The ME Global Chronicle

www.let-me.be

38 –December 2020

1. Colofon / Personalia

Advisor: ***Leonard A. Jason***
Editor/Editorial team: ***Colleen Steckel, Eddy Keuninckx, Rob Wijbenga***

<u>To this issue of the ME Global Chronicle contributed in one way or the other:</u>

Alice Vertommen
Alisha Whittam
Allison Haynes May
Ari SF
Bettina Becker
Betty Hough
Cathrine Engsig
Chantal Somm
Colleen Steckel
Corina Duyn
Czech Club of ME Patients
Dr. Ben Marsh
Dr. Charles Shepherd
Dr. David Newton
Dr. Nina Muirhead
Dr. Rosamund Vallings
Dt. Gesellschaft für ME/CFS
Eddy Keuninckx
Ellen Piro
Emerge Australia
Fennine de Weerd
Forward ME
Greg & Linda Crowhurst
Helga Lathinen
Helle Rasmussen
Herman Jan Couwenberg
Ingrid Torjesen
Invest in ME
James & Pam Lutey
Jelle Bouwhuis
Jennifer Brea
Josh Biggs
Kathleen Morgan
Kathy Dallest
Kerstin Heiling
Libby Boone
Llewellyn King
Marathon Mike Harley
Margaret Williams
Marie H. Curran
ME Association
Michiel Tack
Millions Missing Finland
Millions Missing France
Monica Arranz
NAAC
Naomi Whittingham
Natalie Boulton
NCNED
Nina E. Steinkopf
Olav Osland
Open Medicine Foundation
Prof. Donald Staines
Prof. Leonard Jason
Prof. Ola Didrik Saugstad
Prof. Sonya Marshall-Gradisnik
Retha Viviers
Rob Wijbenga
Simon McGrath
Steungroep ME en Arbeidsongeschiktheid
Stine Aasheim
Suzy Chapman
Tom Kindlon
Tom Tahowksy
Whitney Dafoe
ZonMw

Distribution & Layout: ***Eddy Keuninckx***
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Picture front page: ***Eddy Keuninckx***

2. Table of Contents

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

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

3. Editorial

From the Editors,

Dear reader,

Before you 'lies' the last publication of the ME Global Chronicle in its classic style. More information on this will follow.

Once again, the editors have made a selection of the most significant ME-related developments and publications across the entire globe of the last three months. Covering everything would require tens, if not hundreds of publications of the MEGC each quarter.

It remains hopeful that a shift in attitude is taking place and that patients are getting an increasingly larger stake in the form of participation in research and government policy, as has happened in the UK with the revision of the NICE guidelines as well as in the Netherlands, where a 10-year biomedical research agenda has been established.

But personal experiences from patients in the form of columns and poems also constitute the building blocks of the Chronicle, and developments in numerous countries. After all, sharing is caring, and such important breakthroughs can only be pushed forward on a global scale.

Either way, ME can no longer be denied, despite the success the mental illness lobby has had over the course of the last decades.

An important notice for those who (may) contribute to the ME Global Chronicle: as of now, deadlines have been removed. Submitted entries will, after approval by the editors, be immediately posted to the ME Central web page https://mecentraal.wordpress.com and in most cases will also appear on the Chronicle's Facebook page in abbreviated form https://bit.ly/3myMLED. This can be done any day.

The editorial staff wish you a relaxed holiday season and hopefully the slightest (but preferably, significant) improvement in health of readers who suffer from ME. Our strong wish for all of us is that the interconnection between ME patients worldwide will only expand and intensify. It is a massive privilege that we are able to pitch in our own dime in this.
With the best of wishes,

Colleen Steckel   **Eddy Keuninckx**   **Rob Wijbenga**
December 23, 2020

4. Dutch Citizen Initiative

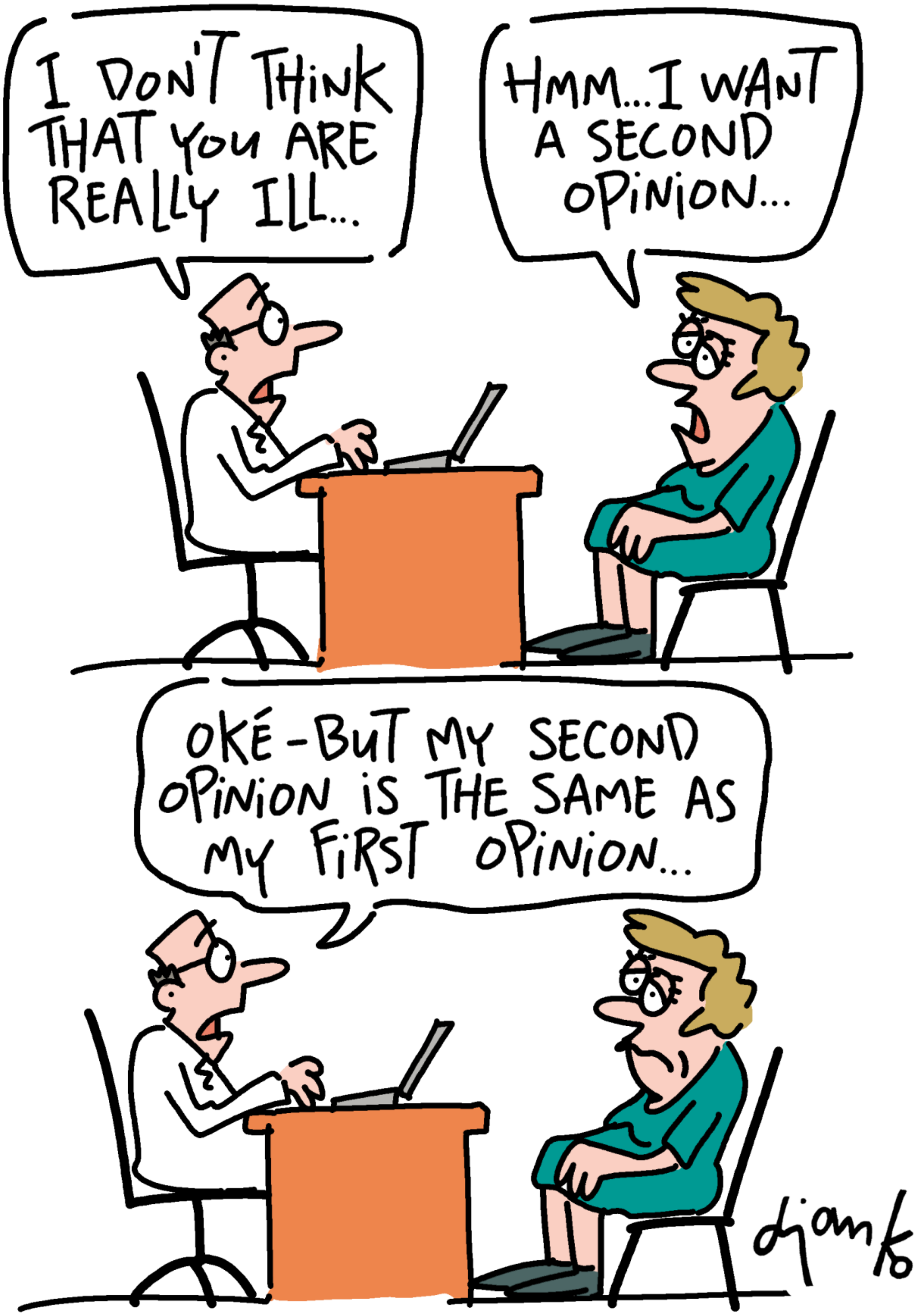
Completion of The ZonMw Research Agenda

In The Dutch Citizens Initiative section of this magazine, we have kept you informed in recent years about the developments resulting from the successful citizens' initiative to recognize ME as a biomedical disease. After offering 56,000 signatures to the Dutch parliament, the Minister of Health, Welfare and Sports instructed the Health Council to map out the state of affairs regarding ME in the Netherlands and to issue recommendations. The Health Council's ME/CFS report was published in March 2018. In response to one of the recommendations contained therein, the minister has instructed ZonMw to draw up a research agenda and program. ZonMw put together a steering group of 8 people, half of which were patient representatives and the other half Dutch researchers. At the beginning of December, after intensive consultation, consultation of international scientists, working sessions at 3 academic hospitals and 1 university, and an international knowledge day (for contents see under News from the Netherlands in this issue), the steering group determined the final text of the research agenda, including a budget to be provided. This text has now been sent to the Minister for approval. As elections will be held in the Netherlands in March 2021, the minister's response is not expected until May or June. Until the text is presented to the parliament, it is subject to an embargo.

Yet we would like to announce a few hopeful points about it:

- It will be a complete biomedical research program
- Basic, epidemiological and clinical research will take place. Validation studies (so that a link is made with research done elsewhere) will play an important role.
- The steering group recommends a 10-year term for the research program. This duration is necessary because of the construction of a patient cohort, a research infrastructure and the research along the lines described above. It is expected that a total budget of € 20 to 29.5 million will be required.
- All research proposals will have ME patients as a core group in accordance with the ICC.
- ZonMw attaches great importance to the participation of patients through their representation by the patient organizations and this will also be reflected in the program committee to be formed.
- An ICC-based research cohort will be formed. This is expected to entail significant costs.
- An important aspect of research will be clinical scientific research, the results of which must already be applicable in clinical practice. After all, both the Health Council and ZonMw recognize that there is some catching up to do in the field of ME
- A number (4-6) (young) researchers must be able to participate in a fellowship program. This is in order to connect with and gain knowledge from internationally leading biomedical research(ers) into ME
- In addition to the aforementioned research, the research results will also have to be implemented and the increasing knowledge about ME will be transferred.

Cartoon Djanko



5. Grassroot

Dialogues For a Neglected Illness

Earlier we published information about this projectbeing created by **Natalie Boulton** and **Josh Biggs**. They previously made Voices from the Shadows. Just this month **Natalie** and **Josh** finished a series of 8 impressive videos. https://bit.ly/3atG9Fg

Natalie writes: "This collection of videos illustrates key symptoms of ME/CFS: important when making a diagnosis. Patients describe these symptoms themselves. They had been ill for between two to thirty five years when interviewed and their age at onset ranged from ten years to middle age. The interviews give an idea of both the range and consistency of key symptoms.

The videos provide a body of first-hand evidence. They can be just started, or dipped into, to get a 'taste' of the disease. They help recognition of the distinctive qualities of the symptoms in ME/CFS. Some supplementary information relevant to diagnosis is also included. Originally it was intended that the patients would all have been assessed by and donated blood samples to the UK ME/CFS Biobank. Due to difficulties with timing, the unpredictability involved when interviewing severely ill patients and then the dangers of Covid19, we included two patients who had been diagnosed by ME specialist **Dr William Weir**. We also made use of interviews with advocates with longer illness, to enable a more comprehensive picture of ME/CFS.

Sadly, between a third to half of contributors have deteriorated substantially since being interviewed: due to further infections, the impact of overly demanding life conditions, or in one case hospitalisation has had a very serious impact. We are extremely grateful to all these contributors. They have made this project possible, by being willing to share their experiences for all to hear and learn from. Thank you"

The videos are here – https://bit.ly/3rdV0tB The subjects covered are:

- Reduced Function
- How does the disease start?
- Post ExertionalMalaise
- Cognitive Impairment
- Sleep
- Othostatic Intolerance
- Pain
- Hypersensitivity

Another video, released just as the NICE Draft was published, addresses Activity and Energy Management - Pacing https://bit.ly/3p3SZhy

The next video **Natalie** and Josh are working on, in collaboration with **Valerie Eliot Smith**, is a video addressing the wider historical/ medical/ social/ political context of ME. A final event at the London School of Hygiene and Tropical Medicine is planned for September 2021

I’m Still me, But With #ME

I’m still me, but with #ME
Don’t hate me, hate #ME
Resent #ME , not me
Believe me, believe in #ME
Don’t forget me, I’m still here
I am me, not #ME

Dr. Ben Marsh,
Acute & Neurodisability Paediatrician,
fighting to educate re Postviral syndrome & #ME/CFS on twitter

https://bit.ly/3mBM0L4

When your inner party animal goes wild.

Position Paper ME International

Myalgic Encephalomyelitis is a Distinct Neurological Disease
ME International Supports Adoption of the #MEICC1 & #MEIC Primer2

Introduction

Much has been written3,4,5 and discussed about diagnosing myalgic encephalomyelitis (ME), myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), chronic fatigue syndrome (CFS) and systemic exertion intolerance disease (SEID aka ME/CFS). Here we clarify ME International's position on whether ME, CFS, ME/CFS, and ME/CFS-SEID are the same disease and whether the diagnostic criteria for ME, CFS, ME/CFS, and ME/CFS-SEID select the same group of patients. The non-standardized and overlapping definitions in the USA have resulted in an inability to compare results of multiple studies because those suffering from chronic fatigue unspecified (ICD code R53.82) are mixed in with those suffering from ME (ICD G93.3).6

Background

ME, CFS, ME/CFS, and ME/CFS-SEID are the recognized diagnostic criteria in the USA7:

1988	CFS	Holmes, CDC
1994	CFS	Fukuda, CDC
2003	ME/CFS	Canadian Consensus Criteria (CCC)
2011	ME	International Consensus Criteria (ICC)
2015	SEID (uses ME/CFS label)	Institute of Medicine (IOM) (Now NAM)

As stated in the 2012 ME IC Primer, the ICC advances the successful strategy of the CCC of grouping coordinated patterns of symptom clusters that identify areas of pathology. CCC is the precursor to the ICC and is closely aligned with the definition of ME as a distinct neurological disease separate from CFS and ME/CFS-SEID.

The IC Primer defines ME as:
"Profound dysfunction/dysregulation of the neurological control system results in faulty communication and interaction between the CNS and major body systems, notably the immune and endocrine systems, dysfunction of cellular energy metabolism and ion transport, and cardiac impairments." (International Consensus Primer pg.1).

In 2011, the International Consensus Criteria panel consisted of clinicians, research investigators, teaching faculty, and an independent educator. They represented diverse backgrounds, medical specialties and worldwide geographical regions. Collectively, the members of the panel diagnosed and/or treated more than 50,000 ME patients and their expertise represents more than 500 years of clinical experience. (IC Primer pg. ii)

In 2015, against the requests of experts, patients and stakeholders[8], the Institute of Medicine (IOM renamed as National Academy of Medicine) convened a committee that led to a broad criteria based on research focused on CFS studies from approximately 2004 to 2014.[9] This narrow focus resulted in a lack of recognition for the cause of symptoms seen in patients who fit an ME criteria. This IOM report proposed a new diagnostic criteria that they determined would facilitate a simplified diagnosis of those who fit this broad criteria and recommended renaming this combined group of ME and CFS patients as having systemic exertion intolerance disease (SEID). MEadvocacy.org compared the ICC to the IOM criteria in a chart which shows the inadequacy of using the IOM diagnosis for ME patients.[10]

ME International’s Position

- ME is a distinct neurological disease separate from CFS and ME/CFS or SEID.
- ME is defined accurately in the ICC.
- The ME IC Primer provides step wise guidance for diagnosing and treating myalgic encephalomyelitis.
- In view of research and clinical experience that strongly points to widespread brain and spine inflammation and multisystemic causes, it is more appropriate and accurate to use the term myalgic encephalomyelitis.
- Research into ME needs to select a more homogenous patient population using the ICC with diagnostic methods found in the IC Primer.
- ME International supports this statement: “Patients diagnosed using broader or other criteria for CFS or its hybrids (Oxford, Reeves, London, Fukuda, CCC, etc.) should be reassessed with the ICC.” (IC Primer pg ii).
- In addition, ME International supports recognition of the original description by Dr. Ramsay, research into the multiple outbreaks, as well as recognition of the possible connection to polio and/or retroviruses.

Conclusion

ME International’s position is that myalgic encephalomyelitis is a complex, acquired multi-systemic disease apart from CFS and ME/CFS, that all patients need to be screened for ME in accordance with the IC Primer, and all research labeled “ME” use the ICC.

More detailed information can be found on our website at ME-International.org

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- 2021 ICD-10-CM Diagnosis Code G93.3 https://bit.ly/3mxTmzs
- NOTE: World Health Organization combines ME and CFS under one code. Current WHO code is G93.3 and will become 8E49 in future update.
- Criteria information with links: https://bit.ly/3mwMiD1
- An open letter to the honorable **Kathleen Sebelius**, U.S. Secretary of Health and Human Services, September 23, 2013: https://bit.ly/34ojiqQ
- Committee on the Diagnostic Criteria for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome; Board on the Health of Select Populations; Institute of Medicine. Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness. Washington (DC): National Academies Press (US); 2015 Feb 10; doi: 10.17226/19012 https://bit.ly/2KFGgTc
- ICC_compared_to_IOM.pdf chart (MEadvocacy.org): https://bit.ly/2J1K40G

#MEAction

I am writing today with some big news. After five years as co-founder and Executive Director of #MEAction, I plan to step down from that role sometime in the coming months, while continuing to serve as a member of our Board of Directors. We will officially launch our search for #MEAction's next Executive Director. I wanted to offer a small window into why now and what's next.

Making a film, building an organization, and growing a movement, all while living with moderate to severe myalgic encephalomyelitis (ME), was challenging, to put it mildly. I did not do it alone. I had the support of my husband, and we had the support of so many friends and family. I also had the strength I drew from you and from our community. With the help of fellow patients and the passion and commitment of our #MEAction staff, I have been able to keep going and keep doing this work that I love, for longer than I ever imagined possible. I am incredibly grateful for that. Every time I was crashed, bed-bound, or facing a new health crisis, our staff, volunteers, and donors stepped up, the organization grew and, together, the work thrived.

Over the last two years I have had to push through more personal crises than I care to count. I had surgery for thyroid cancer, which dramatically worsened my symptoms of craniocervical instability, atlantoaxial instability, and tethered cord syndrome. I then had multiple major neurosurgeries and a 40-day hospitalization. The recovery and rehabilitation from these surgeries, hospitalizations, and eight years spent largely in bed or in a wheelchair due to ME was challenging and is ongoing. However, these diagnoses and the treatments for them afforded me the ability to move, think, and exercise without being crushed by the post-exertional malaise, sensory sensitivity, and dysautonomic flares that for so long had become the cost of living. I could walk, I could hike, I could close out the dance floor. It felt like a miracle.

In spite of all these challenges, in May of last year, when I announced the remission of my ME symptoms, I committed to continuing in my role as Executive Director. I did so because I believe deeply in this organization, in its vision that an empowered, connected, thriving community can change the world, and I knew that with my newfound, post-operative capacity, there was so much more that I could dream, build, do, contribute.

Then in March, my husband **Omar** and I both got COVID-19. While my ME symptoms did not come back, I became bedbound again, this time for different reasons.

COVID-19 was the moment that I finally accepted my fragility. I know that is a strange thing to say, given how sick I have been. I've always encouraged others, especially patients involved in advocacy, to put their health first, to know when to step back, take a break, or pass the baton. It is an ethic we have worked hard to cultivate within our #MEAction community, but it is advice I have never given myself the permission to take.

I have a lot of work to do to heal emotionally and physically from all that I have been through, and I've reached a point where that has to be my primary focus. I have always put the work first. Now, it is time for me to pass the baton, to put my body first.

The good news is, I have never felt better about doing so than I do at this moment.

