronicle includes more ME-related news from several countries, excerpts from several research publications and other news from the worldwide ME community.

We wish you happy reading once again, and would like to point out that, instead of reading everything one-by-one, you can skip to an article of your choice by clicking it in the Table of Contents.

Contributions to December's release (in Word, font Verdana, size 12), are to be submitted by the end of November via contribute@let-me.be

A beautiful fall to those on the northern hemisphere, and a promising spring to those down south.

The editors

Colleen Steckel
Eddy Keuninckx
Rob Wijbenga

Last issue in this format will be published on December 31, 2020. More info to follow. Please do contribute any article or suggestion at any time via contribute@let-me.be

4. NIH/CDC/HHS



ME-funding of the NIH

I've tried to make a preliminary overview of (extramural) NIH grants for ME/CFS research for the funding year 2020. The info is available in pdf format in the link below, the attached image shows a brief overview of the grants and funding.

Only three new projects were submitted in 2020: **Jason's** follow-up on his cohort of adolescents who experienced mononucleosis, **Shungu's** study of N-acetylcysteine as a treatment for ME/CFS, and a third one of only 35.000 dollars to help organize the recent IACFS/ME conference.

Total funding thus far is less than 12 million, with 60% going to the collaborative research centers. The funding for the NIH intramural research into ME/CFS still needs to be added to this amount but last year **Avindra Nath's** study only received 0.75 million.

So at the moment, it looks like NIH funding for ME/CFS research will be close to 13 million dollars rather than the 16 million the NIH projected.

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

Michiel Tack Me-cfs
(<https://bit.ly/3j7f8ZG>)

5. Dutch Citizen Initiative



The Dutch Citizens Initiative and its Aftermath

Right from the start of the ME Global Chronicle in January 2014 we have been publishing about the Dutch citizens initiative to recognize ME as a biomedical research and its consequences.

Due to it right now a biomedical research agenda is being developed with substantial input of patients representatives.

Finally these amazing and unique developments are drawing international attention, British ME-patient, blogger and former moderator of Phoenix Rising, Simon McGrath writing an excellent blog about it.

It can be read here: <https://bit.ly/3i09vvf>

McGrath writes:

“To make this a success, ZonMw (<https://bit.ly/33XpAN3>) wants to engage the Dutch research community. It will consult the community about the research agenda at workshops in the autumn. In November, it will discuss the draft agenda with a wide range of Dutch researchers at a programme day where international speakers will present relevant research and patient representatives will play an active role. ZonMw’s (<https://bit.ly/33XpAN3>) aim is to highlight the opportunities to make progress in ME/CFS research and the funding available.”

On September 15, 2020 the first workshop did take place at the Erasmus University in Rotterdam which apart from attracting interested researchers also functioned as a test-case for upcoming workshops of which at least three more will be organized.

On November 19, 2020 the program day mentioned has been scheduled, which due to COVID-19 will be an online event. Based on the experiences during the workshops and the program day the steering committee of ZonMw will finalize the text of the biomedical research-agenda in December, after which it will be sent to the minister of health for approval.

If (s)he does (which is most probable), during the first half of 2021 a research program committee will be formed which will compose the text of a research program to be subsidized for 20-29,5 million Euro over 10 years.

After that, applications for grants can be submitted. In the program committee patients will have a say as well.

Submitted by **Rob Wijbenga**

COVID-19-PATIENT
(3 MONTHS POST-VIRAL COMPLAINTS)



M.E.-PATIENT
(24 YEARS POST-VIRAL COMPLAINTS)



6. Grassroot



Confirming Diagnosis of Myalgic Encephalomyelitis - Brain Scans



ME International is an all-volunteer organization. Our purpose is to support ME organizations, educate the general public, medical providers, and governments throughout the world as well as support ME patients, caregivers, advocates, family and friends.

Encephalomyelitis means inflammation of the brain and spinal cord. The World Health Organization coded ME as a neurological disease in 1969. Research evidence demonstrates that ME has both structural and functional brain consequences including reduced resting brain blood flow, differing connectivity among brain regions, alterations of whole brain metabolism, reduced gray and white matter volume, increased presence of white matter lesions, increased neuroinflammation and altered brain function during cognition.

So, why do brain scans?

Read our latest blog at <https://bit.ly/2ZEgB2e> to learn about SPECT brain scans and one patient's experience in getting the scan. Also, learn about what to expect from the test results. The blog is also available in French.

James Lutey,
President

ME International

Congressional Briefing “Women’s Chronic Illness During a Pandemic” Highlights ME/CFS Experiences

On Aug 12, as part of Solve M.E.’s collaboration with the Congressional Bipartisan Women’s Caucus, Miles for Migraine, and the Headache and Migraine Policy Forum, Solve M.E. hosted a virtual congressional briefing on COVID-19, ME/CFS, and Migraine Disease.

Moderated by two-time Emmy nominated TV host, **Jedediah Bila**, “Women’s Chronic Illness During a Pandemic” (<https://bit.ly/3mpDSP2>) was designed to educate members of congress and their staff about COVID-19’s impacts on women’s clinical care and economic burdens through the experiences of women with ME/CFS and Migraine Disease. Featured panelists included Caucus Vice-Chair Representative **Madeline Dean**, **Dr. Nancy Klimas**, **Jamie Sanders**, **Dawn Buse** (PhD), **Ashanti Daniel** (BSN, RN), and **Joanna Kempner** (PhD).

As emerging evidence indicates lasting health complications in COVID-19, how is the ongoing pandemic going to impact women with chronic illness? Through the lens of ME/CFS and Migraine Disease, this virtual roundtable explores the increasing economic burden, lagging clinical care, and potential scientific opportunity of women’s chronic illness during the current crisis.

Watch the virtual congressional briefing here <https://bit.ly/32wKeUG>.



Solve M.E. Joins Forces with the “Protecting the Immunocompromised” Coalition

As Congress continues deliberating additional legislation to respond to the novel Coronavirus (COVID-19) pandemic, Solve M.E. has joined a coalition led by the Immune Deficiency Foundation to ensure the needs of immunocompromised Americans, including the ME/CFS community, are adequately addressed.

We’ve signed onto a letter requesting that Congress task the Centers for Disease Control and Prevention (CDC) to work with the immunocompromised stakeholder community and related health experts to develop and regularly update recommendations aimed at addressing the needs of the immunocompromised.

These recommendations would include recognizing the needs of this population and ensuring immunocompromised individuals are provided protections and accommodations to meet these needs. These recommendations and resulting state and federal policies should include flexibility to ensure that individuals are treated fairly and without discriminatory consequences. Read the letter to Congress here <https://bit.ly/3izDPhk>.



The First Meeting of the Interagency ME/CFS Working Group

Led by the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC), U.S. agencies have come together to coordinate their efforts to further research, treatment, and prevention of ME/CFS and to facilitate stakeholder input and community participation with the creation of the new Interagency ME/CFS Working Group.

Solve M.E. participated in the first meeting of the Interagency ME/CFS Working Group, represented by Chief Executive Officer Oved Amitay and Chief Scientific Officer **Dr. Sadie Whittaker**. The meeting was live streamed and you can watch a recording of it here <https://bit.ly/3ccLrUJ>.

Submitted by **Karman Kregloe**

4 Things Considered 'Lazy' That Are Really Self-Care

Although not entirely applicable to ME-patients, this blog contains some points ME-patients might recognize. Here are some issues:

In society today, it's all about the hustle, the go go go, rush rush rush lifestyle, where people are often measured by their productivity. With that frame of mind being so prominent these days, it's easy to feel like you're a failure if you don't accomplish as much as everyone else.

People are quick to assume that if you're not continuously productive, you must be lazy. But the truth is that you don't have to compete with anyone else or accomplish as much as anyone else. The only one you have to compete with is yourself, to be the best you can be and do the best you can do. But you must also take time to practice self-care.

🚧 Not Having an Immaculate House Does Not Mean You Are Lazy

Many people live by the creed that appearances are everything, that a tidy house is needed for a tidy mind, and that clutter leads to chaos. It is easy to succumb to those feelings that if anything in your life is a mess, you as a person must also be a mess, and that not having everything in your life clean and pristine is a sign you are lazy.

🚧 Not Cooking Fancy Meals for Yourself Does Not Mean You Are Lazy

It seems today that the internet is filled with Instagram chefs.

Especially when it comes to those of us with severe or chronic conditions, it is hard to even muster up the energy to cook, let alone the inspiration. It is perfectly fine if you don't even feel up to cooking at all because you don't physically or mentally feel up to preparing anything big. It doesn't mean you are being lazy.

🚧 Not Going Out and Being A Social Butterfly Does Not Mean You Are Lazy

There are a lot of people sometimes assume that just because you are not out alongside them, living the high life, you must be lazy and unmotivated.

But it is perfectly fine to acknowledge your own limitations and to excuse yourself from activities you do not feel capable of doing. It does not mean you are being lazy. It means you are respecting your body and yourself enough to not push yourself beyond your limits.

🚧 Not Having a Job Does Not Mean You Are Lazy

Often one of the first questions people ask when they meet someone is "What do you do for a living?" The widespread shame placed on disabled people who cannot work is horrendous.

It is hard enough to feel internally that you are not able to accomplish as much as you wish you could without being shamed by others. But please know you are not being lazy.

To conclude with

Once again, you do not have to compete with anyone else or keep up with the Joneses. The only person you have to compete with, answer to and please is yourself. And you must take time to take care of yourself, as well.

Everything in life does not have to be perfection and every moment of your day does not have to be filled in order to be worthy or good enough. All that truly matters is that you are doing your best and continuing on. It is OK to have limitations. It does not mean you are lazy. It means you are human.

B.L. Acker

Source: The Mighty <https://bit.ly/32zIJFA>

#MEAction

What a Summer for Advocacy and Education!

We know the summer isn't over yet, but A LOT has been happening with ME advocacy and education in the United States and the United Kingdom, and we want to make sure you are up to date, in the loop, and ready for next steps!

Activism in Virtual Spaces

Dr. Fauci at the NIH says the Covid-19 long haulers' symptoms are "highly suggestive of ME/CFS" (<https://bit.ly/32SzIr7>) thanks to #MEAction New York Leader, **Terri Wilder** asking a question about ME during an International AIDS Society Covid-19 press conference. At #MEAction, we believe we must use every opportunity possible to get ME the attention it deserves- and this



worked! This video and quote have been referenced in major news outlets in the US and UK

NIH Review

#MEAction has published a thorough 2-part report (<https://bit.ly/32UjEVH>) on what changes the NIH has—or hasn't—made to its research efforts in light of COVID-19. We've worked hard (especially Director of Community and Campaigns, **Ben Hsuborger** and the amazing work of US volunteers) to organize this information and make it available to the community so that it can inform all our activism going forward.

Open Letter to **Matt Hancock**

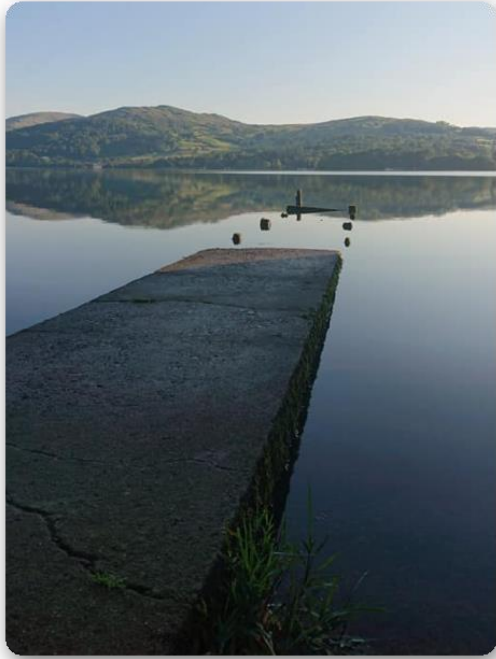
#MEAction UK sent an open letter to Matt Hancock asking him to recognise the harm caused by graded exercise therapy. We are calling on him to ensure all advice for people with ME, and those at risk of developing ME post-COVID, warns of the harm from graded exercise therapy. Join us by asking your MP to write to Matt Hancock too and telling them about your experience of ME. Learn more here (<https://bit.ly/3crevri>).

Long Haulers Facebook Group

We have a new facebook group (<https://bit.ly/3kHqDHP>) for people with post-COVID. Our group statement: This is a place to find support, build community, and take action at the intersection of long COVID-19 and myalgic encephalomyelitis (ME), also known as chronic fatigue syndrome (ME/CFS). This space is open to COVID-19 long haulers who meet ME/CFS criteria; #pwME who subsequently got COVID-19 and are exploring how their health has been impacted; and their caregivers and allies. We also discuss postural orthostatic tachycardia (POTS) and mast cell activation syndrome (MCAS).

In solidarity, All of us at **#MEAction**

Marathon Mike



Feb/Mar/Apr Update

Well that was an interesting 3 months!

By now I should have Italy and Germany ticked off the list and be waiting for Croatia in October as my final race on the challenge. But obviously Coronavirus had other plans and has shut down the challenge for the foreseeable future. The most important thing at the moment is that none of my family, friends and every one of you reading this are suffering from this nasty disease. Rome and Hamburg are pretty big street marathons and I'm really not sure either will be deemed safe to take place until we have a vaccine for Covid-19. That could be more than a year away, so I'm mentally adjusting things to expect a 2022 finish, maybe. It's going to be a real challenge to keep fitness and focus to

get to the finish line but I've come too far to stop and whilst motivation isn't at it's highest, I will get this done. Unfortunately as you can expect, marathons are generally large gatherings of people in small spaces with people flying in from all over the world - probably the worst possible thing for suppressing a deadly pandemic.

I'm struggling a bit physically when running at the moment, everything is a bit achy and my movement feels a bit restricted. I think a fair bit of it is down to having a few knotted muscles as I've not had a massage since October (700 miles ago). Dying to get Martin round to get me straight again but social distancing and lockdown makes that impossible for now. He has diabetes too which must be making things very difficult for him as he'll most likely be in the 'shielded' most vulnerable category. Mentally too it's been horrendous. Training for a marathon that you know won't happen is very challenging. My weekly mileage is very much reduced, I'm drinking and eating more and have lost a fair bit of focus in life generally. I know how lucky I am to have my health and I don't want to bleat on given the seriousness of the pandemic, it's just how things are at the moment. I'm working at home full-time which makes it difficult to make time to get out for a run when it feels like any spare moment I have should be spent trying to help save our business from going under. I'm also conscious that I need to pull my weight with parenting too and now we have a very mobile toddler with a very set routine, there's not much flexibility. Tough, but hopefully things will improve if and when our hapless government gets the virus under control!

(read more <https://bit.ly/3hzVV18>)

Thanks for your support!

Mike

Always Another Chance

Toni Bernhard has published a new book, *How To Be Sick: Your Pocket Companion* (<https://bit.ly/3hy7VAy>). Whether you have read **Toni's** other books or not, I think you will find this one to be the perfect fit.

This book is not a regurgitation or abridged version of the best-selling *How To Be Sick* (which I have previously reviewed here <https://bit.ly/2E8JIDe>). **Toni** received requests from readers for a smaller version of the book that they could carry with them and refer to when obstacles arise. *Your Pocket Companion* is literally designed to be just that. It's small and light enough to go in a purse or pocket, and is packed with concrete suggestions that will help people deal with the many challenges of chronic illness.

Your Pocket Companion is not necessarily meant to be read straight through, although I did. It is organized around ten specific challenges, and **Toni** offers multiple strategies and practices to help relieve the mental suffering that these challenges bring. I like to think about it as **Toni's** greatest hits, because she focuses on the issues that come up most frequently and cause the most pain.

For example, we've all had days when our symptoms seem too intense to bear and distraction fails to help. When I am trapped in pain and brain fog, I can't come up with a strategy to ease my suffering. *Your Pocket Companion* offers ten suggestions for "Responding Skillfully to the Relentless of Symptoms." Many may be familiar to **Toni's** readers, like "weather practice" and self-compassion. **Toni** has distilled these practices to their essences. For example, in the second edition of *How To Be Sick*, **Toni** devotes four pages to describing Drop-It Practice, and shares a story of how she used it to deal with frustration at a doctor's appointment. In *Your Pocket Companion*, **Toni** describes the exercise in 120 words--all you need to apply it in the moment.

Among the other challenges **Toni** addresses in *Your Pocket Companion* are how to handle the pain of receiving dismissive medical care, coping with disappointment when a new treatment doesn't help, and coping with new medical problems. She also shares suggestions for loneliness and the pain of being dismissed by family and friends.

There's one challenge that I think everyone can identify with right now, whether or not they are sick: "Accepting Without Bitterness How Restricted Your Life Has Become." I wish I could hand **Toni's** advice on this to everyone in America right now. She writes, "Life is one surprise after another. Some of them will be to your liking; some will not." **Toni** couples that reality check with compassion. It's okay to be unhappy about how restricted your life has become. Then gently, she suggests we acknowledge our suffering and treat ourselves with compassion. **Toni** doesn't say "suck it up;" she says we should do the best we can and then "take the rest as it happens."

One of the hallmarks of **Toni's** work is her unfailing kindness. She encourages us to abandon self-blame, saying, "Blaming yourself for something that isn't your fault wastes your precious energy." Self-compassion is an essential practice because, "There's no reason to be anything but kind to yourself, both in your speech and your actions." **Toni** never says we can overcome these obstacles in a forceful, mind over matter, bootstrap way. Instead, her hope is that "you can learn not to let those challenges diminish you." She reminds us that it is possible to find some peace and happiness, even if you are sick.