Needless to say, I am so unbelievably proud of all we have achieved, together!

While I am confident and hopeful about what lies ahead, this decision has been a weighty one for me, personally. There has been a lot of joy, marveling at how far we have come, and a lot of tears. I want to be clear, though, that I am not going anywhere tomorrow—the search for our next Executive Director could take a few months, it could take up to a year.

I also want to be clear that I am not leaving the larger fight. I plan to remain actively involved in #MEAction as a Board Member, and to support and contribute to the work of all our organizations, as I am able, for many years to come. I have no doubt that #MEAction, our community, and our work will continue to thrive, thanks to our thousands of volunteers, donors, staff, board, and every-day activists around the world. I look forward to supporting, advising, cheerleading, and amplifying all of that exciting work to come.

With a gratitude deeper than I will ever have the words or the art to convey,

Jen

Read online https://bit.ly/2KcgGFx

Marathon Mike

I had no idea how successful the trip would be in drawing in more funding for biomedical research and how much support I would get.

With no races since November 2019, I went into this one having trained pretty solidly for 11 months and approx 150 runs and 1200 miles under my belt. I wasn't sure how I was going to run but I knew it could be the last time I run a race until there's a vaccine for Coronavirus. Only Sofia and Vilnius Marathons appeared to be going ahead out of all the street races I could find. Vilnius required runners to quarantine whilst they were there for 2 weeks which wasn't going to be possible, so I had another look at Sofia. When I checked out flights it felt almost perfect - £60 return flight from Heathrow, a flight that would get me in the night before and the day after and a small, cool weather marathon. I drove to Heathrow, parked up and had a fairly average pasta meal followed by a mask-wearing half-empty flight watching films. The hotel picked me up, my name on a sheet of A4 at Arrivals, never had that before! Pretty amazing place -pool, 2 bars, 2 restaurants and a fairly busy casino(!). It was only £60 a night and came with breakfast and free airport transfers which was awesome really.

Fellow EU marathon collector **Mark Openshaw** was going, we'd met and run in Cyprus together and got on well. It was great to see a familiar face over there and swap stories of the races and experiences we'd had on our respective challenges. It would make an interesting addition to the book and a proper, slightly crazy adventure. We tried to get a beer at the hotel bar but there was nobody around to serve us so we ventured out at the mercy of Google Maps to a small cafe/bar up a side street where they were playing heavy metal whilst showing a **Willie Nelson** concert. Back at the hotel I did a quick video post to thank people for their sponsorship (£800 donated in 24 hrs at that point) and went to bed. I got up at 6am, got changed ready to race and walked down to the 'race expo', a 30 min walk in the dark to go and pick up my race number. It was cool to see the sights of the city through a foggy dark mist before a very social distanced buffet breakfast (only one in the breakfast room!) and a short walk with **Mark** to the start-line.

(read more http://mikeseumarathons.blogspot.com/)

Thanks for your support!

Mike

The Enduring Light of Love

Christmas can be an especially difficult time for those living with severe ME. This year, for the first time, I write of my experience as the loved one of someone severely affected by the illness. I see him in the hushed beauty of a winter sky; in the gold-streaked clouds of an expectant dawn. I feel his presence in music and candlelight. He is never fully here, yet with me always. Unknown to much of the world, yet a constant in my heart. The prison of his suffering is nearly impenetrable. I want my love to melt the darkness and agony, and to set him free. My helplessness stalks me every day of the year but is particularly felt at this time of love and giving. The ache of missing; the emptiness of absence. And the sting of my own powerlessness.

I thought I knew all that could be known about suffering, through my own illness. Now I have learnt the unique torment of witnessing a loved one's pain. My sadness could choke the sun with thick cloud; my anger rip holes in the sky. Music has no place here: I want to silence it with a scream. Candlelight is too forgiving when fire consumes me. As I move through Advent, I know I am preparing for a day in which he cannot share. It can be hard to accept light into my world, when I know that none penetrates his. There is a difficult balance to find between allowing my life to continue (as far as it can), while acknowledging the essential part that is missing. The loss is not only mine: the whole world is poorer without him. A person's intrinsic value is not extinguished when their body fails. A loved one can be locked in extreme suffering, yet still be a source of comfort, of inspiration, and even joy.

Suffering forms the framework of his life; and, by proxy, mine. Absence and loss are the starting point of each moment. And yet there is so much more. I have discovered, many times over, that beyond the glitter and noise of the world known as the real one, we have something far deeper: love, and a strength of spirit that is often beyond comprehension. A person's intrinsic value is not extinguished when their body fails. A loved one can be locked in extreme suffering, yet still be a source of comfort, of inspiration, and even joy. I have discovered that when severe illness enforces absence, there is still presence: a presence both meaningful and profound.This Christmas and always, in spite of an unimaginable bleakness of suffering, there remains one defiant truth. He is still my gift of light.

Naomi Whittingham, 7th December 2020

Source: A Life Hidden https://bit.ly/2KFINNc

Further reflections on Christmas can be found in Christmas Darkness and Light (https://bit.ly/3apueZ3), where I explore the meaning of Christmas when severely ill. Find out more about severe ME here: https://bit.ly/34ongQg.

“ME Expert” is Not Researching ME

Vegard B.B.**Wyller** has been referred to as an «ME-expert» in Norway for almost 20 years. But… is he really studying ME?

Recently it became known that Norwegian health authorities support a controversial study in which ME patients are to be treated with the alternative method Lightning Process. **Vegard B. B. Wyller** is part of the research team, and the project description states that he is Norway’s most published researcher in the field of chronic fatigue with more than 40 published articles. In Dagbladet’s tabloid articles in May 2020, he is presented as ME researcher, and that he «has been studying ME for almost twenty years».

I’ve taken a closer look at **Wyllers** research.

In 2014, the Norwegian Directorate of Health published guidelines for CFS/ME. The Canadian criteria, the Fukuda criteria and Jasons Pediatric criteria are recommended for diagnosis and research on the patient group. Post Exertional Malaise (PEM) is a cardinal symptom. A whole range of symptoms must be present before the diagnosis can be set: The 2003 Canadian criteria require at least 12 symptoms in addition to fatigue and PEM.

The 1994 Fukuda definitions require more than 6 months of continuous, unexplained fatigue, and PEM is one of 8 additional symptoms where at least 4 are required.

Jason’s pediatric criteria from 2006 require more than 3 months of unexplained and continuous fatigue, PEM, and at least 6 symptoms.

By all these criteria, psychological disorders must be excluded as the cause of the symptoms.

Wyller’s hypothesis from 2007 is that CFS / ME is a sustained arousal stress response and that personality, emotions and psychological trauma contribute to the development of the disease. The hypothesis is still not proved. Here is an overview of 39 scientific articles that **Wyller** has published or has co-authored. As far as I can see, the only requirement is that the study participants have had unexplained fatigue for more than 3 or 6 months, with no requirements for any other symptoms. Can this be called ME-research?

See an overview here: (**Wyller**: articles and criteria (https://bit.ly/3r5voii).

Wyller has been allocated most of the research funding in the field over the last 15 years. In April this year he was awarded NOK 12 million (almost $ 1,4 million) for a new study.

Vegard B.B.Wyller recently published a study in which adolescents with acute EBV infection were treated with music therapy and a method that has many similarities with the Lightning Process. It will most likely be used as an argument for getting the LP-study (https://bit.ly/3atM2SS) approved by REK. Read my analysis of the study here: Cure ME with music? (https://bit.ly/34saXm4) The study has also received international criticism (https://bit.ly/37ypbE4) where several professors recommend it to be revised and temporarily withdrawn.

A Norwegian article in the journal for Research Ethics, “The War on Truth” explains some of its history. **Ellen Piro**, founder of the Norwegian ME-association: “The professional teams’ use of different diagnostic criteria is like comparing apples and oranges. We are aware that there are major biases in this research area”. This was in 2007.

I question whether **Vegard B.B.Wyller** can be called an ME-expert, and whether his research is relevant to ME. I also question that health authorities, the Norwegian Directorate of Health and the National Competence Service for CFS/ME refer to **Wyller**’s research.

Nina E. Steinkopf

Source: https://bit.ly/2Kn94jD

Being Honest About my Life as a Carer

Alisha Whittam is a British ME-patient with severe ME who wrote about herself on her own site https://alishawhittam.com: "I was diagnosed with ME in 2012 at the Royal Liverpool Hospital, after my consultant went over everything and I was ready to leave my consultant apologised to me.

As you can imagine everything was running through my head. I got home and looked for support groups or just anyone who could help me, my life had just been turned upside down. I felt so alone, I lay on my bed and started writing. I kept notes of new symptoms, foods, pain levels. My notes turned into a blog and my how it helped. Fast forward a few years and my blog has saved me so many times. If something hurts me I write about it, it can be something as simple as friends posting pictures of nights out. That feeling of life going on while yours has stopped hurts, I should be going out with them not laying in a bed unable to stand up without help.

Welcome to my life, I hope knowing someone feels what you feel helps somehow." Alisha has also just launched a video to her YouTube channel https://youtu.be/xiCJjJg9eww about which she writes:

"…the video is how ME has affected my Daughter. She was only 12 when I was diagnosed so her whole high school experience was directly affected by my illness.

She went from being a normal child to having to take over my role in our home, before she turned double digits she was able to cook, clean and do all of the laundry

Unfortunately, in the run up to my diagnosis she would regularly have to call ambulances as the pain levels had not been controlled correctly. She would also have to call my Husband who worked full time as a Retail Manager to inform him. She would then stay with her Nan until we returned.

While life is hard for us it is also hell for the closest people around us, the people who know the most and see far too much.

We have been so fortunate that we have such a perfect daughter as life could have been very different.

As parents we have always been open with her about my illness, we rightly or wrongly told her everything. I know some choose to keep things away from young children but I strongly believe that they are able to see exactly what is going on, choosing to keep things indicates a lack of trust or faith in them or that they wouldn't be able to handle it. This can always backfire, we were lucky.

Rebecca is now away at University but still FaceTimes several times a day. We are so proud of her and we know we are very lucky.

I hope that seeing how she feels will help relationships of other sufferers and we can only hope that if you are struggling sharing that you can show this to your family.

We do also have an email set up ask@alishawhittam.com

Rebecca is available on the email and I know that she would love to help others who feel the same way.

Here is hoping that our support can form a support group of their very own.

Alisha Whittam

Controversial Study on ME-Patients

Controversial study on ME-patients receives ethical approval (of Norwegian committees)

On November 10th, 2020, English health authorities published a draft of a new set of guidelines for ME/CFS. It is confirmed that ME is a physiological disease, and it is advised against therapy and exercise as treatment. There is a special warning against the Lightning Process (LP). Read more here: English health authorities reject therapy as treatment for ME (https://bit.ly/2Wu4hzt) and here: The Guardian, Fatigue syndrome: Exercise therapy loses NICE recommendation (https://bit.ly/3aqJNzS)

The Regional Committees for Medical and Health Research Ethics (REK) have now approved a controversial Norwegian study in which 120 ME patients are to be treated with LP. The decision dated November 16th, 2020, states that: “After an overall assessment of the project application and feedback, the committee believes that the participants’ integrity and welfare are well safeguarded, and that the project will be able to produce new, socially useful knowledge. Provided that the conditions below are complied with, REK considers that the project is justifiable to carry out.”

Read the decision letter here (in Norwegian): Final decision from REK (https://bit.ly/34rapwN)

Nina E. Steinkopf

Note from the editors:
Read on here: https://bit.ly/3p0oskG in which a storm of protests against this decision and therapy from both scientists and patients.

COVID-19 Vaccine Eligibility

COVID-19 vaccine eligibility, safety and ME/CFS – what we know so far

With the start of vaccination against COVID-19 occurring this week, we are receiving queries about where people with ME/CFS will be on the priority list.

The Joint Committee on Vaccination and Immunisation (JCVI) has produced a list of different groups of people in the order that they are going to be offered one of the new COVID-19 vaccines. Find the JCVI list HERE (https://bit.ly/2WrolCw).

At the top of the list are people who are living and working in care homes, health workers, the very elderly (ie those over 80 years of age) and people who are extremely vulnerable to COVID-19 – because they have a very significant risk of developing serious or life-threatening complications if they catch COVID-19. Which is fair enough….

And while anecdotal evidence indicates that people with ME/CFS are likely to suffer an exacerbation or relapse of their ME/CFS symptoms if they catch COVID-19, there is no evidence to indicate that they are at significantly increased risk of developing serious or life-threatening complications.

So it will be an uphill struggle to get ME/CFS onto the very high priority list.

There is then a group of people with what are termed by the JCVI as having ‘underlying health conditions’ that also make them vulnerable in relation to COVID-19. This list includes people with chronic neurological conditions.

ME/CFS should be included in the ‘underlying health conditions’ list – as it is classified as a neurological disease by both the WHO and NHS England: (https://bit.ly/3pjMIP9).

And COVID-19 will almost certainly exacerbate pre-existing ME/CFS symptoms or cause a relapse of ME/CFS.

However, it looks as though people on this list will only become high priority once the over-65 age group has been vaccinated.

So it seems unlikely that people with ME/CFS below the age of 65 will be offered a COVID-19 vaccine until March or April next year – but it could be sooner if supplies of the Oxford/Astra Zeneca vaccine are approved and released

We will continue to update you on what is happening in relation to all aspects of COVID-19 vaccines and ME/CFS.

In the meantime there is no point in contacting your GP to see if you can have a COVID-19 vaccine – unless you are in in one of the high priority groups who are going to be given the vaccine over the coming weeks.

How safe are these Covid-19 vaccines for people with ME/CFS

The safety data so far on all three vaccines indicates that they all have a potential to cause short-lived side-effects – ie sore arm, fatigue, slight fever – that are found with any other vaccine.

There is no indication at present of any serious side-effects with any of these vaccines.

However, two cases of transverse myelitis has been reported in relation to the Astra Zeneca vaccine.

So, as with any other vaccine, it is possible that the COVID-19 vaccines will also cause a temporary exacerbation of flu-like ME/CFS symptoms.

And there is also a possibility that they could trigger a more significant exacerbation of ME/CFS symptoms.

At present, we have no data from the clinical trials as to what happens to people with ME/CFS with any of these vaccines – and I suspect that nobody with ME/CFS has taken part in any of the clinical trials.

This is data that is only going to come from patient evidence once people with ME/CFS start having the vaccine in 2021.

So everyone is going to have to make a personal judgement that involves:

- A definite risk of some ME/CFS symptoms being exacerbated
- A much lower risk of a more significant exacerbation of ME/CFS symptoms
- The possibility that once very large numbers of people have been vaccinated we will learn about some rare but serious side effects.
- A fairly high degree of protection from COVID-19 in return for taking these risks.

Dr. Charles Shepherd, December 7, 2020
Source: ME Association https://bit.ly/3msfdYY

Dear Recruitment Agent

Dear recruitment agent
Who sent me a lovely e-mail this morning
Asking if I'm interested
In an Accounts Assistant job currently vacant:

Unfortunately I'll have to decline.
You see I haven't worked outside my home
In over three years
And in my home, I work casually:
Sometimes I clean yesterday’s dishes
Sweep dirt under my couch with my four day old sock.

Sometimes I pick up a sweeping brush
Proudly make my own meals,
Sometimes I chop the tops off my fingernails
Forget that a knife is sharp,
Sometimes I burn myself
Forget that a grill pan and toaster are HOT
Sometimes I forget what I'm doing
Find myself searching for clues.

As for outside my home?
I like to take an amble in my garden
Where I often find my legs stuck.
I rarely leave my four walls alone
Don't drive beyond my local town
Only do so after days of rest
Repeating no sooner than a month later.

A visit to a friend leaves me recovering
The way an ultra-runner recovers
From a blistering race across the Sahara.
Road trips? They're out too
My body seizes while sitting in the one spot.
Nausea swirls easily and the headaches come on
At the slightest sound of noise.
I don't remember the last time I went clothes shopping
I only go food shopping now, joining my husband
He takes care of the list, I mind the trolley
Holding it with both hands
Carefully pulling my legs.

These legs aren't made for walking
They saunter, grump up when asked to move
My hips seize, legs weaken
Don't ask them to take on stairs
Stairs make my legs and heart race,
My arms throw tantrums too
Refuse to raise themselves beyond my shoulder
Burn at my shoulder, wrist and hand.

Oh and the exhaustion, that's present everyday
I sleep for twelve to fourteen hours,
Spend my days amid avid rest
Either on my trusty couch, or outside
On my garden bench.
I can't follow the plots of TV
Or concentrate on the words of a book
I like to read poetry
(Skipping poems more than a page in length)
I re-read poetry
Forgetting which one I've read.

Dear recruitment agent,
Please call me back again.

Marie H. Curran

Fighters & Survivors

We are fighters
we are survivors
living in completely crazy situations
missing our former healthy selves
missing our life
missing friends
missing family
missing work
missing dancing, running, walking
missing going out
.... every normal activity

loosing dear friends to ME
falling in huge black canyons of desperation
living with grief
and
"guilt of the survivors"
still

finding happiness in nature
or tiny bits of colour
finding a purpose in life in helping other PwME
and if doctors, advocates and judges
fail and
are not able to protect us from further harm
it is completely okay to stop fighting
and

to step back
from further harm and cruelty
and even if it feels like defeat
I am not a victim
I am a survivor
I am a fighter
and I will rise again like a phoenix.......

B.Becker
Nov 2020

My Art and M.E.

My Art and M.E.: The Demands of a Creative Mind

What does one do with a creative mind that continues its battle to be heard? A mind that will not rest until the journey of understanding life lived with Myalgic Encephalomyelitis (M.E.) is deemed complete? It seems I have to comply with its demands to reach the point of knowing the work is done.

Before illness irrevocably changed my life 22 years ago, I worked as a professional Doll Artist depicting Irish life and folklore. In illness my creative mind demanded to explore my inner landscape instead. I resisted. I failed. I blamed hard work as a self-employed artist for becoming ill. I vowed to never engage with art again. Yet having lost my ability to sculpt, I found myself drawing very basic sketches: Eggs, birds, ladders, and even drawings about not wanting to be creative… Reluctantly I accepted the power of my creative mind to help me heal.

A new language of illness

To understand this new language of illness I consulted the dictionary. For a drawing of an egg standing upright on a pillow, a hand reaching out of the broken top, the dictionary told me that 'eggs have the capability of growing into a new individual.' That made sense. I was so very ill. I had an opportunity to start life again.

Eggs hatched, fledglings emerged, birds tentatively left the nest and started to fly. With the publication of my first book 'Hatched – a Creative Journey Through M.E.' (https://bit.ly/38mUPDo) (2006) I truly believed I could put M.E. on the shelf and move on with my life. I was improving, but certainly not recovered. Years later, when sculpting again, I made a series of figures on tree roots. Acceptance had set in. I became more 'rooted'. Perhaps I hadn't been flying freely as a bird but had been flying away from my reality.

A slow but fruitful process

I can only safely work twenty minutes a day. The benefit of this slow progress is that the true story reveals itself over the months it takes to finish a piece of work. With 'Birth Dance' (2016), a dance between a young woman and a crane bird, I realised that it begged for the transition back to puppetry. To movement. To dance with life again. To take my rightful place back in society after many years of often being housebound.