For me, one of the most hopeful things **Toni** says in Your Pocket Companion is to "Try counting each moment as a separate life," and a chance to start anew. It's OK if I criticize myself or feel resentment about my symptoms. In the next moment, I can try again. As I've gotten older, I have sometimes felt like my life is over because my "prime" was lost to illness. **Toni's** suggestion to always start anew reminded me that there is always another chance. Even if I never feel any better physically, there is always another chance to respond to my circumstances. I can always try again, and again, and again.

How To Be Sick: Your Pocket Companion is a portable reference guide, like a how-to manual for coping with illness and caregiving. Having it with you can help you remember to examine your feelings and perhaps find a new way to minimize your suffering. As with all of Toni's books, I cannot recommend it highly enough.

Both the e-book and hard copy versions are now available to order (from the publisher (<https://bit.ly/2RvVKtb>), Amazon (<https://amzn.to/3itH7CF>), Barnes and Noble (<https://bit.ly/2E2ZKOO>), and Indiebound (<https://bit.ly/2H0y669>)).

Jennie Spotila

Source: Occupy ME <https://bit.ly/2E3E5Gd>

Awareness Starts With Us

I was inspired by the movie Milk about **Harvey Milk**. He gathered his early group of gay men and told them they had to come out of the closet despite the prejudice they would face because every person they didn't tell was someone who didn't know they personally knew a gay person which puts a face to it, humanizing it, making it harder to be prejudicial.

"Every gay person must come out. As difficult as it is, you must tell your immediate family. You must tell your relatives. You must tell your friends if indeed they are your friends. You must tell the people you work with. You must tell the people in the stores you shop in.

Once they realize that we are indeed their children, that we are indeed everywhere, every myth, every lie, every innuendo will be destroyed once and all. And once you do, you will feel so much better."

Harvey Milk

"Rights are won only by those who make their voices heard"

Harvey Milk

"We will not win our rights by staying quietly in our closets"

Harvey Milk

I have thought for some time that ME/CFS is in a similar place as the LGBTQ community was back then. Honestly we're probably worse off because we're so sick we can't even live some sort of private life like an LGBTQ person could. But it doesn't matter it's similar and we can learn from history.

This is one of the reasons I decided to "come out" about having ME/CFS on my photography website.

<http://www.whitneydafoe.com/news>

I thought that not only would everyone I know learn about the illness but people who found my website would also see it. They would hopefully connect my photography work with an ME/CFS patient and make it more difficult to de-humanize me with all that artwork staring them in the face. All horrific acts in the history of humanity have been done by dehumanizing a group of people. From prejudice to genocide. So we need to humanize ME/CFS. This is how real awareness will begin.

Let's learn from history. Awareness starts with us. We can no longer sit around waiting for other people to spread awareness about our illness or worse, lying to the people in our lives to avoid discomfort and prejudice while privately complaining about the lack of understanding or awareness on ME/CFS social media (which might feel good but accomplishes nothing).

There are exceptions of course. Many of us are dependent on people and doctors who don't understand and in these cases it may be necessary to minimize use of the ME/CFS diagnosis in order to continue receiving the care you need both at home and from a doctor in order to survive. Feel no shame in having to do this and know how sorry we all are that you have to.

I've been lucky in this way. Yes I've had lots of horrible experiences with prejudicial doctors and friends but my family truly understands that I have ME/CFS and that it's a horrible disease. And I've been lucky enough to eventually find doctors who understand as well.

I tell everyone, and I use both names (ME and CFS). I'm not afraid of telling anyone that I have Chronic Fatigue Syndrome. If they judge me they can fuck off.

Remember - every person you don't tell that you have ME/CFS is a person who doesn't realize they personally know someone with the illness or worse doesn't even know the illness exists.

A huge part of the reason there's so little awareness and funding is because patients so often hide their illness from the people in their lives. They do so because of the prejudice they experience but in the long term, it only perpetuates it. It's time to stop the cycle. If you're in a position where it's physically possible, even if it's uncomfortable, tell the people in your life.

Whitney Dafoe Davis

Source: <https://bit.ly/3iNF6RT>

Hermitism

Hermtised: (urban dictionary)

when you are adapted to the hermit/ life and accepted that is your life style.-

So much of my day is spend in solitude, in silence. I know of course that I am not alone in this – I am just one in a worldwide community of hermits (<https://bit.ly/2ZOUJRu>), a life imposed on us due to chronic illness. In my case M.E.

Most of the time I am utterly comfortable in my own space. I don't need the radio or have 'white' noise around me. I am comfortable in the silence of my own breath and the sounds of life around me, like the weather. The birds my fateful companions (as long as the feeders are filled regularly!) On a good day I bask in the sound of birds through the open door, or on an even better day, I am among the birds and soak in the sound of nature. These moments brings joy to my heart.

In my hermit life I have stopped watching television about 18 months ago. I do occasionally watch a movie or documentary on Netflix in the afternoons. If something really touches me, I end up writing down quotes from these film-sessions. Some of these musings end up in some shape or form in my creative work.

Anyway.

Solitude: living like a hermit...

It truly is a 'funny' thing. Although I am comfortable with this hermit status, the reality is that I can't actually fully live on my own. Be a true hermit. I am in need of basic care to remain living at home. Two sides of the same coin. Yet at times I wonder would I actually be able to totally retreat from the world? Would I be ok with being a 'monk'? Or is it more a case that I have adapted to this life, and is not so much by choice...

I am very aware that the way I see the world, who I am, how my creative work and writing has evolved is as a result of this hermitised life. I can mostly see this as a positive.

But yet, I so very much appreciate and enjoy the company of friends and family, in person, on the phone or via video links. I also value the contacts made via social media. However, the other side of having company is, that these wonderful interactions often take more energy than I actually have, so I end up in need of more solitude.

And round the circle goes.

It is all a matter of balance. Of careful planning.

The bit that is most challenging with hermatism is that at times I have a desperate need to escape beyond the walls, which keep me 'captive'.

A note in my journal reads:

"it remains to fricking hard... It is a most beautiful day. Almost clear sky, a hint of spring after days of heavy rain.

A lovely day for a walk!

I can't – or can I? Walk, of course, as in spin in my wheelchair. I can't, as I wouldn't have enough energy to put on a coat, and shoes, and hat, and scarf and take it all off again after an escape of ten minutes...

So the answer is: Nope."

That sunny mid January day I resolved to go out into the garden instead. I put on a jacket hanging by the back door. I was out for all of five minutes, pulling up some dead leaves covering tiny sprigs of new growth. In terms of the garden, the result was most gratifying. My body however was a lot less impressed. I had jelly legs; arms were like lead. I needed to lie down as I was in a lot of pain.

Joy so close to tears.

Later I wrote

"I feel at times my heart is breaking."

The solution is to do one little thing a day which brings fulfillment. I need to be able to say at the end of the day that I had a lovely day, that I did something that brought me joy. Even if it consist of some very small achievement: A bit of 'gardening'; sit out among the birds; sort out 'stuff' (my current favourite); or something creative, perhaps colouring, or writing; or catch up with a friend.

Re-evaluate again what I can and cannot do. Then hermitism isn't such a bad place to be in.

PS ... and as I now have (very few) PA hours (<https://bit.ly/3kt4ZXJ>) in which I can be assisted to go outside my home with support, maybe hermitism is a little more manageable too!

Corina Duyn

source: <https://bit.ly/2EgdEgJ>

Severe ME Day – August 8, 2020

Severe ME Day – August 8, 2020; Desperate Plight Continues in Darkened Rooms



Myalgic Encephalomyelitis (ME) is a chronic, often severely disabling disease, that affects the autonomic nervous system, immune system, endocrine system, among others. It afflicts over one million men, women, and children in the United States alone and as many as 17 million worldwide. ME is a disease that robs individuals of their health, similar to untreated HIV. There are those that refer to ME as non-HIV AIDS - with good cause, as the disease can leave sufferers confined to a bed, with little capacity to fend for themselves.

August 8th has been set aside as Understanding and Remembrance Day for Severe ME. It is the birthday of the late severe ME patient, **Sofia Mirza** who died at the young age of 32 as a result of medical abuse and ignorance. Since her tragic death in 2005, too many ME patients have succumbed to the disease due to the ongoing medical negligence.

Severe ME patients, estimated to affect 25% of those with ME, are suffering from a harsh, disabling form of myalgic encephalomyelitis. These patients are isolated due to the severity of their symptoms and are often unable to leave their homes even to seek medical care.

The plight of these severe patients has been misunderstood, trivialized, and even disbelieved. They suffer in silence, unseen by the world, in darkened rooms because their hyper-sensitivities to light, sound, and touch make it impossible for them to lead any semblance of a normal life.

Severe ME patients are seldom seen by a doctor because they cannot travel to a doctor's office. Consequently, they lack proper medical treatments and appropriate care which are crucial for the well-being of these patients.

Moreover, because of their physical limitations, these severe ME patients have not been able to take part in studies and their integral, unique symptoms have been omitted or ignored in the studies' designs and results. The medical literature for this disease, therefore, is completely biased and distorted.

Some of these unique symptoms include seizures, paralysis, intractable pain, blackouts, coma-like experiences, incontinence, tremors, cardiac dysfunction, gastroparesis, dyscalculia, and dysphasia. By neglecting these severest patients, the medical community - and especially world government health agencies - have done a great disservice to ME patients.

They have failed to set up policies and procedures for getting a proper diagnosis via home medical care as well as ensuring there is ongoing palliative care for these severest of patients.

This lack of concern for the severest and most vulnerable ME patients has arguably compromised the ability of the expert medical establishment to develop proper disease criteria. It is hard to imagine any other illness having their severest patients omitted from research studies, criteria development, and even choosing a name for the disease!

It is the duty of government health agencies to ensure the health and well-being of all in a nondiscriminatory way. The severest 25% of ME patients have been ignored long enough.

We call on the US Department of Health and Human Services (HHS), including all its agencies as well as doctors and researchers to start concentrating their medical and scientific attention to those in this group who are most in need of medical attention and care. HHS can do that by adopting and using the International Consensus Criteria (ICC). Severe ME patients are also the group with the strongest disease imprint which should bring the most accurate results in scientific studies.



MEadvocacy.org

Learn what you can do at: <https://bit.ly/2RMV2YB>

Long Term Illness is no Joke

As the harsh realities of living in a pandemic unfold and as each new day brings new research and understanding as to how Covid-19 behaves and more people speak up about the lasting effects of this virus, I hope every ear in this country is tuned to the correct frequency.

Long term illness is no joke.

I should know.

Having suffered from swine flu in the winter of '09 and a second respiratory illness in the winter of '11 I was left at the age of 30 with lasting effects and the diagnosis of ME. Myalgic Encephalomyelitis.

Back then I was fit and healthy, working in finance for a multinational company and filling my spare time with hot yoga, horse riding and running with my local athletics club.

In short, I had a life. That was until I lost it all.

My hobbies and social life were the first to go as I tried desperately to hold onto my job. My husband and I own a house with a mortgage. Our wages were important.

Attempting to keep my job was difficult. Attempting to get out of bed was difficult and by the time I dressed and washed my teeth, my energy for the day was almost gone so driving to work became a huge chore. The forty-minute drive was peppered with naps as I struggled to remember what the red traffic light meant. Arriving at work and taking on a set of steps meant I was more than cooked so I'd head to the toilet for a time out before finally making it my desk.

At my desk there were e-mails that appeared as though they were written in some foreign tongue, there were colleagues asking questions and there were meetings I fell asleep in.

Within hours of my first day back to the office after my GP declared my respiratory illness had dissipated, it became clear I was in trouble so my manager granted me a shorter working day and by GP delighted in the fact I was trying while she sent me for further tests.

While I awaited a hospital stay and copious tests, my shorter hours at the office made no difference to me. No matter how hard I tried to keep my eyes open and concentrate I was beaten and as the weeks rolled on and my phone calls and texts of "I'll be late into the office today," and "I'm sorry but I can't get out of bed," became old records, I finally received my diagnosis of ME.

Like a naive child I waited to be told what my treatment would be and what cure there was only there was silence and so in May 2012 I lost my job, I lost the last semblance of myself.

After three consultants, a therapy which made me worse and a drug which made me worse, the only thing that keeps me somewhat upright now is pacing and sleep and resting. I require 12 hours sleep just to function at a basic level, my basic being cooking, scanning the newspapers, pottering in the garden when I can and having the odd visitor.

I haven't read a book in years. I'd struggle to walk a mile. I find it difficult to follow the TV. Noise goes through me. Light goes through me. My eyes hurt, my head hurts and my body hurts. A bad day is dragging myself about as though dragging a corpse.

A good day is being able to function between resting periods. If I overdo it, I crash. A crash means a week to ten days in bed. If I slightly overdo it I'm stuck to the armchair for a few days, struggling to make dinner and struggling to walk upstairs. My symptoms include nausea, muscle pain, bone pain, migraines, spasms, electric shocks in my fingers, restless legs, digestive issues, a racing heart, fever like chills, night sweats, constant fatigue and every so often a new symptom is added to the list.

As **Dr Fauci** in the US said recently, there's a possibility some long term sufferers of Covid-19 will eventually be diagnosed with ME and so I ask everyone reading this today to think twice about risking your life over a party or family gathering.

Long term illness is exactly that. Long term.

Marie H. Curran

News from ME Research UK

ME Research UK is delighted to announce that we have approved funding to **Prof. Jo Nijs** at Vrije Universiteit Brussel and **Prof. Lode Godderis** at the University of Leuven for a new research project investigating the role of epigenetic changes to brain-derived neurotrophic factor (BDNF) and histone de-acetylases (HDACs) in the pain and post-exertional malaise experienced by people with ME/CFS.

Epigenetics refers to genetic changes occurring not as a result of alterations in the DNA sequence, but instead caused by changes in gene activity and expression (how information from the gene is used to make proteins).

In previous studies, levels of BDNF – which is released during exercise and physical activity, but can also increase the sensitivity of pain pathways – were increased in ME/CFS patients, while methylation of DNA within the BDNF gene (an epigenetic mechanism) was lower than normal.

Similarly, HDACs are increased during neural sensitisation and pain, although their activity is decreased during exercise (in contrast to BDNF), and they have not yet been studied in ME/CFS.

The investigators hope that epigenetic changes in BDNF and HDACs may provide a marker of ME/CFS and potentially lead to new treatment strategies.

For more information about this study, please visit our website: <https://bit.ly/3hOsJUi>

Submitted by **Dr. David Newton**

News from the ME Association

Severe ME Week was the most recent event. The first blog appeared on 03 August, but they can all be found here: <https://bit.ly/3cd3fik> with the last blog about **Merryn Crofts** appearing on 07 August.

On the 1st of September, Forward ME published their letter about Post-Covid/ME/CFS management and caution about exercise. It's available for anyone to use: <https://bit.ly/35On9in>

The ME Association had a rather dismissive response to their letter to NHS England on a similar theme: <https://bit.ly/3kziEg2>

Good article in The Times from **Sean O'Neill** Chief Reporter, which covers Post-Covid and ME/CFS management with **Countess of Mar** and **Charles Shepherd**: <https://bit.ly/3cdKpYh>

Sean O'Neill also produced some excellent articles during ME Awareness Week. Unfortunately The Times is paywalled. If you scroll down this page, you will find the 4 articles from **Sean**: <https://bit.ly/33L14P0>

Submitted by **Russell Fleming**

On Fear

Whitney Dafoe hardly needs introduction. Being the son of ME-researcher **Dr. Ron Davis** and having very severe ME, it's a miracle that since about half a year there are moments that thanks to certain medication and help of others he succeeds in communicating messages.

This one is of July 9, 2020 and most recognizable for man a patient with ME.

I woke up this morning and The Fear was stronger than it's been in a long time. Just nervous and stressed and had a harder time doing things.

There's some strange relationship to necessity with my case of ME/CFS. Like I said earlier, I get an adrenaline boost (I think it's adrenaline but I don't really know) when I feel #2 coming on that allows me to get up and walk 7 feet to the bathroom. But without the #2, doing that would really hurt me because I wouldn't have that necessity adrenaline.

And as The Fear was stronger this morning, there were many times I was limited in my ability to do routine things because my brain didn't deem them necessary.

Usually things that are stress driven are big targets. Like being stressed about having enough of something when I know I do. In this case I can't get or put out a signal for more because it's not deemed necessary. It's little things.

I mentioned my hair cleaning routine yesterday - a baby wipe wrapped around a vibrating scalp brush. I scrub my whole head and then again with a second baby wipe and do a pre and post wet paper towel water rinse because it helps the baby wipes clean better.

Well today I couldn't push the button to turn off the vibrating scalp massager while I got out the second baby wipe. Recently I've been able to. But my brain decided it wasn't necessary today so I couldn't. It's so strange when this happens. It's like the opposite of the force. I can put my hand close to it but I can feel that I cannot push that button. If I do it anyways it hurts my brain so bad.

As I get worse what is deemed necessary seems to lower. When I get a little better, I can do little things like turn off the scalp brush in between baby wipes without even thinking about it.

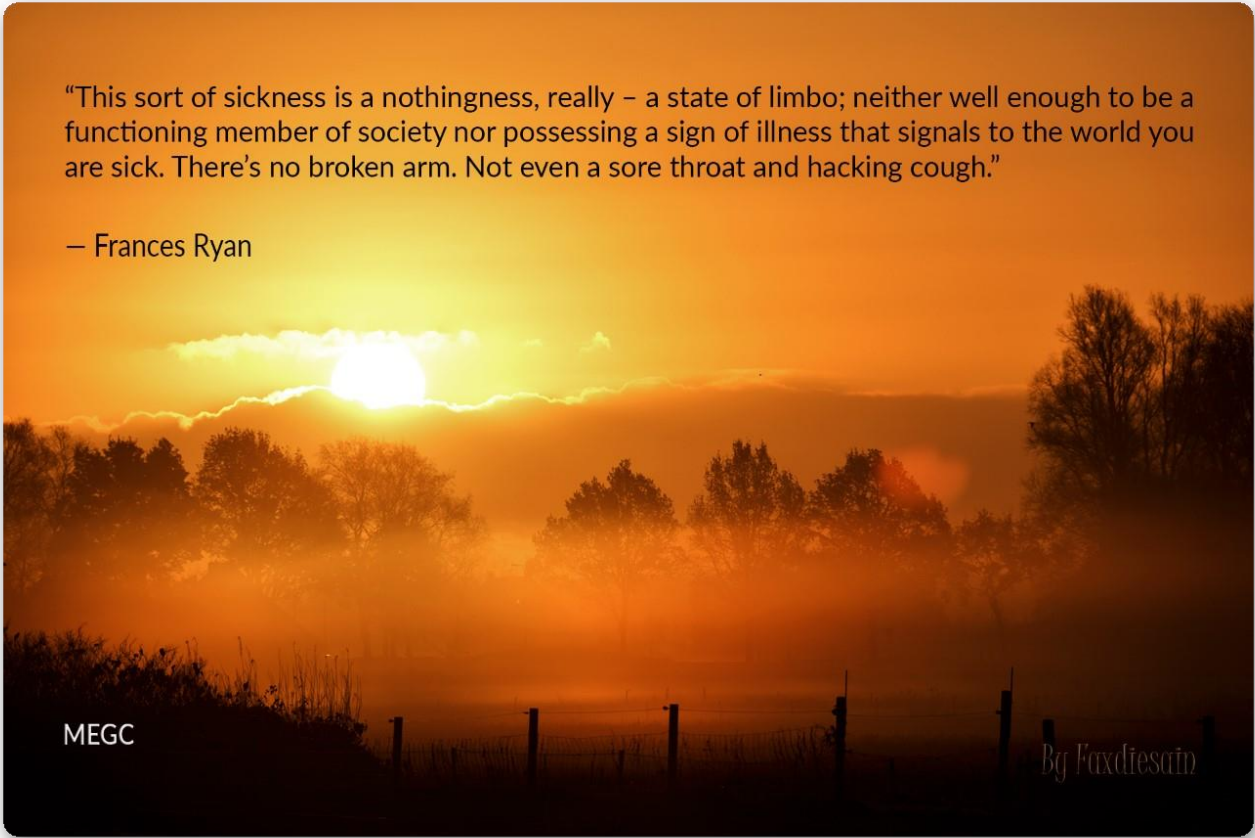
It has its limits though. My stomach functioning is necessary, but I was slowly starving to death before IV and then PICC line (long term IV that is inserted into a bigger blood vessel) and later, J-tube. And this necessity boost didn't kick in. I would have died without modern medical technology.

It's so frustrating to feel The Fear come back a little bit. I don't know why it did, maybe it was just a bad morning or maybe I was especially hungry or dehydrated.

The Fear is exasperated by my situation which is extremely stressful but it's definitely chemically induced. So when you feel The Fear don't blame yourself. It's the ME/CFS monster. Nothing more.

Whitney

Source: FB <https://bit.ly/3hS5eKk>

A photograph of a sunset over a misty landscape. The sun is low on the horizon, partially obscured by a thin layer of clouds, creating a bright orange and yellow glow. The foreground is dark, showing the silhouettes of trees and a fence. The overall mood is serene and somewhat melancholic.

"This sort of sickness is a nothingness, really – a state of limbo; neither well enough to be a functioning member of society nor possessing a sign of illness that signals to the world you are sick. There's no broken arm. Not even a sore throat and hacking cough."

– Frances Ryan

MEGC

By Faxdiesain

The PACE Trial - Part 4: Politics

A historic survey

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

The defining symptom of ME is that even minimal exertion can cause a crash (flare in symptoms) for days/months/weeks. In severe cases it can cause relapses and patients become significantly more disabled for months/years; some never recover. Multiple surveys have consistently shown that Graded Exercise makes over 50% of patients worse [1].

The PACE trial was published in 2011 and was widely reported in the media as a success, with headlines like "Exercise and positivity 'can overcome ME" [2]. Patients made numerous freedom of information requests for the data but were refused. After a long legal battle, some of the data was released [3].

The authors also refused to share the data with other researchers. An 'Expression of Concern' was added to a related paper after they broke the journals data sharing policy [4].

The data was reanalyzed using the authors original protocol and found the claim that patients can recover is "not justified by the data" and "highly misleading" [5].

The Journal of Health Psychology dedicated an entire issue to understand the many problems with the PACE trial and described it as a "textbook example of a poorly done trial" [6]. 80 charities, 10 MPs and over 100 academics signed an open letter to the Lancet in 2018 requesting an independent re-analysis of the trial [7]. The Lancet failed to respond.

"Researchers have put massive effort into discrediting the whole community and rallying other researchers to their defense. It's been a collective ad hominem attack" [8]. "The patient community has been publicly vilified by the trial authors and colleagues but they have turned out to be right" [9]. Claims of harassment made by the PACE authors were found to be "grossly exaggerated" in court [3].

The Science Media Centre (SMC) provides science information to the media in the UK. The SMC are "proactive", they "changed the whole course of coverage" on pandemic swine flu in 2009 [10]. One of the most influential researchers in ME/CFS sat on the advisory committee and the board of governors of the SMC and was involved in the PACE trial [11, 12].

The SMC has helped place articles about harassment in the press. They 'gave' the original story to the BBC in 2011 [13] and released an 'inaccurate' factsheet the day before a reanalysis paper was published [14].

The behaviour of one of the PACE authors was criticised in parliament after he emailed the organiser of a debate about the PACE trial [15].

- [1] <https://bit.ly/2ZQCR90>
- [2] <https://bit.ly/2ZQD4Jk>
- [3] <https://bit.ly/2FChQrU>
- [4] <https://bit.ly/33KAHbZ>
- [5] <https://bit.ly/3ckFg0H>
- [6] <https://bit.ly/3ci1wZ1>
- [7] <https://bit.ly/32Kz6E3>
- [8] <https://bit.ly/3cfHXAHA>
- [9] <https://bit.ly/2FIpuRr>
- [10])<https://youtu.be/MDZQi7Xnrk0> (5 mins 46 & 8 mins 26
- [11] <https://bit.ly/3ktsGz2>
- [12] https://me-pedia.org/wiki/Simon_Wessely
- [13] <https://bit.ly/3kxIUbs>
- [14] <https://bit.ly/2FCisOe>
- [15] <https://bit.ly/33JeFXm>

Source: **Broken Battery**

Update to Report: NHS Digital Requests Addition of SEID to SNOMED CT

SNOMED CT Report Two | September 2020

In the ME Global Chronicle's March 2020 issue, I reported on a request submitted in November 2019 for addition of the term "Systemic exertion intolerance disease" to the SNOMED CT terminology system.

The SNOMED CT terminology system is a systematically organized computer processable collection of medical terms used in electronic medical records, clinical documentation and data reporting.

SNOMED CT is used in over 30 countries and is the recommended terminology system in the UK, US, Canada, New Zealand and Australia.

For NHS England, SNOMED CT UK Edition is the mandatory terminology system for use at the point of care across all primary and secondary healthcare settings.

Request #30104 (submitted November 30, 2019) requested addition of the term, "Systemic exertion intolerance disease" as a Synonym under the existing SNOMED CT Concept: 52702003 Chronic fatigue syndrome.

The brief rationale text in support of this request can be read on the NHS Digital Request Submission Portal, here: <http://bit.ly/39Pz4vy>

NHS Digital, who manage the SNOMED CT UK Edition, had referred the request on to SNOMED International's terminology leads for their consideration.

After drawing attention to this request on Twitter, a senior member of SNOMED International's team contacted me and confirmed that NHS Digital had submitted the request for consideration for addition to the SNOMED CT International Edition.

I was advised that this request had already been processed and pending any further changes, was scheduled for implementation in the International Edition's July 2020 release.

(Note: If the term "Systemic exertion intolerance disease (SEID)" was added to the International Edition, the term would then be absorbed by the various national editions when they released their next updates.)

I outlined my concerns about the potential addition of the (unadopted) SEID term to the SNOMED CT system and these were passed back to SNOMED's terminology specialists for their consideration. I also provided a copy of the report prepared for the ME Global Chronicle's March 2020 issue.

You can read a copy of that report here: NHS Digital requests addition of SEID to SNOMED CT: <http://bit.ly/2wdYVij>

In early June, I was advised that the information I provided had been reviewed by the terminology team; that the team now considered it would be premature to add "Systemic exertion intolerance disease" to SNOMED CT; that approval of this request had been retracted and SEID would not be included in the July release.

This decision is documented on a SNOMED CT internal production page (see last entry under heading: Concepts to be removed completely from the Alpha release content): <https://bit.ly/2Xed60V>

The July 2020 release was published on July 31: <https://bit.ly/39HA1a2>

I can confirm that the two Synonyms terms that had been added under 52702003 Chronic fatigue syndrome for the Alpha production release:

- 🚩 • 3902795018 - SEID - systemic exertion intolerance disease
- 🚩 • 3902796017 - Systemic exertion intolerance disease

were removed for the finalized July 2020 release.

In the event of a request for a change or addition to SNOMED CT not being accepted there is an appeals process and the submitter may request a further review of the decision.

SNOMED International confirmed that NHS Digital did not submit an appeal against their decision not to add SEID to the finalized July release.

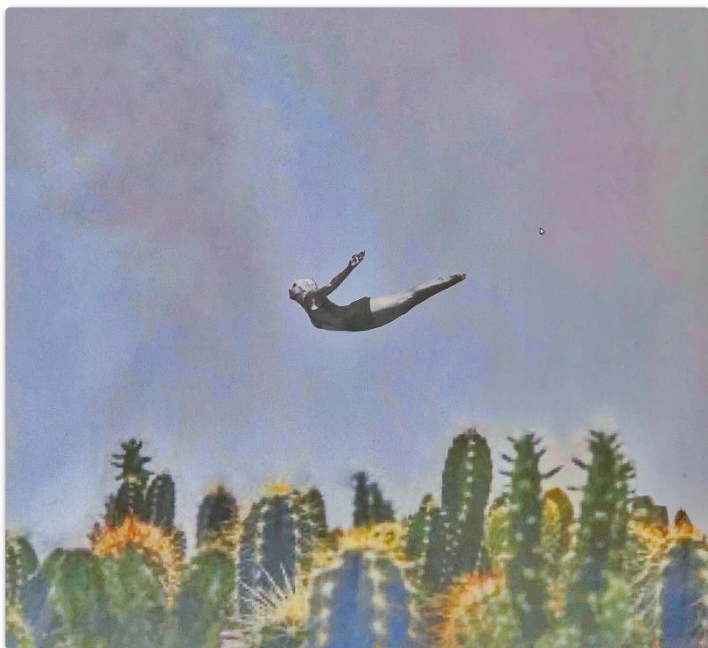
Suzy Chapman

Dx Revision Watch

<https://dxrevisionwatch.com>

dxrevisionwatch@page1.myzen.co.uk

Momentary Flight



This collage was inspired by post-exertional malaise (PEM), one of the hallmark symptoms in ME/CFS. It's about that fleeting feeling of free will when you're immersed in something you love.

There's always a bit of denial about what's to come for me, but these moments are meant to be seized and lived.

ID: An image of a women swan diving through the air. Instead of a pool, she is plunging into a field of cacti.

Christina Baltais

Source: <https://www.facebook.com/c.j.baltais/posts/10103414235592509>

ME/CFS Alert

Episode 113

<https://youtu.be/n7gojx3rl2o>

Lisa Hall is a retired nurse and currently focusing on nurse advocacy. **Lisa's** nursing career specialized in Integrative Medicine - bringing together conventional medicine and alternative medicine - for persons suffering from various chronic illnesses. Her focus in the ME/CFS community is on patient care and providing adequate resources for ME/CFS patients at every stage of life. **Lisa** contributed to the creation of a program for school nurses to better diagnose ME/CFS in children, and facilitate an alternative plan for their education. **Lisa** is also an advocate for ME/CFS coverage in nursing school curriculums.

Episode 114

<https://youtu.be/QYDwf5Z2I3E>

Llewellyn King interviews Charmian **Proskauer** of the Massachusetts ME/CFS & FM Association. She discusses how the association is helping ME patients in the time of COVID-19.

Episode 115

https://youtu.be/hD8_wTC51dc

Linda Tannenbaum, CEO and president of the Open Medicine Foundation, talks with Host **Llewellyn King** about how research on COVID-19 might stimulate research on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS). She also talks about the history of the California-based foundation and the research it supports.

Episode 116

<https://youtu.be/0pq-JI8bGbc>

In this episode, **Llewellyn King** interviews **Dr. Mache Seibel**, a Harvard Medical School faculty member who practices at Beth Israel Deaconess Medical Center in Boston, Massachusetts. His specialty is women's health and menopause, and he has treated many patients with ME. He is insightful and compelling.

Episode 117

<https://youtu.be/T-I-mXFXAuE>

Llewellyn King interviews **Linda Marban**, CEO of Capricor Therapeutics, a Los Angeles-based clinical-stage biotech company. Their discussion centers on where biomedical research across the board stands, and the positive fallout for ME/CFS from research on COVID-19 and other diseases.

Episode 118

<https://youtu.be/41iV9uyU6tY>

Janet "Jan" Montgomery has had ME for 30 years. She was active in the original CFIDS association in San Francisco and now lives in Kailua, Hawaii. She talks with **Llewellyn King** about her ME activism and why she calls herself a "disability activist."

Chronic Fatigue Syndrome

A Roadmap for Testing and Treatment

Introduction

Myalgic encephalomyelitis / chronic fatigue syndrome (ME/CFS) is a disease characterized by fatigue, post-exertional malaise (symptoms get worse after exercise), cognitive dysfunction, unrefreshing sleep, and many other symptoms.

This roadmap will help you determine (1) whether you have ME/CFS, and if so (2) which lab tests you can take to identify the infections and other factors that may underpin your ME/CFS, and (3) which treatments and therapies you can use to tackle these infections and factors, to improve your health.

- ✚ Introduction
- ✚ Diagnosis of ME/CFS
- ✚ Ruling Out Similar Diseases
- ✚ Overview of Causes and Treatments
- ✚ 1ST ROUND: Viral Infections — Tests
- ✚ CVB/EV • EBV • HHV6 • CMV • PB19 • VZV • Cpn • Mold
- ✚ 1ST ROUND: Viral Infections — Treatments
- ✚ Antiviral Drugs Summary
- ✚ General Therapies for ME/CFS
- ✚ 2ND ROUND: Comorbid Diseases — Tests
- ✚ Dysbiosis • Leaky Gut • IBS • SIBO • Allergy • Low T3 • POTS • NMH/OH
- ✚ 2ND ROUND: Comorbid Diseases — Treatments
- ✚ 3RD ROUND: Less Common Infections — Tests
- ✚ HSV • HHV7 • Cox • Giardia • Mycoplasma • Bart • Bab • Bru • WNV • RRV
- ✚ 3RD ROUND: Less Common Infections — Treatments
- ✚ 4TH ROUND: Rarer Causes — Tests
- ✚ Vax • Trauma • CCI • TMJ • Jawbone • Sinusitis • Meningitis • Imp • Pesticide
- ✚ 4TH ROUND: Rarer Causes — Treatments
- ✚ Testing Labs
- ✚ ME/CFS Doctors and Clinics
- ✚ World Map of ME/CFS and CIRS Doctors
- ✚ Sourcing Pharmaceutical Drugs
- ✚ Sourcing Cheap Supplements

See <https://bit.ly/30agXxI> for all information and even more... where all the above topics are listed with a direct link to their contents.



A Canadian patient, **Val about ME**, writes about it:

"This roadmap provides an introductory overview of ME/CFS therapies, with the purpose of helping new ME/CFS patients learn about some of the more effective ME/CFS treatments.

The author of this roadmap is **Hip**, an ME/CFS patient who lives in the United Kingdom, and is usually to be found on the Phoenix Rising ME/CFS forum. The author has a BSc in mathematics and physics, and an MSc in cognitive science.

Nothing in this roadmap should be construed as medical advice. Only you and your doctor can decide whether any medical treatment is appropriate.

😊 An amazing website , very complete & up to date!"



In Memoriam: René Mebus



René Mebus, 26, died on June 30, 2020 of extreme severe ME.

René successfully studied mechanical engineering (bachelor's degree) and graduated with the best grades.

In his free time he was involved in the voluntary fire brigade and took over the press work there, he also was a youth worker. He also supported the district fire brigade association and designed and created their website, furthermore he helped to organize the event "experience fire brigade".