For one hour a week, I became an 'Artist in the Community' through facilitating the 'Life Outside the Box' (https://bit.ly/3mAocam) puppet project with fellow members at the Dungarvan IWA Resource Centre. A very empowering project in terms of the emerging story of stepping out of society's disability box, but also for me personally: I was teaching again after a 17-year gap, albeit with support. This project catapulted me into the world of puppetry at the first Broken Puppet Symposium (https://bit.ly/3ap8BrZ) (Cork, 2017). I became immersed in the powerful intersection of puppetry, disability and health. This groundbreaking event led to lecturing opportunities worldwide, some in person, now only via video link.

Challenge of body or mind?

My body, however, renewed its efforts to challenge my creative mind. Or is it the other way around? Three years ago, I lost the ability to hold the cross of my marionette puppets. I devised a puppet which I could animate on my lap while seated in the wheelchair. A year later I could no longer sculpt my puppets. During a spell in hospital early in 2019 I sought mentoring support from puppet master Dr. Emma Fisher to find a way forward.

Working on what turned into the 'Invisible Octopus' project inexplicably forced me to examine and establish the truth about what is my normal. I had to come face to face – puppet to face – with my strengths and weaknesses. My creative enthusiasm was not enough to bring the many ideas into being. My mental wellbeing thrived while my physical wellbeing suffered in equal measure. Puppetry forced me to look deep into my reality. Poetry defined the experience.

Shadow puppetry

The introduction to shadow puppetry brought me renewed creative freedom. I am able to cut paper puppets and other images while lying in my recliner. With each single tiny movement on the overhead projector, I portray my story on the opposite wall. It is powerful beyond words. My previous work is often translated into a sense of beauty, light and hope into a dark situation. With shadow work there is no hiding. It is stark. Clear. After the creation of the two-minute 'Invisible Octopus' video-poem (https://bit.ly/3p7W9AV) I said out loud to myself: 'my work is done.' With the 12 images accompanying the 12 stanzas of my poem I had transformed pain into poetry.

This work became the basis of the shared 'Ribbon of Light' (https://bit.ly/2Wr8rbr) exhibition in 2020. My last public exhibition. It was simply all too much. I now rarely leave my home but I did get to visit the exhibition on the very first day. Due to Covid-19 we had no official opening. The immensity of seeing my work on the gallery wall was both beautiful and difficult. The following day the Government imposed Level 3 restrictions. Galleries were to be closed. Art about isolation in isolation.

A huge disappointment…

I am having difficulty comprehending that this final big work might be forever hidden. But it simply can't be the end of my story. It feels too personal. Hidden. Yet again. I am experiencing a sense of numbness. Having no desire to create and having trouble writing. There is a great need to retreat. (Partly due to other life events.) However, an image of a suitcase keeps entering my mind. Is this the next work to be created? If so, as yet I don't see the connection with M.E. Perhaps I have on that front fulfilled the demands of my creative mind. My work on M.E. is done.

Corina Duyn

Source: Arts & Health https://bit.ly/3mztN0S

ME Research UK

Cara Tomas and colleagues have recently published the latest results from their ME Research UK-funded study exploring the metabolic abnormalities in muscle cells from people with ME/CFS. This latest exciting research looks at the cells' ability to use glucose in the production of energy.

In this latest paper, published in Scientific Reports, **Cara** has been looking more closely at how skeletal muscle cells produce energy from the different fuel sources (or substrates) available, and how this differs between people with ME/CFS and healthy individuals.

Importantly, she has built on the team's previous work by using cultured muscle cells rather than the white blood cells used in some of the earlier experiments.

The cells of the body – including muscle cells – produce energy by breaking down glucose (a sugar that we get from our food) and converting it into the molecule ATP, which is used to transport energy for use within the cell. There are four steps to this process: glycolysis, pyruvate oxidation, the citric acid cycle and oxidative phosphorylation (OXPHOS).

In this study, skeletal muscle cells from people with ME/CFS had a reduced ability to use glucose as a fuel to produce energy via OXPHOS, while they were able to use galactose and fatty acids normally, and glycolysis was also normal.

This impairment in energy production may underlie the muscle fatigue that is characteristic of the illness, and the results help narrow down where in the metabolic pathway the abnormality occurs.

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

Dr. David Newton

Something to Think About...

Although some passages in this text may sound very painful for people whose possibilities of expression are utterly limited due to a severe disease, in a limited way they still can be put into practice and may even be your own experience already.

Did you know that when Einstein gave lectures at the numerous US universities he was invited to, the recurring question that students asked him was:
Do you believe in God?

And he always answered:
I believe in the God of Spinoza.

The ones who hadn't read Spinoza didn't understand...
I hope this gem of history, serves you as much as it does me:

Baruch de Spinoza was a Dutch philosopher considered one of the three great rationalists of 17th-century philosophy, along with René Descartes in France, and Gottfried Leibniz in Germany.

Here's some of his wisdom:

God would have said:

Stop praying and punching yourself in the chest!
What I want you to do is go out into the world and enjoy your life. I want you to enjoy, sing, have fun and enjoy everything I've made for you.

Stop going to those dark, cold temples that you built yourself and say they are my house! My house is in the mountains, in the woods, rivers, lakes, beaches. That's where I live and there I express my love for you.

Stop reading alleged sacred scriptures that have nothing to do with me. If you can't read me in a sunrise, in a landscape, in the look of your friends, in your son's eyes... you will find me in no book! Trust me and stop asking me. Would you tell me how to do my job?

Stop being so scared of me. I do not judge you or criticize you, nor get angry, or seek to punish you. I am pure love.

Stop asking for forgiveness, there's nothing to forgive. If I made you... I filled you with passions, limitations, pleasures, feelings, needs, inconsistencies... free will. How can I blame you if you respond to something I put in you? How can I punish you for being the way you are, if I'm the one who made you? Do you think I could create a place to burn all my children who behave badly for the rest of eternity? What kind of God would do that?

Forget any kind of commandments, any kind of laws; those are wiles to manipulate you, to control you, that only create guilt in you.

Respect your peers and don't do what you don't want for yourself. All I ask is that you pay attention in your life, that your consciousness is your guide.

My beloved, this life is not a test, not a step, not a rehearsal, nor a prelude to paradise. This life is the only thing that exists here and now, and it is all you need.

I have set you absolutely free, no prizes or punishments, no sins or virtues... no one carries a marker, no one keeps a record.
You are absolutely free to create in your life heaven or hell.

I could tell you if there's anything after this life, but I won't... but I can give you a tip. Live as if there is nothing after... as if this is your only chance to enjoy, to love, to exist.

So, if there's nothing, then you will have enjoyed the opportunity I gave you. And if there is, rest assured that I won't ask if you behaved right or wrong, I'll ask. Did you like it? Did you have fun? What did you enjoy the most? What did you learn?...

Stop believing in me; believing is assuming, guessing, imagining. I don't want you to believe in me... I want you to feel me in you when you kiss your beloved, when you tuck in your little girl, when you caress your dog, when you bathe in the sea.

Stop praising me, what kind of egomaniac God do you think I am? I'm bored being praised, I'm tired of being thanked. Feeling grateful? Prove it by taking care of yourself, your health, your relationships, the world. Express your joy!... that's the way to praise me.

Stop complicating things and repeating as a parakeet what you've been taught about me.
The only thing for sure is that you are here, that you are alive, and that this world is full of wonders.

What do you need more miracles for? Why so many explanations?
Look for me outside... you won't find me.
Find me inside... there I am beating within you.

The Ever Changing Perimeters in Daily Life With ME

This morning my PA (Personal Assistant/carer) cut back some of the growth in my back garden. I feel elated by the space this created. I feel elated that the job was done. (More to do). I sat in my wheelchair by the open door, blanket over me. I felt the fresh air. Even a bit of sunshine on my face. Very welcome after many days in bed.

I am painfully aware that not too long ago I would have done this job myself. Even at 5 minutes at the time, 10 minutes a day. I would see progress over the weeks it would have taken me to do the same as my PA did in twenty minutes. I know over the past year I was not able to clear away the cuttings. But would have had the satisfaction of having done some ‘gardening’.

I used to get such a kick out of doing this kind of job myself. I love to feel the plants in my hands. To sit on my stool and touch the earth. To smell the various herbs. To be close to a flowering plant. To observe the colours, the scent. To create space for new growth. To have clear paths. To be one with my garden. To be near the birds. A feeling which can not be exchanged by just watching... I miss it. I took such pleasure out of my garden. Now it is often one more job that needs to be done and I need to ask to be done for me. The list grows... And so do my plants...

I must admit I am tired after this ‘directing’ job: “Please take out the huge sweet-pea. It can all go. Yes, please do cut the oregano. Please finish the ‘Mohican’ haircut I had given the lavender a month or so ago. (I had cut a good bit but had let the top flowers for remaining bees.) ...That plant there? It is a overgrown lemon balm, which had seen the opportunity to grow big now there was nothing in it’s way...” Etc. Etc.

Lately I see a big shift in the perimeters of what I can still do. Or maybe it is gradual, but rapid at the same time. There is an acceleration in the ‘not possible anymore’ lately. The simple things I now need to hand over to others. From filling some of the bird’s feeders to the more basic things like often needed help in getting dressed.

For now though I am grateful to have my PA and other carers whom are almost like ‘prosthetics’ to my body.

Corina Duyn
Source: https://bit.ly/3h1zbsp

The WHO Approves My Proposal

The WHO approves my proposal for removal of "Benign" from "Benign myalgic encephalomyelitis" for ICD-11

ICD-11 Report Four | December 2020

"Benign myalgic encephalomyelitis" was first listed in the International Statistical Classification of Diseases and Related Health Problems (ICD) in 1969 as an index term in the ICD-8 Alphabetical Index, as "Encephalomyelitis (myalgic, benign)".

"Benign myalgic encephalomyelitis" wasn't included in the ICD-8 Tabular List.

For ICD-9 (1975), "Encephalomyelitis (myalgic, benign)" remained an index term in the Alphabetical Index (1978) and again, there was no listing of the term in the ICD-9 Tabular List [**1**].

International version of ICD-10

"Benign myalgic encephalomyelitis" wasn't included as a Tabular List term until the release of ICD-10, in 1992.

ICD-10 included many modifications, including relocation of some ICD-9 categories to different chapters of the classification.

The WHO created a new Tabular List category block G93: Other disorders of brain, in Chapter VI: Diseases of the Nervous System.

The ICD-9 category, "Postviral syndrome" (coded in ICD-9 Tabular List under the Symptoms, Signs And Ill-defined Conditions chapter) was moved under this new G93 parent block as "Postviral fatigue syndrome" and assigned the code G93.3.

The index term "Benign myalgic encephalomyelitis" was moved into the ICD-10 Tabular List as the inclusion term under the new Concept Title: G93.3 Postviral fatigue syndrome.

"Chronic fatigue syndrome" was added to ICD-10 Volume 3: Alphabetical Index and indexed to the G93.3 code [**2**].

A request for removal of the "Benign" prefix for ICD-10

In March 2016, a representative from Canadian Institute for Health Information submitted a request and brief supporting rationale to the WHO-FIC ICD-10 Update and Revision Committee (URC) for removal of the "Benign" prefix from "Benign myalgic encephalomyelitis".

The URC approved this request for ICD-10 in September 2016 for implementation after January 2018. View a copy of the request here [**3**].

The change was implemented for the final update of the WHO's International version of ICD-10 (ICD-10 Version: 2019) which was released in January 2020.
Note: "Benign myalgic encephalomyelitis" has been retained as an ICD-10 index term for backward statistical compatibility and comparability over time with earlier versions of ICD-10 and with the national modifications of ICD-10.

View the change for the ICD-10 (Version: 2019) Tabular List here: https://bit.ly/33CrdjM

Although this change for ICD-10 had been approved in September 2016, it had not been carried forward to ICD-11 by the WHO or by the ICD Revision committees with oversight of the ICD-11 development process.

March 2017 proposals for ICD-11 rejected

In March 2017, **Suzy Chapman** and **Mary Dimmock**; and Lily Chu MD (on behalf of the IACFS/ME) submitted two separate proposals for ICD-11 which, among other recommendations, had included rationales for the removal of "Benign" from the "Benign myalgic encephalomyelitis" inclusion term.

ICD Revision rejected both sets of proposals outright in March 2019. The WHO/ICD Revision provided no rationale for their decision to reject this recommendation.

(It was not apparent until January 2020 that the URC had already made a decision back in 2016 to approve the retirement of the "Benign" term from the next update of ICD-10, so this historical decision could not inform our proposal rationales.)

A new proposal for ICD-11

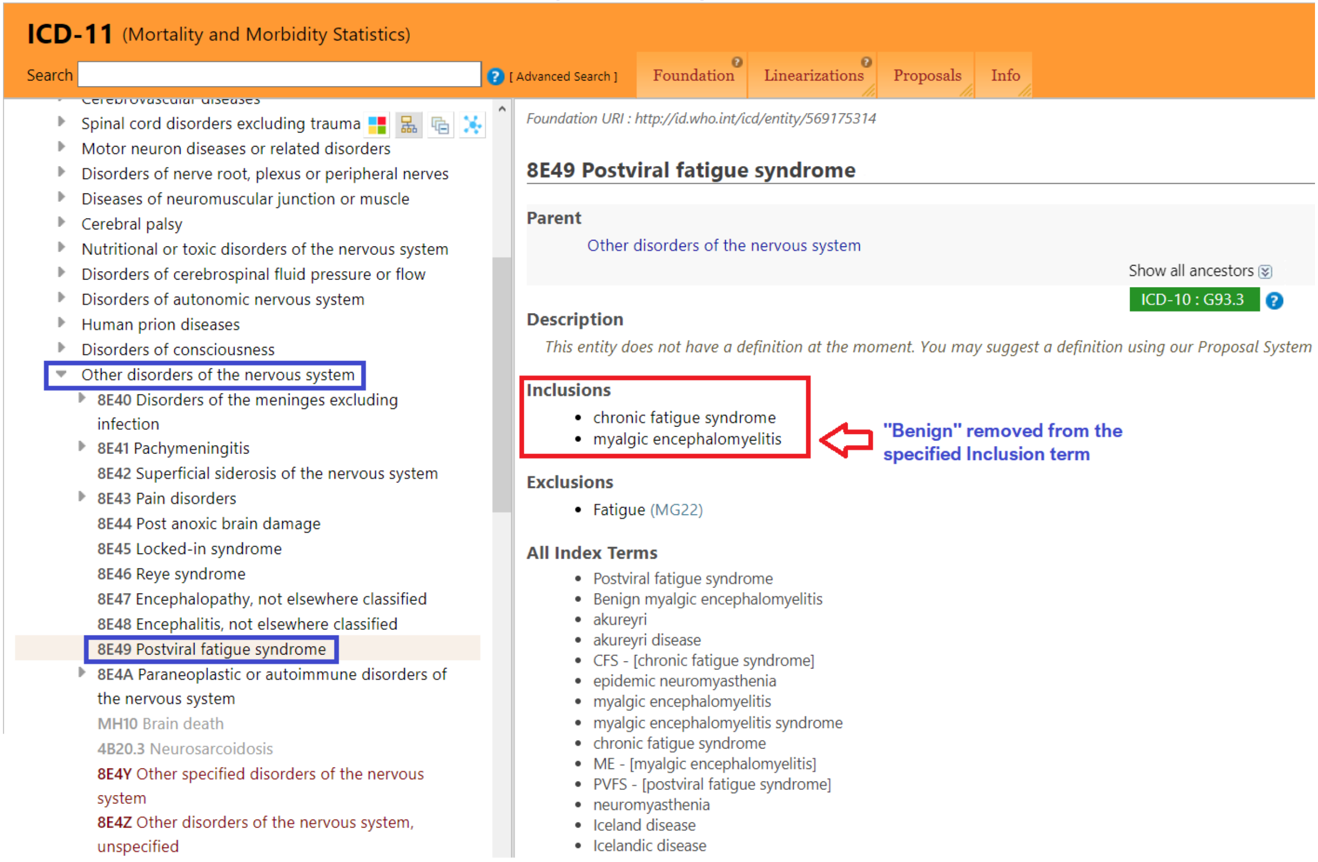
In February 2020, I submitted a new proposal and rationale text for removal of the "Benign" prefix for ICD-11 citing among other reasons, the precedent decision of the URC in September 2016 and the implementation of that decision for the final release in the life of ICD-10.

View a copy of my proposal and rationale text here: http://bit.ly/BenignICD11
I had hoped this new proposal might be reviewed in time for potential addition to the next annual update of the ICD-11 for Mortality and Morbidity Statistics (ICD-11 MMS), which was expected to be released at some point after April 2020.

Despite approaching WHO Director-General **Dr Tedros Ghebreyesus** with a request that this proposal was fast tracked for review, it sat unprocessed for over six months and missed the deadline for potential inclusion in the annual update of the ICD-11 for Mortality and Morbidity Statistics, which was released in September 2020 [**4**].

However, this new proposal was finally approved on November 13, 2020.

Image: ICD-11 (Mortality and Morbidity Statistics) Maintenance Platform, Accessed November 20, 2020: https://bit.ly/3lZdY3U



- Cerebrovascular diseases
- Spinal cord disorders excluding trauma
- Motor neuron diseases or related disorders
- Disorders of nerve root, plexus or peripheral nerves
- Diseases of neuromuscular junction or muscle
- Cerebral palsy
- Nutritional or toxic disorders of the nervous system
- Disorders of cerebrospinal fluid pressure or flow
- Disorders of autonomic nervous system
- Human prion diseases
- Disorders of consciousness
- Other disorders of the nervous system
  - 8E40 Disorders of the meninges excluding infection
  - 8E41 Pachymeningitis
  - 8E42 Superficial siderosis of the nervous system
  - 8E43 Pain disorders
  - 8E44 Post anoxic brain damage
  - 8E45 Locked-in syndrome
  - 8E46 Reye syndrome
  - 8E47 Encephalopathy, not elsewhere classified
  - 8E48 Encephalitis, not elsewhere classified
  - 8E49 Postviral fatigue syndrome
  - 8E4A Paraneoplastic or autoimmune disorders of the nervous system
  - MH10 Brain death
  - 4B20.3 Neurosarcoidosis
  - 8E4Y Other specified disorders of the nervous system
  - 8E4Z Other disorders of the nervous system, unspecified

Foundation URI : http://id.who.int/icd/entity/569175314

8E49 Postviral fatigue syndrome

Parent

Other disorders of the nervous system

Show all ancestors

ICD-10 : G93.3

Description

This entity does not have a definition at the moment. You may suggest a definition using our Proposal System

Inclusions

- chronic fatigue syndrome
- myalgic encephalomyelitis

"Benign" removed from the specified Inclusion term

Exclusions

- Fatigue (MG22)

All Index Terms

- Postviral fatigue syndrome
- Benign myalgic encephalomyelitis
- akureyri
- akureyri disease
- CFS - [chronic fatigue syndrome]
- epidemic neuromyasthenia
- myalgic encephalomyelitis
- myalgic encephalomyelitis syndrome
- chronic fatigue syndrome
- ME - [myalgic encephalomyelitis]
- PVFS - [postviral fatigue syndrome]
- neuromyasthenia
- Iceland disease
- Icelandic disease

The Exclusions for PVFS; BME; and CFS under 6C20 Bodily distress disorder have been revised to reflect the removal of the "Benign" prefix: https://bit.ly/36yBrUp

Exclusions for PVFS; BME; and CFS under MG22 Fatigue have also been revised to reflect this revision: https://bit.ly/3mxIguR

As with ICD-10, the term, “Benign myalgic encephalomyelitis” has been retained as an ICD-11 index term, for backward compatibility and comparability over time with older versions of ICD and the national modifications.

This revision to the terminology will be incorporated into the next annual release of the ICD-11 for Mortality and Morbidity Statistics (ICD-11 MMS), anticipated around September 2021.

Removal of “Benign” from “Benign myalgic encephalomyelitis” for the final update of the WHO’s International version of ICD-10 — and now approved for ICD-11 — has been widely welcomed and sets a precedent for all the national modifications of ICD-10.

Note that Germany’s ICD-10-GM and Australia’s ICD-10-AM had already retired the “Benign” prefix some years ago for their national modifications of the WHO’s International version of ICD-10.

References

1 Screenshots from the ICD-8 and ICD-9 Tabular Lists and Indexes: Science for ME Forum (S4ME): https://bit.ly/3fx2yCe

2 A Summary of Chronic Fatigue Syndrome and Its Classification in the International Classification of Diseases Prepared by the Centers for Disease Control and Prevention, National Center for Health Statistics, Office of the Center Director, Data Policy and Standards, March 2001: https://bit.ly/3ql6ElV

3 Proposal ID: 2211, March 16, 2016, ICD-10 Update and Revision Platform: https://bit.ly/3qlf1he

4 ICD-11 for Mortality and Morbidity Statistics (Version: 09/2020) annual release, September 2020: https://bit.ly/37uztDD

Suzy Chapman
Dx Revision Watch
https://dxrevisionwatch.com - dxrevisionwatch@page1.myzen.co.uk

Are Infections Seeding Some Cases of Alzheimer’s Disease?

A fringe theory links microbes in the brain with the onset of dementia. Now, researchers are taking it seriously

- Remember that ME has a lot of overlap with Alzheimers with respect to the brain functioning and aspects

Two years ago, immunologist and medical-publishing entrepreneur **Leslie Norins** offered to award US$1 million of his own money to any scientist who could prove that Alzheimer’s disease was caused by a germ.

The theory that an infection might cause this form of dementia has been rumbling for decades on the fringes of neuroscience research. The majority of Alzheimer’s researchers, backed by a huge volume of evidence, think instead that the key culprits are sticky molecules in the brain called amyloids, which clump into plaques and cause inflammation, killing neurons.

Norins wanted to reward work that would make the infection idea more persuasive. The amyloid hypothesis has become “the one acceptable and supportable belief of the Established Church of Conventional Wisdom”, says **Norins**. “The few pioneers who did look at microbes and published papers were ridiculed or ignored.”

In large part, this was because some early proponents of the infection theory saw it as a replacement for the amyloid hypothesis. But some recent research has provided intriguing hints that the two ideas could fit together — that infection could seed some cases of Alzheimer’s disease by triggering the production of amyloid clumps.

Read on here: https://go.nature.com/34WnoqJ

NICE Draft Updated Guideline

NICE Draft Updated Guideline on the Diagnosis and Management of Myalgic Encephalomyelitis – 2 reactions

Last November the draft of the guideline to be updated by the British National Institute for Health and Care Excellence (NICE) was the biggest news in the global ME-community. British Invest in ME is always at the heart of the developments on ME in the UK and here are some paragraphs from their reaction, followed by a reaction of long-term patient activist Margaret Williams

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“Today (9 november) the National Institute for Health and Care Excellence (NICE) issued a press release regarding myalgic encephalomyelitis (ME). Invest in ME Research is a stakeholder in the NICE guidelines for ME and has commented frequently on the NICE response to ME over the years. Until the charity is able to examine the full draft guidelines document then our comments relate only to this NICE press release.

From the NICE press release it appears that GET is to be removed as a recommendation from the new NICE guidelines and the recommendation of prescriptive CBT that was manufactured for ME is to be replaced by an offer of supportive CBT as proposed for use in other chronic illnesses.

In January 2018 the charity had lengthy correspondence with NICE Guidelines director Professor Mark Baker and requested that NICE remove immediately the recommendations for the deleterious therapies (CBT and GET) from the existing guidelines while the new guidelines were being drafted as

CBT in the existing NICE guidelines is tightly connected to GET as it asserts that fear of exercise and false illness beliefs perpetuate the condition.

CBT and GET are the two major components causing the damage being done to people with ME. Their continued use affects everything. We do not accept that “in particular” GET is not acceptable.
CBT must be removed also in parallel with GET.

By leaving CBT as a recommendation, you will leave the door open for continued funding of the same bogus research that has monopolised and compromised the lives of people with ME and their families for so long. It is unacceptable.

Professor Baker and NICE declined this request.

When the new NICE guidelines are finally published in 2021 it will be three years since we wrote to **Professor Baker**. We wonder how many more ME patients' lives will have suffered over those three years by being prescribed, or coerced into trying, these harmful therapies based on the still existing NICE guidelines.

The NICE press release states that the draft guidelines
"..stresses the need for a tailored, individualised approach to care based on establishing a partnership between the person with ME/CFS and those providing their care that allows joint decision making and informed choice."

The NICE press release also states
"The draft guideline also highlights the importance of ensuring that people remain in their 'energy envelope' when undertaking activity of any kind. It recommends that a physical activity programme, in particular, should only be considered for people with ME/CFS in specific circumstances."

The NICE press release also says that a physical activity programme should only be offered on the basis that it is delivered or overseen by a physiotherapist or occupational therapist with training and expertise in ME. Will all the physiotherapists and occupational therapists currently involved in ME get retrained as the past 13 years of CBT and GET advice has been based on a false illness belief model of ME?

Tellingly, the NICE statement implicitly recognises the failure of national research councils to fund and initiate adequate research into ME by including this observation: "The committee wasn't able to make any recommendations for treatments because of a lack of evidence of effectiveness"

The reason for a lack of evidence is a result of a lack of funding for fundamental biomedical research – a task that has been taken up instead by patients and carers.

Whilst NICE might well expect to be congratulated for finally listening, in part, to the needs of people with ME, it would be premature to think that all is now well.

Yet the existing NICE guidelines have been allowed to remain for thirteen years with flawed recommendations. How many lives have been harmed over these thirteen years since the previous guidelines were created – guidelines that were criticised by most charities at the time?

Just to put into context the failure of NICE and its supporting organizations:

- 13 years covers the teenage years and young adulthood of a child diagnosed at the age of 13;
- it covers the early adulthood of somebody diagnosed in their twenties;
- it covers the middle age years of those diagnosed in late adulthood;
- it covers the later years when diagnosed in their forties.

These years are forever blighted, these times are never recovered. They are lost. So no, no reason for congratulations.

NICE failed people with ME and their families for thirteen years despite having many chances to improve the situation. Yet NICE has never been made accountable.

We can only hope that there is enough change in the new guidelines to overcome the misinformation about ME that has been allowed to be built up over the years despite objections from the patients.

The charity’s full analysis of the draft guidelines will be completed in due course.

Source: Invest in ME (https://bit.ly/3mzFxjG)

* * *

Margaret Williams commented on this important step of NICE:
"It is not surprising that **Professors Wessely**, **White**, **Sharpe** and **Chalder** commented as they did for the Science Media Centre’s press release on the NICE draft guideline. They are well-known for being either unable or unwilling to face reality by their persistent refusal to accept the proven failure of their PACE trial.

They apparently prefer to delude themselves because otherwise they would have to accept that their careers have been nothing but null and void. As Ioannidis noted 15 years ago: “Of course, investigators working in any field are likely to resist accepting that the whole field in which they have spent their careers is a ‘null field’. However …advances in technology and experimentation may lead eventually to the dismantling of a scientific field” (PLoS Medicine 2005:2:8:e124)

To its credit, by accepting that ME/CFS is a biomedical disorder, NICE has dismantled a scientific field, from which it can be concluded that the Wessely School have spent their careers in a “null field” in relation to their efforts to designate ME/CFS as a behavioural disorder.

Could the refusal of Wessely et al to face reality have anything to do with their long-term close involvement with the medical insurance industry (which must now be quaking in its boots at the prospect of having to accept that if NICE no longer designates ME/CFS as a psychiatric disorder, it can no longer be excluded from cover)?

Margaret Williams
10th November 2020

Forward-ME Call For Health Warning

Forward-ME call for health warning to be put on existing NICE guideline for ME/CFS

A highly influential UK campaign group is demanding that a health warning be put on the existing NICE guideline for ME/CFS – to try and stop more patients being damaged by graded exercise.

Some 24 members of the Forward-ME Group – led by founder The Countess of Mar – have signed up to the statement below.

In it, they say:
"As long ago as 2002, the Chief Medical Officer's Working Group recognised that 'substantial concerns exist regarding the potential for harm' in respect of graded exercise, and that patients reports 'clearly indicate that the York review results do not reflect the full spectrum of patients' experience.'

"We do not consider that it is acceptable for this situation to continue unabated pending the publication of the revised guidelines, presently scheduled for April 2021.

"We are aware that the Health Department in Scotland has recently. cautioned against graded exercise 'therapy' – see https://tinyurl.com/y5txhdv9 (announcement Nov 2020) and https://tinyurl.com/yyherfp5 (publication August 2020).

"We call on the Department of Health to make a similar caution public now in order to help safeguard patients in England. "

Forward-ME also note that the existing guideline doesn't give health or social care professionals the tools they need to comply with a 2015 Supreme Court judgement which made it clear that, in order to obtain informed consent to treatment, patients need to know whether any "material risks" were involved.

"If professionals are unaware that there is potential for harm, how can they possibly furnish patients with the information required to make an informed decision?"

Among signatories to the statement were **Dr Charles Shepherd** and paediatrician **Dr Nigel Speight**, who are both medical advisers to the ME Association.

Source: ME Association
https://bit.ly/3nFBRi4

BMJ: NICE backtracks

BMJ: NICE backtracks on graded exercise therapy and CBT in draft revision to CFS guidance

Graded exercise therapy (GET) should no longer be offered for the treatment of chronic fatigue syndrome (CFS, also known as myalgic encephalomyelitis), the National Institute for Care and Health Excellence (NICE) says in draft guidance.

Instead, patients should be encouraged to remain within their “energy envelope” so as not to worsen their symptoms, it advises. Likewise, cognitive behavioural therapy (CBT) should no longer be offered as a treatment, NICE adds, although it can be offered as a psychological therapy that aims to help patients to manage their symptoms. The revisions have been based not only on published evidence but also on patient reports that the treatments did not benefit them, and that in some cases GET caused harm.

In July, NICE cautioned against the use of GET for patients recovering from covid-19 who were experiencing post-viral fatigue, saying that its current advice on managing chronic fatigue may not be appropriate for this group of patients and hinting that its advice for other groups might be out of date. Hopes were raised among groups representing patients with CFS that NICE’s review of its 2007 recommendations might take account of multiple reports of harms associated with GET from patients.

The long-awaited draft update recognises that CFS is a complex, multi-system, chronic medical condition for which there is no “one size fits all” approach because an intervention that may benefit some could harm others. It stresses the need for a tailored, individualised approach based on establishing a partnership with the patient that allows joint decision making and informed choice.

The draft guidance says that patients should remain in their “energy envelope” when undertaking activity of any kind, emphasising that “each person has a different and fluctuating energy limit, and they are the best judge of their own limits.” Specifically, because of the harms reported by patients and the guideline committee’s own experiences, the guideline says that GET should not be offered.

Any physical activity programme should establish the physical activity capability level that does not worsen symptoms, be overseen by a physiotherapist or occupational therapist with expertise in CFS, and reviewed regularly, it says.

The guideline also recommends reducing the time that a patient needs to have persistent symptoms before a diagnosis can be confirmed from four to three months.

Paul Chrisp, director of the Centre for Guidelines at NICE, said:
"Controversy over the use of GET and CBT has served to alienate many people with CFS and in some cases undermine the confidence of those caring for them.

"The recommendations in this draft guideline have been developed by an independent committee that was guided not just by the clinical evidence, but also by the experience and testimony of people with CFS.

"The result is a guideline that will provide much needed clarity, set new standards for health professionals, and ensure that people with CFS have access to the right care and support."

Some doctors were disappointed that GET and CBT would no longer be recommended by NICE.

Alastair Miller, deputy medical director at the Joint Royal Colleges of Physicians Training Board, said that while he was aware of the controversy over GET and CBT, many of his patients had benefited from them.

"There has never been any evidence of harm and they remain the only evidence-based treatment approach in CFS. It's disappointing that NICE has chosen to exclude them from the updated guidelines," he said.

Peter White, emeritus professor of psychological medicine, Queen Mary University of London, said:

"NICE is usually commended for being led by the science. It is therefore a surprise that this guideline proscribes or qualifies treatments for CFS for which there is the best evidence of efficacy, namely GET and CBT.

"It is also remarkable that the committee use the symptom of post-exertional fatigue as a reason for not providing GET, when the largest ever trial of GET showed that it significantly reduced this symptom more than staying within one's energy envelope."

References

1. National Institute for Health and Care Excellence. Guideline: myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: diagnosis and management. Draft for consultation, November 2020 (https://bit.ly/3nzdtyr).
2. **Torjesen I.** NICE advises against using graded exercise therapy for patients recovering from covid-19. 21 July 2020. https://bit.ly/2KdwI2e
3. National Institute for Health and Care Excellence. Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy): diagnosis and management. Clinical guideline [CG53]. 22 Aug 2007 (https://bit.ly/3muQqUd).

Ingrid Torjesen, British Medical Journal, 10 November 2020
Source: ME Association https://bit.ly/3regCpu

Opening of Special Care Service

Opening of Special Care Service for Severely Ill ME Patients

In Norway there is a great need for a specialised care service for ME patients, a place where they are taken care of and treated by professionals with specialist expertise in ME.

It is not uncommon for very severe ME patients and their relatives to have to fight hard to receive dignified and functional treatment. EMEA Norway - Norges ME Forening (NMEF)- has announced that during the spring of 2021, such a care and nursing service will be opened at Røysumtunet in the Gran municipality.

"We have long been looking for a place where the sickest ME patients could get proper treatment. Through the dialogue with Røysumtunet over time, we were gradually convinced that this could be what we were looking for", says chairman of the board of the Norges ME Forening, **Bjørn Getz Wold**.

The general manager at Røysumtunet, **Erik Nordengen**, says that for some time they have looked for an opportunity to expand the activity and business. The timing of the talks with the Norges ME Forening were fortuitous. "The offer that is now in place will fit very well into our profile", says **Nordengen**. The official opening date has not yet been fully determined. The ambition is spring 2020, and then there will be a total of 12 places set aside for ME patients.

Røysumtunet is located just outside Jaren in the Gran municipality in the Inland, in a beautiful cultural landscape just under an hour and a half from Oslo. The organisation offers various services within rehabilitation, housing and assistance and mental health, and has, for example, a close collaboration with the Special Hospital for Epilepsy and the Norwegian Epilepsy Association.

While Røysumtunet itself will be responsible for, amongst other things, operations, personnel and the content of the upcoming offer, Norges ME Forening will be an active contributor to both the design and content. NMEF will also contribute with skills development and training of the staff group along the way.

Norges ME Forening has had several visits to Røysumtunet. On Friday 12 December, five members of the association met, among them **Professor Ola Didrik Saugstad** from the association's medical professional council, to sign the final agreement. "Røysumtunet has gradually become a large organisation I have followed this collaboration since the beginning and been involved in discussions. It is great to finally get an agreement in place", says chairman **Jakob Ruud**.

"We have seen that the service for ME patients is deficient today, and we want to contribute. Central to us in the design of this is input from users and relatives, says **Nordengen**.

From Norges ME Forening's side, Secretary General **Olav Osland**, adviser **Mette Schøyen** and **Professor Ola Saugstad** have been key driving forces in working out the agreement. Osland and Schøyen also participated in the signing, via video call. Until the opening date, there are now only practical tasks left about the design. A total of 12 places will be available for ME patients, although all 12 will probably not be earmarked for long-term stays, for example.

Otherwise, the service will be offered to the country's municipalities and districts in Oslo. It will be the GP who sends the application for residence after clarification with the patient's home municipality / district.

Ola Didrik Saugstad is a professor, pediatrician and a member of Norges ME Forening's medical professional council (and also of the European ME Research Group (EMMERG). He has been central, especially at the beginning of the process, in finding a suitable place for institutional places for the seriously ill with ME.

"I have traveled a great deal to patients and relatives over the years and have seen the enormous need for institutional places for seriously ME patients. They are housebound, often cared for by relatives, and in some cases, they have not been in contact with the health service for several years", says **Saugstad**. "Many have contacted me and asked about this. I have great trust in this development", he says.

In addition to offering care to ME patients, both parties believe that Røysumtunet could, in the future, be a place to carry out research projects towards the patient group. "There is nothing concrete here yet. But we have faith in Røysumtunet as a place where one can conduct medical research, for example to test various forms of symptom treatment, under controlled conditions. In the long run Røysumtunet can become a competence institution for ME", says **Saugstad**.

"But an opportunity to conduct research will also be an important contribution, and not just nationally but potentially beyond national borders. If long-term Covid-19 causes an increase in the number of ME patients in Norway, the need for these places will also increase", he says.

Source: EMEA https://bit.ly/34sC4xw
Thanks to **Alice Vertommen**,
ME Vereniging België

Episode 119
https://youtu.be/2hrPnK1OWXQ
Llewellyn King interviews **Tom Kindlon**, one of the curators of CO-CURE. **Kindlon**, who is Irish and lives in Dublin, played an important role in disproving the Pace trials.

Episode 120
https://youtu.be/TVb-GbMFXDU
Llewellyn King interviews **Leonard A. Jason**, professor of psychology and director of the Center for Community Research at DePaul University in Chicago.

Thirty years ago, Jason was stricken with ME/CFS, after a bout of mononucleosis. When he began researching the disease in the 1990s, it was called the "Yuppie Flu."

He does meticulous, case ascertainment research on ME/CFS.
"How do we know that a case is a case?" he says. **Jason** cites some important research achievements.

As a psychologist, he discusses the importance of community for ME/CFS patients in order to "break down the loneliness" from rejection by the health care system, friends, and even family.

6. Save4Children – An Update

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

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

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

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

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

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

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

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

New way of donating

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

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

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

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

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

7. Science

Changes in DNA Methylation Profiles of ME…

Changes in DNA methylation profiles of myalgic encephalomyelitis/chronic fatigue syndrome patients reflect systemic dysfunctions

A M Helliwell, **E C Sweetman**, **P A Stockwell**, **C D Edgar**, **A Chatterjee**, **W P Tate**

Abstract

Background: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) is a lifelong debilitating disease with a complex pathology not yet clearly defined. Susceptibility to ME/CFS involves genetic predisposition and exposure to environmental factors, suggesting an epigenetic association. Epigenetic studies with other ME/CFS cohorts have used array-based technology to identify differentially methylated individual sites. Changes in RNA quantities and protein abundance have been documented in our previous investigations with the same ME/CFS cohort used for this study.