René fell ill with severe ME in December 2017 during the master studies, after a few months he suffered from the most severe orthostatic intolerance, became bedridden and laid horizontal 24/7 in absolute darkness and silence.

It got worse and worse, and he suffered from extreme light, noise and touch sensitivity. As also from severe immunodeficiency (NK cells decreased, extreme high cytokines, HHV-6).

He was too weak to chew food. From May 2019 onwards he was completely paralyzed, had seizures, and was therefore admitted to a hospital. Various pathological values were found in the clinic but he was sent home without help.

Through hospitalization he deteriorated further. His whole body was in extreme pain but painkillers, even morphine, were not sufficient.

He is unendingly missed by his brother (also ME sufferer), his parents, his relatives and his friends.

Submitted by **Jannik Mebus**

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



OMF Scientist Receives Grant Funding for ME/CFS Study

Open Medicine Foundation (OMF) is thrilled to share that our staff science liaison, **Christopher W. Armstrong**, PhD, has been awarded a grant to further his research into the relationship between the altered metabolism of nitrogen and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS). The research will be completed at the ME/CFS Collaborative Research Center at Stanford University (<http://bit.ly/39XZDyL>), under the direction of **Dr. Ron Davis**, Director of OMF's Scientific Advisory Board.

Dr. Armstrong first noted increased usage of amino acids, which contains nitrogen, in the metabolism of people with ME/CFS while working at the University of Melbourne. He was the first to apply metabolomics to the field of ME/CFS, publishing his results in 2015. Metabolomics is the study of small molecules (metabolites) using common standards of detection that enable different studies to be comparative and additive.

In 2018, he defined a hypothesis that "nitrogen-containing by-products of energy production accumulate more readily in the cells of people with ME / CFS, these nitrogen-containing by-products can be damaging to the cells and their process of producing energy." This means that the process of producing energy in people with ME/CFS may be causing damage and could reduce their ability to make further energy.

Chris was recruited to join Open Medicine Foundation in 2019 as a science liaison to communicate between the research collaborative groups at Stanford, Harvard, Uppsala, and Montreal universities, as well to help communicate their work to the broader ME/CFS community. During this time, he further developed the nitrogen hypothesis as it pertains to the broader research findings in the ME/CFS field.

"I'm extremely excited to have received funding for the continuation of this research. This hypothesis is the culmination of the many research studies on people with ME/CFS," Dr. Armstrong says. "We will be able to test the hypothesis, and in the process, we will be providing a large body of data on nitrogen metabolism in ME/CFS."

The grant will fund over 10,000 measurements of molecules in biofluids and cells from people, with and without ME/CFS, to track how nitrogen flows through the energy production system.

OMF Participates in Interagency ME/CFS Working Group Meeting

Open Medicine Foundations' ME/CFS and COVID-19 research project was brought into national focus at a recent, federally-sponsored meeting of the first-ever virtual Interagency ME/CFS Working Group Meeting.

This first meeting of the new Working Group focused on ME/CFS and those suffering from post-COVID-19 symptoms (aka "long-haulers").

This meeting, unique in its scope, was the first time that representatives of multiple federal research programs met collectively with three leading ME/CFS focused nonprofits, OMF, Solve ME/CFS Initiative and #MEAAction.

Hosted by the NIH and the CDC, representatives of federal research programs included:

- ✚ Three branches of the NIH
- ✚ Three branches of the CDC including the Domestic COVID Response Program
- ✚ Department of Defense: CDMRP
- ✚ Veterans Administration: Gulf War Research Program
- ✚ Department of Education: Office of Special Education Programs
- ✚ Social Security Disability Office

OMF's CEO & Founder/President **Linda Tannenbaum** and OMF's Chief Medical Officer **Ron Tompkins** provided an update on the OMF-funded study on COVID-19's possible conversion to ME/CFS. The presentation can be viewed here (<https://bit.ly/35QusWZ>).

OMF looks for every opportunity to accelerate research. The study will examine individuals from early severe COVID-19 illness through their recovery and rehabilitation phase, offering an unprecedented chance to identify biomarkers and discover drug targets and prevention strategies for ME/CFS.

View the slides from the presentation here (<https://bit.ly/3kx8Tij>).

New OMF Funded Research Paper

Open Medicine Foundation (OMF) is pleased to share the published results of an exciting fully-funded study conducted under the direction of **Jonas Bergquist**, MD, PhD, Director of the ME/CFS Collaborative Research Center at Uppsala University (<https://bit.ly/3iOfynG>).

This study was designed to validate the increase of autoantibodies observed in the blood of people with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) that was observed in a previous study. In addition, the study investigated potential differences in autoantibody levels in the blood and cerebrospinal fluid (CSF) of those with ME/CFS and healthy controls.

Autoantibodies are antibodies (immune proteins) that mistakenly target and react with a person's own cell structures. The increased autoantibodies observed previously in the blood of people with ME/CFS appear to be targeting 'signaling molecules' (named adrenergic and muscarinic receptors) on cell surfaces that are responsible for regulating energy metabolism, immune system activation, muscle activity, heart muscle activity and neurocognitive function.

Method

Blood, cerebrospinal fluid and health-related questionnaires were collected from two ME/CFS cohorts. Blood and cerebrospinal fluids were collected from the first cohort, while only blood was collected from the second cohort along with blood samples from healthy controls.

All samples were analyzed for autoantibodies. The questionnaires were used as measures of the disease's severity in patients.

Findings

"While no significant correlations between autoantibody levels and disease severity were evident in the study, our collaborators have conducted subsequent treatments to remove these autoantibodies and this has improved ME/CFS symptoms in a subset of patients,"

Dr. Jonas Bergquist

Results from this study validated those previously found of an increase of autoantibodies against adrenergic and muscarinic receptors in the blood of people with ME/CFS.

*"We are thrilled to fund this paper by **Dr. Bergquist** and his team at Uppsala," OMF founder and CEO **Linda Tannenbaum** says. "This critical work speaks to the importance of our mission — to support and accelerate the research needed to tackle the global health crisis that is Myalgic Encephalomyelitis/Chronic Fatigue Syndrome."*

Read the full paper (<https://bit.ly/3hMoMQ1>) published in Brain, Behavior, & Immunity – Health.

OMF Announces New "Brain Fog" Study

About the Study

Open Medicine Foundation (OMF) is excited to announce a new collaborative study between the ME/CFS Collaborative Research Center at Uppsala (<http://bit.ly/2TWVhCC>), Sweden and the Harvard ME/CFS Collaboration (<http://bit.ly/39TBtW4>).

This study focuses on biomarkers for long-term neurocognitive outcomes. It provides an excellent opportunity to understand the mechanism of long-lasting viral-induced cognitive complications, commonly referred to as "brain fog." Brain fog is one of the significant symptoms of those suffering from Myalgic Encephalomyelitis/chronic fatigue syndrome (ME/CFS) and is also seen in patients with herpes simplex encephalitis (HSE).

Objectives:

Investigate the correlation between biomarkers for brain inflammation and long-term neurocognitive outcomes in patients with herpes simplex encephalitis (HSE).

Method:

Fifty patients with Herpes Simplex Encephalitis (HSE) had blood and cerebrospinal fluid (CSF) sampled at three separate intervals – while in ICU, two weeks later and three months later. During these three months, all 50 patients appear to suffer from post-viral fatigue syndrome (PVFS), and many are expected to qualify for ME/CFS diagnosis at six months.

Markers of neuroinflammation will be measured in the CSF, while markers of altered metabolism will be identified in the blood. These markers will be correlated to symptom expression. A panel of markers from each time point will be used to biologically distinguish those that develop ME/CFS from those that do not.

Our findings could give predictive evidence of long-term neurocognitive outcomes in HSE and suggest a causative chain of events where brain tissue damage increases the risk of subsequent prolongation of CSF inflammation and post-viral fatigue. The data could guide a future intervention study of immunosuppressive therapy administered in the recovery phase of HSE and other viral infections with neurological sequelae.

This study reveals why OMF uses the word “Collaborative” to describe the research that we fund! Our guiding philosophy is that a collaborative approach accelerates research.

In the words of OMF founder and CEO **Linda Tannenbaum**:

“We are delighted to fund this important project, which allows for collaboration between the Uppsala and Harvard Collaborative Research Centers. We want to thank our OMF family, whose support and advocacy make our research possible.”

Meta-Analysis Investigating Post-Exertional Malaise Between Patients and Controls

Abstract

Post-exertional malaise is either required or included in many previously proposed case definitions of myalgic encephalomyelitis/chronic fatigue syndrome.

A meta-analysis of odds ratios (ORs; association between patient status and post-exertional malaise status) and a number of potential moderators (i.e. study-level characteristics) of effect size were conducted.

Post-exertional malaise was found to be 10.4 times more likely to be associated with a myalgic encephalomyelitis/chronic fatigue syndrome diagnosis than with control status. Significant moderators of effect size included patient recruitment strategy and control selection.

These findings suggest that post-exertional malaise should be considered a cardinal symptom of myalgic encephalomyelitis/chronic fatigue syndrome.

Abigail Brown and **Leonard A Jason**

Source (open access): <https://bit.ly/2FMoU5c>

Activity Measurement in Pediatric Chronic Fatigue Syndrome

Abstract

Objectives

Individuals with myalgic encephalomyelitis (ME) and chronic fatigue syndrome (CFS) experience debilitating symptoms, including post-exertional malaise, an intensification of symptoms after physical or cognitive exertion. Previous studies found differences in the activity levels and patterns of activity among individuals with ME and CFS, compared to healthy controls; however, limited research exists on the activity levels of pediatric patients. The objective of this study was to examine differences in activity between healthy children and youth with ME and CFS.

Methods

The present study examines the objective (i.e., ActiGraphy) and self-reported levels of activity among children (ages 5 to 17) enrolled in a community-based study of pediatric CFS.

Results

Children with ME and CFS evidenced lower activity levels than healthy control children. Moreover, participants with ME and CFS evidenced increased nighttime activity and delayed initiation of daytime activity. Participants' self-reported activity data significantly correlated with their ActiGraph data, suggesting that children with ME and CFS are able to accurately describe their activity level.

Discussion

This study highlights differences in activity level and diurnal/nocturnal activity patterns between healthy children and those with ME and CFS. These differences should be considered in identifying appropriate supports and accommodations for children with ME and CFS.

Bernardo Loiacono, Madison Sunnquist, Laura Nicholson, Leonard A Jason

Source (paywall): <https://bit.ly/2FDmdD5>

Conversation With Mike VanElzaker

A conversation with **Mike VanElzaker**: how his research team studies neuroinflammation

Michael VanElzaker, PhD, is a neuroscientist affiliated at Massachusetts General Hospital, Harvard Medical School, and Tufts University.

He conducts his imaging research at the Martinos Center for Biomedical imaging (<https://bit.ly/2EksYZL>). We discuss how he uses fMRI and PET imaging to study neuroinflammation in patients with chronic disease, including the condition Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS).

One of the topics **Mike** talks about is microglia, which are immune cells in the brain. **Mike** uses the imaging technique PET with a PBR28 radioligand to detect where microglia may be activated in the brain of a living patient.

If you want to hear Mike talk more about activated microglia in ME/CFS watch this talk (<https://bit.ly/3hRtg85>) he gave on the subject.

Mike also mentions perivascular spaces – fluid filled spaces surrounding blood vessels that penetrate from the skull into the brain, and are enlarged during neuroinflammation. If you want to hear Mike talk about preliminary data his team has collected on perivascular spaces in ME/CFS watch this talk: https://youtu.be/OLdb9sqZi_o

Source: MicrobeMinded, **Amy Proal** <https://bit.ly/2Ej8xME>

Epidemiological and Clinical Factors

Epidemiological and clinical factors associated with post-exertional malaise severity in patients with myalgic encephalomyelitis/chronic fatigue syndrome

Alaa Ghali, Paul Richa, Carole Lacout, Aline Gury, Anne-Berengere Beucher, Chadi Homedan, Christian Lavigne & Geoffrey Urbanski

Abstract

Background

Post-exertional malaise (PEM), the cardinal feature of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), occurs generally after exposure to a stressor. It is characterized by the worsening of ME/CFS symptoms and results in aggravating the course of the disease and the quality of life of patients. Due to its unpredictable onset, severity, and recovery time, identifying patients with higher risk for severe PEM would allow preventing or reducing its occurrence. We thus aimed at defining possible factors that could be associated with PEM severity.

Methods

Adult patients fulfilling ME international consensus criteria who attended the internal medicine department of University hospital Angers-France between October 2011 and December 2019 were included retrospectively. All patients were systematically hospitalized for an etiological workup and overall assessment. We reviewed their medical records for data related to the assessment: epidemiological data, fatigue features, clinical manifestations, and ME/CFS precipitants. PEM severity was appreciated by the Center for Disease Control self-reported questionnaire. The study population was classified into quartiles according to PEM severity scores. Analyses were performed with ordinal logistic regression to compare quartile groups.

Results

197 patients were included. PEM severity was found to be positively associated with age at disease onset ≥ 32 years (OR 1.8 [95% CI 1.1–3.0] ($p = 0.03$)), recurrent infections during the course of the disease (OR 2.1 [95% CI 1.2–3.7] ($p = 0.009$)), and when ME/CFS was elicited by a gastrointestinal infectious precipitant (OR 5.7 [1.7–19.3] ($p = 0.006$)).

Conclusion

We identified some epidemiological and clinical features, which were positively associated with PEM severity in subsets of ME/CFS patients. This could help improving disease management and patients' quality of life.

Source: <https://bit.ly/3kEVzZ1> (open access)

A Mathematical Reconsideration of the Royal Free Epidemic of 1955

Myalgic Encephalomyelitis (ME) outbreaks can be modelled as an infectious disease: a mathematical reconsideration of the Royal Free Epidemic of 1955

F. G. Waters, G. J. McDonald, S. Banks & R. A. Waters

In 1970, two clinicians, **McEvedy** and **Beard** [**McEvedy** CP, **Beard** AW (1970) Royal Free Epidemic of 1955: A Reconsideration The British Medical Journal 1: No. 5687: 7-11] re-analysed some of the case notes, and hypothesised that the Royal Free outbreak was epidemic hysteria. This hypothesis was the beginning of an entrenched belief that the disease at the Royal Free, and similar cluster outbreaks, were psychosomatic. This was to have a profound effect on the interpretation of the same illness for nearly 50 years as a presumptive psychosomatic, an interpretation that has lasted nearly 50 years.

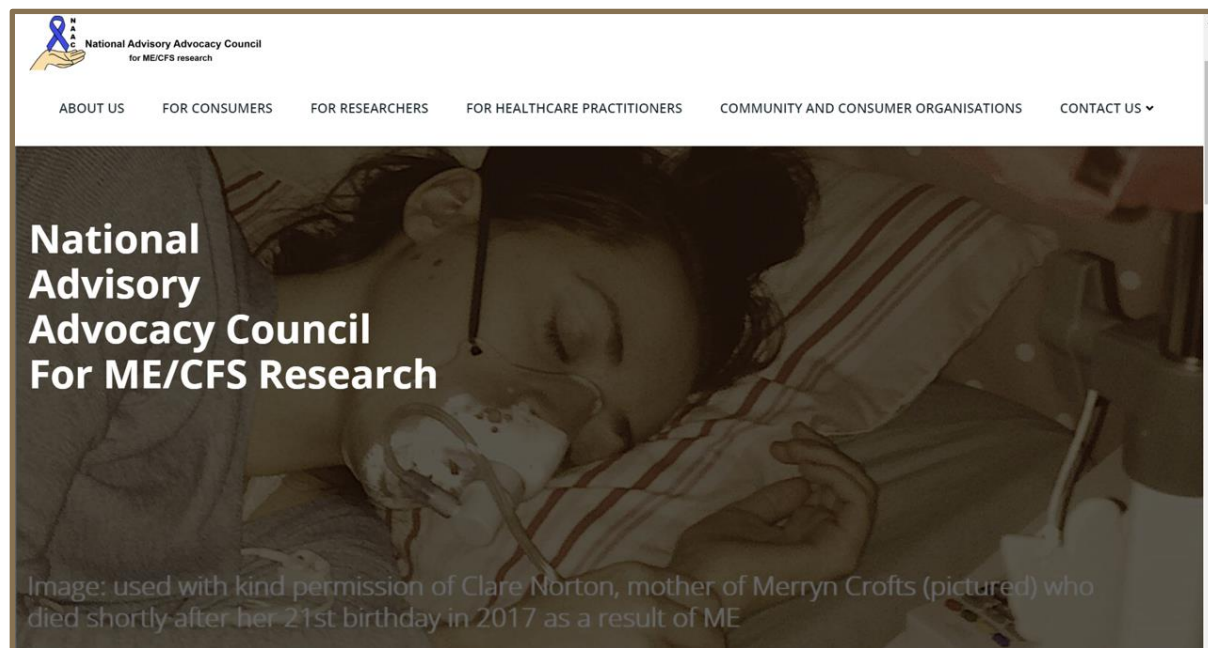
Methods : The 1927 Susceptible Infected Recovered (SIR) mathematical model [**Kermack** WO, **McKendrick** AG. Contribution to the mathematical theory of epidemics. Proc Royal Soc London. 1927;772:701–721] for the transmission of disease has been used to examine the published admission data from the Royal Free Hospital. for the purpose of finding out if the disease had the characteristics of a contagious disease. Similar cluster outbreaks have also been modelled to assess whether they have similar characteristics to the Royal Free outbreak.