Results: DNA from a well-characterised New Zealand cohort of 10 ME/CFS patients and 10 age-/sex-matched healthy controls was isolated from peripheral blood mononuclear (PBMC) cells, and used to generate reduced genome-scale DMAP identified 76 differentially methylated fragments and Methylkit identified 394 differentially methylated cytosines that included both hyper- and hypo-methylation. Four clusters were identified where differentially methylated DNA fragments overlapped with or were within close proximity to multiple differentially methylated individual cytosines. These clusters identified regulatory regions for 17 protein encoding genes related to metabolic and immune activity. Analysis of differentially methylated gene bodies (exons/introns) identified 122 unique genes.

Comparison with other studies on PBMCs from ME/CFS patients and controls with array technology showed 59% of the genes identified in this study were also found in one or more of these studies. Functional pathway enrichment analysis identified 30 associated pathways. These included immune, metabolic and neurological-related functions differentially regulated in ME/CFS patients compared to the matched healthy controls.

Conclusions: Major differences were identified in the DNA methylation patterns of ME/CFS patients that clearly distinguished them from the healthy controls. Over half found in gene bodies with RRBS in this study had been identified in other ME/CFS studies using the same cells but with array technology. Within the enriched functional immune, metabolic and neurological pathways, a number of enriched neurotransmitter and neuropeptide reactome pathways highlighted a disturbed neurological pathophysiology within the patient group.

Source: https://pubmed.ncbi.nlm.nih.gov/33148325

Myalgic Encephalomyelitis / Chronic Fatigue Syndrome CPD

FREE online resource composed of 10 clinical cases assessing your knowledge of ME/CFS. You'll receive 1 hour of CPD on successful completion of the resource, created by **Dr. Nina Muirhead**

Resource Overview

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) is a common and severe complex multisystem disease with many sufferers waiting years for a diagnosis. The narrative and education to date has neither aligned with the patient experience of this illness, nor communicated the emerging biomedical evidence.

Following the coronavirus pandemic thousands of people will know how severe and debilitating the symptoms of fatigue can be. Millions will understand the experience of being housebound, but for most these experiences will have lasted days, weeks or months.

Imagine feeling viral, exhausted, unwell and in pain, confined to your bed or house, lying in a dark room for years or even decades. The world has been shocked by the damage that viruses can do, and soon we will need to examine the consequences of chronic post-viral illness including ME/CFS.

In writing this module I have started from scratch. I have drawn on the international peer reviewed literature and emerging international ME/CFS educational resources and have been fortunate to receive significant contributions from medical experts, scientists and patients.

I am humbled by the contributions of those who are severely ill and the effort and energy they have devoted to this collaboration.

Read on here for what this project is aimed at: https://bit.ly/3at0ZV8

Dr. Nina Muirhead

Role of Mitochondria, Oxidative Stress and Response to Antioxidants in ME

Role of mitochondria, oxidative stress and the response to antioxidants in myalgic encephalomyelitis/chronic fatigue syndrome: a possible approach to SARS-CoV-2 ‘long-haulers’?
Emily Wood, **Katherine H. Hall**, and **Warren Tate**

A significant number of SARS-CoV-2 (COVID-19) pandemic patients have developed chronic symptoms lasting weeks or months which are very similar to those described for myalgic encephalomyelitis/chronic fatigue syndrome.

This paper reviews the current literature and understanding of the role that mitochondria, oxidative stress and antioxidants may play in the understanding of the pathophysiology and treatment of chronic fatigue. It describes what is known about the dysfunctional pathways which can develop in mitochondria and their relationship to chronic fatigue. It also reviews what is known about oxidative stress and how this can be related to the pathophysiology of fatigue, as well as examining the potential for specific therapy directed at mitochondria for the treatment of chronic fatigue in the form of antioxidants.

Changes in mitochondrial function and markers of oxidative stress may be the biological component most impacted upon by CoQ10 supplementation, due to CoQ10’s vital role in the electron transport chain. There is also clear need to establish whether MitoQ does indeed improve mitochondrial function and oxidative stress and lessens symptoms in both ME/CFS and chronic symptoms from SARS-CoV-19.

There is a biologically plausible mechanism for expected improvement with MitoQ’s superior bioavailability to cells and to mitochondria within them, and by how it can restore oxidative balance and therefore improve mitochondrial function. A respiratory index, like the BHI, also has the potential to predict and monitor pathophysiology in both ME/CFS and ‘long-haulers’ from SARS-CoV-2.

This review identifies areas which require urgent, further research in order to fully elucidate the clinical and therapeutic potential of these approaches.

Source: PMC https://bit.ly/3ny36Ld

Systematic Review of Primary Outcome Measurements for ME

Systematic Review of Primary Outcome Measurements for Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME) in Randomized Controlled Trials

Do- Young Kim, **Jin-Seok Lee** and **Chang-Gue Son**

Background: Due to its unknown etiology, the objective diagnosis and therapeutics of chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) are still challenging. Generally, the patient-reported outcome (PRO) is the major strategy driving treatment response because the patient is the most important judge of whether changes are meaningful.

Methods: In order to determine the overall characteristics of the main outcome measurement applied in clinical trials for CFS/ME, we systematically surveyed the literature using two electronic databases, PubMed and the Cochrane Library, throughout June 2020. We analyzed randomized controlled trials (RCTs) for CFS/ME focusing especially on main measurements.

Results: Fifty-two RCTs out of a total 540 searched were selected according to eligibility criteria. Thirty-one RCTs (59.6%) used single primary outcome and others adapted ≥2 kinds of measurements. In total, 15 PRO-derived tools were adapted (50 RCTs; 96.2%) along with two behavioral measurements for adolescents (4 RCTs; 7.7%). The 36-item Short Form Health Survey (SF-36; 16 RCTs), Checklist Individual Strength (CIS; 14 RCTs), and Chalder Fatigue Questionnaire (CFQ; 11 RCTs) were most frequently used as the main outcomes. Since the first RCT in 1996, Clinical Global Impression (CGI) and SF-36 have been dominantly used each in the first and following decade (26.1% and 28.6%, respectively), while both CIS and Multidimensional Fatigue Inventory (MFI) have been the preferred instruments (21.4% each) in recent years (2016 to 2020).

Conclusions: This review comprehensively provides the choice pattern of the assessment tools for interventions in RCTs for CFS/ME. Our data would be helpful practically in the design of clinical studies for CFS/ME-related therapeutic development

Full text: Journal of Clinical medicine, Open access
https://www.mdpi.com/2077-0383/9/11/3463

A Hierarchical Logistic Regression Predicting Rapid Respiratory Rates From Post-Exertional Malaise

Joseph Cotler, **Ben Z. Katz**, **Corine Reurts-Post**, **Ruud Vermeulen** and **Leonard A. Jason**

Abstract

Background: Past research has found high rates of hyperventilation in patients with Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS), but hyperventilation can be influenced by psychological factors.
Clinical respiratory rates have been less frequently assessed.

Aim: This study aimed to identify the predictors of rapid respiratory rates in patients referred to an outpatient clinic specializing in ME/ CFS.

Methods: Adults (n = 216) referred to an outpatient clinic specializing in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) participated in a two-day cardiopulmonary exercise test.

As part of that evaluation, subjects had resting respiratory rates measured on two consecutive days. The current study used questionnaires to assess the relationship between tachypnea (rapid respiratory rates) and a variety of domains including post-exertional malaise (PEM), a common complaint in patients with ME/CFS, and psychiatric/somatic symptoms, using hierarchical logistic regression analysis.

Results: PEM was a significant predictor of tachypnea, while psychological/somatic assessments and sedentary behaviors were not significantly predictive of tachypnea.

Conclusions: These findings suggest that respiratory rate may be useful as an objective clinical metric of PEM, and potentially ME/ CFS.

Source: https://bit.ly/3r9HZ3Z

Chronic Fatigue Syndrome, M.E., Symptoms, Diagnosis, Management

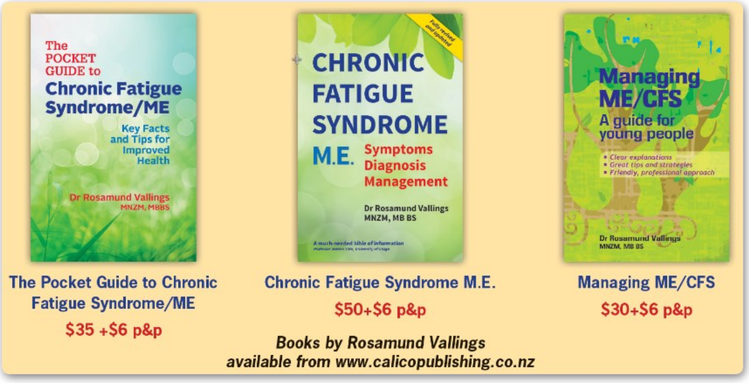
By **Dr Rosamund Vallings,** MNZM, MB BS

Often known as 'ME', Chronic Fatigue Syndrome is notoriously difficult to diagnose and treat, yet its effects are profound, and often prolonged and debilitating.

Dr Vallings describes the process for accurate diagnosis, and clearly explains all aspects of the illness.

In separate sections she provides useful strategies for dealing with specific symptoms, as well as positive suggestions on how to cope with the disorder on a daily basis.

In this fully revised edition, Dr Vallings updates the huge body of research into this condition and explains the science and current understanding of the illness.It is particularly pertinent with the emergence of COVID-19 and provides an important resource for ongoing management.



The Pocket Guide to Chronic Fatigue Syndrome/ME
$35 +$6 p&p

Chronic Fatigue Syndrome M.E.
$50+$6 p&p

Managing ME/CFS
$30+$6 p&p

Books by Rosamund Vallings available from www.calicopublishing.co.nz

Dr Rosamund Vallings is a leading expert in Chronic Fatigue Syndrome/M.E. and has been assisting those with this condition for more than 40 years. Her books have helped thousands of people around the world. In 2008 she was awarded Membership of the New Zealand Order of Merit for services to Chronic Fatigue Syndrome. This book is the distillation of her many years' experience as a doctor diagnosing and treating this condition.

Cytokine Profiling of Extracellular Vesicles Isolated from Plasma in ME

Cytokine profiling of extracellular vesicles isolated from plasma in myalgic encephalomyelitis/chronic fatigue syndrome: a pilot study
Ludovic Giloteaux, **Adam O'Neal**, **Jesús Castro-Marrero**, **Susan M Levine**, **Maureen R Hanson**

Cytokines are present in both plasma and extracellular vesicles, but little investigation of EVs in ME/CFS has been reported. Therefore, we aimed to characterize the content of extracellular vesicles (EVs) isolated from plasma (including circulating cytokine/chemokine profiling) from individuals with ME/CFS and healthy controls.

Results: ME/CFS individuals had significantly higher levels of EVs that ranged from 30 to 130 nm in size as compared to controls, but the mean size for total extracellular vesicles did not differ between groups.

Cytokine-cytokine correlations in plasma revealed a significant higher number of interactions in ME/CFS cases along with 13 inverse correlations that were mainly driven by the Interferon gamma-induced protein 10 (IP-10), whereas in the plasma of controls, no inverse relationships were found across any of the cytokines.

Network analysis in EVs from controls showed 2.5 times more significant inter-cytokine interactions than in the ME/CFS group, and both groups presented a unique negative association.

Conclusions: Elevated levels of 30-130 nm EVs were found in plasma from ME/CFS patients and inter-cytokine correlations revealed unusual regulatory relationships among cytokines in the ME/CFS group that were different from the control group in both plasma and EVs. These disturbances in cytokine networks are further evidence of immune dysregulation in ME/CFS.

Source: PubMED https://pubmed.ncbi.nlm.nih.gov/33046133

Effect of Disease Duration in a Randomized Phase III Trial of Rintatolimod,

Effect of disease duration in a randomized Phase III trial of rintatolimod, an immune modulator for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome
David R. Strayer, **Diane Young**, **William M. Mitchell** Published: 29/10/2020

Abstract

Background: Rintatolimod is a selective TLR3 agonist, which has demonstrated clinical activity for ME/CFS in Phase II and Phase III double-blind, placebo-controlled, randomized, multi-site clinical trials.

Methods and findings: A hypothesis-based post-hoc analysis of the Intent to Treat (ITT) population diagnosed with ME/CFS from 12 independent clinical sites of a Phase III trial was performed to evaluate the effect of rintatolimod therapy based on disease duration. The clinical activity of rintatolimod was evaluated by exercise treadmill tolerance (ETT) using a modified Bruce protocol. The ITT population (n = 208) was divided into two subsets of symptom duration. Patients with symptom duration of 2–8 years were identified as the Target Subset (n = 75); the remainder (<2 year plus >8 year) were identified as the Non-Target Subset (n = 133). Placebo-adjusted percentage improvements in exercise duration and the vertical rise for the Target Subset (n = 75) were more than twice that of the ITT population. The Non-Target Subset (n = 133) failed to show any clinically significant ETT response to rintatolimod when compared to placebo. Within the Target Subset, 51.2% of rintatolimod-treated patients improved their exercise duration by ≥25% (p = 0.003) despite reduced statistical power from division of the original ITT population into two subsets.

Conclusion/significance: Analysis of ETT from a Phase III trial has identified within the ITT population, a subset of ME/CFS patients with ≥2 fold increased exercise response to rintatolimod. Substantial improvement in physical performance was seen for the majority (51.2%) of these severely debilitated patients who improved exercise duration by ≥25%. This magnitude of exercise improvement was associated with clinically significant enhancements in quality of life. The data indicate that ME/CFS patients have a relatively short disease duration window (<8 years) to expect a significant response to rintatolimod under the dosing conditions utilized in this Phase III clinical trial. These results may have direct relevance to the cognitive impairment and fatigue being experienced by patients clinically recovered from COVID-19 and free of detectable SARS-CoV-2.

Trial registration ClinicalTrials.gov: NCT00215800 (https://bit.ly/2WmAPeE)

Source: Plos One https://bit.ly/2WqZnDe

National Centre for Neuroimmunology and Emerging Disease ME/CFS

National Centre for Neuroimmunology and Emerging Disease ME/CFS: Australia's peak ME/CFS Research and Clinical Centre, Griffith University, Queensland, Australia

Professor Sonya Marshall-Gradisnik, **Dr Helene Cabanas**, **Cassandra Balinas**, **Natalie Eaton-Fitch**, **Stanley**, **Du Preez**, **Associate Professor Leighton Barnden**, **Dr Kiran Thapalyia**, **Rebecca Mousard**, **Breanna Weigel** and **Donald Staines**

The national and international reputation of the National Centre for Neuroimmunology and Emerging Disease (NCNED) ME/CFS Clinical and Research Centre has been built on promoting patient engagement in research through understanding the pathophysiology of the illness; discovering diagnostic tests; and establishing effective pharmaco-therapeutics in laboratory models.

Recently, NCNED research achievements are recognised through a National Health and Medical Research Council (NHMRC) grant of $1.46 million, and other philanthropic and competitive grants.

Specifically, the award of this NHMRC Grant to NCNED researchers will enable researchers to investigate potential diagnostic tests as well as suitable pharmaco-therapeutic interventions.

Importantly this project will, for the first time, address NHMRC priorities to discover the pathophysiology of the disabling illness and it will pave the way for diagnostic tests and treatments using highly innovative research techniques known as patch-clamp electrophysiology. This technique used by NCNED researchers in ME/CFS studies has demonstrated impaired calcium ion channels as a contributing cause of the pathology. These ion channels, known as Transient Receptor Potential (TRP) ion channels are associated with pathology in a number of neurological and other illnesses.

NCNED researchers will also collaborate with national and international researchers from the University of Western Australia, Queensland University of Technology, WHO's Australian Rickettsial Research Laboratory, Geelong and ME/CFS consumer groups around Australia.

It also links a number of overseas institutions including chief investigators and researchers in USA, Japan, Poland, and the UK.

The collaboration of leading research institutions will set the scene for unparalleled international cooperation in this research field.

NCNED research achievements include:

- Australia's largest and longest running longitudinal biobank of ME/CFS and neurological samples
- Over 60 novel publications for the identification of the pathology, genetics, epidemiology, health economics and potential pharmaco-therapeutic interventions.
- Establishing the contribution to ME/CFS pathophysiology of Transient receptor potential (TRP) ion channels
- Discovering the role of calcium signalling in ME/CFS pathophysiology
- Developing the world's most advanced laboratory diagnostic for ME/CFS to date with a natural killer cell electrophysiology model (NKEM)
- Undertaking advanced drug testing for pharmacotherapeutic treatments in ME/CFS using NKEM
- Undertaking evidence-based evaluation and systematic reviews of a number of posited pathomechanisms and treatments in ME/CFS.

NCNED has extensive international collaborations through our Consortium Health International for ME (CHIME). These collaborations will be strengthened through our NHMRC grant over the next three years.

NCNED look forward to a close relationship with the ME Global Chronicle to bring exciting updates of research progress to the ME Global Chronicle's international readership.

Prof. Sonya Marshall-Gradisnik & **Prof. Donald Staines**

Promising Research Underway at Montréal Research Center

I'm very pleased to share with you, a valued supporter of Open Medicine Foundation (OMF), an update from my team at the OMF-established ME/CFS Collaborative Research Center at Université de Montréal!

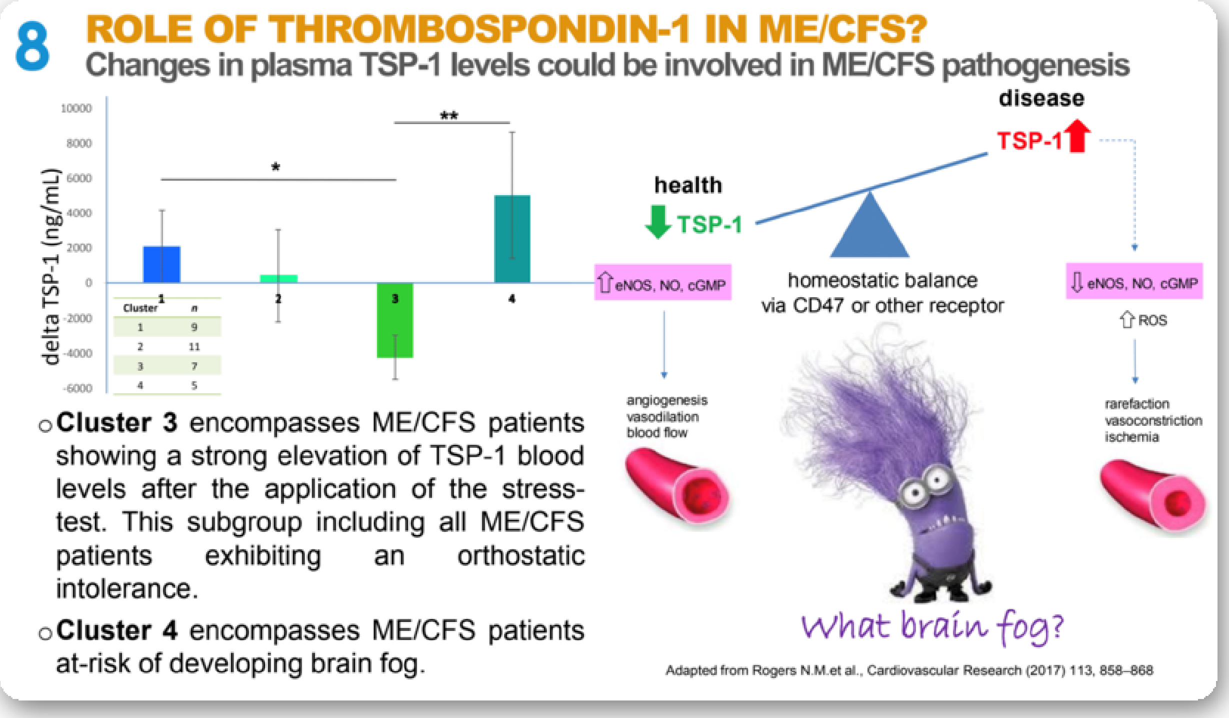
Developing a diagnostic tool and prognostic test

Our researchers are actively working to understand the molecular mechanisms that underlie ME/CFS. My team has developed an exciting new diagnostic test, which explores the molecular mechanisms and patterns that change during the early development of Post-Exertional Malaise (PEM) in severe ME/CFS patients.

This test, using a Hexoskin Smart Shirt (https://bit.ly/2IZrVRj) to induce mild-but-reproducible PEM, has so far uncovered eleven different microRNAs associated with ME/CFS that are capable of differentiating ME/CFS patients from healthy patients — with a 90 percent accuracy! MicroRNAs can represent potential indicators for diseases such as ME/CFS, and changes in microRNA expression could indicate cellular dysfunction and degeneration. Our research could lead to the development of a diagnostic test for ME/CFS and a prognostic tool used to predict future cases.

Studying the role of Thrombospondin-1

Our team of experts is also actively working to understand the role of Thrombospondin-1 (TSP-1) in those with ME/CFS. An important biomarker, TSP-1 appears to be associated with changes in the patients' blood flow to the brain as evidenced in our discovery cohort. Elevated blood levels of TSP-1 have been associated with brain fog and memory impairment while reduced levels have been associated with orthostatic intolerance (symptoms that develop when standing but are relieved when reclining) and POTS (Postural Orthostatic Tachycardia Syndrome, a condition that affects circulation) in a group of severely ill ME/CFS patients. After validation in larger cohorts, if these findings are confirmed to be important in ME/CFS, then drug therapies can be developed in order to prevent or treat these severe symptoms in ME/CFS patients.



8 ROLE OF THROMBOSPONDIN-1 IN ME/CFS?

Changes in plasma TSP-1 levels could be involved in ME/CFS pathogenesis

Cluster	*n*
1	9
2	11
3	7
4	5

- **Cluster 3** encompasses ME/CFS patients showing a strong elevation of TSP-1 blood levels after the application of the stress-test. This subgroup including all ME/CFS patients exhibiting an orthostatic intolerance.
- **Cluster 4** encompasses ME/CFS patients at-risk of developing brain fog.

Adapted from Rogers N.M.et al., Cardiovascular Research (2017) 113, 858–868

Click here for more details about the studies: https://bit.ly/34n4mJC

Understanding environmental and genetic influences

Additionally, our team in Montréal seeks to understand how both environmental and genetic influences affect gene expression in the most complex diseases such as ME/CFS. In order to identify the most promising candidate genes, we are currently studying identical twins in which one twin has ME/CFS and the other twin does not, as well as multigenerational families that have many affected members.

These promising studies underway at the University of Montréal are, I believe, bringing us one step closer towards finding a diagnostic test, treatments and a cure for ME/CFS.

Source: OMF https://bit.ly/38gteDN

Recent Articles From or Featuring Prof. Leonard Jason

- 2020 (Nov 20) **Jackie Cameron**. BizNews.com. Inside COVID-19. https://bit.ly/3r0Zcg9
- Entire interview is on my Youtube channel: https://youtu.be/l682mpvB-_Y
- 2020(Nov. 2). **Leonard Jason**, **Vernita Perkins**. Psychology Today Blog. COVID's Greatest Threat Is to Our Democracy https://bit.ly/3mpmf0p
- 2020 (Oct. 30). **Leonard Jason**, **Vernita Perkins**. Psychology Today Blog. Halloween Nightmare: The Long-Hauler Tragedy. https://bit.ly/3peDsvF
- 2020 (Oct 29). **Markham Heid** (https://bit.ly/34juDIz). Elemental. The Latest Scientific Theories Around Covid-19 Brain Fog https://bit.ly/3mt0ZHj
- 2020(Oct 26). **Phoebe Pinder**. Clear Health Costs. Coronavirus (Covid-19) and children: Yes, they get it, and sometimes it's really bad. https://bit.ly/3p1DtCN
- 2020(Oct.24). **Cort Johnson**. HealthRising. Starving for Energy? and The Immune Hole That Produced ME/CFS? - The IACFS/ME Conference Reports Pt. II https://bit.ly/37qSus2
- 2020(Oct. 24). **Llewellyn King**. ME/CFS Alert. Interview of **Leonard Jason**. https://bit.ly/386MhQU
- My webpage: https://youtu.be/3IZXJ58RcpE
- 2020 (Oct. 20) **Lois Parshley**. Vox. "We just don't know what's happening in our bodies": Covid-19 long-haulers are still suffering. The terrible uncertainty of symptoms that persist for months and months. https://bit.ly/3oWxU8A
- 2020 (Oct 19). **Marissa Nelson**. WTTW News. COVID-19 'Long-Haulers': Symptoms Persist for Some Patients https://bit.ly/38d3VTp
- 2020(Oct. 13). **Lynn Allison**. Newsmax. Children Facing COVID-19 Symptoms Months After Infection http://nws.mx/3p80rsd
- 2020(Oct. 12). **Ryan Prior**, CNN. Kids struggle with Covid-19 and its months of aftermath https://cnn.it/34kKnLq
- 2020(Sept. 11). **David Tuller**. STAT. Seeking the causes of post-Covid symptoms, researchers dust off data on college students with mononucleosis https://bit.ly/3r90Z2P
- 2020 (Sept. 2). **Megan E. Doherty**. Undark. When Children's Covid-19 Symptoms Won't Go Away https://bit.ly/2KCXtwx

Submitted by **Prof.Leonard Jason**

News From The OMF

Montréal ME/CFS Research Center Paper Published in Scientific Reports

On behalf of Open Medicine Foundation (OMF), I am pleased to share that an article authored by my research team at the OMF Funded ME/CFS Collaborative Research Center (CRC) at Université de Montréal has been published online by Scientific Reports (https://go.nature.com/3mDNep2)!

You might remember in my last update from the Research Center at Montréal, I shared a brief update about this study, entitled "Profile of circulating microRNAs in myalgic encephalomyelitis and their relation to symptom severity, and disease pathophysiology," and our groundbreaking discovery and validation of different microRNAs associated with ME/CFS.

MicroRNAs can represent potential indicators for diseases such as ME/CFS, and changes in microRNA expression could indicate cellular dysfunction and degeneration. Using a test to induce mild-but-reproducible Post Exertional Malaise (PEM), our team has so far uncovered and validated 11 different microRNAs associated with ME/CFS that are capable of differentiating ME/CFS patients from healthy patients — wit 90 percent accuracy!

This post-exertional stress challenge provoking PEM in ME/CFS patients has helped us gain unprecedented insight into the pathophysiology of ME/CFS. Based on the 11 different microRNA signatures discovered in ME/CFS, machine learning algorithms have also led to the classification of ME/CFS patients into four clusters associated with symptom severity.

These exciting results could lead to the development of a new, non-invasive diagnostic test for ME/CFS, a prognostic tool used to predict future cases, and identification of effective treatment options.

Prof. Alain Moreau
Source: https://bit.ly/3pbIJDX

* * *

Grant of $784,000 for ME / CFS research

Open Medicine Foundation is excited to announce that our Science Liaison, **Christopher Armstrong**, PhD has received a grant of $784,000 for ME / CFS research from the National Health and Medical Research Council (NHMRC) in Australia. The NHMRC is the primary agency of the Australian Government responsible for medical and public health research. This is one of the first biomedical research projects to be funded by the Australian government to investigate ME / CFS.

Dr. Armstrong received the research grant in collaboration with **Professor Paul Gooley** at the University of Melbourne and Associate **Professor Adam Scheinberg**, **Dr. Sarah Knight**, and **Dr. Elisha Josev** at the Murdoch Children's Research Institute.

This research proposal seeks to understand pathological mechanisms of paediatric ME/CFS (13 to 18 years old) using metabolomic, proteomic and genomic approaches. They have chosen to examine ME/CFS in this understudied group as the disease is likely to be at an early stage. Further, the social, developmental, and economic impact of the debilitating symptoms of ME/CFS on young people and their carers is significant and deserves focussed research.

There are two main parts to the study: an initial case-control comparison study; followed by a longitudinal study. The case-control comparison study will identify differences between ME/CFS and healthy cohorts in their metabolites, proteins, genes and the way they process amino acids, fats and carbohydrates for energy production. The longitudinal study will assess the metabolism of the ME/CFS during ten self-identified "good" and "bad" days. During a "good" or "bad" day, the patient will provide a self-assessment of symptom severity and a blood micro-sample and 24-hour urine will be collected for metabolomics analysis. During the longitudinal study, participants will have wearable technology and a phone application that will enable them to update symptom changes.

Complex diseases such as ME/CFS will often have an etiological mechanism that entails predisposing, triggering, and maintaining factors. The variety of factors that can lead to the disease, taken with the variety of symptoms expressed by those that suffer ME/CFS, suggest the underlying basis of the disease needs to be a broad biological anomaly with layers of anomalies that are specific for individuals and help define their pathogenesis. The combination of deep profiling with longitudinal sampling enables patients to be compared to themselves during "good" and "bad" days, which will help observe the biochemical signatures that relate to the disease or symptom expression.

Our research findings have the potential to identify diagnostic biomarkers of the condition, aid in prognosis and development of novel treatments, and improve the lives and futures of children with ME/CFS. Ultimately, this study will benefit people of all ages with ME/CFS by improving our understanding of the disease pathogenesis for the further development of specific treatments.
Source: https://bit.ly/3mGsKMu

✣

Transforming the Diagnosis and Treatment of ME/CFS, Post-Treatment Lyme Disease and Fibromyalgia

As you may know from personal experience, many primary care physicians lack the dedicated time to properly diagnose chronic complex diseases such as ME / CFS, with the result that most people with these diseases are either not diagnosed or misdiagnosed.

We are creating a “Personalized Automated Symptom Summary” or PASS, which is a tool that bridges the communication gap between patient and doctor, helping patients to more accurately and efficiently convey their symptoms to their treating physician.

This project is under my direction as co-lead of the OMF funded Harvard ME/CFS Collaboration, in partnership with **Dr. Lewis Kazis** at the Boston University School of Public Health, with extensive participation and funding from OMF and its supporters. Using machine learning and artificial intelligence, the PASS tool will enable the patient to create a symptom summary in less than 30 minutes that accurately describes their current symptoms in great detail from their own perspective.

Through this tool, a patient can provide their clinician personalized and specific symptom descriptions and significantly improve their diagnosis and treatment options.

Collaboration is Key

Because many chronic complex diseases have overlapping symptoms, we have engaged a diverse team of experts and advocates to represent the ME/CFS, Post-Treatment Lyme Disease and Fibromyalgia communities. Our partners will provide project oversight and ensure that each disease and its defining symptoms are accurately represented during the PASS tool development.

This is an exciting and unique opportunity for the Harvard Collaboration to work closely with fellow chronic disease experts and pool our knowledge to improve diagnostic and treatment outcomes for patients with chronic complex diseases. We believe this new tool will facilitate the patient’s initial encounter and suggest testing, treatments, referrals, and follow-up management strategies.

As of publication, our current list of strategic partners includes:

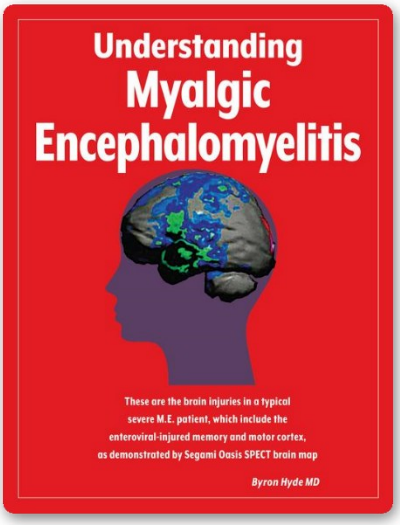
- Bay Area Lyme Foundation
- Massachusetts ME/CFS & FM Association
- #MEAction USA
- Solve ME/CFS Initiative

A Patient-Centered Approach

So what does all this mean for patients with an undiagnosed chronic illness? Or someone seeking better medical treatment? We envision that the PASS tool will help both the patient and their doctor, providing a more streamlined and personalized healthcare experience for people seeking a diagnosis, for patients managing their symptoms, and for doctors treating those with chronic, complex diseases.

Source: https://bit.ly/3auSN6Z

Understanding Myalgic Encephalomyelitis



Byron Hyde MD

This easy to read, hard cover, coloured, library quality 8.5 x 11-inch (22 x 28 cm) book with sewn pages is the best and most comprehensive book ever written on M.E. and CFS containing essential advice for patients and physicians. Now Shipping!!
You can order here: https://bit.ly/38uqvGX

Understanding Myalgic Encephalomyalitis Discusses The History of M.E. /CFS from the American Civil War ending in 1865 to the present described by multiple physicians including:

- **Dr. Francis Dercum**, physician to the President of the USA, **Woodrow Wilson**,
- **Dr. William Osler**, Canadian born, co-founder of Johns Hopkins Medical School.
- The diagnoses differing M.E. from CFS,
- M.E.'s historic relation to Poliomyelitis.
- M.E. epidemics beginning with the world's first major Polio epidemic in 1905.
- The usefulness of Segami brain maps to demonstrate the degree of an M.E. patient's chronic encephalitic illness, clearly indicating why M.E. patients have rapid long-term memory and muscle exhaustion, following even modest intellectual or physical activity.
- The 18 serious cascading illnesses that occur regularly in patients who fall ill with M.E. This has never been previously mentioned in any other book. These are illnesses, you and your physician should know about, many which can be treated.
- The 12 significant potentiators that make M.E. worse
- The previously almost unmentioned South East Asian epidemics of M.E. and Polio following enteroviral infections that began in 1989, or earlier in North America continuing today, leaving tens of thousands, possibly millions with M.E., Polio, paralysis or death and chronic disease. This is the same epidemic which has been associated with the Europe and North America pan-epidemic disease that began in 1984.
- The dangerous overlapping hybrid Polio/M.E. occurring with the New Polios in the USA, Canada and the UK, (known in the USA as Acute Flaccid Myelitis (AFM) / also termed Acute Flaccid Paralysis (AFP) by WHO), increasingly obvious since 1990
- Important and unbelievably devastating patient histories

This is just a few of the 22 chapters in Understanding Myalgic Encephalomyelitis.

Source: https://nightingalepress.ca

8. Severe ME

Care Guide #4 Bedroom

There are many things to be aware of when helping someone who is in bed. People may be stuck in bed in bed until they can be helped to get up or they may be totally bed bound and require all care in situ all day and night. They may need help to get in and out of bed, yet return there again and again through the day. The process of getting in and out of bed is often arduous and unpredictable.

Just helping someone move to try get comfortable, to eat or to wash can be complicated and time consuming; you need incredible patience and understanding to safely and assuredly help someone in the correct way. The risk of deterioration, through getting it wrong, is always present. I have seen my wife badly harmed by professionals, who should have known better.

Each person is different. You need to know and understand how to care for them, when to wait, when to respond, when to try again at another time. Great flexibility, understanding and a willingness, on your part, to get it right are so important when helping the person, especially the more severely affected they are.

Never just sit on the bed when the person has Severe ME. You can cause unimaginable pain, shock and upset unintentionally.

The slightest wrong pressure on the mattress or bedding, can have the worse affect unexpectedly and unintentionally.

Be aware of when and how you make the bed: I have to make sure I smooth out every single crease in the sheets, my wife's skin is so sensitive to pressure, I also have to make sure that my wife is not disturbed by the noise of bed making – ensuring sure the door is closed.

Be aware of where the bedroom is in relation to other rooms so that the activities you perform in other parts of the home do not cause unnecessary or avoidable pain. My office, for example, where I am writing this, is directly above the downstairs bedroom. I have to try to be extremely quiet and still here.

Noise in the bedroom

My wife is exceptionally hypersensitive when paralysed in bed, any noise is intolerable to her. In ME World you always have to pay extra attention, just pulling the curtains, for example, can be unbearably loud to someone with noise sensitivity. Be aware of every noise your movement, actions and clothing make. It may require that you think hard about what you wear, as some materials can be very noisy and may be intolerably irritating to hear, even if you do not notice. Become aware of footsteps and floor covering, of how you open and shut doors and windows, of how you move about the room.

Be aware that even the sound of your breath might be painful for the person, or indeed even their own!

Never just chatter about things, if you know the person has noise sensitivity. Knowing when to speak and how loud it is safe to speak or how to communicate in other ways is imperative. Communication will be complicated by cognitive difficulties, the level of energy available and amount of noise the person can tolerate. My wife cannot tolerate me scratching my head, for example and very often cannot process what I am trying to say.

Learn how to work quietly and effectively. Be aware as much as possible about the noise you make and see if you can reduce it. Respect the person's reality; try to understand the impact you have and how to work with the person in the way they need. It is not easy.

Be aware that if you have a mobile phone, it is switched off or so that it will not ring. Sudden shrill noises can be devastating.

Only do what you have been told is safe to do. Understand what is expected of you. Each person is different and their care needs may vary from moment to moment.

You need to know what to do in differing circumstances, with different symptom deterioration, to stay calm and effective and supportive and safe for all concerned.

Light in the bedroom

When someone is in bed it is essential to keep bright light sources away from them if they have photophobia. Understand how sensitive they are. As in the other areas of the house, do not open curtains, switch on lights, use bright torches unless you are certain this will not harm the person. You have to respect the pain of light sensitivity and work with the person to figure out how to meet need safely for you both.

Chemical sensitivity in the bedroom

Make sure, as carer, you have no perfume on you and that bed linen and clothing of the person do not inadvertently get chemicals of perfumes on them.

Perfume smell is incredibly hard to remove and can linger for a very long time, making anything that has been in contact with perfume a jeopardy to the person.

Be aware of which soaps and toiletries etc are safe to use if the person is bed bound.

Movement in the bedroom

Moving around a person in bed who cannot tolerate movement easily or at all is very difficult. The slightest wrong move can make the person deteriorate rapidly.

You must develop incredible awareness of your own posture, proximity to the person, your movements; learn how to flow slowly and gently. It may help if you indicate to the person that you are coming into the room and have to move about. Learn to do things incredibly carefully, gently, slowly in as tolerable way as possible.

Touch sensitivity in the bedroom

The same information regarding touch in the bathroom applies to the bedroom, where intimate contact, helping someone in bed or in and out of bed is often needed and where people may feel most vulnerable.

Always be aware of the pain the person is in and any hypersensitivity to pressure and contact. Flow with the person and work in partnership to help them safely and as gently as possible, to avoid distress and deterioration.

Helping someone in the right way takes time to learn.

Always approach someone with awareness and check if this is the right moment to help them.

Greg Crowhurst

source: Severe ME: Notes for Carers, p.127-129
Kindle: https://amzn.to/37yj0jf
Lulu: https://bit.ly/3p7kOFH

Announcing the Publication of "Severe ME: More Notes For Carers."