Results: Using the 1927 Susceptible Infected Recovered (SIR) model [**Kermack** WO, **McKendrick** AG. Contribution to the mathematical theory of epidemics. Proc Royal Soc London. 1927;772:701–721] for the transmission of disease, we show that the epidemic of a disease of an unknown aetiology at the Royal Free Hospital in 1955, and other similar twentieth-century outbreaks, have the characteristics of a communicable disease. The disease causing the Royal Free outbreak was given the name 'Benign Myalgic Encephalomyelitis' by Acheson [A new clinical entity? Lancet. 1956;1:789–790] in 1956, now identified as ME.

Conclusions : By showing that the Royal Free and other ME attributed outbreaks fit the SIR disease model, we demonstrate that the **McEvedy** and **Beard** hysteria hypothesis is mathematically incorrect. The ensuing management of the treatment of ME/CFS-like conditions evolving from that, now mathematically improbable belief may need to be re-evaluated.

Source: <https://bit.ly/2ZT0cqM>

National Advisory Advocacy Council for ME/CFS Research (NAAC) Australia



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

Follow NAAC on Facebook for updates: <https://www.facebook.com/NAACMECFS>

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 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 also delivers research updates with their Monthly International Research Update found on the NAAC website. Subscribe here <https://bit.ly/33Kp7xL> to receive a copy in your email inbox.

About our council

Our members and contributors are connected leaders and influencers of the research agenda nationally and globally for ME/CFS. We connect people with a passion for further understanding of ME/CFS through research and the translation of robust findings to healthcare practice and consumer self-management for improved quality of life.

Who we are

Our diverse membership and contributorship represents researchers, citizens, consumers, carers, healthcare practitioners, service delivery leaders, educators, policy makers and others; all with a special interest in quality research in ME/CFS including translation of research findings into healthcare delivery and care services.

Our Values

The NAAC values are shared understanding, respect, transparency commitment and evidence-based.

In addition to supporting the scientific research agenda in ME/CFS, NAAC promotes integrity and ethical standards in research to deliver meaningful benefits to those living with ME/CFS and to the public.

Our Mission

To provide a reference point for patients, consumers health practitioners and researchers to find up to date information on ME/CFS research.

To provide a robust communication and collaboration platform between researchers, consumers, carers, healthcare practitioners, service delivery leaders, educators and policy makers in state and federal governments to enable relevant and high quality translatable research to deliver outcomes of value to consumers, carers and governments.

NAAC aims are:

- ✚ To facilitate a collaborative culture and encourage the best outcomes in ME/CFS research.
- ✚ To identify ME/CFS research priorities that will deliver benefits to consumers,
- ✚ To champion the translation of quality research into health and social policy,
- ✚ To build the capability of consumers and researchers to engage in ME/CFS research,
- ✚ To give consumers a voice in ME/CFS research,
- ✚ To support the engagement of clinicians through research,
- ✚ To lead and influence the progression of ME/CFS research innovation and discovery.

Research Unveiling the 'Invisible Illness'

ME/CFS Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) in New Zealand affects about 0.4% of the population. There will be up to 100 affected among our university student population. It is not surprising then when I mention our ME/CFS research in a lecture, those affected make contact.

When they talk to me they initially seem healthy, bright and interactive ("the invisible illness"). But having been part of an ME/CFS family now for 30 years, I understand they have rested and prepared for the visit, and after relatively short conversation fatigue often sets in.

This phenomenon explains why health practitioners and social agencies without a good knowledge of the illness are perplexed; indeed there are examples of WINZ-required designated doctor consultations of seven minutes resulting in pronouncement that the ME/CFS patient can work full time, despite being homebound long term by the ravages of their 'invisible' illness. For this reason my research group's focus has been to lift the 'veil of invisibility' and find biological explanations for the illness.

We have studied multiple classes of human biomolecules and how they differ between ME/CFS patients and healthy controls. We have discovered changes in the production of proteins that make up the complexes making energy in our cells, and patient - specific defects in the functioning of these complexes.

Significant changes have been discovered in the expression of genes in the DNA, particularly encoding proteins involving inflammation and the immune system, as well as metabolism and energy production. The tags on these genes (called the epigenetic code) that regulate this expression show many differences between ME/CFS patients and healthy controls.

These results provide an explanation why patients are so debilitated by their illness. Major research centres, set up in 2019 at Stanford and at Harvard Universities, after a resolution in the US senate acknowledging the seriousness of ME/CFS, give hope of our completely understanding the pathophysiology and finding therapies for the disease.

Prof. Warren Tate

Validation of the Severity of ME/CFS

Validation of the Severity of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome by Other Measures than History: Activity Bracelet, Cardiopulmonary Exercise Testing and a Validated Activity Questionnaire: SF-36

By **C. (Linda) M. C. van Campen**, **Peter C. Rowe** and **Frans C. Visser**

Abstract

Introduction

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a severe and disabling chronic disease. Grading patient's symptom and disease severity for comparison and therapeutic decision-making is necessary. Clinical grading that depends on patient self-report is subject to inter-individual variability. Having more objective measures to grade and confirm clinical grading would be desirable. Therefore, the aim of this study was to validate the clinical severity grading that has been proposed by the authors of the ME International Consensus Criteria (ICC) using more standardized measures like questionnaires, and objective measures such as physical activity tracking and cardiopulmonary exercise testing.

Methods and results

The clinical database of a subspecialty ME/CFS clinic was searched for patients who had completed the SF 36 questionnaire, worn a Sensewear™ armband for five days, and undergone a cardiopulmonary exercise test. Only patients who completed all three investigations within 3 months from each other—to improve the likelihood of stable disease—were included in the analysis. Two-hundred-eighty-nine patients were analyzed: 121 were graded as mild, 98 as moderate and 70 as having severe disease. The mean (SD) physical activity subscale of the SF-36 was 70 (11) for mild, 43 (8) for moderate and 15 (10) for severe ME/CFS patients. The mean (SD) number of steps per day was 8235 (1004) for mild, 5195 (1231) for moderate and 2031 (824) for severe disease. The mean (SD) percent predicted oxygen consumption at the ventilatory threshold was 47 (11)% for mild, 38 (7)% for moderate and 30 (7)% for severe disease. The percent peak oxygen consumption was 90 (14)% for mild, 64 (8)% for moderate and 48 (9)% for severe disease. All comparisons were $p < 0.0001$.

Conclusion

This study confirms the validity of the ICC severity grading. Grading assigned by clinicians on the basis of patient self-report created groups that differed significantly on measures of activity using the SF-36 physical function subscale and objective measures of steps per day and exercise capacity. There was variability in function within severity grading groups, so grading based on self-report can be strengthened by the use of these supplementary measures.

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

End of the Cognitive Era of Post-Viral Conditions

Scientific understandings of diseases have never been static but always subject to change and revision. Often, big scientific leaps take place in times of crisis. My prediction is that the wave of #LongCovid-19 (<https://bit.ly/3iQIUD8>) will fundamentally change how we view post-viral conditions.

I believe that the “cognitive era” of post-viral conditions will find its end rather soon. That is not to say that CBT won’t have its place in the treatment of patients. It can be crucial in helping them cope with their illness. But it cannot solve its physical causes.

Evidence for the biological basis of diseases such as #MECFS (<https://bit.ly/2FDLe0V>) is mounting and promising early developments of diagnostic blood tests have been recently published in world-leading journals such as PNAS. <https://bit.ly/2G0t60I>

As always, some, and especially those most invested in the old-fashioned approach, will resist these developments. But others will adapt. Indeed, for ambitious researchers, this is a scientifically exciting area where large discoveries still can be made.

So, why do I write this tweet today? I write it to give hope to all those suffering from chronic debilitating illnesses that have been ignored for too long. I believe that the coming years will bring unprecedented biomedical advances and hopefully effective treatment for many.

Jonas R. Kunst

Professor of Psychology

@UniOslo on twitter on Sunday July 12, 2020

<https://bit.ly/2ZT4jDe>

Free Leaflet: DecodeME – The Largest Ever Genetics Study!

July 1, 2020

Dr Charles Shepherd, Hon. Medical Adviser, ME Association.

This is a free 2-page leaflet (<https://bit.ly/3cvrMzh>) about an exciting new study that we hope will be shared with anyone who has ME/CFS and might be interested in taking part.

Please register your interest now by visiting the DecodeME (<https://bit.ly/2G1xXPo>) website. The study will begin in September with recruitment from March 2021.

Full details about the study's launch, with comment from all involved, are available in the press release (<https://bit.ly/3hRwvMF>) from 23rd June 2020.

Please note:

Members of the ME Association will receive this free leaflet with the July issue of ME Essential magazine.

Patients, Scientists and Advocates Celebrate
£3.2m Funding for DecodeME, the Largest Ever Genetics Study!

Leaflet Extract:

Funding for the world's largest genetic study into myalgic encephalomyelitis (M.E.), led by a partnership of patients and scientists, was announced on 23rd June.

Despite its high cost to patients, the economy, the NHS and society, very little is known about the causes of M.E., also diagnosed as chronic fatigue syndrome (CFS, or ME/CFS), including how to treat it effectively.

Now, thanks to £3.2 million funding, awarded jointly by the Medical Research Council and National Institute for Health Research, work can begin on DecodeME, the ME/CFS DNA study that hopes to reveal the tiny differences in a person's DNA that may affect their risk of developing ME/CFS and the underlying causes of the condition.

DecodeME will look at samples from 20,000 people with ME/CFS, in the hope that the knowledge discovered will aid development of diagnostic tests and targeted treatments.

ME/CFS affects an estimated 250,000 people in the UK, of all ages, and from all social and economic backgrounds.

📄 Download this new free leaflet here (<https://bit.ly/3cvrMzh>) or find it in the ME Association website shop (<https://bit.ly/32UUiat>).

Post-exertional malaise, an adverse reaction to levels of exertion that many might consider trivial, is often considered to be the defining symptom – this can leave patients suffering from symptoms including extreme levels of fatigue, pain, inability to process information, and light and noise sensitivities.

One in four people with ME/CFS are so severely affected they are house- and frequently bed-bound.

“Having been involved in the planning and development of the DecodeME study we are delighted to learn that the Medical Research Council and the National Institute for Health Research have agreed to provide a massive grant of over £3 million to ensure that this research can now commence.

“This type of ‘genetic fingerprint’ study is already providing important information about the cause of some types of eye disease, Parkinson’s disease and prostate cancer.

“Finding the genetic fingerprints for ME/CFS could therefore provide us with vital clues to help with diagnosis, treatment and even the prevention of ME/CFS.

“Active patient involvement is right at the centre of the Decode ME study and the CURE ME team at M.E. Biobank, which is funded by the ME Association Ramsay Research Fund, will be playing a central role in patient recruitment.

“So we hope that people will now sign up and register their willingness to take part in this exciting new biomedical research project.”

Dr Charles Shepherd

Hon. Medical Adviser, ME Association.

Source: ME Association, <https://bit.ly/3kHo7kR>

Link to the leaflet talked about: <https://bit.ly/3cvrMzh>

Plasma Proteomic Profiling Suggests an Association Between Antigen Driven Clonal B Cell Expansion and ME/CFS

Milica Milivojevic , Xiaoyu Che , Lucinda Bateman, Aaron Cheng, Benjamin A. Garcia, Mady Hornig, Manuel Huber, Nancy G. Klimas, Bohyun Lee, Hyoungjoo Lee, Susan Levine, Jose G. Montoya, Daniel L. Peterson, Anthony L. Komaroff, W. Ian Lipkin

Abstract

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) is an unexplained chronic, debilitating illness characterized by fatigue, sleep disturbances, cognitive dysfunction, orthostatic intolerance and gastrointestinal problems.

Using ultra performance liquid chromatography-tandem mass spectrometry (UPLC-MS/MS), we analyzed the plasma proteomes of 39 ME/CFS patients and 41 healthy controls.

Logistic regression models, with both linear and quadratic terms of the protein levels as independent variables, revealed a significant association between ME/CFS and the immunoglobulin heavy variable (IGHV) region 3-23/30.

Stratifying the ME/CFS group based on self-reported irritable bowel syndrome (sr-IBS) status revealed a significant quadratic effect of immunoglobulin lambda constant region 7 on its association with ME/CFS with sr-IBS whilst IGHV3-23/30 and immunoglobulin kappa variable region 3–11 were significantly associated with ME/CFS without sr-IBS.

In addition, we were able to predict ME/CFS status with a high degree of accuracy (AUC = 0.774–0.838) using a panel of proteins selected by 3 different machine learning algorithms: Lasso, Random Forests, and XGBoost.

These algorithms also identified proteomic profiles that predicted the status of ME/CFS patients with sr-IBS (AUC = 0.806–0.846) and ME/CFS without sr-IBS (AUC = 0.754–0.780).

Our findings are consistent with a significant association of ME/CFS with immune dysregulation and highlight the potential use of the plasma proteome as a source of biomarkers for disease.

Source: Plos One (open access) <https://bit.ly/2FZXAk2>

A Proteomics Study From The Center: Searching For The Criminal

By **Dr. Anthony Komaroff**

On July 21, 2020, the results of a proteomics study by the Center for Solutions for ME/CFS was published by the journal PLoS ONE (<https://bit.ly/332nV9E>).

Milivojevic M, Che X, Bateman L, Cheng A, Garcia BA, Hornig M, Huber M, Klimas NG, Lee B, Lee H, Levine S, Montoya JG, Peterson DL, Komaroff AL, Lipkin WI.: Plasma proteomic profiling suggests an association between antigen driven clonal B cell expansion and ME/CFS.

Dr. Antony Komaroff wrote a survey, parts of which follow:

What did the latest study from the Center show? Basically, two things:

- ✚ There appears to be a distinctive “signature” of a small group of proteins that distinguishes people with ME/CFS from healthy people;
- ✚ The proteins involved in that “signature” are primarily involved in the immune response—particularly the response of immune cells called B cells—to infections, and the response seen in autoimmune diseases.

It is possible that the “signature” that has been found might some day become a diagnostic test for ME/CFS. A perfect diagnostic test for a disease (in this case, ME/CFS) has two essential elements:

- ✚ It must have no “false negatives”: the test result can never be negative (“normal”) in a person who really does have the disease.
- ✚ It must have no “false positives”: the test result can never be positive (“abnormal”) in a person who does not really have the disease.

There are very few perfect diagnostic tests in medicine, but there are many that come pretty close to perfection. For the signature that the Center’s study has identified to become a diagnostic test it will need to be tested again:

- ✚ In larger numbers of people with ME/CFS from all over the world to determine whether the test has a very low false negative rate;
- ✚ In large numbers of people with diseases other than ME/CFS that also can cause the hallmark symptoms of ME/CFS—fatigue, post-exertional malaise, unrefreshing sleep, cognitive impairment, orthostatic intolerance—to determine whether the test has a very low false positive rate in those diseases.

The new study is consistent with prior studies that have found abnormalities related to B cells in people with ME/CFS.

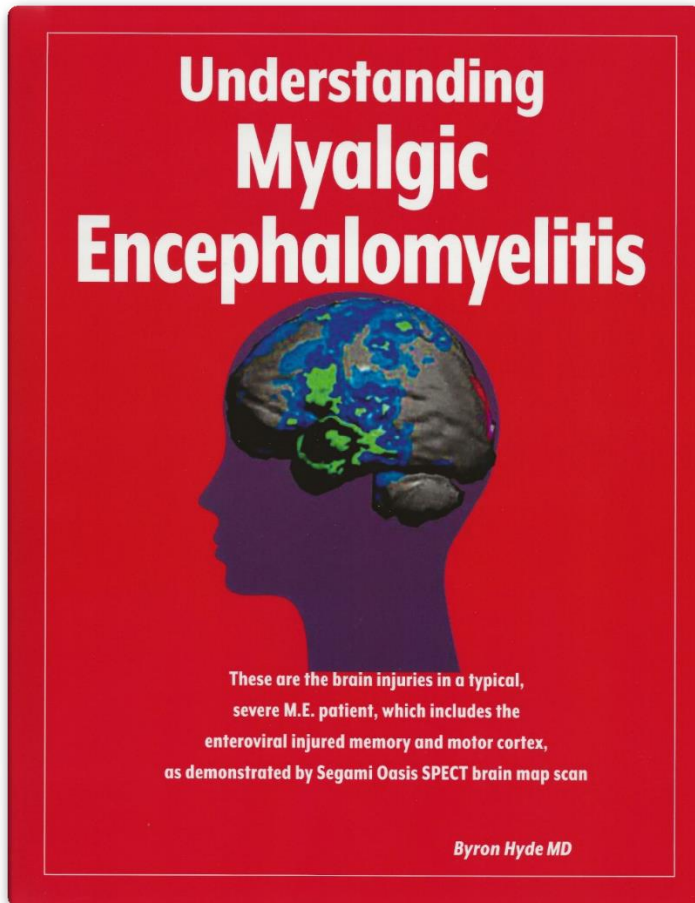
Does this study have implications for treatment?

The study—like most studies—seeks to identify what is going wrong in the body of people with this illness. The reason for this is not just because the answer might be interesting, but because the answer might provide a target to shoot at with a treatment.