I see very few people, in fact one of the last, was **Rob Wijbenga** and that was back in 2015! I vividly remember sitting in a coffee shop and me reaching into the bag that I had been carrying around and pulling out a newly printed copy of Severe " ME: Notes For Carers".

"You are the first person in the world **Rob** to hold the book!" I laughed, with joy and pride as I handed it to him. Looking back, it was an idyllic few days, me and **Rob** cycling through the leafy, sun soaked country lanes, in the few brief snatched moments, when I could. Sitting on rocks by the sea and most poignant of all, **Rob** on the pavement outside our cottage. Linda, my wife was far too ill to see anyone, so he couldn't come in, but he seemed so deeply honoured to be close to her; I was deeply moved.

How quickly the years go by. Here we are, over five years later, the coffee shop, under Covid restrictions, is long shut. I no longer dare cycle the lanes, instead I exercise daily on a stationary machine, outside in the garden. And my new book," More Notes For Carers", has just been published.

Which gives me a few days left, to compose a Stonebird response to the Draft NICE Guideline. There is much to say, but not enough time, limited by the demands of caring full time for someone with a Very Severe ME diagnosis.

Apart from all the insights gained through decades of torture and agony, both of the experience of this devastating disease, as well as the profoundly sensitive way care must be offered, More Notes for Carers takes a look at the other pertinent issues, such as the critical importance of starting from a correct name for the disease, a proper definition, clear criteria and accurate diagnosis.

Sadly, after all this time, we still seem to be a long way from that starting point!

Given the very real possibility of inadvertently doing harm, or making a terrible situation much worse, the book constantly reminds the reader how ultra aware they have to be of their Approach, their Posture and their Communication, when attempting to help the most ill, who are at an unimaginably extreme level of illness, disability. It shows you how to do this.

It emphasises, in detail, the seriousness and devastating impact of Cognitive Dysfunction, especially in Very Severe ME. It is so incredibly important that this grossly under-appreciated symptom is recognised and accommodated, which has serious implications for any recommendation of Cognitive Behaviour Therapy (CBT).

By far, More Notes aims to be much more than a basic Care Book. After 26 years of struggle at local and national level, it outlines the Core Components of an ME Service, it details the Training that is required, it outlines the necessary elements of an ME-aware Risk Assessment and importantly, it offers Self-Reflective questions to stimulate good Carer and Professional practice.

Embraced within a person-centred posture of Partnership, the entire book is about waiting for the right moment to provide aware care in the best possible way for the person.

After decades of caring full time for my wife, who has been diagnosed with Very Severe ME, I think I am qualified to write about walking your talk, identifying and living by your deepest values, letting compassion, empathy, honesty and congruence guide you at all times, especially through the most difficult and challenging of moments.

Maybe, one day, when Covid is behind us, I will once again be able to share a coffee with **Rob** and hand him his copy! I look forward to that.

https://stonebird.co.uk/morenotes/index.html
To buy: https://www.amazon.co.uk/dp/B08QW7932V

My Whole World Exists In Bed

Something I think people who haven’t experienced being bedridden don’t understand is that when you’re bedridden your whole world exists in bed. You don’t climb into bed to sleep or nap or get cozy and then get out of bed and live in the rest of the room/house/world.

You are always in bed. It’s your whole world. And I think this contributes to some of the sensitivity that severe ME/CFS patients experience. Definitely exasperated by increased sensitivity from the illness but anyone would get particular about their bed if they were bedridden.

Half of my bed is dedicated to me and the other half to storing things I need access to because I can’t get up to get things.

All on my bed are: my stomach massagers (for my severe gastroparesis), ice for my stomach (ice helps my stomach feel and function better), a stack of paper towels, remote door bells which I use as call buttons when I need something, a container of water for cleaning or rinsing off baby wipe soap, a basket with odds and ends like the remote control to my A/C, masks for the smoke from the forest fires before I got an air purifier, the towel I use to cover my eyes when people come in, my white noise earphones, my earmuffs, a stack of adult diapers because I got a urine infection once and had trouble holding it in time to get a urinal and now I keep them accessible just in case, a little jar for trash, boogers, etc. you get the idea.

And under my bed I’ve packed as much as possible within reach like a vibrating massager for my feet and legs which get restless leg syndrome (tingly feeling in the legs and feet that can be unbearable) from being so still or nervous system weirdness I don’t know which. Also extra backup stomach massagers in case one fails, my heating pad which I use on my feet to keep warm since I have ice on my stomach all the time. And lots more. All these items are to me like all the stuff in your house. You are just as particular about how your house is arranged as I am about how my bed is arranged. And you get to leave the house and get away from all that stuff and move freely with few possessions. I don’t. This bed is where I reside 24/7 and I need access to this stuff 24/7.

Some symptoms of severe ME/CFS are partly just normal reactions to horrid nightmare living conditions. And they are of course compounded by the sensitivity that severe ME/CFS causes. But I think it’s important for caregivers, doctors and healthcare professionals to understand how challenging the living conditions are with severe ME/CFS and the fact that any healthy person would also react adversely and wind up acting "abnormally" in response to these conditions.

Whitney Dafoe
Source: https://bit.ly/2WstaLZ

9. News from

Australia

The new Australian ME/CFS Centre for Collaborative Research is expected to officially open early in 2021 and will play a vital role in the global search to determine the cause of ME/CFS, find a cure, treat symptoms better and define a biomarker for speedy, accurate diagnosis.

"ME/CFS is a highly disabling condition that affects an estimated 250,000 Australians, about 1% of the population," Emerge Australia CEO **Dr Heidi Nicholl** explained. It's a complex, multisymptomatic, life-altering condition which can cause headaches, joint pain, cognitive impairment, profound fatigue and post-exertional malaise. Around 25% of people with ME/CFS are so unwell they are bedbound or housebound.

"The cause is unknown, there is no known cure, and there are no effective treatments. There is only pacing – managing energy levels – and stepwise management of symptoms which may have limited success." Announced in October 2020, the new research centre will be directed by **Dr Chris Armstrong**, best known for his research using metabolomics to observe biochemical alterations in ME/CFS patients.

Dr Armstrong said the centre would develop a research approach that focuses on the individual patient and the biology that underlies their disease by analysing 100 ME/CFS patients over three years, monitoring their health data via wearables and sampling and analysing their blood and urine. The outcome of the research will be a condensed, personalised analysis that can then be applied to treatment trials, enabling tracking of the development of ME/CFS prior to diagnosis, stratification of the ME/CFS patient population, and a better understanding of the underlying biology of the disease processes of the condition.

The longitudinal study approach is the cornerstone of personalised medicine, **Dr Armstrong** said. "By looking at the biological differences in an individual at mild and severe moments of their disease we can start to piece together what may be causing their illness and, at the very least, work out what improves or exacerbates their symptoms," he said.

The Centre for Collaborative Research was founded by Emerge Australia in partnership with Open Medicine Foundation (OMF) and is the fifth international research centre in the OMF network, placing Australia in the largest, concerted worldwide non-profit effort to diagnose, treat and find a cure for ME/CFS

Source: Emerge Australia https://bit.ly/3mrrD3m

Belgium

On 6 December, four Belgian patient organizations wrote letters to politicians in the Federal and Flemish parliaments.

At the federal level, the patient organizations advocate for a new agreement for the ME/CFS centers, one that no longer frames ME/CFS as an extreme form of fatigue, is based on the biomedical model, shifts focus from rehabilitation to coping and symptom management, better documents the disability of patients and provides outpatient care for persons with severe ME/CFS.

At the Flemish level, the letter by the patient organizations pleads for evidence-based information on ME/CFS, better training and education of general practitioners and other care providers, funding of biomedical research into ME/CFS by the Fund for Scientific Research (FWO), and better care for people suffering from severe ME/CFS.

Both letters by the patient organizations can be read in full on the forum ME-gids (In Dutch): https://bit.ly/37nhe4q

Czechia

On November 25, 2020 a clinical webinar with the title Contemporary view of chronic fatigue syndrome (ME/CFS) was held in Prague.

The webinar was intended mainly for general practitioners and so it was primarily focused on clinical aspects of ME/CFS.

Its main goal was to present a modern view of ME/CFS as a standalone diagnosis with a focus on distinguishing ME/CFS from other illnesses that can cause chronic fatigue and provide accurate information about this syndrome (differential diagnostics, diagnostic criteria, onset, symptoms, prognosis, management/therapy options).

The list ofspeakers:

- MUDr. **Milan Trojánek**, Ph.D. (Infectious Medicine Department – Na Bulovce Hospital, Institute for Postgraduate Medical Education, Czechia).
  ME/CFS and infections – infection as a trigger vs. Chronic infection

- Ing. **Jan Choutka** (Czech ME/CFS Association, Czechia)
  Insights from a patients association

- MUDr. **Tomáš Pluhař** (General University Hospital in Prague, Czechia)
  ME/CFS from an internist‘s point of view – differential diagnostics, diagnoses for exclusion, recommended examinations

- MUDr. **Jakub Šimek** (General University Hospital in Prague, Czechia)
  How to distinguish ME/CFS from depression or other fatiguing illnesses?

- **Susan Levine**, MD (Center for Solutions for ME/CFS, Columbia University, Center for Enervating Neuroimmune Disease, Cornell University, USA)
  Basic clinical features and differential diagnostics of ME/CFS

- **Betsy Keller**, Ph.D. (Ithaca College, NIH-funded ME/CFS Collaborative Research Center, Cornell University, USA)
  Current understanding of PEM and CPET testing in ME/CFS

- Dr. **Libuše Ratcliffe** (The Liverpool CFS/ME Service, UK)
  Experiences from a specialized NHS center (diagnostics, clinical care)

- Dr. **Kristian Sommerfelt**, Ph.D. (University of Bergen, Norway)
  Pediatric ME/CFS

The webinar was organized jointly by us (the Czech Club of ME/CFS patients) and Dr. **Milan Trojánek**, Ph.D., who is an infectious disease doctor on one of the major Prague hospitals and a chair of the Infectious medicine department of the Institute of Postgraduate Medical Education in Prague.

The webinar was held under this institute and under the official auspices of the Minister of Health.

We hereby thank all those who made this event possible. Special thanks to Dr. **Trojánek**, without whose initiative the webinar could not have taken place.

We would like to thank all Czech and foreign speakers for their helpful approach and excellent lectures. We really appreciate it.

It was the first such educational event about ME/CFS in the Czech Republic and we were very pleased with the interest of the doctors in it.

Hopefully, it will be possible to follow up this event in the future.

Czech Club of ME/CFS patients
10/12/2020

http://me-cfs.eu

MINISTERSTVO ZDRAVOTNICTVÍ
ČESKÉ REPUBLIKY

ME/CFS.czech
Klub pacientů s myalgickou encefalomyelitidou
syndromem chronické únavy

China

The international #MillionsMissing movement, that works for recognition of the disease ME/CFS, has reached Greater China!


WE ARE THE #MILLIONSMISSING#TAIPEI

The famous Taiwanese singer **Fan Ching Hsiang** is an ambassador for #MillionsMissing in Greater China. Last year, he released a song on Warner Brothers about ME/CFS, called Beside You https://bit.ly/3npAO5H

In 2020, **Ching Hsiang** released a music video called "Tide Play Healing Slow Life" in benefit of ME/CFS patients. The music video was presented at a #MillionsMissing event in Taipei, Taiwan, on September 25th where he was assisted by the singer **Sherry Cheng**.

Fan Ching Hsiang calls his campaign "ME/CFS Slow City Life". He has also worked on a video project with the price rewarded actor **Kang-Sheng Lee**, retranslating "Slow Man" into a caring campaign of ME/CFS. http://www.digitaljournal.com/pr/4857031.

Fan Ching Hsiang has been involved in many charitable causes for years, including ME/CFS. He has arranged several #MillionsMissing events in both Taiwan and The People's Republic of China. He now lives in Shanghai where he plans to do monthly #MillionsMissing events, if possible. He often cooperates with commercial firms to promote the events, and he reaches out to millions of people via tv and other media outlets.

In China, the ME/CFS promotion has to be carried out in a healthy and positive way. "I must participate in a safe and positive attitude to get support and response from the government and society", **Fan Ching Hsiang** writes. Hopefully, the new knowledge about patients with long-covid and their risk of developing ME/CFS symptoms, including Post Exertional Malaise, may lead to a better biomedical understanding and more appropriate treatments of both diseases, in China as well in the rest of the world.

You can follow **Fan Ching Hsiang** on facebook and like and share his posts.
I have now corresponded with **Ching Hsiang** for a year, using google translation of Chinese.

He would very much like to get in contact with more representatives from #MillionsMissing organizations around the world, and to spread the word about what is going on in Greater China regarding ME/CFS.

Therefore, I will encourage anyone who is interested in this, to contact **Fan Ching Hsiang**. If you know Chinese, it would be perfect! But any other language is also possible if you use Google translate https://bit.ly/389R7wP

You can find more information about the famous Taiwanese singer **Fan Ching Hsiang** [or **Fan Jingxiang**] and his charity work on Wikipedia: https://bit.ly/388lZOh

Fan Ching Hsiang can be contacted via Messenger at his facebook "Fantrend Trend Charity"
https://www.facebook.com/maxmara.sportmax

and his facebook "Fan Ching Hsiang"
https://www.facebook.com/FanChingHsiang.

He can also be contacted via email: fantrend@sina.com

The #MillionsMissing movement is truly becoming global!

Best Regards,
Helle Rasmussen
Administrator of #Millionsmissingdenmark
millionsmissingdk@gmail.com

Denmark

I was interviewed by the Danish national Newspaper Information about the lack of implementation of the unanimous decision by the Danish Parliament in March 2019 to separate ME from functional somatic syndromes diagnoses. This is not happening at all and Danish ME patients are more than ever sent to the regional centers for functional somatic syndroms where they are getting CBT and GET - in spite of the new draft of the NICE guidelines.
https://bit.ly/3akf5rX

* * *

We also won a price for our ME-work with the Danish ME Association which was an amount of money and this film on ME:
https://bit.ly/3mtSoUK

* * *

At the invitation of the Finnish doctor's association - DUODECIM - we also attended a hearing on SKYPE on their upcoming guidelines for ME in Finland that are supposed to be released at the start of the new year. A lot of good ME-doctors from the Nordic Countries - Sweden and Norway - also took part of the hearing-group.

Right now - as with the NICE-guidelines - it is possible to leave a written comment to the guideline at the DUODECIM homepage (unfortunately it is in Finnish which eliminates many). DUODECIMs draft, however seems pretty thorough, and recommends the Canadian Consensus criteria.
https://bit.ly/3r8jmVm

* * *

Finally Norway and Denmark are working on a mutual digital platform called the "ME-toolbox" where materials for children with ME can be downloaded by teachers and schools. The financing is not yet finalized but some of it is being secured by the Norwegian party.
https://www.meogskole.no/verktoykasse

Cathrine Engsig
ME Foreningen, Denmark https://bit.ly/3r0Pbj3

Finland

1. "Good practice" guidelines for ME/CFS

The Finnish Medical Society Duodecim published in November a draft for new guidelines for ME/CFS for open consultation. The deadline was 4.12 and the final Hyvä käytäntö/’Good practise’ guidelines will be published at beginning of 2021.

The timing was good as the historic NICE guidelines for ME/CFS (draft) were published in time to be taken into consideration. NICE takes a drastic turn from psychosocial model to biomedical approach and lists GET (graded exercise therapy) and CBT (cognitive behavioral therapy) not to be offered as treatments for ME/CFS.

The Finnish draft for new guidelines for ME/CFS proposes diagnostic criterias that include PEM, which is an important step forward in Finland, where the definitions of ME/CFS are very vague and confusing among the healthcare professionals at the moment. GET and CBT are still mentioned as treatments in the draft though. Finnish ME-patients wish that the final guidelines will take into consideration the research reviews the new NICE guidelines are based on. https://bit.ly/2IVAigB

2. Helsinki University Hospital`s Outpatient Clinic for Functional Disorders treats ME/CFS patients

The Finnish Ministry of Social Affairs and Health defines ME/CFS officially as a "functional disorder" and the Helsinki University Hospital treats it as one at their bit over a year old Outpatient Clinic for Functional Disorders.
https://bit.ly/3oUXCKT

ME/CFS-patients have started to share publicly their experiences of the treatments Functional Disorder Clinic offers to them.

Woman, 36 years old ME patient:

"I only got pressured from the clinic to believe that my symptoms were "functional" and shouldn't be studied any longer, as it would only make my symptoms worse. I was also suggested to start a DNRS brain exercise program."
https://www.me-media.fi/2020/12/husn-toiminnallinen-hairio.html

Woman, 39 years old ME patient:

“I was recommended at the clinic to get acquainted with the DNRS method, which means retraining the brain. The Gupta and Lightning process were also recommended. These are all commercial programs that you can attend at your own expense. These programs are not based to any medical evidence.”
https://www.me-media.fi/2020/12/husn-toiminnallinen-hairio_3.html

Woman, healthcare professional, ME patient:

“In their view, ME/CFS is just a matter of a dysfunction in the autonomic nervous system and can be corrected with psychophysical physiotherapy and a gradual increase in exercise. I told about physical findings in me, found in medical studies, but they were completely ignored. For example, the changes found in my brain were caused by the "fact" that we are all different and so is our brain, so they think the physical findings are thus useless.”
https://www.me-media.fi/2020/12/husn-toiminnallinen-hairio_4.html

The Functional Disorder Clinic is offering also an online therapy course to treat ME/CFS, the course is developed by **Kela**, The Social Institution of Finland.

Woman, 45 years old, Psychologist and ME patient went through the whole online therapy course and describes her experiences:
"The course emphasized the need to commit to exercises and asked constantly how motivated I was to do them and go through the course. This is a classic form of manipulation, the same is used in different cults and revival movements. If you want to heal, do as they say. In the beginning there is pressure to act, and if a person doesn't get better, he's guilty of not trying hard enough. It's also unethical to give us unveiled hope of healing because we know that you can’t cure ME by thinking - otherwise I'd be healthy already."
https://www.me-media.fi/2020/11/husn-toiminnallinen-hairio.html

3. The Finnish Parliament

During the autumn several members of the Parliament have submitted written questions to the Government about the issues ME-patients face in Finland.

https://bit.ly/3gVVEH6
Member of the Parliament, **Timo Heinonen** (National Coalition Party) has submitted a written question to the Minister of Family Affairs and Social Services, **Krista Kiuru**:

"Why does the Government define ME/CFS as a functional disorder and not as a neurological disease following the WHO classifications?"

Till this day **Minister Kiuru** has’nt been able to give an answer, but instead she has released avoidant statements. **MP Heinonen** has repeated the written question already twice and has promised Finnish ME patients to submit the same question again for the third time. https://bit.ly/3gVlDhT

France

Open letter to the French health authorities

This letter was sent on November 30, 2020 to nearly 100 recipients (political leaders, representatives of Health Authorities, scientific councils, learned societies, heads of COVID-19 reference centers, etc.). It is supported by more than 30 associations and organizations and a hundred researchers, academics and clinicians of international renown.

- It is unjustifiable that exercise rehabilitation continues to endanger the health of patients with systemic exercise intolerance, contrary to scientific evidence and despite the proven risks.
- Orientation towards appropriate care: pacing
- Acting for equal rights: the need to recognize ME and PVS
- In France, more than half of practicing physicians do not recognize ME as a true clinical entity and, therefore, do not diagnose it. The vast majority of patients endure years of medical wandering.