In this case, the study may prompt scientists to test more ways to quiet overactive B cells (some past attempts have failed), particularly the production of autoantibodies. Also, if further studies can identify the antigens that the activated immune system is activated by, these results may reveal underlying toxins, infectious agents, or other foreign molecules that can themselves be targeted .

Source: CENTER FOR SOLUTIONS FOR ME/CFS, <https://bit.ly/3ic1Vhf>

News on behalf of Dr. Byron Hyde



The final version of the book "Understanding Myalgic Encephalomyelitis" is now finished and the final details are being sorted out regarding distribution, online selling, shipping, etc.

We have not been able to update the Nightingale website since 2018 so we ask for patience while it is updated to reflect the new book. It can still be pre-ordered from there (<http://www.nightingale.ca>).

The book is over 300 pages with many photos, diagrams etc. and now has a red cover instead of green. This is because it can be read as a companion book to the small book "The Return of Polio to the USA", which also has a red cover.

[The Polio book will be withdrawn from Amazon/Kindle in the near future and replaced with a 2nd edition, re-titled "Myalgic Encephalomyelitis and The Return of Polio to the USA". This was done because updated statistics and graphs regarding Acute Flaccid Paralysis became available from more countries and have been added.]

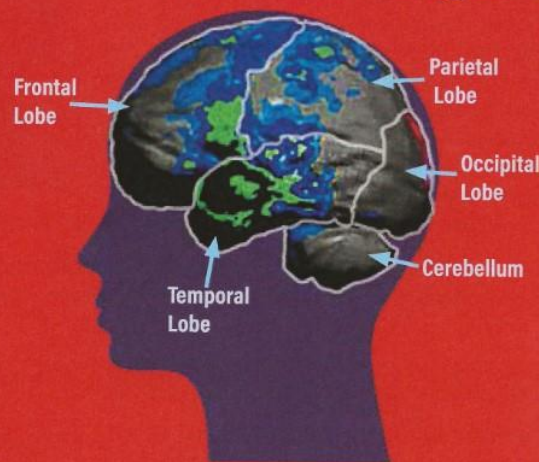
But back to "Understanding Myalgic Encephalomyelitis". A quote from **Dr. Hyde** : "My interest in SPECT and PET technology was stimulated by my meetings and long-time friendship and association in California and Chile with **Dr. Ismael Mena** and **Dr. Sonia Neubauer** concerning in part, the otherwise invisibility of:

- ✚ Post-infectious enteroviral brain diseases, i.e. Myalgic Encephalomyelitis,
- ✚ Toxic chemical chronic brain injuries, just one of a group of the many pathologies mislabeled as Chronic Fatigue Syndrome (CFS),
- ✚ Sports and other minor and moderate repetitive brain traumatic injuries, and
- ✚ Multiple other progressive either acquired or genetic brain injuries often missed and labeled, in their early stages, as anxiety or minor psychiatric disease.

None of the above four mentioned items is generally visible on CT and MRI scan nor are they generally demonstrated on routine blood analysis, yet cause tens of thousands of chronic diseases and disabled patients in the USA, Canada, the UK and Australia, where I have had the good fortune to have investigated patients. Because of their relative invisibility, these serious debilitating chronic and sometimes progressive illnesses are not diagnosed correctly and thus they are frequently discounted by primary care physicians and internists.

Understanding Myalgic Encephalomyelitis

The New Polio & The Chronic Fatigue Syndromes



These are the brain injuries in a typical, severe M.E. patient, which includes the enteroviral injured memory and motor cortex, as demonstrated by Segami Oasis SPECT brain map scan.

The black area (Brodmann 38) involves most of the left anterior temporal lobe. This is the brain's principal memory retrieval and despatching area sending information to the cingulate gyrus in order to activate any demands. This woman's memory has been seriously and permanently made dysfunctional.

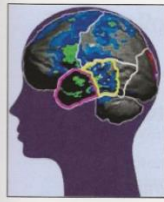
The left motor cortex at the posterior part of the left frontal lobe, though not as severely injured as the memory cortex, is also seriously injured. This is probably one of the central causes of this patient's rapid muscle fatigue and weakness.

At the base of the central sulcus, at the base of the motor cortex there is another largely black area. That is overlying the Insular Cortex. When the (1) Insular Cortex and the (2) Vermis area of the anterior superior cerebellum is involved, as in this patient, the patient have an inability to organize their circulating blood volume and pressure as seen in POTS, (Postural Orthostatic Tachycardia Syndrome). This patient is so injured. What that means is when she tries any rapid movement she risks losing consciousness and her heart rate accelerating.

This woman who fell ill doing her MA at Queens University over 20 years ago, has never recovered and has been largely housebound ever since. This, in one patient, explains a typical M.E. injury causing major and usually permanent disability. This is also how easy it is to diagnose a major M.E. injury.

Byron Hyde MD

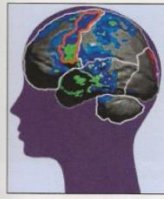
M.E. represents a neurological injury caused by enteroviruses and can be most easily observed employing Segami SPECT software, as in these images, even by physicians who are not trained nuclear radiologists.



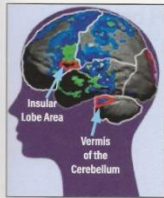
When an M.E. patient finds their memory, or "their brain is not working" or defective, what they mean in neurological terms is that the anterior left temporal lobe, (encircled in pink in this image) has been injured by an enteroviral infection. The anterior left temporal lobe is the librarian of all processing, recovering of information data storage and retrieval. It is also the area of the brain which sends off information to the posterior cingulate gyrus of the limbic system, (not shown here) to be acted upon as part of the administrative system, to administer body functions. This does not mean the temporal lobe had been destroyed, it means the blood supply, providing the memory brain with blood (energy & oxygen) has been compromised, exactly like the arterioles

to the anterior spinal cord have been compromised in a paralytic Polio patient.

If the anterior temporal lobe is the librarian, the mid-temporal area, (encircled in yellow), is equivalent to the runners in the library who retrieve or return books (information) to and from the stacks.



Orange Circled Area: This is the visible motor cortex of the brain, the area which directs striated muscle function in the body. When this area is injured as in this patient, the muscles tend to be weak or tire rapidly, in the same way as the memory function becomes dysfunctional when the blood supply (energy) is compromised.



Autonomic Function Control: The three most important areas controlling Autonomic Function are in (a) the brain stem, (which we cannot visualize with this technology), (b) in the area of the insular lobe and (c) in the Vermis of the Cerebellum, shown in this brain model. When these brain areas are injured, the patient has Dysautonomia. This means they can no longer control the autonomic functions supplying various body and brain parts with sufficient blood (energy) to function adequately. This results in POTS, (Postural Orthostatic Tachycardia Syndrome). The patient may fall, lose consciousness, their heart rate can go from a normal 60-80 to 150-200. They find it very difficult to even get out of bed, (but they must).

It is therefore necessary to know if the brain has been:

- ✚ physiologically damaged, and from a scientific and clinical understanding,
- ✚ what part of the brain has been damaged and to what degree. All of which may have resulted from a serious, chronic physiological injury.

Most if not all of the above can be documented by the physiological and microvascular mapping of brain functions and injury with SPECT and PET scanning technology. They are otherwise invisible on CT and MRI brain scans."

We hope to be publishing and shipping "Understanding Myalgic Encephalomyelitis" in October.

Dr. Hyde's work is even more prescient and relevant in 2020 as we now see how certain

countries' inadequate response to viral outbreaks in the past has left them unprepared for the current pandemic.

The book covers a vast scope of M.E. history and science, but above all it advocates for precise diagnosis of M.E., through both enteroviral testing to prove infection, and SPECT scans to prove brain dysfunction. There is extensive explanation of SPECT procedure and interpretation in this publication, which will be useful for patients and physicians alike. The goal is diagnosis for all patients, those with M.E. and those who have been grouped under the false constructs of "CFS" or "ME/CFS".

We thank you for your support and your patience with this book's progress. Sept.2020, Ottawa, Canada.

Submitted by **Allison May**

9. Severe ME



Don't Let Us Down

Sadly this is a list of some of the ways people with Very Severe ME are let down:
Families who do not seek to truly understand Very Severe ME, let us down.
Friends who walk away, judge, blame or just get tired of people with Severe ME, as being too difficult to connect with, let us down.

Neighbours who chose to ignore the needs of people with Severe ME because they are too inconvenient for them to be bothered with, let us down.

Charities who support, in any way, the Biopsychosocial interpretation of ME in any form, by collaboration or validation or simply by not standing up against the misinformation and mistreatment of ME, let us down.

Clinicians and other practitioners who chose to follow a psychosocial interpretation and agenda that completely denies the reality of the disease let us down.

GP's and other medical professionals who chose not to do home visiting to those unable to go to them, let us down.

Anyone who puts their own opinion and pet theory above the truth of Severe ME, lets us down.

Anyone who says, this disease does not exist lets us down.
Anyone who says, "but you look so well...." lets us down.
Anyone who ignores the reality of people with Severe ME , lets us down.

Anyone who chooses to misuse the name Myalgic Encephalomyelitis and change its meaning from an Enteroviral Disease to a generalised fatigue state lets us down.

Anyone who believes there is no underlying pathology to the disease, lets us down.

Anyone who ignores the fact that paralysis is a very real symptom of people diagnosed with Severe/Very Severe ME, lets us down.

Anyone who negates the reality of a person diagnosed with Severe ME and mistreats them as a consequence, lets us down.

Anyone who misinterprets people with Severe ME, lets us down. Anyone who mistreats people with Severe ME, lets us down.

Anyone who misdiagnoses people with Severe ME, lets us down. Anyone who misunderstands people Severe ME, lets us down.

Anyone who denies Severe ME, lets us down.
Anyone who collaborates with people who deny the physical reality of Severe ME, lets us down.

Anyone who denies the underlying pathology to the the disease, lets us down.

Anyone who does not provide ongoing Clinical Support to people with Severe ME, lets us down.

Anyone who does not listen to people with Severe ME, lets us down

Anyone who does not teach correct information about the disease, lets us down.

Anyone who leaves people with Severe ME neglected with little or no proof of the severity of their illness, lets us down.

Anyone who pretends to consult, but not following through with the findings, lets us down.

Anyone who is not up to date with medical research and information about Severe ME, lets us down.

Anyone who uses poor research criteria, lets us down. Anyone who ignores patient input, lets us down.

Anyone who does not create a biomedical health pathway for people with Severe ME, lets us down.

Anyone who writes wrong reports about people with Severe ME, lets us down.

Anyone who is self-justified in their ignorance, lets us down. Anyone who fails to reach out to people with Severe ME , lets us down.

Anyone who is not committed to staying with and helping people with Severe ME, lets us down.

Anyone who allows people with Severe ME to be underfunded for basic living needs, lets us down.

Anyone who ignores the key symptoms of Severe ME, lets us down.

Anyone who plays down the severity or experience of Severe ME, lets us down.

Anyone who leaves the most ill to get on with it alone in isolation and separation, without the ability to speak up or help themselves, lets us down.

Anyone who is hostile to people with Severe ME, lets us down,

Greg & Linda Crowhurst, September 2, 2020

Source: Stonebird <https://bit.ly/2RKbvgf>

The British 25% Group

The 25% ME Group celebrated both its 25th anniversary this year and Severe ME Awareness and Remembrance Day on 8 August.

As part of our honouring this day, we featured severe ME sufferers' short stories/images of how the illness affects them. Please see examples below.

Please get involved if you can to help us raise awareness of severe ME. We feature these stories/pics on our website and newsletter and also feature/share them on Facebook.

<https://25megroup.org/severe-me-day-2020>

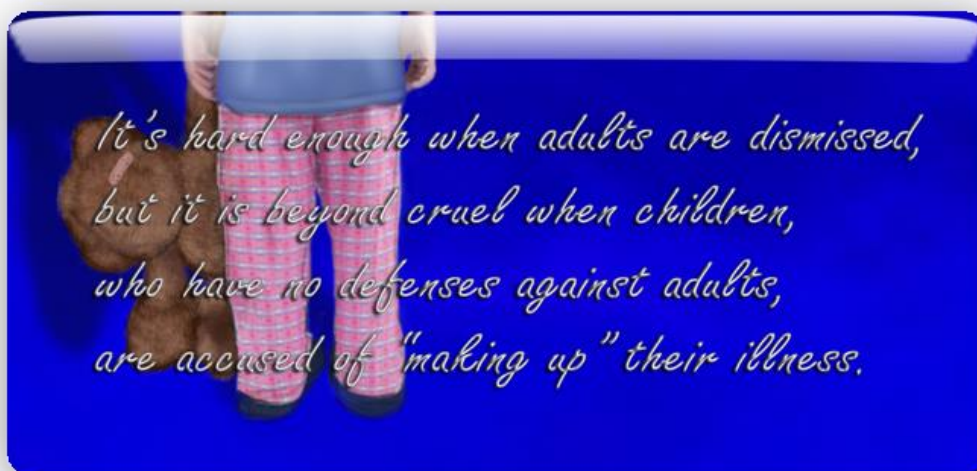
"I became ill so many years ago, back in the 1990's. We thought I had a really bad case of flu to start with, but I just didn't get better. I couldn't believe how ill I felt. What was this mystery illness? I eventually had to go back to work, but I wasn't able to do anything else and my health was getting worse and worse. And no one seemed to care! I looked well, but I certainly wasn't well. Turns out I originally had mild-moderate ME, but due to being constantly advised to just try harder I became more and more ill and now I have Severe ME. I still look well, people don't see the PENE (post exertional neuroimmune exhaustion) cos I'm hidden away in my bed, having to reduce my interaction with others, being looked after by paid carers. I was originally told by doctors that everyone got better from ME, that I was the only one who hadn't got better. Then I heard about 25% ME Group. I learned that 25% of ME sufferers remain long term ill and are severely disabled. The doctors were wrong. I was not alone. I would never be alone again. I was so happy to find the 25% ME Group and it's members."

"I've made lots of friends since joining 25% ME Group. I'm a member of both the charity and the Facebook group. I've learned that we all have the same core symptoms of ME, but we also differ in many ways. Some can't tolerate heat, others can't tolerate cold. Personally, I need to keep warm all the time. Thank goodness for my electric blanket and central heating!"

"My life has changed dramatically since I developed severe ME. I used to be extremely active and had a good career and social life. I was fit and healthy, I was a keen sportswoman and assumed I would always be like that. But severe ME changed all that. I'm now almost bedridden. I can't care for myself. I'm lucky because I have kind carers. They try to make life more comfortable for me, but I have to discourage visitors because they exhaust me too much."

"My 25% ME Group Newsletter is always a great to read. I love it. I wait to read it until I have some uninterrupted time. I make sure I have a drink and maybe some biscuits and then I start reading it. I try to start at the beginning and work my way through, but sometimes I skip the longer articles and come back to them later when I can concentrated on them better because I'm too keen to see what's on the next page. I've learned some interesting tips from other people from the newsletters and I especially like the one that arrives (hopefully) just before Christmas "

10. ME And Children



Severe ME in Children

Healthcare 2020, 8(3), 211; <https://doi.org/10.3390/healthcare8030211>

Received: 21 May 2020 / Revised: 6 July 2020 / Accepted: 9 July 2020 / Published: 14 July 2020 (This article belongs to the Special Issue ME/CFS – the Severely and Very Severely Affected <https://bit.ly/3j5YKsn>) - Link to the complete study: <https://bit.ly/340leEX>

Abstract

A current problem regarding Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) is the large proportion of doctors that are either not trained or refuse to recognize ME/CFS as a genuine clinical entity, and as a result do not diagnose it. An additional problem is that most of the clinical and research studies currently available on ME are focused on patients who are ambulant and able to attend clinics and there is very limited data on patients who are very severe (housebound or bedbound), despite the fact that they constitute an estimated 25% of all ME/CFS cases. This author has personal experience of managing and advising on numerous cases of severe paediatric ME, and offers a series of case reports of individual cases as a means of illustrating various points regarding clinical presentation, together with general principles of appropriate management.

From the article:

Take Home Messages

- ✚ Severe ME constitutes a major challenge for both patient and doctor.
- ✚ Mismanagement in the form of “activation regimes” can result in permanent harm or even death of the patient.
- ✚ The patient deserves the total commitment of one doctor, who is willing to visit at home on a regular basis.
- ✚ Referral to a psychiatrist who does not believe in ME/CFS can be harmful.
- ✚ The patient should be protected from sensory overload.
- ✚ The doctor should resist the temptation to overinvestigate, or involve too many other professionals.
- ✚ Nursing at home is usually far preferable to admission to a busy general hospital.
- ✚ Tube feeding is indicated when the patient has problems with eating and drinking.
- ✚ Urinary catheterization may be helpful in reducing the stress of having to micturate.
- ✚ Symptomatic treatment for pain and sleep problems is worthwhile.
- ✚ Full recovery is possible.
- ✚ The role of immunoglobulin deserves further study.
- ✚ There is a need to improve both undergraduate and postgraduate medical training in this area, and to provide greater resources for the patient population affected.