The absence of training on the pathology leads to a false perception of the disease, to the risk of abusively psychiatrizing the patient, or even of lack of care, mistreatment and denial of what he is experiencing and a cruel lack of support. It eads to prescriptions which can be aggravating factors for patients. Many patients testify to mistreatment, whether by poor general practitioners, poorly trained specialists, or even hospital services.

Our requests to the French health authorities

In order for equal rights to be restored, we ask that the following actions be taken as soon as possible:

- The official recognition by the French Health Authorities of myalgic encephalomyelitis and post-viral fatigue syndrome, under their classification of neurological disease by the WHO (CIM-10 G93.3) and as a long-term disease (ALD 30; failing that, ALD 31 100% supported).

- The implementation of a national diagnostic and care protocol, including the creation of multidisciplinary reference centers for ME, in partnership with patient associations and patient-experts. These centers can be directed by French specialist doctors who have been taking charge of the disease for several years. They are essential to provide the best possible support to patients with ME, to offer them appropriate care, as well as to supervise biomedical research programs.

- The immediate publication of a warning to healthcare professionals contraindicating the prescription of exercise rehabilitation in the presence of systemic exercise intolerance. This warning should be sent as a priority to hospital structures where patients with long COVID are treated and to general practitioners.

- The implementation of dedicated medical training, including a therapeutic patient education program on pacing, with patient associations and patient-experts, with valuable experiential knowledge in the face of this debilitating disease. This training must first be provided in structures following ME patients and long-term Covid patients. The Angers University Hospital, a pioneer in this field, is today the only one in France to offer a program of this type, at the initiative of **Dr Ghali**. ME patients and those with long COVID presenting symptoms of systemic exercise intolerance should benefit from appropriate early management. This measure is essential to limit the peak triggering of ME linked to the pandemic.

- The establishment of biomedical research programs, as required by European resolution 2020/2580 (RSP), designed and carried out from start to finish with patient associations and patient experts. ME is an orphan disease, untreated at present: treatment protocols must be evaluated. Large immunological, neurological, genetic and epigenetic studies must be funded. As a first step, recent promising work could be replicated, such as that of the American NIH research centers on ME and the diagnostic test by **Professor Moreau**'s team at the CHU Sainte-Justine in Montreal. The teams of **Dr Ghali** (University Hospital of Angers) and **Prof. Jammes** (European Hospital of Marseille) must be supported in their research on systemic intolerance to stress. The creation of a biological bank, like the UK ME/CFS Biobank, optimize and accelerate the research process. Faced with the intolerable situation experienced by hundreds of thousands of myalgic encephalomyelitis patients in France and faced with the risk of their consequent increase with the COVID-19 pandemic, the French health authorities must act now, without further delay

This info has been taken from an article by Millions Missing France https://millionsmissing.fr/article11/lettre-autorites-france on a much longer letter which can be read here:
https://cloud.millionsmissing.fr/s/6Ak6t4wQnHj95yW#pdfviewer

With thanks to **Millions Missing France**

Germany

The German federal government is providing 900,000 EUR to establish a ME/CFS register and a ME/CFS biobank over the next three years.

In addition, two federal German agencies – the federal agency of education and research (BMBF) and the federal agency of health (BMG) – have announced initiatives for ME/CFS.

The federal agency of education and research has announced a call for study proposals on unknown pathomechanisms of individual diseases with high disease burden but insufficient treatment options. They mention that this offers opportunities to fund ME/CFS research.

The federal agency of health will commission a scientific report on the current state of knowledge on ME/CFS.

Both federal agencies have announced to meet (for the first time) with the four German patient organizations. Prior to that the four German patient organizations had written an open letter to the federal agencies about the EU-resolution on ME/CFS and proposed a round table.

Links and discussion: https://bit.ly/3h5w5DX.

New Zealand

The German federal government is providing 900,000 EUR to

Our AGM was held in Dunedin on the 7th of November.
We welcomed three new committee members **Virginia Boyle**, **Fiona Morris** and **Fiona Charlton**, also a new Medical Adviser **Doctor Sarah Dalziel**. **Dr Erin Sweetman** and **Emeritus Professor Warren Tate** were present, as was one of our medical advisors **Dr Rosamund Vallings**.

Erin gave a presentation on their latest research, which is available on the ANZMES YouTube channel, along with a question and answer session with **Dr Sweetman**, **Dr Vallings**, and **Prof Tate**.

In celebration of our 40th anniversary year in 2020, a cake was served to those who were able to attend the AGM, following the election of executive committee officers https://bit.ly/2WBaJ7H

Prof Tate also did a lecture for the Brain Research Centre at Otago University last month. This talk was recorded and a link to it is posted here, which directs the reader to the YouTube channel of Otago University. ANZMES is proud to have been one of **Prof Tate**’s sponsors for the last few years https://bit.ly/34uqIsQ

The media team at Otago University sent out a press release following that lecture, and various news outlets recently picked up on the story. We were not aware of the press release until the stories and interviews began airing on television, broadcast on Radio NZ National, or otherwise became available through the webpages of the news outlets.

One of our new committee members is helping to upload these stories to our website as they become available and they are also on the ANZMES Facebook page. Our members are generally happy about any publicity that helps raise awareness of ME/CFS in Aotearoa/NZ https://anzmes.org.nz/category/news

Heather's latest President's Report will be published in the upcoming Issue of Meeting Place. Our medical advisor **Dr Rosamund Vallings** has written an updated edition of one of her books, which is available through Calico Publishing in New Zealand https://bit.ly/3pbDZOD

Submitted by **Libby Boone**

Norway

The Norwegian ME Association now has more than 5400 members and is still growing.

In Norway the Directorate of Health has started the process of developing a patient course for patients with ME/CFS. But this will take a long time. We have been invited to join the expert group and two of our members will join. But there will be a lot of discussion on the matter.

Besides that, we have protested against a large study of how Lightning Process can be of help to patients as the research-group got approval to go on with a study at one of the largest universities. Many people are furious about that decision.

We had our national meeting of the association at the end of October, and the Board was reelected with **Mt Bjorn Wold** as the chair.

The meeting was a new experience as we had to hold it digitally because of Corona. So 45 delegates were participating from their homes developing strategies for the next year.

We are looking forward to 2021 and hopefully will come back to a normal setting in our daily lives.

Olav Osland,
Secretary

https://www.me-foreningen.no

Spain

Why does the SSC theory not benefit us, patients with Myalgic Encephalomyelitis, ME?

Because its "treatment" answer is CBT, Cognitive Behavioral Therapy and GET, Gradual Exercise Therapy. Simply because of that, it is already known that it does not benefit us. ME- patients loose even the little bit of health they have left in it. Since they are all "treated" the same, FM, ME, MCS and EHS (electronic hypersensibility). It is well known that what benefits some can make others worse. Everything cannot be seen as a "WHOLE" at this point.

This is based on a theory of a single doctor, **Mohammad B. Yunus**, from 1994 onwards, capped and deformed. And on a fraudulent English study, the famous and dangerous, Pace Trial.

Yunus is a rheumatologist, not an internist, nor immunologist, neurologist, geneticist, or endocrinologist and his theory was formulated for all types of chronic or intense pain ... from headaches to fibromyalgia, through premenstrual syndrome, migraines, post-operative pain, rheumatoid arthritis ... .and an immense sea of diseases, in which ME is lost. Psychological aspects of fibromyalgia syndrome: a component of the dysfunctional spectrum syndrome https://bit.ly/3nqenNN **Dihub**, **Mohammad B. Yunus**, 4, November 1994.

Because in the next study by Yunus he added all those diseases of which little is known, it was then that ME, Lyme, etc. were added. **Yunus** himself acknowledges in the year 2015 that there are proven damages in some patients with “EFS” diseases. This implies that the concept of the year 1994 has become obsolete.
(Editorial review: an update on central sensitivity syndromes and problems of nosology and psychobiology https://pubmed.ncbi.nlm.nih.gov/26138918 Review, **Mohammad B. Yunus**, 2015. Source: PubMed).

Because of course it does not include MCS (which I also suffer from in a severe degree, my intention is not less to appreciate them, do not be misinterpreted), or EHS, since they are not recognized as diseases at the international ICD level.

The theory of **Mohammad B. Yunus** is based on "nociception", that is, you do not have pain, but your CNS is deceiving you and that is why you notice it. Calling these diseases "central sensitization syndromes" is one thing (it encompasses all diseases that involve the CNS), but to speak of the Central Sensitivity Syndrome (in the singular) as a single disease is a perversion of the original theory.

ME (ICD 10. 93.3G) and FM (ICD 10. M79.7), have an ICD code and are diseases recognized by the WHO, but "SSC" Does Not Exist: It Does Not Have An ICD Code. Therefore, it is not recognized by the WHO. If you are diagnosed with a disease that does not exist, you have no right to anything. They leave us in an administrative limbo.

If they use the word "sensitivity", they are talking about "awareness" which is the original word and therefore the one you will find if you are looking for relevant medical information. Sensitivity means you have a reason to react, Sensitization means that you react because you are convinced that it will hurt you.

That is why **Yunus** uses the word sensitization, which he describes as not distinguishing between physical (organic) diseases and biopsychosocial based (which has always been called psychosomatic diseases). They use the word Sensitivity because if they would use the other, the patients would jump on them. There is no international consensus that supports this theory, apart from that of Yunus and his followers.

The word "Biopsychosocial" is basic in all this, and the result is that the treatment begins with CBT, thanks to **Yunus** and ends with GET, thanks to the Pace Trial. I remind you again what a fraudulent study is, demonstrably. All this is being promoted by a Society created by the same people who support this theory in Spain (and only in Spain), although they use names in English to give themselves the hype and make it seem like an international society. Which reinforces the theories of skeptics and detractors about ME that ‘we are overdiagnosed by a medical lobby."

The most recent research clearly shows that ME has a strong immunological component and is also associated with certain genetic mutations, so the fact that the CNS is affected is secondary (consequence, not cause of the disease). If research continues to demonstrate immunological involvement in the pathophysiology of ME, why should we endorse a "biopsychosocial" approach, a therapy that is proving harmful to patients and that binds us to diseases that do not exist (at least for now, in the CIE) or that they are clearly classified in completely different sections of said CIE?

Because, after all these arguments who can benefit from all these grassroots errors being imposed? I'll give you a hint: the patients, Zero. I'll give you another clue: there are a few public and private "chiringuitos" that are getting on this bandwagon, in a cheeky "Juan Palomo" and want to extend their networks to the rest of the Spanish communities. We have plenty of "WHY’s". Don't use the term "SSC," or help spread it. With this you help making ME, Myalgic Encephalomyelitis, even more invisible, if possible. And with it all the pathologies that this perverse term encompasses.

This is the current situation in Spain. I hope you find it interesting and help make visible the ME problem in Spain.

Ari SF

Submitted by **Monica Arranz**

South-Africa

ME in South-Africa

Rarely ME-advocacy in a country depends upon one person only. This is especially so, when there is still nothing known about the disease and knowledge and information about ME has to be built up from scratch. Such is the situation in South-Africa where ME-patient and warrior **Retha Viviers** took upon herself to start an 'ME-movement' and society. The news from South-Africa we were lucky to publish in earlier issues of the ME Global Chronicle all came from her. Unfortunately, she fell severely ill with cancer about a year ago which prevented her greatly from fighting for the rights of PwME in her country and in fact the whole African continent. Her friend Betty Hough wrote this tribute on het last birthday.

My Friend **Retha Viviers**

Our ME and cancer warrior Retha has reached another milestone. It is her birthday on the 28th of October. At the beginning of the year when **Retha** was diagnosed with stage 4 ovarian cancer, it was doubtful if she would reach this birthday. **Retha** does not have medical aid [insurance] and could not access effective treatment. We started fundraisers to help her access private tests and treatments. The ME community and friends rallied around with support and Retha got excellent private treatment. She was a good candidate for Chemotherapy, and after six sessions, her cancer markers were sufficiently down that she could joyously ring the bell. The magic word remission was bandied about. **Retha** returned to her life as ME advocate with renewed vigour.

- She started a regular ME/Cancer blog which was well-received throughout the world.
- She was back working hard, educating and helping people with ME through the ME/CFS Foundation. Retha helped a family who was living in a Wendy house to acquire another room and to make it much more comfortable
- She taught herself to make graphics and is busy renewing the website of the ME /CFS Foundation
- She started a drive to get donations for the Foundation to help people with ME to access doctors, buy medication and necessities like food
- **Retha** is active again on quite a few pages which she admins. I know that she is in regular contact with people who need help or advice or even just a listening ear. She has started doing Saturday morning VIRTUAL calls for ME/CFS, Fibromyalgia and other chronic illness patients. It has become the highlight of the week for some people and beautiful friendships have and are being formed. A platform similar to ZOOM (called Jitsi Meet) is being used.
- She did a photoshoot with **Jade & Valvet** - a lovely boutique with stores in Johannesburg and Cape Town area. This will be used to raise awareness of ME, especially in South Africa.

I'm always amazed at **Retha**’s mental strength and courage despite all the challenges that she is facing. Unfortunately, this period of remission has come to an end after six weeks. Her cancer markers have gone up, and **Retha** started a new round of chemotherapy last week. She will be receiving six sessions and will be suffering the unpleasant side effects once again. **Retha** says that last week’s chemo session hit her hard.

Despite all this, **Retha** stays positive; she did not only coin the phrase #Imhopeful, but she lives it. When she lost her hair quickly with the previous round of chemo, she joked that she is happy with that. If chemo can do that to her hair, imagine what it is doing to cancer!

Retha says that she is beyond grateful for all the support she has received and is continuing to receive. She never knew there were so many kind-hearted people in the world. The best birthday present would be to ring that bell once again and go into remission.

Retha, we hope that you will have the best birthday possible with your loved ones, even with side-effects from chemotherapy. We are hopeful with you that the chemotherapy will kick cancer‘s butt and that you will have many birthdays in the future.

You are such inspiration. Thank you for everything you are doing for people with ME in South Africa and all over the world. We love you and will support you in every way possible.

Happy Birthday 🎉 🎂 🌈 🎁

For regular updates, testimonials and videos on what our ME and Cancer warrior **Retha** did to help others visit our Facebook Page “My Friend **Retha**” at https://www.facebook.com/myfriendRetha

Sweden

Good and bad news from Sweden

The Stora Sköndal Foundation which has hosted the ME-clinic near Stockholm has cancelled the care agreement with the ME-clinic for financial reasons.

This is a hard blow to all ME-patients and RME is working hard to influence those responsible for the decision. We are also insisting that the bad deals in the agreement for the ME-clinics in the Stockholm Region have to be changed. The current contract terms do not cover the real costs.

- Good news however is that another ME-clinic will be opened at the Umeå University Hospital (in the north of Sweden) in the beginning of 2021.

About the bad news, a press release of the Swedish ME-association, RME reads: Serious consequences when one of the country's two specialist clinics for about 40,000 ME sufferers ceases.

The Stora Sköndal Foundation is forced to close its ME/CFS reception. The consequence is that tens of thousands of people living with the severely disabling multisystem disease ME risk being left without care. At the same time, doctors and researchers warn that the corona pandemic could cause a new wave of ME patients.

The country's only two county council-affiliated specialist clinics for the care of people affected by ME (Myalgic Encephalomyelitis) are located in the Stockholm Region. One of these receptions is now forced to close due to, among other things, insufficient agreements.

Approximately 40,000 people in Sweden today live with the serious and chronic disease, which in 75 percent of cases begins with a viral infection. There are many indications that the patient group will increase sharply as more and more people become long-term ill after covid-19 and show symptoms that are consistent with ME. **Professor Jonas Bergquist**, who is researching ME and covid-19 at the Biomedical Center, Uppsala University, says:
"We know that the vast majority of ME sufferers make their debut after a virus-related infection and we fear that the number of patients with long-term post-viral fatigue and ME will increase very sharply in the wake of the covid-19 pandemic."

The announcement that the ME/CFS clinic will be closed has been met with great concern among victims and relatives. Already today, many have had to stand in line for several years to get there. The clinic also for a long time has accumulated valuable experience and knowledge about the disease, arranged training for other regions, and participated in important research collaborations both nationally and internationally.

Knowledge that is now at risk of being lost. **Kerstin Heiling**, chairman of RME (The Swedish Association for ME Patients) believes that this is a disaster:
“On average, it currently takes just over 9 years for an ME patient to receive a diagnosis and care. The closure of the clinic means great personal suffering for the victims and their relatives, as well as a great financial loss, as more patients will be locked around without receiving adequate care. At the same time, the risk increases that seriously ill people become even sicker because they do not receive help in time. It is a development in the completely wrong direction."

There are currently two ME specialist clinics; the Bragée ME-center and the ME/CFS reception at Stora Sköndal. In addition to this, there are also two pain clinics that currently accept ME patients.

The region Stockholm has a fact page about ME/CFS in its knowledge https://www.viss.nu, type ME/CFS in the search box.

Source: RME, The Swedish Association for ME Patients, https://rme.nu

Contact information
Kerstin Heiling, chairman of RME (National Association for ME Patients):

Email: kerstin.heiling@rme.nu
Phone number: +46 70 722 30 73
RME: pressmail: press@rme.nu

The Netherlands

A Step Forward

The hopeful report about a research agenda (see under Dutch Citizens Initiative in this issue) is a follow-up to one of the four recommendations in the ME/CFS report of the Health Council (March 2018).

The fourth recommendation was addressed to medical assessors in the context of disability insurance, Wmo, Wlz and Participation Act (Dutch institutes involved in work and welfare of diseased and disabled persons). It reads: "Acknowledge that ME/CFS is a serious illness associated with substantial functional limitations and do not consider a patient's choice not to have CBT or GET as "inadequate recovery"."

The Dutch Steungroep ME en Arbeidsongeschiktheid (ME and Disability Support Group) in particular is committed to the social rights of ME patients in the Netherlands. Partly thanks to their efforts and the contacts of all four patients organisations with politicians, the UWV (https://bit.ly/2KEkOOK) will put into practice a motion submitted by a parliamentarian, supported by the entire parliament. This motion is based on the above-mentioned fourth recommendation.

This only applies to a certain group of patients, namely those "for whom the UWV insurance doctor has assumed that they have not (yet) done enough with their recovery because they have not followed cognitive behavioral therapy (CBT) or graded exercise therapy (GET) and who have been disadvantaged in the assessment of their incapacity for work. That is why the ME and Disability Support Group concludes: "The result is not quite what we wanted, but we hope that a number of ME patients will still benefit from it".

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Open day Dutch ZonMw

On Thursday November 19, 2020 an open day was organized by ZonMw, with participation of four foreign speakers.
Their presentations can be viewed here: https://bit.ly/3mCjglm
timings:

12:**39 Dr. Anthony Komaroff**	Research agenda for ME/CFS: a view from the United States
30:38 **Dr. Michael VanElzakker**	Model for a collaborative Dutch ME research pipeline
1:00:04 **Prof. Jonas Bergquist**	Biomolecular Aspects of ME - A brief update from the Uppsala CRC for ME/CFS Research
1:24:49 **Dr. Jennifer Frankovich**	PANS & ME/CFS

Over 100 persons from all over attended online.
About the purpose and context of this day you can read more under the heading Dutch Citizens Initiative in this issue.

10. 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."