By **Nigel Speight**

Paediatrician, Southlands, Gilesgate, Durham DH1 1QN, UK

11. News from





Media Opportunity for Young People and Carers in Australia

- ✚ Junkee Media has put a call out for young people, and for family members and carers of young people, to be interviewed on-camera to speak about their experiences of ME/CFS.
- ✚ “Our aim is to present a collection of interviews that show a range of different lived-experiences with ME/CFS, without sensationalism and with careful attention to the health-literacy objectives of the ME/CFS community,” explains Junkee Media’s **Alex Sutcliffe**.
- ✚ “We want to help shift our youth audience’s literacy beyond an awareness of ME/CFS and towards an understanding of how it feels to live with ME/CFS.”
- ✚ Junkee Media is seeking to interview:
 - People aged 16-30 living with ME/CFS (where it is safe to do so)
 - Family members and carers of people aged 16-30 who would like to represent loved ones who are homebound, or unable to safely share their story on camera
 - The Sydney-based media organisation hopes to film the interviews from their Surry Hills studio. “We understand that this will be prohibitively difficult for many people living with ME/CFS, and would like to foreground the important contributions of family members and carers who are able to represent those unable to travel, or speak with us,” **Alex** says.

The organisation has a full COVID-19 safety process in place and will re-assess government requirements and advice closer to the time of filming to ensure the safety of participants and staff.

For more information or to express interest in taking part please contact **Alex** at asutcliffe@junkeemedia.com



GP Education Anniversary

It’s hard to believe it’s been one year since Emerge Australia launched its first GP Education module!

The one-hour module, Busting the myths and redefining myalgic encephalomyelitis/chronic fatigue syndrome, was developed in conjunction with ThinkGP to address the need for more GP education about ME/CFS. The module is free for health professionals and provides continuing professional development points (CPD) as an added incentive for doctors in both Australia and New Zealand. This is the first ME/CFS GP education program to have such approval in both countries.

Since its launch a total of 518 health professionals including more than 400 doctors have completed the module – and the feedback has been overwhelmingly positive, for example:

- ✚ Best online course on the issue that I have seen
- ✚ I have a couple of patients with this and had no idea about the number of available resource
- ✚ This is a very common presentation in my clinic and I'm glad I did this course
- ✚ This should be part of mandatory training

Thanks to our Christmas fundraising appeal we have developed a second module with ThinkGP, which will expand on content in Module 1 as well as providing information specific to severe and paediatric patients, and resources to help GPs support their patients at school, work or when applying for support services.

Module 2 will be launched later in the year and Module 1 has been temporarily paused so both will run concurrently for 12 months.

Keep an eye out for the upcoming quarterly Emerge journal for a full report on our GP Education program!



Severe ME Day 2020

Each year Emerge Australia joins the global chorus of voices to mark Severe ME Day on August 8, to honour the strength of spirit of the severely affected community. The global awareness campaign is dedicated to raising the visibility of the 25% of people who are severely affected by ME/CFS.

This year our online campaign asked the ME/CFS community to:

- ✚ Send messages of support and solidarity on our Facebook page to the estimated 60,000 Australians with ME/CFS who are completely confined to their beds and homes and the most invisible in research, support, awareness, education, work and every aspect of our society
- ✚ Share a powerful new 15-minute documentary Severe & Very Severe ME/CFS (<https://bit.ly/35ZORsR>) from the UK film team behind The Voices from the Shadows
- ✚ Join the Open Medicine Foundation's Severe ME Day initiative, #TheViewforME, which asked all people affected by severe ME/CFS and their families, loved ones and carers, to show the world what their lives look like with a photo of their daily view through social media

Our deepest thanks goes to everyone who participated in this online campaign. By contributing, sharing, commenting and liking, your support helped to spread the reach of this campaign throughout the world.

Source: Emerge Australia September News

Belgium



Patient organizations have provided extensive feedback to the Supreme Health Council, which is currently working on a new report on ME/CFS.

The process is in its final stages, so the report can be expected to appear in the coming months. It remains to be seen if Belgium will follow the positive developments in the Netherlands and elsewhere.

In 2002 our country invested in several CFS centers where graded exercise therapy (GET) and cognitive behavior therapy (CBT) were offered as standard treatments.

Many of the ME/CFS 'experts' we have today have worked previously in these centers, which could make it difficult for our country to change course.

The 2018 report from the CFS center in Leuven, however, offered hope of change as it accepted some of the published critiques on GET and CBT.

Michiel Tack

<https://12me.be>

Czech Republic



Open Letter to the Medical Authorities in the Czech Republic

On June 22, 2020 our Czech ME/CFS Association sent a letter to the Czech health authorities, supported by 63 international researchers and clinicians and being followed by 22 statements of Czech patients mostly with their picture about the impact ME has on their health and lives.

We decided to take this step after our proposal to develop ME/CFS diagnostic and treatment guidelines for general practitioners was rejected in December 2019. We have been striving for this for many years.

We are also demanding to include the diagnosis G93.3 to the decree on the disability assessment.

The full text of the letter in English can be read here: <https://bit.ly/33F1PsU>

We are pleased that, based on our letter, the issue of creating ME/CFS guidelines will be reopened and the Senate Committee on Health and Social Policy will deal with the situation of patients with ME/CFS.

Moreover, two interpellations have been submitted in the Chamber of Deputies of the Czech Republic. The first one was sent to the Minister of Health, **Adam VOJTĚCH**, who replied:

- ✚ Research funding is not the responsibility of the Ministry of Health, however, the Ministry will support ME/CFS within its capabilities. No proposal for the ME/CFS research project is currently registered in the Czech Republic.
- ✚ The Ministry does not plan to set up a special working group focused on ME/CFS.
- ✚ The Ministry supports the development of clinical guidelines for ME/CFS and therefore has invited the members of the responsible Committee to reconsider this issue.
- ✚ The Ministry does not plan to establish a specialized center for the treatment of ME/CFS.

The second interpellation was addressed to the Minister of Labor and Social Affairs (MPSV), **Jana MALÁČOVÁ**, who replied:

- ✚ The Ministry does not intend to include ME/CFS in the disability assessment regulation, arguing that the issue of "chronic fatigue syndrome" has not been resolved for a long time and unequivocally by experts.
- ✚ Diagnosis G93.3 can only be used in cases when a viral brain disease and subsequent post-viral fatigue syndrome are proven with certainty.
- ✚ If the patient exhibits a state of fatigue without prior evidence of neuro infection and viral brain inflammation, there may be another cause of long-term poor health (immune disorders, mental illness, condition after cancer treatment).
- ✚ The Ministry does not agree with the claim that the fundamental and long-standing injustice is happening to this group of inhabitants.



We cannot agree with those statements (MPSV) in any way, so we are preparing another interpellation on Minister MALÁČOVÁ.

The Educational Seminar: Current View of Chronic Fatigue Syndrome (ME/CFS)

The educational seminar on ME/CFS for general practitioners, outpatient specialists, and other physicians will be held at the

Institute for Postgraduate Medical Education in Prague (IPVZ).

Place and date: Prague, 30.10.2020

In case of an unfavorable epidemiological situation it will be held online.

Lecturers:

- ✚ **MUDr. Milan TROJÁNEK**, Ph.D., Department of Infectious, Parasitic and Tropical Diseases, Na Bulovce Hospital; Department of Infectious Medicine IPVZ, Czech Republic
- ✚ **Kristian SOMMERFELT**, Dr., PhD., Professor of Pediatrics, University of Bergen, Norway
- ✚ **Per JULIN**, MD, PhD., Associate Researcher, Department of Neurobiology, Care Sciences and Society, Karolinska Institutet Senior Consultant, ME/CFS policlinic, Neurological Rehabilitation Clinic, Stora Skondal Foundation, Stockholm, Sweden
- ✚ other experts – it will be specified
- ✚ representatives of the patients

Course topics:

Opinions of leading foreign and Czech experts on epidemiology, pathophysiology, and possible therapy of chronic fatigue syndrome. The course aims to disprove the most common myths and open a rational discussion on this issue.

The details of the course can be found here: <https://bit.ly/2HjQgjz>

A recording will be available.

The seminar is organized by the Czech ME/CFS Association in cooperation with MUDr. **Milan Trojánek**, Ph.D.

The official auspices is provided by the Ministry of Health of the Czech Republic.

Note of the editors: all the pictures mentioned in the first paragraph can be found here: <https://mecentraal.wordpress.com/grassroot/>

Denmark



The Corona situation has completely taken over Denmark at the moment. We also discuss circumcision and whether one may use the word Eskimo.

But **Stig Gerdes** gave up leading the trial, because he had 7 important questions for the court, but the court only allowed him to ask 1 question, and then **Stig** gave up, he would have lost in advance then.

But now he is writing a book about the whole process with **Karina** and his lost authorization. He reckons it may be released around January. He will have it translated into English as well.

The National Board of Health continues to refer to ME as a functional disorder in their new guidelines, and they have come up with such an absurd definition of ME, so that everyone with ME in future will be diagnosed with functional disorders and not with ME.

The National Board of Health apparently believes in their new guidelines that if you have ME, it should be visible in a spinal cord sample, which is not appropriate. And spinal cord tests can be unpleasant and dangerous, and not many people with ME will accept a spinal cord sample.

So because not many people will accept a spinal cord sample, and because spinal cord samples can be without result if you have been ill for a long time, Danish ME-sick citizens will certainly get the diagnosis functional disorders in the future, which is a psychiatric diagnosis, and which is exactly what the National Board of Health wants.

I have asked the Minister of Health if he can be satisfied with The National Board of Health's new guidelines when the Parliament has decided that ME is a PHYSICAL disease, but as usual he has not answered.

Bente Stenfalk

Germany



All four German ME/CFS patient organizations call for round table
In response to the European Parliament's resolution on ME/CFS, all four patient organizations – Deutsche Gesellschaft für ME/CFS, Fatigatio e.V., Lost Voices Stiftung and #MillionsMissing Deutschland – have joined forces to address the political community. The goal is to set up a round table with the Federal Ministry of Health, Federal Ministry of Education and Research, Federal Ministry of Labour and Social Affairs, as well as representatives from the medical and scientific community and ME/CFS patient organizations. The Round Table is intended to address the demands of the European Parliament resolution of June 18. There hasn't been a response from politics yet. <https://bit.ly/2RMJ0ie>



First German initiative for children and adolescents with ME

The first German association for kids with ME/CFS was founded: "Parents' initiative for children and adolescents with ME/CFS Munich". Professor Uta Behrends (University Munich) and other medical professionals are in the committee. The goal is to support and connect families, as well as to inform doctors, schools and authorities to improve the situation for kids with ME.

<https://www.mecfs-kinder-muc.de>



Postcards to politicians

#MillionsMissing actions in ten cities were planned for May - three times more than ever before. Since they had to be cancelled due to Corona, a postcard campaign was launched at short notice by #MillionsMissing Germany. The campaign was supported by all German patient organizations. Regarding the popular topic of isolation due to Corona, pwME wrote postcards to the Minister of Health and other politicians, stating for how many thousand days they have been living in isolation.

<https://bit.ly/3cphG2Q>



Media reports from Germany

- ✚ Tagesspiegel: "How a disease made my friend disappear" <https://bit.ly/2RQ3yq7>
- ✚ Berliner Zeitung: "Chronic illness ME/CFS: Patients demand a round table in Germany" <https://bit.ly/32VhDZ>
- ✚ Short documentary: "Never to dance again?"
- ✚ Popular short documentary about a young ballerina who had to give up her dream of a professional dancing career, when she fell ill with ME. The style of the documentary is aimed at teenagers and young adults.

Submitted by **Johanne**, Dt. Gesellschaft für ME/CFS



Italy & ME, part 3

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 third and final 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.

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

Fabio - Recognition of a standard disability level for ME/CFS patients, free psychiatric and psychological support (ME/CFS is not a psychiatric disorder but as it is a chronic illness it causes a lot of comorbid situations, since people just can't do activities).

Giada - I would like to see more option treatments, supported by scientific evidence.

Rosa - I would like to be able to see a different approach towards us sick people, without putting labels that are not justified by studies and I would like to be included in research and help projects.

Chiara - Since there are no treatments other than antivirals, cortisone, i.e. drugs, I personally think that we would need much more open forms of medicine. Meanwhile at the moment, until a marker is found, we should act on the symptoms to make life more dignified. Personally, we have been followed for three years by doctors who practice quantum medicine and who give us advice from the point of view of nutrition (they are not restricted diets) and supplements. We chose this also because we have seen that the more drugs we took the more side effects we had, especially Valerio, super-sensitive to all chemical drugs; he has been repeatedly saved in extremis, he also reacted to morphine and was saved at the very last moment.

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

Fabio - No reason to be positive at all. I wrote to the UK, Norway and Spain to apply to join ME/CFS clinical trials but they only accept patients from their own countries. We feel alone here in Italy even though we're in the EU.

More info about my ME/CFS in English: <https://www.fable.it/my-mecfs>

Giada - Save for a few dedicated scientists, it doesn't seem there's much interest in pursuing research on the disease in Italy. The future looks brighter than it did because we know more and more and big steps are taken abroad.

Rosa - I want to be positive and hope to see doctors' interest in these diseases as soon as possible so that studies can be started and research can be carried out to help with specific and targeted treatments.

Chiara - I think I am realistic, I am not pessimistic because I see that since 1995, when we started to understand that there could be this condition - but it took another 5 years to get the diagnosis! - we see many steps forward have been taken, especially in our area of Italy (North-Veneto Region). Many doctors know that this disease exists, at least. To say that they know how to manage it, no, but at least they know that it exists. I have been told that now there is talk about CFS ME also in university courses; there was also talk about it in the past but it was done very superficially, now we go deeper, there are some students who graduate in medicine with a thesis on CFS ME (we met one about ten years ago who graduated in Perugia with a thesis on CFS ME). Even if the pathology is a bit more known, we can't be enthusiastic about it, but it will take many years before we understand what it is about and can propose something.

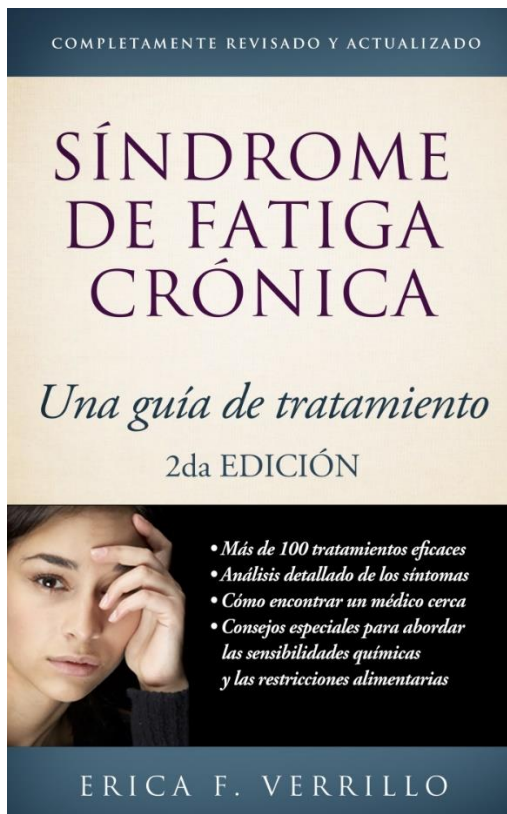
My absolute personal opinion is that if pharmaceutical lobbies get their hands on it will be bad for the sick because any remedy will become a speculation. Unfortunately we have a political class which promises but which cares nothing about the real needs of the citizens and perhaps I have more confidence in Europe. I have heard that there are many families close to the sick and that they are working to raise awareness at all levels. One example is the action of **Evelien Van Den Brink** - our whole family has signed her petition. I hope in Europe because maybe if CFS ME will be accepted as a real, unknown, orphan, invisible but real disease the Italian ruling class will at least take note of it.

In Italy there is the AGENAS document of 2014, we also asked **Professor Tirelli** if it was possible updating the document but he, who participated in the work, believes that the inclusion of CFS ME happened by chance for the interest of a single doctor but not with the desire and will of the signatories."

Mike Harley

Source: <http://bit.ly/2vRKyAa>

Part 1 has been published in the March 2020 issue of the ME Global Chronicle #35, part 2 in the June 2020 issue #36.



Chronic Fatigue Syndrome: A Treatment Guide, 2nd Edition has now been translated into Spanish!

You can buy it on

- ✚ Amazon (<https://amzn.to/33JGZZv>),
- ✚ Barnes and Noble (<https://bit.ly/2FM7pC1>),
- ✚ Google Play (<https://bit.ly/3mHyLJY>),
- ✚ Scribd (<https://bit.ly/3ceNqaY>) and
- ✚ Kobo (<https://bit.ly/2FQKdSO>)

Síndrome de fatiga crónica: Una guía de tratamiento, 2da edición (Spanish Edition) Kindle Edition

Esta referencia única, ahora completamente revisada y actualizada, incluye más de 100 tratamientos eficaces, desde antivíricos a vitaminas, así como ubicaciones de especialistas y clínicas, información sobre pedidos por internet y organizaciones locales, nacionales e

internacionales de SFC/EM. Las secciones nuevas y ampliadas incluyen protocolos médicos e investigaciones sobre las causas y los mecanismos de la enfermedad, todo escrito en un lenguaje conciso y fácil de entender.

Todos los aspectos de la enfermedad se examinan en profundidad, desde el diagnóstico hasta una exposición detallada de los síntomas, desde los tratamientos tradicionales hasta las terapias alternativas y estrategias esenciales de afrontamiento. La nueva edición contiene capítulos para aquellos que padecen hipersensibilidad química múltiple y restricciones alimentarias, así como una sección ampliada sobre niños y adolescentes con SFC/EM. Síndrome de fatiga crónica: una guía de tratamiento, segunda edición, sigue siendo la guía de referencia más completa sobre esta enfermedad.

The Netherlands

Wide Protest Among the Dutch ME-Patients Against a Grant From ZONMW to Prof. Knoop



The granting of a subsidy by ZonMw to **Prof. Hans Knoop** into the effects of CBT on post-viral COVID-19 has (rightfully) caused a lot of commotion both in the Netherlands and internationally.

Three patient representatives in the ZonMw ME/CFS Steering Group also strongly protested against this at ZonMw, and received an unsatisfactory answer.

In response to this and to make ZonMw aware that this is an extremely serious matter for ME-patients from all over the world, a follow-up letter was sent to ZonMw. You can read the text of what is asked therein of ZonMw below.

This message has been published jointly by Groep ME-Den Haag, Steungroep ME en Arbeidsongeschiktheid en ME/cvs Vereniging.



Dear...

Thank you for the explanation in response to our questions about the grant to professor Knoop for ReCOVer, 'Could cognitive behavioral therapy via the internet prevent fatigue symptoms of COVID-19 patients becoming chronic? A controlled and randomized trial', project number: 10430012010025.

First a reaction upon your earlier explanation:

"We know your views on Cognitive Behavioral Therapy (CBT) as an intervention in the treatment of chronic fatigue in ME/CFIDS and respect them. ZonMw has always shown that".

It's not about 'views on CBT', it's about scientifically proven facts and systematically inventoried experiences of many patients at home and abroad. It is to ZonMw's credit that they show respect for the current scientific state of research; it is not about meeting us or doing us a favor. The ZonMw-trajectory of the ME/ CVS research agenda stems from the recommendations of the GR-report of March 2018 and the mandate of the parliament and the minister, not from what we would like to see.

'But that does not mean that ZonMw will have to reject all research requests regarding CBT from the very outset.'

That's a rather limiting representation of what we advocate. It is a widespread misconception that ME patients basically reject CBT (and GET) as an intervention. ME patients disapprove of any intervention that has been shown to exacerbate symptoms, and ZonMw should disapprove of those as well. To us this seems a moral duty. ME patients also reject the specific CGT treatment for CFS according to the protocol of **Prof. Knoop** and the NKCv. This is based on an incorrect, refuted hypothesis about the nature of the disease and contains an activity structure in which the increase in symptoms must be ignored. Furthermore, 'CBT for CFS' is recommended as a curative treatment, while in reality the majority of patients does not improve or even deteriorate as a result.

ME patients are well aware of the fact that CBT in general (i.e. not according to the protocol 'CBT for CFS') can be helpful for some in coping with a chronic disease. At the same time, your sentence implies that ZonMw does indeed have the power to reject an application on medical-scientific grounds. Without sufficient knowledge of the scientific controversy surrounding the research into 'CBT for CFS' and the patient experiences with this treatment, **Prof. Knoop's** proposal cannot be properly assessed. As far as we know, it is ZonMW's responsibility and authority to engage the proper reviewers for this.

More and more publications show the analogy between post viral COVID-19 and ME. For the time being, no research has been done on PEM/PENE in postviral COVID-19. We would like to caution against the consequences of experiments in patients suffering from postViral COVID-19, which could lead to such an exacerbation of symptoms that a very serious clinical picture can arise. Experiments are carried out that potentially are already proven to have harmful consequences. The question is whether this has been taken into account in the research design and, if so, how this will be followed up.

We would like to receive the text of the relevant grant application and the research protocol, as well as how this has been handled procedurally.

- ✚ Which committee processed the application?
- ✚ How did the composition of the committee come about?
- ✚ How was it determined that the committee members do not have a COI?
- ✚ Who have done peer-reviewing?
- ✚ What is the committee's positive conclusion based on?
- ✚ What amount of subsidy is involved?

We assume that all this was done in an open and transparent manner.
Thank you in advance,

Rob Wijbenga, Groep ME-Den Haag
Ynske Jansen, Steungroep ME en Arbeidsongeschiktheid
Lou Corsius, ME/cvs Vereniging

12. Petitions



Factsheets of the EMEC

On August 18, 2020 EMEC – the European ME Coalition, the petitioner of the European Petition, has published 3 new fact sheets which briefly summarize key facts about the economic and societal impact of ME/CFS in Europe and the recent efforts made by ME/CFS advocates including the petition submitted by **Evelien Van Den Brink**. The fact sheets will help to inform politicians and key policymakers about the need for biomedical research on ME/CFS in Europe.

- ✚ One document provides basic information and is supported by ample scientific references. It forms an ideal starting point for anyone who wants to learn more about ME/CFS in Europe <https://bit.ly/3iOnsgz>
- ✚ A second document focuses on key figures. It will be most helpful to those who want a brief overview <https://bit.ly/2Q5VEYy>
- ✚ A third document focuses on recommendations to Member States made in the recently adopted European ME/CFS resolution <https://bit.ly/320vAUt> In Germany, for example, the main patient organizations (<https://bit.ly/2RMJ0ie>) have already used the European resolution to prompt health officials and politicians to take action on ME/CFS.

All info can be read here: <https://europeanmecoalition.com/fact-sheets>



On 18 August, Commissioner **Mariya Gabriel** responded to questions raised by Member of Parliament **Jordi Cañas** regarding the recent ME/CFS resolution. Unfortunately, the answer, provided on behalf of the European Commission, does not acknowledge the underfunding of ME/CFS research in Europe nor does it propose new initiatives to address this urgent problem.

Evelien Van Den Brink has written a response which can be found here: <https://bit.ly/3mGwgYs>

The EMEC team is currently trying to organize a meeting with the Director-General of Research and Innovation. This is unfortunately complicated by the COVID-19 pandemic.

We will continue to raise awareness of ME/CFS at the European level until this results in equitable funding for ME/CFS research.

German Petition to Recognize ME

German petition to recognize ME as a biomedical disease and to substantially fund biomedical research into it.

Everybody from all over the world can sign here: <https://bit.ly/3j5700r>

Unfortunately, there is no medical care for the approximately 240,000 people suffering from Myalgic Encephalomyelitis (ME) in Germany. The disease is also trivialized as Chronic Fatigue Syndrome (CFS) or as ME/CFS.

Although the disease has been recognized by the WHO (ICD-10 G93.3) since 1969, ME is still not taught in medical studies, so most doctors do not know it at all, and therefore cannot help or even recommend harmful therapies based on false information.

Currently, there is only a specialized contact point at the Charité Berlin, but due to the large number of patients, only patients from Berlin/Brandenburg can be diagnosed there! Important: they only diagnose, unfortunately the patient cannot expect a helpful therapy.

The contact point of Prof. Behrends at the Munich Clinic Schwabing is only responsible for young people.

That means: there are currently no contact points for most patients in Germany. The situation is therefore catastrophic for those affected, which also explains why many patients are wrongly diagnosed with burnout/depression, resulting in harmful therapy attempts that do not help the patient but allow the disease to progress.

The main symptom in ME is the so-called PENE (Postexertional neuroimmune exhaustion): this describes "the pathological inability to produce sufficient energy when needed with pronounced neuroimmunological symptoms".

People with ME experience massive physical exhaustion, which cannot be eliminated by resting. Even the slightest physical or mental effort (e.g. brushing teeth, short conversation) leads to immediate or delayed (24-48h) exhaustion and intensification of all symptoms, e.g. chronic pain. Existing painkillers, even morphine, often do not help sufficiently.

About 25% (about 75,000 in Germany) of the patients (including children!) are so severely affected by the disease that they are unable to leave their homes or beds. This means that such cases sometimes require years of care, mostly until the end of their lives.

Especially severe cases are bedridden for 24 hours, even the slightest movement leads to PENE, they do not tolerate any light, noise or touch and sometimes even have to be fed artificially. They are no longer capable of any physical or mental activity.

In order for doctors not to harm ME patients, they must be correctly informed about ME. The "MYALGIC ENCEPHALOMYELITIS International Consensus Guideline for Physicians" (ME IC Guideline) developed by ME specialists is suitable for this purpose. It contains strict diagnostic criteria (the ICC) and information for physicians (e.g. which blood tests show abnormalities). It can be downloaded here free of charge: <http://www.t1p.de/meicleitlinie>

The ME IC guideline lists, among other things, diseases that can cause similar symptoms to ME and which must be excluded (differential diagnosis). In the case of primary psychiatric disorders, an ME diagnosis according to the IC guideline is excluded. This is very important so that the test persons are correctly selected in studies and not people with, for example, purely psychiatric illnesses, who are inadvertently mixed in with them, so that the study does not provide a helpful result for people with ME. However, this is also important so that false diagnoses are avoided.

The experts for care levels/pension insurance, etc. must also be properly informed so that the stigma is eliminated and those affected receive care appropriate to the severity of the disease. Due to the missing or wrong information it is currently very difficult for affected persons to obtain an aid such as a wheelchair.

Stays in hospital, e.g. for the clarification of other diseases, are at present in most cases connected with worsening of the disease condition, since the physicians/nurses are not informed about ME there and therefore e.g. do not consider the light and noise sensitivity of the patients.

Simple blood counts are usually completely inconspicuous in ME patients, which unfortunately often means that no further specific tests are performed.

The current guidelines of AWMF, Degam and DRV are unfortunately a source of suffering for ME patients. In order to really help patients, new guidelines for Myalgic Encephalomyelitis must be developed based on the 2011 International Consensus Criteria for ME and the 2012 ME IC Guideline.

Due to the extremely poor research and the complete lack of funding in Germany, there is not a single approved drug for the treatment of ME. Due to the lack of research funding, patients have recently had to collect donations for research themselves! Therefore, it is essential that funds are made available for independent biomedical research into the causes of ME, so that a biomarker can be found soon and thus a diagnosis can be made easily and quickly by the patient's family doctor in the future.

In other countries blood and organ donation for ME is already prohibited, but not in Germany. Based on the more than 60 cluster outbreaks documented worldwide to date, it must be assumed that ME is a pathogen, e.g. Royal Free Hospital Group London (1955): within 4 months, 292 hospital employees fell ill with the disease, 255 affected persons had to be hospitalized.

It is very important that politicians and the health care system finally react correctly here to prevent this disease from spreading even further, because according to one study, the number of people affected doubled between 2009 and 2014 alone!3

In the Bavarian State Parliament, the Committee for Health and Care discussed a petition regarding "ME/CFS" and supports the petition.

It is clear to me that certain decisions can only be taken by the federal government, so it would be important for the states to join forces to ensure that the federal government takes action.

Also in the European Parliament, following a petition by **Evelien van den Brink**, who herself is very seriously affected, the 1st resolution on "ME/CFS" has now been passed. In this resolution many demands are listed to the responsible authorities, also the member states of the European Union:
<http://www.t1p.de/europaME>

In her petition, "WE WANT OUR LIFE BACK", to Health Minister **Jens Spahn**, **Katharina Voss** calls for many important changes to improve the care of ME patients. Despite more than 17,000 signatures, it has unfortunately not yet led to any reaction from the government: <http://www.t1p.de/ej2w>.

I fell seriously ill with ME in 2012 and have not been able to participate in life as such ever since. The disease is also called "living death", which unfortunately is the right way to describe it. My brother fell ill with severe ME in 2017 and had an extremely fast and aggressive course, which is why he unfortunately died at the age of 26.

Here you can find a list of those who have died of ME so far: <http://www.ncf-net.org/memorial.htm>

Therefore, I very much hope that you will support this petition in order to finally bring the care and research to a level corresponding to the prevalence of the disease (today ME is three times more common than HIV in Germany!)

The Ministry of Social Affairs and Integration and the Ministry of Science, Research and the Arts must urgently take action to improve the situation of those affected.

Please sign this petition! We affected people are of course also grateful for prayers! <https://bit.ly/3j5700r>

With kind regards & thank you for your support

Jannik Mebus

Translated with <http://www.DeepL.com/Translator> (free version)

#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>

13. Events



IACFS/ME Virtual Conference – 2020

Rosamund Vallings, MB BS (Auckland NZ) **Sarah Dalziel**, MB ChB (Rotorua NZ)

On 22nd August at 2.00 a.m. we were privileged to attend the IACFS first virtual on line conference, at 2.00 a.m. because we are in New Zealand, so our time was 28 hours ahead of the event. It was strange not to be there enjoying the company of all the familiar friends and colleagues. But it was brilliantly organised by the IACFS/ME board and team, and all went smoothly. The conference was opened by the President **Fred Friedberg** who welcomed us all and outlined the format. He brought us up to date with the work of the board, including production of the regular journal and support of investigators. The conference was divided up into 5 main segments, with a question and answer time after each and a lunch break midway.

COVID-19 SESSION

Speakers:

Harvey Moldofsky (Toronto, Canada) who had published research following the SARS Covid-1 disease in 2002.

Leonard Jason (Chicago,USA) on risk factors for developing Covid-19 and its aftermath. He described the 1918 influenza epidemic.

Sadie Whittaker (Solve ME, Los Angeles, USA) on further thoughts on understanding susceptibility or resilience to chronic effects of Covid-19, and the hope that this will deepen our understanding of ME/CFS.

Ronald Tompkins (Open Medicine Foundation, Harvard University, USA) addressed the issue of conversion of Covid-19 patients to people with ME/CFS. Covid-19 is likely to increase our understanding of the pathophysiologic features that can be associated with those who ultimately develop ME/CFS.

Luis Nacal (London School of Tropical Medicine and Hygiene, UK) looked at the impact of Covid-19 on the risk and prognosis of ME/CFS. This epidemic provides opportunities to look at the long-term effects of Covid-19 on those who already have ME/CFS

IMMUNOLOGY/METABOLISM/HEART RATE VARIABILITY SESSION

Speakers:

Wakiro Sato (Tokyo, Japan). He described ME/CFS as a neuro-immunological disease, and there is evidence of immune abnormalities.

Ina Petterson (Bergen, Norway) had investigated if defective energy metabolism was contributing to mechanisms in ME/CFS.

Fred Friedberg (Stoney Brook, NY, USA) addressed the issue of why ME/CFS patients improve or worsen. About 50% do not improve.

James Baraniuk (Washington, USA) addressed heart rate variability in exercise-induced postural tachycardia and POTS.

TREATMENT SESSION

Speakers:

Violetta Renesca (Nova Southeastern University, USA) presented her work on the effect of a selfmanagement group programme on health status, fatigue severity and self-efficacy in patients with ME/CFS.

Marvin Medow discussed the benefits of oral rehydration on orthostatic intolerance in children with Postural Orthostatic Tachycardia Syndrome (POTS)

Rhonda (Jane) McKay (Vancouver, Canada) outlined the Vancouver experience of use of low dose naltrexone (LDN) in ME/CFS and FM.

RESEARCH/CLINICAL NETWORKS

Speakers:

Caroline Kingdon (LSHTM, London, UK) gave a compassionate overview of her work visiting the housebound patients severely affected by ME/CFS.

Matthew Schu (N.C,USA) outlined ME/CFS focussed data portal supporting data discovery across multiple biological disciplines. He presented a single platform designed to bring data together, thus promoting a sharing of data

Eliana Lacerda (LSHTM, London, UK) reported on a longitudinal assessment of clinical severity indicators and determinants of quality of life in people with ME/CFS

IMMUNOLOGY/METABOLISM

Speakers:

Ryan Whelan (Incline Village. NV, USA) presented his work on ME/CFS and Autoimmune Associated small nerve fibre neuropathy (aaSFNP).

Daniel Missailidis (Melbourne,Australia) discussed his work on dysregulation of mitochondrial function and fuel preferences in ME/CFS lymphoblasts.

The conference ended on a positive note and **Lily Chu** (IACFS/ME Co-Vice-President) thanked everyone for their attendance and work towards so many excellent presentations. She acknowledged her brilliant support team. Having an online conference such as this certainly heralds the possibility of similar future events. We would like to acknowledge the IACFS and ANZMES for enabling us to attend this prestigious event.

Rosamund Vallings, MB BS & Sarah Dalziel

For the entire report: <https://bit.ly/3cDILR9>

Source: IACFS/ME <https://bit.ly/3665nav>

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14. Poem - Invisible Octopus



The reality of life
with the unpronounceable illness
Myalgic Encephalomyelitis
is hidden and fragile

M.E. as Invisible Octopus
acting as puppeteer
keeping me upright
or making me stumble at will

inflicting pain
challenging my brain
its crushing weight
taking my breath away

Rosie cheeks
looking well they say
summer is coming
happy thoughts will cure you

I live in a disbelieving world
my reality
trivialised
dismissed

My full time carers
witness Octopus' destruction
for others I simply disappear
into the shadows

I am just one in this worldwide
community of hermits
where freedom of movement
is no longer a right

Transcending gravity
I fly among the birds
Their beauty and harmony
uplifting and strengthening

After a short flight
Octopus attacks
Pinning me down
immobilised

each moment is a death
Breathe

Each moment is a living

Finding peace in my solitude
I observe the dance of the trees
There is movement
in stillness

My creative mind
the visible thread
throughout this twenty-two-year long story
Transforming pain into poetry

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Corina

<http://www.corinaduyn.com>

<http://www.corinaduyn.blogspot.com>

15. 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."

